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# STATE OF HAWAI‘I MATERNAL AND CHILD HEALTH NEEDS ASSESSMENT

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**Family Health  
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**CHAPTER 1:**

**TITLE V NEEDS**

**ASSESSMENT PROCESS**

## **Title V and Family Health Services Division**

The Department of Health (DOH) Family Health Services Division (FHSD) is the state maternal and child health (MCH) agency serving the needs of women, infants, children, families and children with special health care needs (CSHCN). FHSD receives a federal MCH Block grant commonly referred to as "Title V" since the federal legislation authorizing the block grant to all states is found in Title V of the Social Security Act. Title V requires the completion of a population based needs assessment every five years. The goal of the needs assessment is to identify and address state priority health issues in partnership with community stakeholders that affect the MCH population.

The mission, vision and goals for FHSD can be found in Appendix A-0.

## **Background to the Needs Assessment**

The Title V needs assessment (NA) was conducted in the midst of a tumultuous period given the state's historically unprecedented economic decline. As a result of the global recession, Hawai'i experienced a very rapid and steep economic and fiscal decline. In one year the state budget went from a \$330M surplus to a projected deficit of \$1.2B deficient for the biennium (out of a \$10B budget)

The state experienced the closure of several major companies (including the loss of one of its oldest airlines), high unemployment with a concomitant increase of enrollment into entitlement programs and services. For state government, the economic decline resulted in dramatic budget cuts, the elimination of programs, and a reduction in workforce, nearly 300 positions for the state Department of Health alone (58 positions for the Title V agency). Furthermore, the state also implemented two day per month furloughs beginning October 2009, reducing the number of days state offices were open for business.

Service programs have lost millions of dollars in state funding and witnessed similar reductions in private donations. The system of services residents have come to depend on is in rapid change at a time when there is increased demand for these programs. Given this context, the Title V NA has proven to be more timely and important. The need to improve coordination and collaboration among services has become ever more critical to assure existing resources are used more effectively.

## **Hawai'i Maternal Child Health Priorities**

Seven priority issues were identified through the Title V Maternal and Child Health (MCH) needs assessment (NA) process. These priorities are expected to be the programmatic focus for the Family Health Services Division (FHSD), the state Title V MCH agency, in conjunction with many of our partnering organizations during the next five years (2010-2015). The 7 priorities for the state MCH population are:

1. Reduce the rate of unintended pregnancy
2. Reduce the rate of alcohol use during pregnancy
3. Improve the percentage of children screened early and continuously age 0-5 for developmental delay
4. Improve the percentage of youth with special health care needs age 14-21 years who receive services necessary to make transitions to adult health care
5. Reduce the rate of child abuse and neglect with special attention on ages 0-5 years

6. Reduce the rate of overweight and obesity in young children ages 0-5
7. Prevent bullying behavior among children with special attention on adolescents age 11-18 years

The priority issues are depicted graphically as key intervention points during the lifespan to assure lifelong health in Appendix A-0.

### **Changes in Priorities Since the Last Needs Assessment**

Five priority needs were dropped from the list of nine:

1. Ensure that all infants and children receive appropriate and timely hearing evaluation and early intervention services;
2. Improve the oral health of children
3. Prevent underage drinking among adolescents
4. Reduce the rate of adolescent Chlamydia
5. Increase abstinence from smoking during pregnancy

The justification to drop these priorities varies. For the hearing screening and early intervention (EI) services issue, sufficient progress had been made as indicated by the performance measure for this priority; however, newborn hearing screening and EI services will continue as a CSHNB program priority to assure that progress is maintained.

Oral health has gained strong attention over the past 5 years with the development of a state oral health plan, the formation of the statewide Oral Health Task Force, and Neighbor Island Oral Health Task Forces.

Underage drinking has been a major priority for the state Lt. Governor and has received major federal funding that supports strong statewide and island coalitions. Coalition members include broad based support from prevention, treatment, and enforcement agencies and also includes both civilian and military sectors. Prenatal smoking and adolescent chlamydia also have ongoing workgroups initiated as a result of the last Title V needs assessment that are now well established and continue to address these issues.

Three new priority health issues were added this year: bullying, child abuse and neglect (CAN), and developmental screening. These priorities were selected because of quantitative and qualitative data that indicate they are areas of critical need. Over 50% of students in public school reported bullying as a problem in school. In the annual Children and Youth Summit hosted by legislators during Hawai'i's Children and Youth month, bullying was also identified as a serious problem.

A statewide stakeholders survey found child abuse and neglect to be the number one priority issue. This may be due to the virtual elimination of the State's major CAN prevention program (Hawai'i's Healthy Start) coupled with several well publicized cases of family violence and child neglect. Many service providers expressed concern that the downturn in Hawai'i's economy would likely result in greater family violence.

Like much of the nation, data from the 2007 National Survey of Children's Health only 27.2% of children ages 10 months-5 years received a standardized screening for developmental or behavioral concerns. The reduction of statewide services from Hawai'i's Healthy Start Home Visitors which provided regular ASQ screening and elimination of the state funded Preschool Development Screening program have created large gaps in the service system for developmental screening.

Four priorities continue from the previous 2005 needs assessment: child obesity, prenatal alcohol use, unintended pregnancy and transition services for Youth with Special Health Needs.

## **Summary of Needs Assessment Process**

### Goal/Vision of the Needs Assessment

The primary goal of the NA was to build FHSD public health capacity and develop staff leadership capability. To achieve this, nearly all the work for the NA is conducted using FHSD staff. The focus is on identifying state priorities and building partnerships to improve the health of the MCH population. The following principles were used to guide the NA Process:

1. Value the role of partners and community in the NA process
2. Integrate the NA activities into existing planning initiatives/processes when possible
3. Look at feasible changes to improve health, not major paradigm shifts
4. Keep the NA process reality based, select goals that are reasonably attainable
5. Ensure the NA process is evidence-informed
6. Use stakeholders strategically
7. Keep the NA process open and flexible, with on-going evaluation given the changing environment

### **NA Phases/Process**

The NA process involved two phases comprised of two major components:

Phase 1:

Problem definition: identify preliminary list of health issues

Prioritization: identify final list of priorities utilizing specific criteria scoring

Phase 2:

Problem Analysis: identify key goals, targeted behaviors, determinants/influencing factors, existing services

Strategy Design: identify strategies in conjunction with stakeholders

### Leadership

The NA process was planned and managed by a Steering Committee comprised of FHSD senior management to provide guidance, assure progress, and coordinate efforts between work groups.

Neighbor island FHSD Coordinators were also included on the Steering Committee to ensure that the issues are of statewide concern. A workgroup was established for each of the three target populations:

Women and Infants (WI),

Child and Adolescent (CA), and

Children with Special Health Care Needs (CSHCN).

Leadership for each workgroup was provided by senior managers. WI was led by the Women's Health Section Supervisor. CA was led by the Child and Youth Wellness Section Supervisor and CSHCN was led by the CSHN Branch Chief.

Planning for the NA began in 2008 to assure activities would be complete in time for the 2010 deadline. Key evaluation comments from the 2005 NA were considered in designing/guiding NA planning:

1. Strengthen staff involvement across FHSD programs and promote more front line staff participation
2. Strengthen involvement of neighbor island staff and stakeholders

3. Continue to support staff professional development/learning, particularly on problem mapping
4. Improve integration of the NA into on-going programmatic work
5. Ensure NA planning/work is realistic
6. Provide a clear step-by-step process
7. Involve more stakeholders in the process
8. Communicate results to all stakeholders who provide input to the NA process
9. Identify health issues that are specific, not global or vague

### **Issue Identification**

FHSD began work on issue identification at a 2008 Division meeting of over 100 staff and stakeholders. After hearing presentations on the progress achieved on the seven 2005 state priority issues, participants broke up into three population workgroups (CSHN, Women/Infants, Children/Youth) to review existing priority issues and brainstorm lists of emerging issues.

At a NA training for 65 FHSD program staff in January 2009, the 3 population workgroups worked with lists of existing issues to conduct a prioritization exercise and also began to identify key stakeholders that should be involved in the NA. Over the remaining 5 months the population workgroups compiled stakeholder input through stakeholder surveys, reviewed data, and assessed capacity to develop a short-list of issues to present to the NA Steering Committee, which then made the final selection of state priority issues.

Each population workgroup conducted stakeholder surveys including service providers, advocates, and consumers. Working together, staff learned skills in survey design/methodology, electronic methods for survey distribution (Survey Monkey), identification of key stakeholders, the challenges of getting survey participation, understanding how survey is data analyzed and interpreted, and working with limitations of the findings. The Women/Infants group conducted its stakeholder survey early by taking advantage of a statewide Perinatal Summit held in October 2008 as an opportunity to survey stakeholders to identify priority issues for this population. The survey design and analysis of the results were included as part of the NA training in January 2009 on "How to Use Stakeholder Input" by FHSD's epidemiologist. Reports on the stakeholders surveys and the major results are found in Appendix A-1. Reports were shared with stakeholders who were surveyed.

Each population workgroup used a tailored process/criteria to develop the short-list of issues. Groups started with a list of issues numbering from 15-20 from initial input received from staff, stakeholders, literature reviews, and existing data. The results of the stakeholder surveys were used to reduce the list of issues. All three population workgroups used the similar criteria as the basis to select their final list of issues:

- Extent of the Problem (measured by data on HI rates)
- Urgency/Severity (measured by comparison of HI rates to national rates, trend data)
- Amendable to Change (existing best practices/programs in place found to be effective)

The Child/Youth group added two more capacity criteria given the looming threat of staff layoffs and substantial budget cuts:

- Available community resources/partners and
- Available FHSD leadership/staffing

Issues were scored by group members based on the criteria and through consensus final issues were selected.

The CSHN group did not score issues but used a matrix to regroup/reclassify issues to arrive at a final selection. Specific individual CSHCN topics were merged into larger CSHCN topics. For example, the individual CSHCN topics of development-behavior, social-emotional, developmental-behavioral screening, and autism screening could be merged into the larger CSHCN topic of child development. Issues were also assessed based on how CSHCN topics were interrelated, based on the life-course perspective and the interplay of child-, family-, community-, and societal-level factors in influencing health over time (see Appendix A-2).

PowerPoint (PPT) presentations were developed for the final issue selections made by each population workgroup.

### **Priority-Setting**

Final state priority setting was conducted in June 2009 over 2-days in June 2009. In preparation for the June priority setting meetings, the NA Steering Committee identified selection criteria (see Appendix A-3). After the PPT presentations were made on the eleven issues, the Steering Committee members scored the issues using the criteria and eight state priority issues were selected: Bullying, Child Abuse & Neglect, Child Obesity, Prenatal Alcohol Use, Unintended Pregnancy, Access to Specialty Care on the Neighbor Islands for CSHN, Identification of Children with Developmental Delays, and Transition to Adult Healthcare for YCHCN. Because some of the issues were very close in scoring, issues were selected to assure an equitable number of issues were chosen for each population workgroup. The three issues dropped from consideration were: chlamydia, perinatal depression, intimate partner violence.

The Steering Committee had initially discussed selecting only the minimum number of priority issues required by the Title V Block Grant (seven minimum) anticipating the imminent staffing reductions. However, strong arguments were made to retain all eight issues. A letter was sent to thank stakeholders for their input and participation, inform them of the final outcome, and invite participation in further NA work.

### **Formation of Issue Workgroups**

Workgroups were established for each of the eight priority issues led by FHSD staff. A general process for the workgroup was developed by the NA Steering Committee with staff (see Appendix A-4). The process was largely based on the previous NA process with more detailed instructions, staff support, and training.

Issue workgroups were also required to develop problem maps, fact sheets, resource lists, and identify a performance measure (to monitor progress in the annual Title V Block Grant report), and conduct an evaluation/summary of the work completed (to assure staff were honoring their achievements, skills developed, capture lessons learned that could help improve the NA process in the future).

## **Problem Analysis**

The purpose of conducting the problem analysis is to understand the nature of each health issue based on research, data, expert opinion, experience and practice in the field and stakeholder input. Contributing factors, determinants, that influence or are associated with the health issue are identified and can include: key behaviors, risk/protective factors, demographic characteristics, systems issues, or societal influences. The information is “mapped” into separate levels: individual behaviors/attributes, community/institutional, and societal.

Training on problem analysis and mapping was proved for staff in June 2009 because of the difficult this activity generated in the last needs assessment. Staff evaluation comments identified problems with the format selected and the extensive length of the problem maps due to the complexity of the issues selected.

This year a one-day training was held on problem analysis in June 2009 following the selection of the final eight state priorities. The FHSD epidemiologist, a member of the NA Steering Committee, also provided valuable follow-up guidance to the individual issue workgroups to keep the problem maps and research manageable. The CSHN Branch Chief also developed a helpful template that was used for the final issue problem maps. Issue groups collaborated to standardize and modify the original template. Input was also provided by key stakeholders working with the issue groups.

Most of the issue workgroups dedicated several meetings to develop and refine their problem maps. These sessions proved to be invaluable learning experiences among the workgroup participants. Issue leaders shared their experience to help other groups that struggled with this exercise. Neighbor island participation was also invaluable and instructive. Several of the groups used the maps in presentations and circulated the maps to key stakeholders for input to ensure the information was easy to understand. Copies of the issue problem maps are in Appendix A-5.

## **Resource Assessments**

The purpose of the resource assessment and listing report is to capture the major resources that can be utilized to identify and help implement strategies to address the health issue. Resources include programs, services, policies, funding, expertise, key stakeholders. Issue workgroups were asked to develop a list of the ten major programs, services, policy initiatives that affect their health issue and provide a short description of each resource. The resource list also included a description of how the resources have been affected by the economic downturn (loss of key programs, loss of staffing/funding, increased caseloads/needs), if at all. The intent was to make the workgroup identify the key partners/resources rather than just brainstorm a list and get a timely update of the status of resources (i.e. programs and services). Lastly, Issue workgroups were asked to identify any opportunities for new funding or new collaborations (i.e. federal American Recovery and Reinvestment Act funds).

Workgroups employed various methods to complete this task including conducting “environmental scans”, surveys, key informant interviews, other research to get updated information. In the summer of

2009 the national Child Safety Network (CSN) provided technical assistance to further the needs assessment work on the two injury/violence related issues: child abuse and neglect (CAN) and bullying prevention. To assist with the identification of strategies to strengthen the state's service system, FHSD conducted a brief survey of family service programs that help prevent child abuse and neglect to identify potential service system needs in light of the poor economy. A similar scan was conducted for bullying prevention programs. The preliminary results were presented at a November 2009 conference of select stakeholders sponsored by CSN to promote greater service integration. A list of possible strategies was developed at the conference. The results have also been used for the CAN fact sheets and a legislative information hearing. A report for the surveys is being finalized for publication.

Moreover, the TA project provided further TA and experience with survey design and implementation. CSN also provided extensive TA for the analysis of the data and worked closely with the CAN workgroup to produce useful findings to direct strategies.

Many of the direct service staff have found the development of the Resource list particularly helpful for their program work, networking with major agencies and compiling timely updates given the funding and staffing reductions to state programs and services. FHSD staff has also been able to share the impact of the budget cuts on its programs with other agencies.

### **Strategy Design**

Given the current working environment, the Issue workgroups were asked to select 1-3 strategies and plan implementation. A critical part of the strategy design is to identify the strategies in collaboration with the key partners identified through the Resource Assessments. The Issue workgroups were asked to consider evidence-based or recommended practices, determine if any best or promising practices exist in Hawai'i and lastly, to develop a logic model for each strategy. Many of the Issue workgroups are using the dissemination of the fact sheet to generate discussion on strategies with stakeholders, inviting external stakeholders to regular workgroups meetings, conducting key informant interviews, and attending meetings of related groups to collect input. A few groups are also considering short surveys to collect feedback. Collaborative planning software, like "Boardroom", which is being used by other DOH programs are also being investigated.

### **Fact Sheets**

Issue workgroups were asked to develop fact sheets to help build awareness and mobilize stakeholder involvement. A template for the fact sheet was developed to highlight the information/lessons learned through the NA process. Staff are developing essential communication skills to effectively describe their health issue, present one or two key data points, summarize the problem (from the problem analysis), highlight a few major resources (from the resource assessment), and present possible strategies for consideration. The draft fact sheets are attached in Appendix A-6. Many of the Issue groups are circulating the draft fact sheets to engage stakeholders and it has been an effective tool generating some lively, thoughtful discussion and feedback.

## **Performance Measure**

Issue workgroups were also asked to identify a performance measure to monitor progress over the next 5 years for the Title V annual Block Grant report/application. The measures for each health issue are listed in Appendix A-7.

## **Refining of Issues**

With the capacity of FHSD decreased by state budget cuts, elimination of programs, and imminent staff reductions and early retirements, FHSD decided to eliminate one of the original priorities identified in June 2009: access to specialty care on the neighbor islands. While CSHNB would continue to address this issue through its programmatic work, the FHSD NA Steering Committee decided the scope of the issue was too broad and was largely outside the purview of the Division.

Based on data/information compiled through September 2009, several of the issues were refined to focus on specific target groups. This made the issue work more manageable and helped to further clarify the role of the FHSD in the larger service system.

Because FHSD includes the WIC Service Branch and administers the federal the Early Comprehensive Childhood Systems Child, the child obesity issue focused on children ages birth to 5 years. With the loss of the FHSD Child and Youth Wellness Section, the leadership for this issue is shared with WIC and the ECCS coordinator. Moreover, preliminary findings from the Resource Assessment indicated there was a general lack of attention to this age group since most of the obesity prevention work focused on adults and school age children.

Based on an initial environmental scan, the bullying prevention group decided to focus efforts on adolescent since many bullying prevention programs focused on elementary school children.

The Transition workgroup decided to focus its efforts on transition to adult health care for Youth with Special Health Care Needs versus all aspects of transition. A review of the National CSHCN survey found that all of the survey questions actually pertain to health care transition. The workgroup will partner with other agencies focused on providing transition planning and support services for employment, education, and independent living.

## **Stakeholders**

Input from stakeholders was collected for all steps in all phases of the NA including planning of the process. Various methods were used to assure ongoing input and participation including videoconferencing, telephone conference calls, community meetings, focus groups, coalition meetings, email, surveys and interviews. Stakeholders were used strategically to take advantage of their specific expertise and interest in the NA process. The process has helped to identify new stakeholders and improve working relationships with existing agency partners. Descriptions of the key MCH stakeholders, agencies and programs are provided in the subsequent chapters in this report.

## **Training/Technical Assistance**

Training and technical assistance is an essential component for effective NA implementation. Given the knowledge and practice of the FHSD staff, training is vital to so participants understand the purpose

of NA, the actual process to be undertaken, communication strategies, expected roles and expected results. Trainings included:

- In preparation to plan the NA process, the Title V Steering Committee and key program staff attended a training in July 2007 from Juan Acuna, MD, MPH, who was then serving as Medical Epidemiologist and MCH EPI Team Leader with the Centers for Disease Control's (CDC) Division of Reproductive Health. Dr. Acuna presented on "How to use data to inform program planning."
- In January 2009 FHSD's former Title V CDC-assigned epidemiologist, Dr. Cheryl Prince conducted a 2-day training with the assistance of FHSD Division Chief Loretta Fuddy and Epidemiologist, Don Hayes on NA. The presenters utilized the curriculum from the federal MCH Bureau NA training conducted at the National MCH Epidemiology Conference the previous December. The steps of the FHSD NA process was also presented and exercises conducted with staff on prioritizing issues and identifying stakeholders.
- In August several Title V staff attended a 3-day training on Public Health Core Skills Development. The training was sponsored by the DOH Injury Prevention Program and the Chronic Disease Management Branch. The trainings focused on the "Getting to Outcomes" framework which was designed to help increase capacity of prevention programs through effective planning, implementation and evaluation. Lessons from the training were incorporated into the NA process.
- Dr. Acuna returned in June 2009 after priority setting was completed for the NA and conducted a one-day training on problem analysis and mapping. He followed up with half day meetings with each of three NA population workgroups to address specific concerns.
- To build staff resiliency and capacity to cope with the dramatic changes at FHSD and DOH, Beth Terry, a professional organization consultant and trainer, conducted a half-day training on "Managing Organizational Change," at a November Division meeting. Over 40 of the FHSD employees who would be leaving FHSD due to Reduction in Force (RIF) were also honored at that meeting.
- FHSD partnered with DOH Injury Prevention and the national Children's Safety Network to develop a state training program and toolkit, **Weaving a Safety Net**, that assures injury and violence prevention are integrated into Maternal and Child Health programs. A two-day training was conducted on promoting collaboration and service integration with a focus on the two violence related NA issues (CAN and Bullying Prevention). Stakeholders were invited and initial strategies were identified.
- Other training opportunities provided to staff include: Developing Logic Models, Facilitation Training, Developing Effective Public Health messages.

#### Data Publications

This NA report presents a summary of the data reviewed during the course of the FHSD NA. Instead, FHSD chose to develop a number of separate data publications to support ongoing NA efforts. The reports serve as routine surveillance publications to monitor the health for the MCH population and provide updates on FHSD services and programs. FHSD intends to periodically update the publications over the next five years as resources permit. The leadership and efforts of the CDC-assigned MCH Epidemiologist, Don Hayes, and resources from the federal State Systems Development Initiative grant have been essential to support the achievements in this area. The publications include:

A **Compendium of Perinatal fact sheets** publication was completed using PRAMS, hospital

discharge data, and vital statistics data in October 2008. It provided data on trends and disparities on important perinatal health issues for the statewide Perinatal Summit. The data was used to assist perinatal health stakeholders to complete a NA survey to identify priority health issues for this population.

The **Family Health Services Division Program Profiles** was published in August 2009. This report was intended to serve as a reference for the various populations served by FHSD and the health issues facing these vulnerable populations. In addition, the profile provided a description of the various programs within FHSD, its activities and progress on improving the health statistics and outcome measures tracked by FHSD including many Title measures.

In January 2010, the Division published the **Hawai'i Primary Care Needs Assessment (PCNA)** databook, one of the few state health publications with community level data. The Data Book serves as a source of comparative health statistics on 28 primary care service areas in the state. The book demonstrates significant differences in risks related to geography, race-ethnicity, gender, age, education, poverty and other factors that may explain observed disparities. The document highlights a number of MCH health indicators like infant mortality and prenatal care that utilize the linked infant birth and death certificate dataset. The publication has been expanded this year to include indicators developed in collaboration with an advisory group comprised of members from the state Primary Care Association including many of the neighbor island community health centers. More than 500 copies have been distributed statewide and has served as foundation for many community grant applications.

After 10 years of administering the PRAMS survey, a Hawai'i PRAMS **9-Year Trend Report** is scheduled for release in July 2010. The report includes the first eight years of PRAMS data from 2000-2008 (the latest available data from the Centers for Disease Control) on 16 key health issues. Over 500 copies of the 100-page report will be printed and distributed to policy makers, health care professionals and perinatal service providers. The document will be the first major PRAMS publication and will help promote the importance of the data source for increasing awareness about important perinatal health issues.

FHSD developed a report on **Hawai'i Children's Health Disparities** based on the 2007 National Survey of Children's Health. This report highlights 22 child health indicators representing the following: 1) physical, mental, and dental health, 2) health care access, quality, and insurance coverage, and 3) community, school, and family life/health. Disparities for each indicator was assessed by age, race, gender, federal poverty level categories, and insurance type.

#### **Needs Assessment Priority Health Issue Fact Sheets**

Work is being completed on the development of fact sheets for each of the seven state MCH priority health issues (see Appendix A-6). Data from PRAMS, YRBS, WIC PedNSS, National Survey of Children's Health, National Survey of CSHCN, and vital statistics are some of the data sources used in the fact sheets which are designed to build public awareness for the health issues and mobilize partnerships around collaborative strategies.

#### **Other Issue Fact Sheets**

Additional fact sheets have been completed and are in development addressing intimate partner violence, diabetes during pregnancy, characteristics among women who smoked throughout pregnancy compared to those that quit during pregnancy, obesity during pregnancy and birth outcomes. Also, planned is a fact sheet on adolescent sexual violence.

Future publications include a summary of the National Survey of CSHCN data and a short brochure on the Early Childhood data from the National Survey of Children's Health as requested by stakeholders. The targeted publications are much more user-friendly than a comprehensive compilation of MCH data. Consultation with stakeholders is being collected to improve existing publications and identify new

projects. Data for this report was largely drawn from these publications.

### **Strengths/Weaknesses of the NA Process**

The information from this section is derived from summary reports by the NA Issue workgroups that reported on the work completed over the past year and also provided evaluation comments on the NA process conducted with the Issue groups. Just a few areas are highlighted for review due to limited time.

Two groups did not submit summary reports for inclusion. This may be reflective of the groups' lack of engagement with the NA process. Staff and management will focus efforts on these two groups as the NA process continues.

#### Leadership Development

For many of the staff, providing leadership for a new programmatic area was and continues to be challenging. Many are accustomed to working in well-structured, well-defined program settings which change little from year to year. The NA process allowed participants to develop essential leadership skills including problem solving, facilitating/implementing change, strategic thinking, collaboration/team stewardship, many forms of communication, system thinking, conflict management, meeting facilitation, and relationship building. Most importantly, the process supports group learning and self-development in a relatively comfortable environment since many of the tasks and responsibilities differ from regular program work. Comments reflect the difficulty of the NA work (which is often very new for many program staff), but also reflect learning and skills development that occurred as challenges were overcome and problems were addressed.

The largest criticism of the NA process is its lack of structure and "vagueness" which made goal setting and achievement challenging. This criticism was made during the last NA and efforts were made to provide more structure in this 5-year cycle. However, the diverse nature of the issues (some well established, others just emerging), the varied service system and stakeholders may prohibit a NA process that is too highly structured. The lack of structure does create a challenge for staff who must address high levels of uncertainty, somewhat ill-defined tasks, respond to situational demands, and most importantly solve problems. Staff were provided general process guidelines and were given substantial flexibility and; importantly, the authority to develop approaches to complete each of the NA tasks. Thus, slowly participants developed ownership over the NA process. Ideas and innovations were shared among the Issue workgroups that helped to improve the content of the products and will be used to "structure" the process in the future.

To ensure adequate progress was made throughout the process, Division staff provided ongoing guidance for many of the Issue workgroups which was identified as crucial in evaluation comments. Strategic involvement by senior management was also found to be helpful particularly with providing vision/direction in problem solving, assistance with decision-making activities, knowledge about important information resources, and greater understanding of larger system issues and stakeholders.

Although progress was varied among the Issue groups, those workgroups that met most consistently over the past year have clearly learned the most and enjoyed being actively engaged in the group

process, and engendering a real camaraderie that improves collaboration within the Division overall.

The other major area of weakness is ensuring active involvement of neighbor island staff and stakeholders. Many of the workgroup meetings are held via teleconference and meeting facilitators must be vigilant to engage neighbor island staff during meetings and prevent discussions dominated by Oahu/Central office participants. Neighbor island staff acknowledged the challenge of participation but expressed deep appreciation for being involved at such a high level with the NA this year.

Limited travel funds allowed the neighbor island FHSD coordinators to attend monthly meetings of the child health issues groups (CAN, Bullying and Obesity). All three meetings were scheduled on the same day to accommodate the FHSD coordinators participation and assure a high level of statewide collaboration. Thus, a unique feature of this NA process was the emergence of strong leadership from the neighbor islands, who are generally more successful and innovative at cross-agency collaboration/integration than Oahu due to their small size, the critical service needs of their rural communities, and limited resources. Several neighbor island models and tools for stakeholder collaboration have been utilized/examined to improve efforts on Oahu.

The training and TA provided by the national Child Safety Network were also acknowledged as helpful to expand the scope of the NA activities. CSN was able to develop environmental scans, sponsor a training and conference to convene stakeholders for the violence-related NA issues. The CAN Issue group reported,

“The process was able to capture the participation, feedback and input from the broad prevention community and... gave participants an opportunity to execute an intensive team-based action learning process which strengthened and increased multi-disciplinary and multi-organizational collaborative partnerships.”

The CSN TA did raise another weakness of the NA process, which was a lack of dedicated funding for TA to design and facilitate the NA activities and process.

Another major strength of the NA process was the opportunity it afforded staff to understand the larger service system (to move beyond daily program work and traditional stakeholders). For the Child Development group,

“the general consensus is that the NA process helped us look at the bigger picture of the system from our different programs. As one team member stated, “The process was enlightening. It provided an opportunity to get a better understanding of the big picture in terms of needs and to have rich discussions to focus on addressing specific needs.”

Another weakness identified focused on the heavy workload required by the NA process which some participants felt resulted in reduced participation. Further discussion with the workgroups will continue and efforts will be made to modify the NA process if necessary.

Staff also raised concerns about the timing and appropriate content of some of the NA training. Some of the training was at a level beyond the ability of the Division staff. More specific/targeted training is also being requested to assist with the development of the NA products (conducting a literature review, developing a logic model, methods to engage stakeholders, developing a fact sheet, using and interpreting data). Other requests have included understanding reliable resources and data; evidence-

based programs and evidence-informed programs; an overview of public health; outcome accountability; and an overview of plan development. Because staff recognize the value of ongoing NA, the suggestion was made to build capacity to offer in-service training opportunities since there are staff who could provide instruction in these areas. Greater effort to identify external training opportunities for staff will also be made. Training on larger cross-cutting skills are also being requested: developing effective public health messaging, use of social marketing and networking technology, website design and maintenance.

Generally, staff found the NA products beneficial. The development of tools (fact sheet, problem map, environmental scan, literature review) helped to build knowledge and skills about the issue and helped new and ongoing partners to gain trust and respect of each other as the products were developed in collaboration. The sharing by partners through this process has led to a better understanding of the gaps in services (including training and staffing needs) as well as a better understanding of what services existed and have been lost due to the economic recession. The NA assessment has positioned FHSD to take advantage of a great desire among service system providers and stakeholders to seek greater collaborative opportunities and get more timely information as changes occur.

The next major challenge for most of the Issue workgroups is actively engaging external stakeholders to identify the 1-3 collaborative strategies to address the seven issues. Learning to work with stakeholders to build partnerships is the most challenging part of the NA process. Training, ongoing support of the workgroup members and mentoring from senior staff will be essential.

As noted earlier, the NA work occurred in the midst of tremendous change and stress for FHSD staff. All of this had a serious impact on staff productivity and morale. However, it is truly commendable that most FHSD staff participated in the NA with sincere dedication despite the difficulty of balancing ongoing program work, additional responsibilities, new working conditions with less time and compensation. The increased collaboration and camaraderie developed through the workgroups helped staff process and cope with the new stressors and changes.

FHSD will build on the lessons learned and continue ongoing evaluation with all NA participants to strengthen the process to assure improved outcomes.

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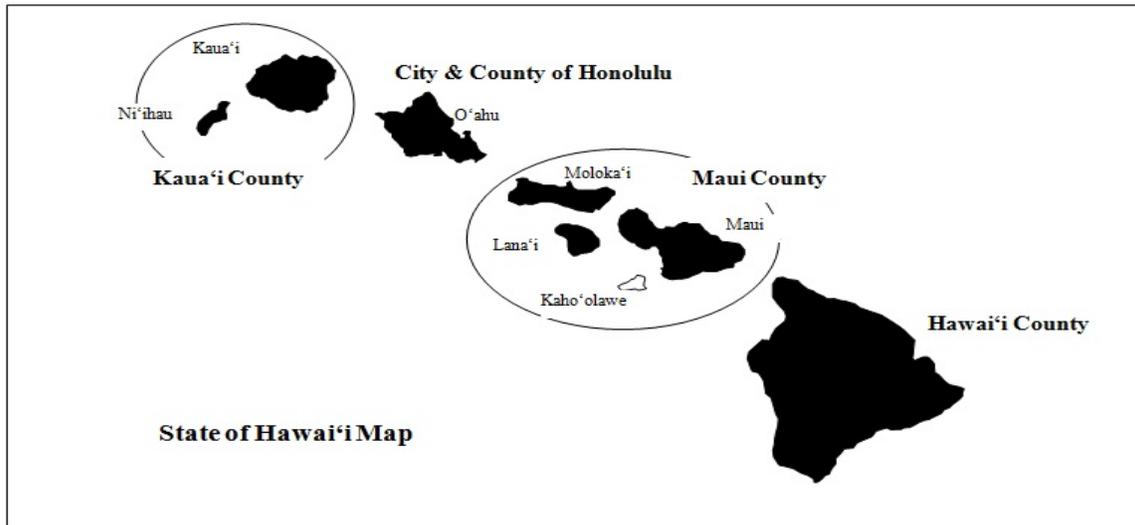
## **CHAPTER 2:**

# **OVERVIEW OF THE STATE OF HAWAI'I**

## Population and Ethnic Diversity

The State of Hawai'i is composed of seven inhabited islands within four major counties, amounting to 6,423 square miles of land area with an estimated total population of 1.8 million in 2008. Figure 1 shows a layout of the islands.

**Figure 2-1. State of Hawai'i**



The City and County of Honolulu encompasses that entire island of Oahu and contains the majority of the population (71.2% of state residents). Honolulu is considered the only urbanized area in the state. The neighbor island counties are Hawai'i, Kauai (includes Niihau island), and Maui (includes Molokai, Lanai and Kahoolawe). Together, the neighboring counties represent only 28.8% of the State's total population. Refer to Table 2-1 for a summary of the population distribution for the state by county.

Overall the state grew by 6.3% between 2000 and 2008.<sup>2</sup> Hawai'i County experienced the largest growth between 2000 and 2008, an 18% increase, followed By Maui County (12%) and Kauai County (9%). Honolulu County experienced a 3% increase over the same time period.

Hawai'i		Honolulu		Kauai		Maui		State of Hawai'i
No.	%	No.	%	No.	%	No.	%	
175,784	13.6%	905,034	70.3%	63,689	4.9%	143,691	11.2%	1,288,198

Source: U.S. Bureau of the Census, Federal-State Cooperative Program for Population Estimates, "Time Series of Hawai'i Intercensal Population Estimates by County: April 1, 1990 to April 1, 2000". Hawai'i State Department of Business, Economic Development & Tourism, State of Hawai'i Data Book 2008.

<sup>2</sup> Hawai'i State Department of Business, Economics Development and Tourism. Subcounty Population Estimates. <http://www.hawaii.gov/dbedt/info/census/population-estimate>. [accessed online July 12, 2010]

Hawai'i's population, like the nation as a whole is aging. The median age of the population has increased from 36.2 years in 2000 to 38.0 years in 2008, higher than the national average of 36.7. The trend toward an aging population is displayed in Table 2-2 through a comparison of the age distribution between 2000 and 2008. There were increases in the proportion in those 20-34, 55-74, and 75 years and older, while the proportion of children and youth age 0-19 years and younger adults 35-54 years decreased. The largest increase was among the elderly, those 75 years and older, representing a 33% increase since 2000, followed by a 26% increase among those 55-74 years of age.

<b>Table 2-2. Comparison of Age Distribution 2000 &amp; 2008</b>				
<b>Ages</b>	<b>2000</b>	<b>% of Total</b>	<b>2008</b>	<b>% of Total</b>
0-19	327,251	27.0%	318,290	24.7%
20-34	254,568	21.0%	273,815	21.3%
35-54	362,156	29.9%	354,020	25.7%
55-74	192,223	15.9%	241,691	18.8%
75+	75,339	6.2%	100,382	7.8%
Median Age	36.2 years	*****	38.0 years	
Source: U.S. Census Bureau, Population Division, "Table 2: Annual Estimates of the Resident Population by Sex and Age for Hawai'i: April 1, 2000 to July 1, 2008. Hawai'i State Department of Business, Economic Development & Tourism, State of Hawai'i Data Book 2008.				

The proportions of females in the population in Hawai'i are generally more evenly distributed than males who have higher proportions at younger ages. It is estimated that 6.0% of the female population is 80 years and older, compared to 3.8% of the male population. At the other extreme, 12.2% of the female population is under 10 years of age compared to 13.0% of the male population. The transition appears to occur around age 40, when the proportions of females begin to exceed the proportions of males in the age groups shown.

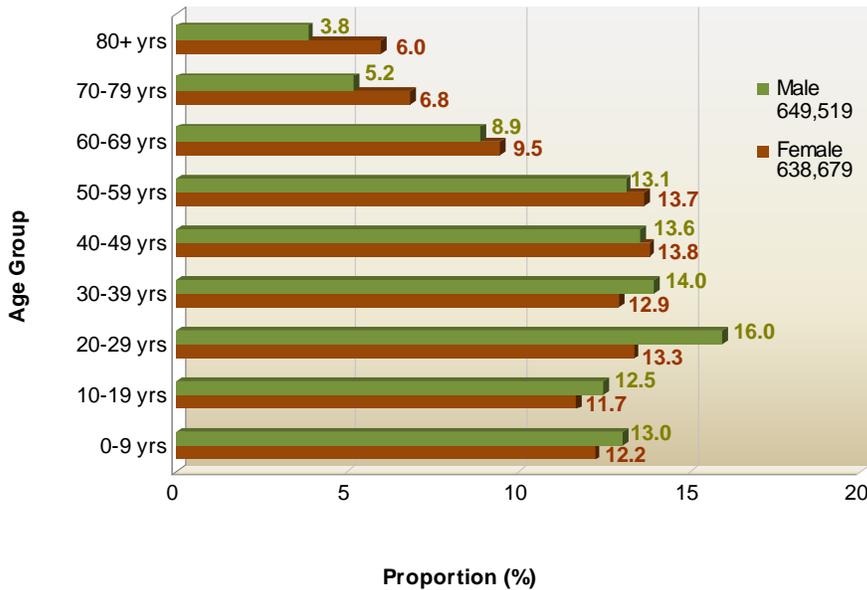
Like the nation, there are slightly more women than men living in Hawai'i. This is due largely to women's longer life expectancy (78.2 years for men compared to 83.3 years for women) in Hawai'i<sup>3</sup> The average life expectancy=in Hawai'i is greater than the U.S. overall (80.8 years in Hawai'i compared to 77.8 years for the U.S.).

The birth rate in Hawai'i (14.8 per 1,000 population) is similar to that of the nation (14.2 per 1,000).<sup>4</sup> There has been little variability since 2000 in the birth rate (range 14.0-14.9) in Hawai'i. The fertility rate in Hawai'i (73.9 per 1,000 women aged 15-44 years) is higher than that of the nation (68.5 per 1,000). The death rate in Hawai'i in 2008 (7.3 per 1,000 population) represents a small increase from 2000 (6.7 per 1,000).

<sup>3</sup> Hawai'i State Department of Business, Economic Development & Tourism, State of Hawai'i Data Book 2008.

<sup>4</sup> Ibid, Table 2-11.

**Chart 2-1 State of Hawai'i, Population Proportions by Age and Sex: 2008**



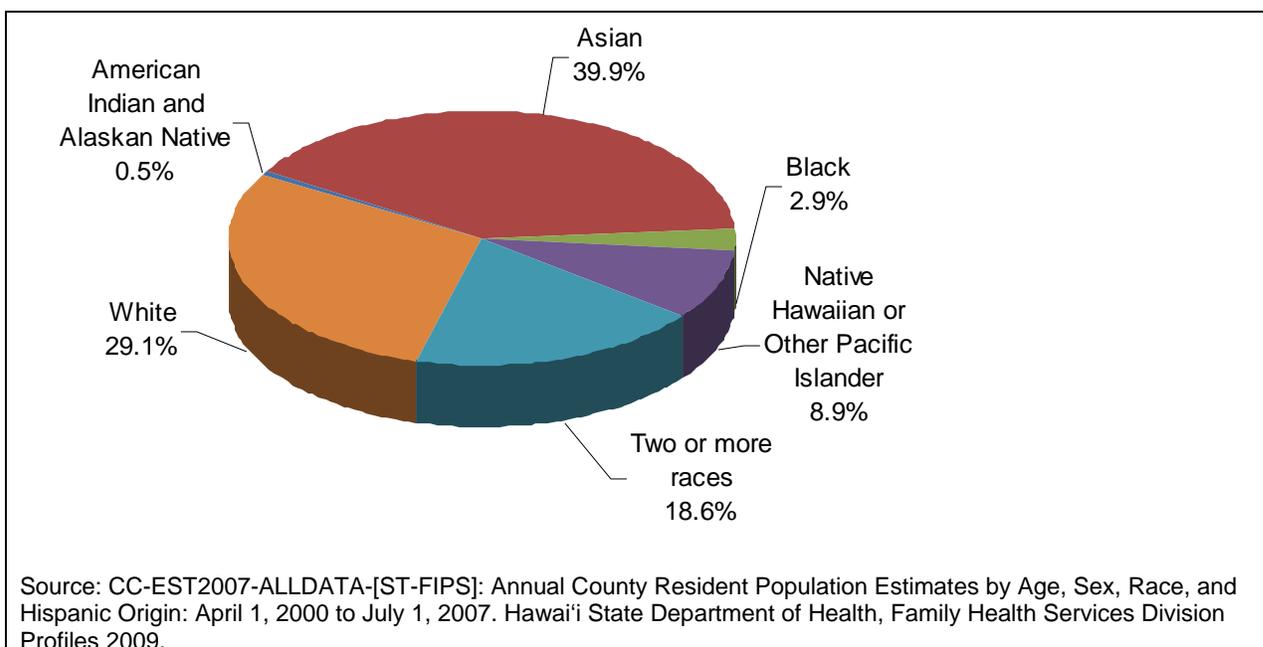
Source: CC-EST2008-ALLDATA-[ST-FIPS]: Annual County Resident Population Estimates by Age, Sex, Race, and Hispanic Origin: April 1, 2000 to July 1, 2008.

The state's indigenous population of Native Hawaiians is descendents of the original inhabitants that settled the islands in 300AD. Prior to Western contact, Hawaiians developed a vibrant, sophisticated culture and a stable land tenure system that supported an estimated population of 1,000,000 people. Over 200 years of western colonization have left Hawai'i's indigenous population with some of the poorest statistics for health and mortality.

The racial/ethnic composition of Hawai'i is unique in the U.S. with no clear majority population, a large Asian, and a large proportion of those that report more than one racial group. Based on census bureau estimates that includes the ability to select more than one racial group, 18.6% of the population in Hawai'i report two or more races. The Native Hawaiian or other Pacific Islander single race group makes up only 8.9% of the population; whereas, the Asian group (which includes all Asian ethnicities) makes up 39.9% of the state population; and the White group makes up 29.1% of the population.

The racial categories typically utilized at the national level are not useful for the state in tracking disparities. African-Americans and Hispanics are large minority groups within much of the U.S., but are small groups within the state. However, Asian, Native Hawaiian, and Pacific Islander groups comprise most of the state population but are so small at the national level the groups are combined into one broad category.

**Chart 2-2 State of Hawai'i, Population by Race: 2008**



Intermarriage is common in Hawai'i and many individuals claim multiple ethnic identification. The local culture tends to celebrate the presence of multiple ethnicities making assignment to any one category difficult as individuals are reluctant to choose a single category and may change their identification over time and under certain circumstances. In the 2000 Census more than 20% of Hawai'i residents reported being multi-ethnic/racial categories compared to 2.4% for the nation. As the trend toward multiple ethnicities increases, tracking the population by single ethnic categories will become more problematic.

The health among race/ethnic groups in Hawai'i varies considerably for the majority of health indicators. However, the overall pattern of health within the state is that the Japanese and Chinese populations often engage in more protective behaviors and experience lower rates of disease and death compared to Whites, Filipinos and particularly Native Hawaiians.<sup>5</sup>

In addition to the ethnic diversity in the State, there are many sub-populations that impact the economy and health care systems. The presence of the U.S. Armed Forces has been well established in Hawai'i but decreased in the 1990s. The 2000 U.S. Census Bureau estimates indicate the Armed Forces (both military members and their dependents), comprised 6.8% of the total resident population of the State, a drop from 10.6% in 1990.

Hawai'i is considered a gateway to the U.S. for immigrants from Asia and the Pacific. According to U.S. Census and the Immigration and Naturalization Service, 17.8% of Hawai'i's population is foreign-born, the 6<sup>th</sup> highest percentage.<sup>6</sup> Nearly 35,000 immigrants were legally admitted to the state between 2005 and 2009 mainly from the Philippines, Japan, Korea and Vietnam. Smaller groups of Hispanic

<sup>5</sup> Hawai'i Outcomes Institute, *Toward a Healthy Hawai'i 2010*. Honolulu, 2005. p. 15. Report is available on [www.hawaiioutcomes.org](http://www.hawaiioutcomes.org). The report presents ethnic comparison data for the major HP 2010 objectives for the state

<sup>6</sup> Source: U.S. Census Bureau, 2008 American Community Survey, "Percent of People Who Are Foreign Born" [http://hawaii.gov/dbedt/info/census/ACS2008/acs\\_2008\\_rank](http://hawaii.gov/dbedt/info/census/ACS2008/acs_2008_rank)

immigrants have settled in parts of Maui and Hawai'i island, attracted by jobs in tourism and agriculture.<sup>7</sup> Estimates of illegal immigrant in Hawai'i range from six to nine thousand.<sup>8</sup>

Because of this ethnic diversity, there are a number of people who speak English as a second language. In 2008, approximately 7.8% (13,791) of the state's public elementary school children were enrolled in the Students with Limited English Proficiency Program. According to the Governor's Council on Literacy, over 155,000 adults or an estimated 16% of Hawai'i's adults are functionally illiterate. The 2008 Census reports that 254,172 people in Hawai'i speak a language in the home other than English.

## **Geographic Characteristics**

The geographic distances between islands are considered immense and are one of the challenging and unique aspects of the State of Hawai'i. The four major counties in the State of Hawai'i are comprised of seven major islands where the vast majority of the population resides.

### Oahu

The island of Oahu comprises all of Honolulu County. It is only 608 square miles but accounts for approximately 71% of the total population. There are four main geologic provinces, which influence its population structure and impact accessibility to services. There are two mountain ranges, a central plateau, and a coastal plain.

Oahu also contains the capital city of Honolulu, the only major urban center in the State. It is the primary center for tourism (the dominant industry for the State) as well as the majority of other economic activity shaping Hawai'i's economy such as heavy industry, shipping, retailing, and the U.S. military. There is also a small, diversified agriculture industry, the remnants of a once viable plantation agricultural industry. Oahu has an extensive roadway system that connects the major sections of the island and encompasses most of the perimeter of the island. There is also an excellent public bus system, which provides service to most of the island.<sup>9</sup>

### Hawai'i

The island of Hawai'i, also known as the Big Island, is the only island comprising Hawai'i County. It is the farthest west of all of the inhabited islands. The primary urban area is Hilo, which also serves as the county seat. Hilo has a resident population of approximately 47,386 people. Located on the opposite side of the island from Hilo, Kailua-Kona has grown rapidly to 37,132 residents.

Hawai'i is the largest of all the islands with an area of 4,039 square miles and contains two large volcanic mountain peaks which reach elevations 3,000 feet higher than any neighboring islands. Of the five total volcanic mountains on the island, two occupy approximately 73% of the entire land mass, one of

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7 Hawai'i State Department of Business, Economic Development & Tourism, State of Hawai'i Data Book 2008. Table 1.61.

8 Yasmin Anwar, "Immigration: Little Room for Leniency," Honolulu Advertiser, February 23, 2001, p A14.

9 Geographic information about Hawai'i largely from Sonia P. Juvick & James O Juvick, Ed. Atlas of Hawai'i (Honolulu: University of Hawai'i Press, 1998). Census data from Hawai'i State Department of Business, Economic Development & Tourism, State of Hawai'i Data Book 2002. Honolulu, 2002. <http://www.hawaii.gov/dbedt/>

which, Mauna Loa, remains active. The other active volcano is Kilauea. The economy is driven primarily by tourism and diversified agriculture, such as papaya, macadamia nuts, Kona coffee, and flower exports. There are large land areas owned by the U.S. Armed Forces; however, this area is used primarily for training with essentially no year long residents.

The Big Island has a limited roadway system developed largely along the perimeter of the island. This is primarily due to the extensive land areas occupied by the volcanoes. Only one road dissects the island and is considered relatively unsafe due to climactic changes at various altitudes combined with limited maintenance. The mass transit system is also limited with respect to bus service connecting Hilo with Kailua-Kona. Limited bus systems exist within each community; however connecting service is infrequent. Both communities contain airports with connecting service to neighboring islands.

### Maui County

Maui County is comprised of four islands, Maui, Molokai, Lanai, and Kahoolawe. The island of Maui is the second largest in terms of land mass but is still significantly smaller than Hawai'i Island with 729 square miles. Molokai is only 261 square miles and located south of Maui Island. Lanai lies directly south of Molokai and is 140 square miles. Kahoolawe, the smallest of the islands, is uninhabited.

### Maui

Maui consists of two large volcanic mountains, one being extinct and the other, Haleakala, considered dormant. Maui's economy is solely based on tourism and agriculture. It is the only island that still grows sugar and pineapple in the State, although both industries are relatively small. The remaining agriculture is heavily diversified. There are large cattle ranches, onion and potato farms, and flower exports. There are no military installations nor is there military land use.

The entire population of Maui County is approximately 138,347, with the majority living on Maui Island. The city of Wailuku is the county seat and has a population of approximately 12,525. The larger commercial center of Kahului contains approximately 20,134 people and is the location for the principal harbor and airport. The center for tourism is located in Kihei, with approximately 16,264 residents. The fourth largest town is Lahaina with approximately 9,201 people is Maui's second major tourism center.

### Molokai

The island of Molokai is predominantly rural and has a large population of Native Hawaiians. Physically, it contains two volcanic mountains with its population of approximately 7,257 living in all habitable parts of the island. Since the closing of the pineapple plantations in the early 1980's, Molokai has experienced little economic development, thus the island has extremely high unemployment. Tourism has been floundering. Cattle ranching and diversified agriculture continue as the viable economic activities. To supplement incomes, many families on Molokai rely on subsistence activities like fishing and small-scale farming. The Department of Hawaiian Home Lands and the island's major private landowner, Molokai Ranch, have large landholdings in central and west Molokai. It has one small airport with service to neighboring islands.

### Lanai

Finally, the island of Lanai has a population of roughly 6386 residents. The island had been dominated by a plantation economy with 98% of the island formerly owned by the Castle and Cook Company which cultivated pineapple. Over the past decade the plantation has closed and is under new corporate ownership. Recently, Lanai's primary economic activity has focused around two new luxury resort hotels. Lanai has a small airport providing service to Honolulu, Maui, and Molokai.

#### Kauai

Kauai County is comprised of the island of Kauai and Niihau. Kauai is 72 miles to the Northeast from Oahu and is 553 square miles. It is considered the oldest of the islands and is known for its single volcanic mountain in the center of the island. Mt. Waialeale, the mountain peak is estimated to receive more rainfall than any place in the world. Residents number approximately 58,463 with the population center in the town of Lihue. The population is ethnically diverse and includes pockets of immigrant groups that pose cultural and linguistic barriers to services. Lihue is also the site of the island's airport. There is limited transportation services on the island, thus access to primary commercial areas is difficult. With the continued closing of large plantations in the past decade, the primary industry remains tourism, military land use, and diversified agriculture.

#### Niihau

The island of Niihau is quite unique compared to the other islands in the State because the entire island is privately owned. The owners prohibit visits by outsiders (including Hawai'i residents) unless the local inhabitants specifically invite them. It is 73 square miles and lies southeast of Kauai by only 17 miles. Since 1864, there has been no infrastructure development on the island. There is no island-wide electricity system, no paved roads, no firearms, no police force, and no medical provider. The small population of approximately 160 is largely 100% Hawaiian (a rarity in the rest of the state) and are the last remaining community of native speakers of the Hawaiian language, although English is taught in the one school on the island. The economy is self-sustaining on exported crops of yams, turkey, charcoal, and honey. Many of the residents must travel by barge (3-4 hours travel time) to access health care. There is a small air tour service that is now in operation.

### **Implications for Health Service Delivery**

As the most populated and urbanized island, Oahu (Honolulu County) is the home to the majority of tertiary health care facilities, most of the specialty and subspecialty care, and the one perinatal Level III facility in the state. For the 29.7% of the population residing on the Neighbor Islands, access to health care on the island of Oahu is a financial hardship. The average round-trip airfare is between \$120 to over \$200 with added costs for food, possibly lodging, and local transportation. This hardship is compounded for those neighbor island residents who do not live within a reasonable distance of their local airports. Most of the Neighbor islands have underdeveloped roadways and limited, if any, public transportation or mass transit systems.

Emergency care for trauma and critical pediatrics must use the state's system for emergency medical air transport that consists of only one private company providing fixed wing air ambulance. Economic

constraints have precluded providing consistent rapid transport to tertiary care for neighbor island residents putting them at risk for poor outcomes compared to urban residents.

## **Economy**

National and global economic events have had a profoundly adverse impact on Hawai'i. The tourism industry has suffered severe setbacks. Visitor arrivals decreased by double digits throughout most of 2008 and the first half of 2009. Private construction building permits went into negative territory for the same time period. Hawai'i's unemployment rate, which had stayed consistently below 3% since 2004 and had been among the lowest in the nation. By 2009 Hawai'i's unemployment rates increased to 7.4% with a record 47,000 individuals unemployed. After years of extraordinary growth when Total Personal Income (TPI) was in the range of 6% to 8% annual gains, Hawai'i's TPI registered essentially no improvement in the first half of 2009.

The lowering of the unemployment rate in several years is encouraging. However, the unemployment rates across the islands are quite variable: Oahu 5.2%, Lanai 6%, Maui, 8.3%; Kauai 8.9%, Hawai'i 9.5% and Molokai 11.8%. Another encouraging sign was attendance at a recent job fair of 5,000 people, somewhat lower than the 6,500 that attended last year's fair. The job market was influenced by the addition of 1,600 jobs as a result of federal stimulus funds. Regardless, there are still 42,569 individuals reported as unemployed; and 8% of Hawai'i workers report they work multiple jobs to make ends meet.

Given recent performance, the Hawai'i economy is projected to show a 1.1% growth in 2010; and expected to increase modestly to 1.4% in 2011.

Bankruptcy filing in April 2010 were up 56% from 2009 (391), this is the highest level in four and half years. Bankruptcies have risen for three consecutive months as people continue to experience economic problems due to unemployment or fewer hours worked.

### **Government**

Faced with a \$1.2B deficient for the biennium (out of a \$10B budget) the Governor's response was to cut services to the public by restricting government contracts for health and human services by 14%; instituting 2 day a month mandated furloughs, and to cut more than 800 state funded government positions equating to a 1% reduction in government workforce. Some government agencies were more greatly affected than others; however the overall net effect was less service provision for the general public and vulnerable populations.

The May 2010 State Council on Revenues reported some indication of the economy slowly rebounding with a prediction that FY 2010 will end with a 0.5% increase in tax revenues; in March the Council predicted a 2.5% decline in revenues. The Council now projects a 6% increase in revenues for FY 2011.

### Tourism

Hawai'i's economy is largely driven by the tourism, real estate and construction sectors. The current national recession has severely impacted Hawai'i's primary economic driver, tourism; although the State is beginning to witness some encouraging signs of recovery. According to the Department of Business, Economic Development and Tourism, visitor arrivals are expected to increase 2.6% in 2010 and 4.1% in 2011. This modest increase is welcomed after experiencing a 10.6% reduction in 2008 and an additional 4.5% in 2009 in visitor arrivals. Hotel occupancy rates are beginning to see a modest increase due to marketing reduced hotel rates to encourage visitors. Hawai'i is expected to see 6.7M visitor arrivals for 2010.

### Construction

In September 2009, residential building permits were projected to fall 44% and it has pushed back by a year its forecast for a surge in federal and state infrastructure spending. Year-to-date nonresidential construction permits, valued at \$811 million, were 24% lower than the same time last year.

### High Cost of Living

While Hawai'i has seen some reduction in the cost for single family homes and condominiums, housing costs are still substantially higher than the national average. The median housing cost is \$563,000 for a single family dwelling and \$388,000 for a condominium. In October 2009, RealtyTrac ranked Hawai'i 17th among states for foreclosures. Foreclosures in Hawai'i grew more than 134% from the prior year.

Hawai'i was listed for the fifth straight year as having the least affordable rental units in the Nation. An estimated 44% of Hawai'i residents rent; an average monthly rate for a two bedroom is about \$500-\$2,000 and \$900-\$1,000 for a studio. This often leads to more than one family living within the same dwelling.

While many in Hawai'i have witnessed either a cut in salary or reduction in hours worked; other costs in the community continue to rise. Gasoline prices have risen to an average of \$3.55 per gallon, with cost over \$4 on the neighbor islands. Higher crude oil rates translate into increased cost not only for personal ground transportation, but rate increases for electricity and other consumables that must be imported to Hawai'i. Service/User fees for county level services have also increased.

## Income

The average per capita income in Hawai'i is below the U.S. average. In 2007 the per capita income for Hawai'i was \$39,242. Honolulu exceeds the state average while the neighbor island counties fall below the average. Hawai'i County has the lowest per capita income for the state.

<b>Hawai'i</b>	<b>Honolulu</b>	<b>Kauai</b>	<b>Maui</b>	<b>State</b>
\$29,702	\$42,015	\$33,356	\$35,835	\$39,242

Source: Hawai'i State, Department of Business, Economic development and Tourism, State Data Book 2008, Table 13.10

The average median household income in 2007 for Hawai'i was higher than the U.S. average (\$62,613 for Hawai'i versus \$50,233 for the U.S.),<sup>10</sup> and is represented in the higher costs of living in Hawai'i compared to most other areas of the nation. The latest available county data for median household income is 2007 (Table 2-4).<sup>11</sup> Again Honolulu maintains the highest median household income, exceeding the state estimate, while the neighbor islands fall below the state estimate. Hawai'i County has the lowest median household income for the state.

<b>Hawai'i</b>	<b>Honolulu</b>	<b>Kauai</b>	<b>Maui</b>	<b>State</b>
\$55,779	\$64,849	\$55,786	\$60,435	\$62,613

Source: Hawai'i State, Department of Business, Economic development and Tourism, State Data Book 2008, Table 13.19.

In Hawai'i, higher household incomes are usually associated with increased age, with income levels falling among people age 65 and over. The income distribution between male and female is similar. Income levels vary according to race/ethnicity, with the Japanese, Chinese, and Caucasians being more likely to earn higher incomes.<sup>12</sup>

## Poverty

A particularly vulnerable population that is at risk for a range of poor health outcomes includes those at or below the poverty level. Since 2000, Hawai'i has seen a decline in the percent of the population at or below the poverty level. In 2007, an estimated 8.5% in Hawai'i lived in poverty, below the national estimate of 12.5%.<sup>13</sup>

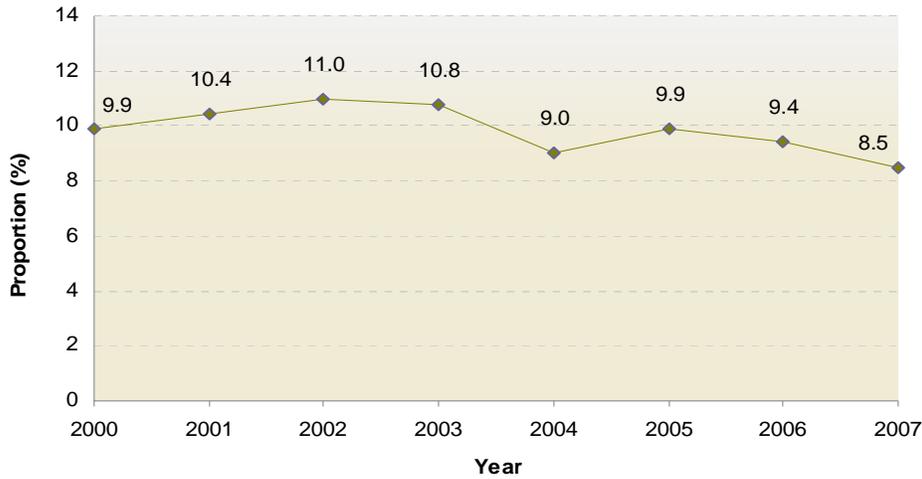
<sup>10</sup> Hawai'i State, Department of Business, Economic Development and Tourism, State Data Book 2008 Update. Table 13.19 & 13.15.

<sup>11</sup> Data for this measure differs from estimates developed for U.S. and Hawai'i comparison.

<sup>12</sup> Hawai'i Outcomes Institute, Toward a Healthy Hawai'i 2010. Honolulu, 2005. p. 16. Report is available on [www.hawaiioutcomes.org](http://www.hawaiioutcomes.org)

<sup>13</sup> 1 Navas-Walt CD, Proctor BD, and Smith JC. U.S. Census Bureau, Current Population Reports, P60-235, Income, Poverty, and Health Insurance Coverage in the United States: 2007. U.S. Government Printing Office, Washington, DC, 2008. US census Bureau

**Chart 2-3 State of Hawai'i, Estimates for All Ages in Poverty: 2000-2007**

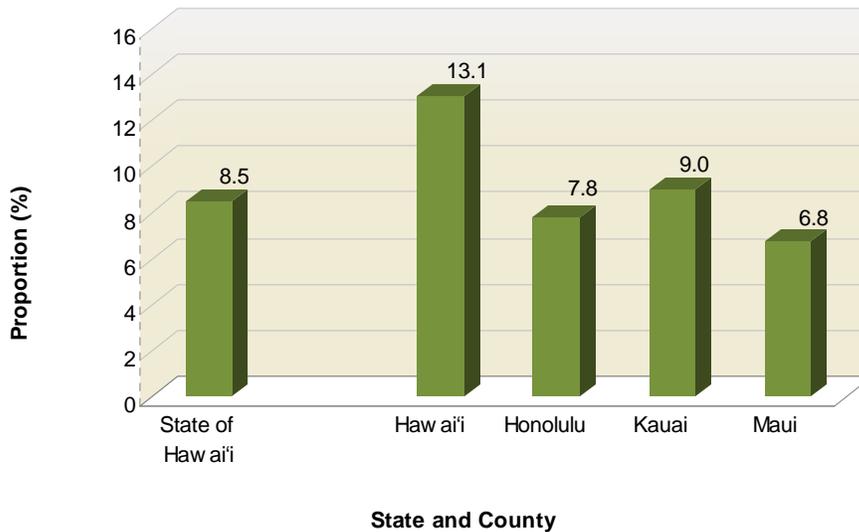


Source: U.S. Census Bureau. Small Area Income and Poverty Estimates (SAIPE) Program.

Note: Beginning with the estimates for 2005, data from the American Community Survey were used in the estimation procedure; all prior years used data from the Annual Social and Economic Supplements of the Current Population Survey. There is uncertainty associated with all estimates in this program. Caution should be used attempting to compare estimates.

In 2007, the highest estimate of individuals living in poverty was in Hawai'i and Kauai Counties with both being above the statewide estimate. Honolulu and Maui Counties had lower estimates of individuals living in poverty.

**Chart 2-4 State of Hawai'i, Estimates for All Ages in Poverty by County: 2007**



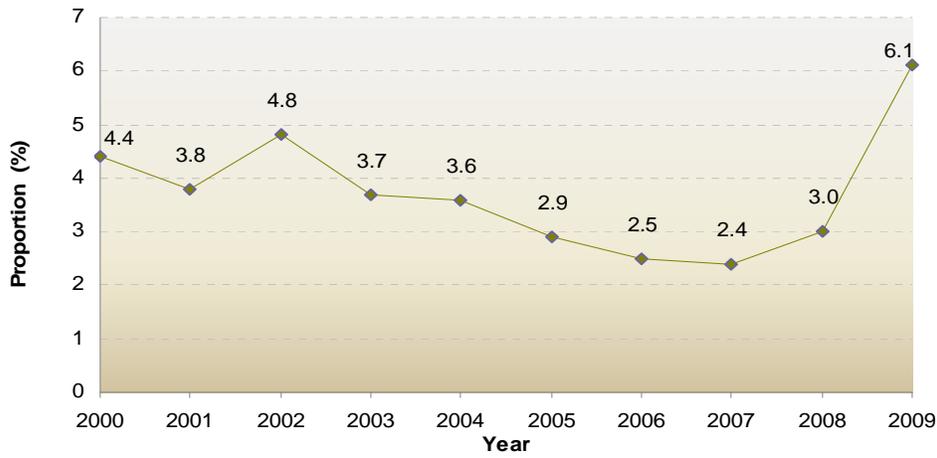
Source: U.S. Census Bureau. Small Area Income and Poverty Estimates (SAIPE) Program.

Note: Beginning with the estimates for 2005, data from the American Community Survey were used in the estimation procedure; all prior years used data from the Annual Social Economic Supplements of the Current Population Survey. There is uncertainty associated with all estimates in this program. Caution should be used in attempting to compare estimates.

## Unemployment

Whether people are employed and working more than one job can have an effect on health status. Different types and amount of employment determine insurance coverage, access to care, variations in income, stress and fatigue, occupational risks, and time to devote to family, exercise and preparing healthy foods. From 2002 to 2007, there was a 50% decrease in the unemployment rate for the state of Hawai'i (4.8% to 2.4%, respectively). Since 2007, the unemployment rate has climbed considerably. Data from January 2009 show unemployment at 6.1% in Hawai'i, below the national rate of 7.6%.<sup>1</sup>

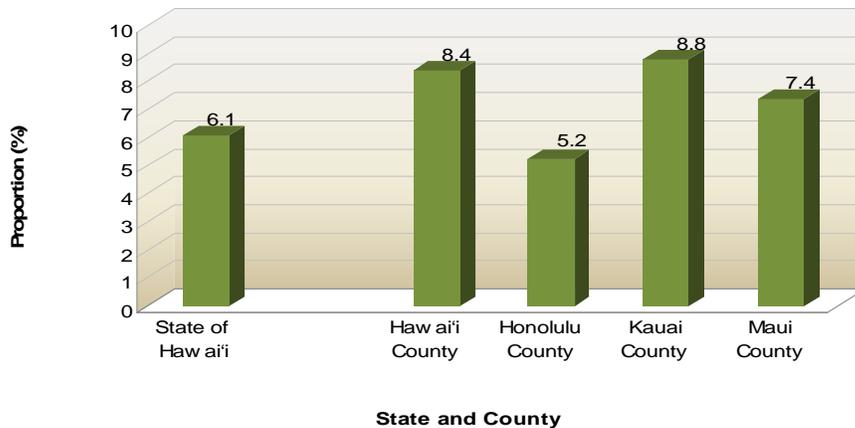
**Chart 2-5 State of Hawai'i, Unemployment Rate by Year (January): 2000-2009**



Source: U.S. Bureau of Labor Statistics Unemployment Rate (seasonally adjusted), 2000-2009. <http://www.bls.gov/data>. Accessed online March 27, 2009.

Unemployment in the State varies by county. In January 2009, Kauai, Hawai'i, and Maui counties all had unemployment rates higher than the state average rate. Honolulu County's unemployment rate, however, was lower than the state average rate.

**Chart 2-6 State of Hawai'i and Counties, Unemployment Rate (January): 2009**

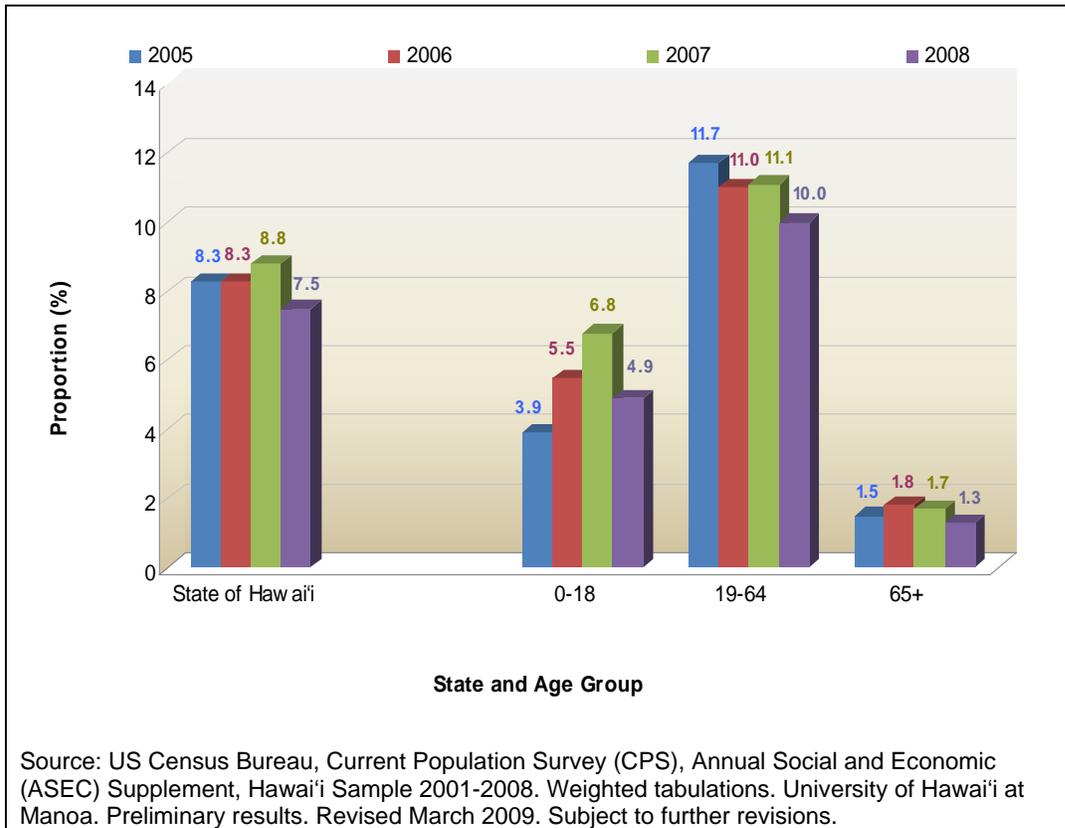


Source: U.S. Bureau of Labor Statistics Unemployment Rate (not seasonally adjusted), January 2009. <http://www.bls.gov/data>. Accessed online Mar 27, 2009.

## Uninsured

Nationally, the rate of uninsured individuals has steadily increased from 2000 to 2007 with an estimated 15.3% of all individuals not having health insurance in 2007<sup>14</sup>. In Hawai‘i, the proportion of the population that is uninsured has generally decreased since 2006, except for those 0-18 years of age which saw an increase in 2006 and 2007 that was followed by a decrease with 4.9% of children uninsured in 2008.

**Chart 2-7 State of Hawai‘i, Uninsured Population, Overall and by Age: 2005-2008**



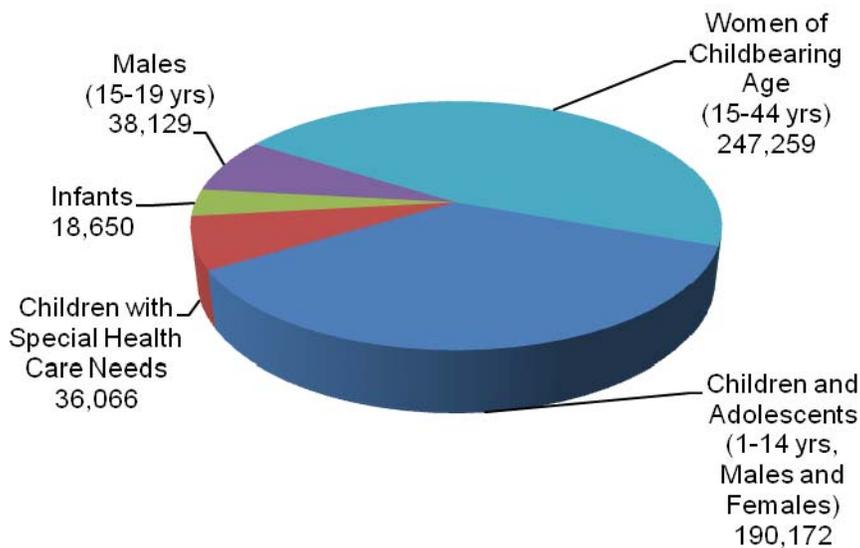
14 Navas-Walt CD, Proctor BD, and Smith JC. US Census Bureau, Current Population Reports, P60-235, Income, Poverty, and Health Insurance Coverage in the United States: 2007, U.S. Government Printing Office, Washington, DC, 2008. US Census Bureau.

## MATERNAL AND CHILD HEALTH POPULATION OVERVIEW

### MCH Population

This section provides an overview of the MCH population and its subgroups for the State. Following this section, the MCH population will be discussed in more detail, specifically, women and infants, children and adolescents, and children with special health care needs. Based on estimates of the Title V target groups, a summary of the MCH population is provided in Figure 2-7. In 2007 the total estimate for women of childbearing age, infants, children and adolescents was 530,276 or 41% of the entire State population. This includes close to 250,000 women of child bearing age, almost 200,000 children and adolescents 1-14 years of age, and just over 36,000 children have special health care needs.

**Chart 2-8 State of Hawai'i, Family Health Services Division Target Population: 2007**



Source: U.S. Bureau of the Census. 2000 Census. U.S. Census Bureau, Population Division, "Annual Estimates of the Resident Population by Single Year of Age and Sex for the United States and States: July 1, 2007" (SC-EST2007-AGESEX\_RES) (May 1, 2008). U.S. Department of Health and Human Services. Health Resources and Services Administration. The National Survey of Children with Special Health Care Needs. 2005-2006

### Geographic Distribution and Racial/Ethnic Composition

The state's unique geography and ethnic/racial composition, relative to the continental U.S., is reflected in the maternal and child health population. The four state counties are comprised of 7 major islands where the majority of the population resides. The distances between islands, the locations of the tertiary and local primary-care centers, ethnic composition, and cultural and language barriers in the state contribute to both the success and difficulty Hawai'i has encountered in meeting the needs of its residents.

Geographically, the distribution of ages is similar in all counties although Hawai'i and Kauai counties had the highest percentage of children under 18 years. This is significant because both counties are two

of the least populated in the state and are both rural areas. With the exception of Oahu, the most populous island, all of the counties demonstrated substantial increases in their population growth in the last ten years.

It is estimated that nearly two thirds of Hawai'i's children and youth (70%) live in urbanized areas, while the remaining one third (30%) live in rural areas. Persons under 19 years of age are more likely to live in the suburbs, while adults are more likely to live in the central urban areas. The State of Hawai'i has no frontier areas.

The ethnic composition of the counties is also diverse creating challenges in service provision and infrastructure design that are both culturally sensitive and community-based. A representation of the ethnic composition of each county is displayed in Table 2-8. The specific health status of these populations will be discussed in the sections following this overview.

Hawaiians are considered to be one of the most vulnerable populations with respect to health and economic indicators. In 2008, Hawaiians comprised 24% of the State's total population. Hawai'i County has the largest proportion of Native Hawaiians in state where they are the largest ethnic group representing 30% of the county population.

<b>Ethnic Group</b>	<b>Hawai'i</b>		<b>Honolulu</b>		<b>Kauai</b>		<b>Maui</b>		<b>State of Hawai'i</b>	
	<b>No.</b>	<b>%</b>	<b>No.</b>	<b>%</b>	<b>No.</b>	<b>%</b>	<b>No.</b>	<b>%</b>	<b>No.</b>	<b>%</b>
Caucasian	54,860	31.9	138,078	15.7	16,707	26.7	46,736	32.85	256,381	20.4
Hawaiian <sup>†</sup>	51,971	30.2	201,331	22.9	17,198	27.4	35,337	24.8	305,838	24.4
Chinese	1,688	1.0	44,706	5.1	405	0.6	968	0.7	45,767	3.6
Filipino	10,455	6.1	106,394	12.1	9,156	14.6	22,768	16.0	148,773	11.8
Japanese	20,279	11.8	179,755	20.4	7,258	11.6	12,915	9.1	220,201	17.5
Others	32,757	19.0	210,042	23.9	11,945	19.1	23,902	16.8	278,646	22.2
<b>Total</b>	<b>172,004</b>		<b>880,306</b>		<b>62,669</b>		<b>142,626</b>		<b>1,255,606</b>	

Source: Hawai'i State. Department of Health, Office of Health Status Monitoring, Hawai'i Health Survey 2008  
<sup>†</sup> Hawaiian includes all those who report being part-Hawaiian.

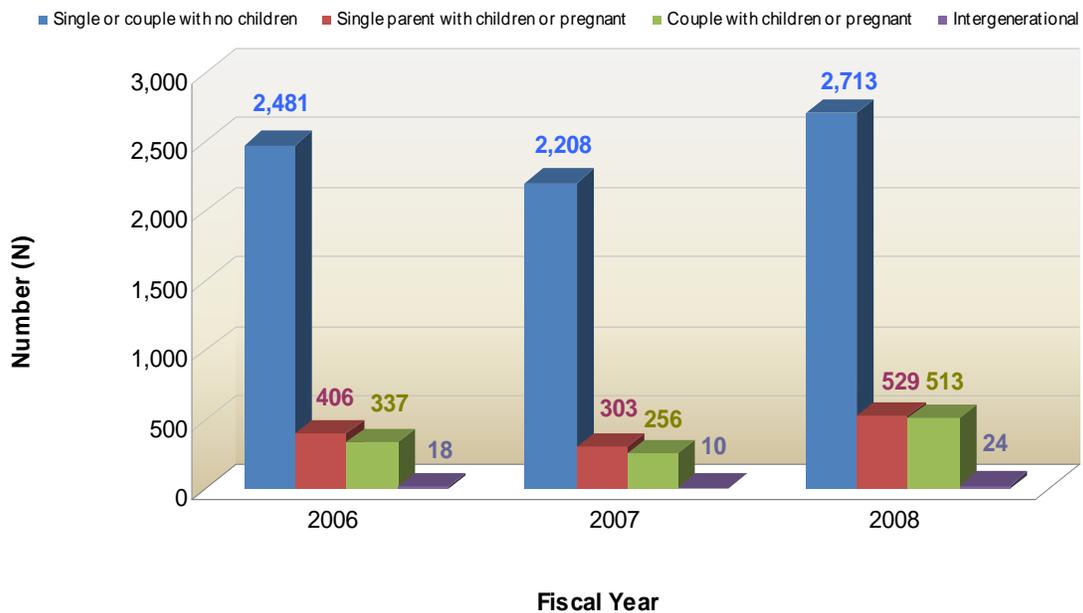
Homeless

Of the 21 cities with data available, 193,183 unduplicated persons used transitional housing or emergency shelters in 2007. Of those people 23 percent were members of households with children, 23 percent were individuals, and one percent was made up of unaccompanied youth<sup>15</sup>.

In Hawai'i, the data on individuals who accessed services from Shelter and/or Outreach Programs that received Hawai'i Public Housing Authority (HPHA) funds show an overall increase in the number receiving services in shelter. In FY 2008, 72% of those receiving shelter services were single individuals, which is a small decrease from previous years.

However, there is a growing concern for the increased number of single (14% in FY 2008 vs. 11% in FY 2007) or couple parents with children (14% in FY 2008 vs. 9% in FY 2007) receiving shelter services. This data only reflects the number of those accessing Shelter and Outreach Programs and thus does not represent all persons experiencing homeless in Hawai'i.

**Chart 2-9 State of Hawai'i, Homeless Service Utilization by Families with Children: 2006-2008**



Source: University of Hawai'i, Center on the Family. Homeless Service Utilization Report.  
 Note: Data reflects Fiscal Year (July1-June 30)

<sup>15</sup> How Many People Experience Homelessness? NCH Fact Sheet #2. National Coalition for the Homeless. June 2008  
[http://www.nationalhomeless.org/publications/facts/How\\_Many.html](http://www.nationalhomeless.org/publications/facts/How_Many.html) [Accessed 4/13/09]

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# **CHAPTER 3:**

**MATERNAL**

**AND**

**INFANT**

## **Introduction**

The health of Hawai'i's mothers and infants is relatively good compared to the nation overall. But, a downturn in the economy and influx of new immigrant groups from Asia and the Pacific may be affecting the health and well-being of the state's women and newborns. Across a spectrum of major health indicators, statewide trends have remained generally stable with no major progress toward greater improvement in population health with a few exceptions such as the continuing decrease in teen births. However, Hawai'i continues to rank in the top half of the states for most health measures including health insurance coverage, and low female mortality rates of for heart disease, and breast and lung cancer.

Despite this general positive overall picture, significant health challenges remain. Like most of the U.S, Hawai'i has witnessed a disturbing upward trend of low birth weight babies and preterm births. There are striking health disparities based on ethnicity, income, and geographic location, especially for Native Hawaiians that are masked when aggregate data is presented. Furthermore, public health infrastructure has been eroded due to budget cuts. The cost of ignoring these troubling trends could result in increased health costs in the future.

## **Women & Infant Priorities**

The State of Hawai'i has recognized the need for improved health services for women to assure healthy outcomes for mothers and infants. As part of the commitment to the health of this population in the state, a Women and Infants (WI) Work Group was convened as a component of the Title V Needs Assessment. Based on a review of the existing MCH priorities, stakeholder input, and review of research and data; the work group submitted a list of five key health issues for consideration as part of the final state priority needs for the MCH population. Using a set of prioritization criteria, 2 final priorities were identified for the WI population group:

- Reduce the rate of unintended pregnancy (including a focus on teen pregnancy)
- Reduce the rate of alcohol use during pregnancy

## **Data Sources**

The data presented in this report is not a comprehensive review of all data of Hawai'i women and children. Since the last needs assessment report, FHSD continues to focus on efforts to improve the health of mothers and children in Hawai'i. FHSD works collaboratively with other divisions and stakeholders to gather and analyze data to inform program initiatives. For the purpose of this report, data from various sources including the Pregnancy Risk Assessment Monitoring System (PRAMS) survey, the Behavioral Risk Factor Surveillance System (BRFSS) survey, the National Survey of Children's Health, Vital Statistics, Birth Defects data, and the use of various reports produced by the division will be highlighted.

Vital statistics provides one of the few types of systematic measures reflecting child well-being that are available fairly consistently across the nation. Of note, Hawai'i is still among the states that have not

adopted the 2003 Revision to the birth certificate so some measures are not directly comparable to data from states that have adopted the revision. The data collected from infant birth and death certificates provide some insight into the conditions at birth that may often shape a young person's life.

## **WOMEN'S HEALTH**

### **Introduction**

Increasingly, the Maternal Child Health profession is embracing the responsibility for issues surrounding women's health. Traditionally, women in MCH were viewed in relationship to childbearing with little attention to women's health during the longer and often more demanding period of child-rearing.

Moreover, recent research indicates that maternal health is one of the most significant factors in assuring healthy birth outcomes. Maternal health is clearly influenced by a complex web of socioeconomic and environmental influences that precede a woman's pregnancy, even by generations. Chronic illness and the general health status of women are important elements in the creation of pregnancy-related risks. The exclusion of these important maternal health factors reduces the effectiveness of existing perinatal services and interventions to improve the lives of infants and children.

Attention on women's health is also important because the reproductive health needs of women require higher utilization of health services during a large portion of their lives (child-bearing years from 15-44). Furthermore, women live longer than men, thus require health services well into their senior years. Women also continue to be primary care givers for children and, often now for aging parents. Yet, women continue to lag behind men in securing the political and economic status necessary to shoulder this important social responsibility. Assuring that women receive continuity of care and adequate access to care before, after and independent of childbearing is a logical extension for the MCH field to assure family well-being.

With this mind, the Family Health Services Division includes in this report a brief section on women's health. On-going assessment efforts in the future will improve data collection and analysis in this area.

Overall, women in Hawai'i enjoy better health than the nation as a whole. In a recent report on the Status of Women in the States published by the Institute for Women's Policy Research, Hawai'i ranked in the top five states for measures on women's health/well-being and reproductive rights and in the top half of states for social/economic autonomy and employment/earnings. In the National Women's Law Center 2004 report, Making the Grade on Women's Health, Hawai'i was ranked 6th among the states. However, the state did receive an unsatisfactory grade, the same grade as the nation received as a whole.<sup>1</sup>

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<sup>1</sup> The National Women's Law Center & Oregon Health & Science University, Making the Grade on Women's Health. Washington, D.C., 2004

## **Demographics**

In 2008, the Hawai'i population was nearly 1.3 million with females representing 49.5 % of the total population, or approximately 640,000 women and girls and nearly 650,000 men. More than half (50.4%) of women were under the age of 39. There are more men than women under the age of 39 with 55.2% of men being in this age group in Hawai'i which may be due to the factors such as an influx of more males due to employment opportunities or related to immigration patterns, and that slightly more boys than girls are born each year. During the ages of 50-59 years, the ratio of women to men reverses with 16.7% of all women being in this age group compared to 6.8% of all men. This pattern continues for older age groups which is probably likely to a greater longevity in women.

The ethnic/racial composition of the female population reflects the diversity of the state with 4 major ethnic groups representing 80% of the population: Native Hawaiians, Caucasians, Japanese and Filipinos. No single group comprising a majority.

## Health Status

In Hawai'i and nationally, women live longer than men on average (in Hawai'i 78.2 for men and 82.3 for women; Nationally 75.2 for men and 80.4 for women).<sup>2</sup> Since women live longer than men, they experience the burden of chronic conditions, live with disabilities, and have an impact on health services.<sup>3</sup> The promotion of healthy behaviors in the reproductive years and is crucial to sustaining good health in later years of life.

## Preventive Care/Health Habits

Women who engage in healthy behaviors can expect to live longer and have a better quality of life than those that engage consistently in adverse behaviors. Data summarized in Table 3-2 examines Hawai'i's women's use of preventive care and overall good health habits compared to the U.S. Hawai'i's women use of preventive care varies compared to the national average. Generally, women in the state have better health habits than estimates for the entire United States.

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<sup>2</sup> State of Hawai'i Data Book 2008, Tables 2.11, 2.12.

<sup>3</sup> Institute for Women's Policy Research, The Status of Women in Hawai'i. Washington, D.C., 2000

<b>Table 3-1. Preventive Care and Health Behaviors in Adult Women, Hawai'i &amp; U.S., 2009</b>		
	Hawai'i	United States
<b>Preventive Care</b>		
Percent of Women Age 40 and Older Who had a Mammogram in the Past 2 Years <sup>†</sup>	78.7	76.0
Percent of Women Aged 18 and Older Had a Pap Smear in the Past 3 Years <sup>†</sup>	82.8	82.9
Percent of Women Aged 18 and Older Who Have Been Screened for Cholesterol in the Past 5 Years	80.3	79.2
Percent of Women with a Routine Visit to a Health Care Provider in the Past Year <sup>†</sup>	69.1	74.1
<b>Health Behaviors</b>		
Percent of Women Who Smoke (100 or more cigarettes in their lifetime and who now smoke everyday or some days)	13.8	16.8
Percent of Women Who Report Chronic Drinking (4+ alcohol beverages during at one occasion in the past month)	10.6	10.6
Percent of Women Who Report No Leisure-Time Physical Activity During the Past Month	23.2	25.6
Percent of Women Eat 5+ Servings of Fruits or Vegetables per Day	27.3	27.7
Source: Centers for Disease Control and Prevention (CDC), Behavioral Risk Factor Surveillance System Survey Prevalence and Trends Data, available at <a href="http://apps.nccd.cdc.gov/brfss/">http://apps.nccd.cdc.gov/brfss/</a> , accessed July 8, 2010.		
† 2008 estimate		

### Chronic Health Conditions

People that have chronic health conditions often have associated disabilities, requiring more health care visits, and generally report worse quality of life compared to those without chronic health conditions. The primary prevention and early identification of chronic disease is increasingly important due to worsening health status of the population. Data summarized in Table 3-3 examines Hawai'i's women's estimates of chronic health conditions compared to the overall estimates for the nation. Women in Hawai'i have lower rates of obesity and similar rates of high cholesterol compared to national estimates. Of great concern, however, is that women in Hawai'i have more chronic health conditions such as diabetes, high blood pressure, and asthma.

<b>Chronic Health Conditions</b>	<b>Hawai'i</b>	<b>United States</b>
Percent of Women who are Obese	20.1	26.0
Percent of Women with Diabetes*	11.0	9.5
Percent of Women High Blood Pressure	30.1	27.8
Percent of Women with High Cholesterol	36.3	36.1
Percent of Women with Asthma	12.2	10.6

Source: Centers for Disease Control and Prevention (CDC), Behavioral Risk Factor Surveillance System Survey Prevalence and Trends Data, available at <http://apps.nccd.cdc.gov/brfss/>, accessed July 8, 2010.  
† 2008 estimate  
\*Includes Gestational Diabetes

### Health Disparities

The aggregate reporting of health data for the state can hide striking disparities by subgroups. One of the more serious examples is the data for Hawai'i women's obesity rates by race/ethnicity. Overall the estimate of obesity in adult women is lower in Hawai'i (20.1%) than the national rate (26.0%). However, analysis of the Hawai'i BRFSS data demonstrates obesity in 68.7% of Samoan women, close to 40% of Hawaiians, 42.0% of Pacific Islanders, over 30% of Hispanics, and about 25% of those who report more than one race are obese. Whereas, white and all Asian subgroups have estimates well below the national and state wide estimate of obesity.

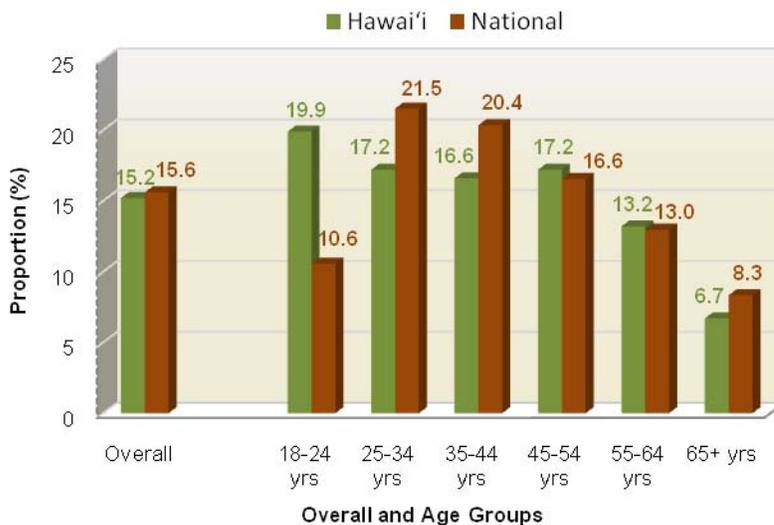
<b>Race/Ethnicity</b>	<b>Percent Obese (BMI ≥ 30.0)</b>
White	16.3
Hawaiian <sup>†</sup>	37.8
Samoan	68.7
Other Pacific Islander	42.0
Filipino	12.0
Japanese	9.6
Chinese	5.6
Other Asian	6.5
Hispanic	31.8
Multi-racial non Hawaiian	24.1
All others	19.8

Source: State of Hawai'i, Department of Health, Family Health Services Division  
† Includes both Hawaiian and part Hawaiian

## Domestic Violence

Intimate partner violence (IPV) is a significant public health problem that involves people in a close relationship. The term "intimate partner" includes current and former spouses and dating partners. IPV exists along a continuum from a single episode of violence to ongoing battering. Nationally, intimate partner violence (IPV) results in an estimated 1,200 deaths and 2 million injuries among women each year. IPV has also been associated with adverse health conditions and health risk behaviors.<sup>18</sup> Analysis of 2007 Behavioral Risk Factor Surveillance System Survey data among four states that asked about lifetime prevalence for IPV among women was done. An overall estimate of 15.6% in the 3 other states, and an estimate of 15.2% in Hawai'i reported ever having been physically abused by an intimate partner. Analysis by age group revealed that the prevalence of self-reported IPV in women in Hawai'i was similar among all age groups compared to the 3 other states.

**Chart 3.1 State of Hawai'i, Women Who Reported Ever Been Hit, Slapped, Kicked or Hurt in Any Way by an Intimate Partner: 2007**



Source: Hawai'i State Department of Health, Office of Health Status Monitoring, Behavioral Risk Factor Surveillance System (BRFSS).

## MATERNAL & INFANT HEALTH

### Birth Rates

The Hawai'i birth rate for 2008 was 15.1 per 1,000 resident population, slightly higher than the U.S. birth rate of 14.0 per 1,000 population for the same year.<sup>4</sup> Hawai'i's birth rate has declined over the past 30 years from 18.8 births per 1,000 population in 1980. There has been an increase since 2005 when it was 14.1 per 1,000 resident population in Hawai'i. This contrasts with the national rate which has remained stable since 2005. The increase in the birth rate in Hawai'i may partly be due to an increase in the number of new immigrants to the state, particularly among Hispanics and Other Pacific Islanders. Birth rates in Hawai'i differ significantly by ethnicity. In 2008, the "Other" race group had the highest birth rate (28.3 per 1,000 live births), followed by Filipinos (18.0), Native Hawaiians (17.6), whites (17.6), and Japanese (7.2).

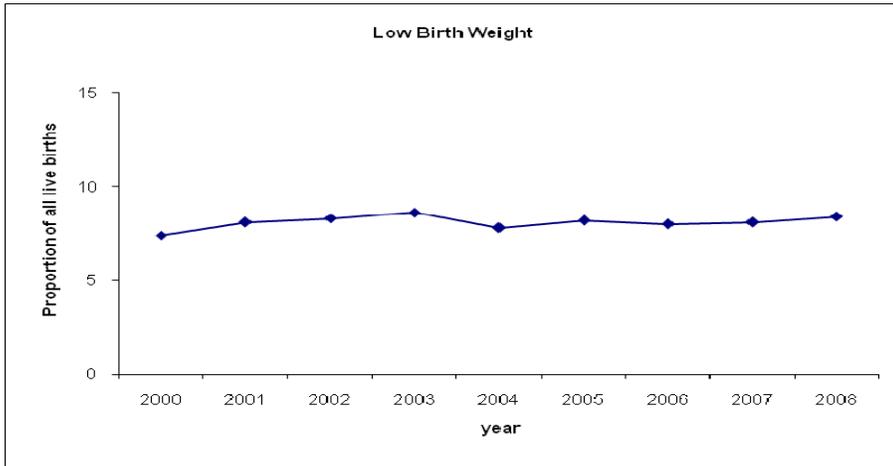
<b>Table 3-4. Birth Rates by Ethnicity, Hawai'i 2008</b>	
<b>Race</b>	<b>Birth Rate (per 1,000 women 15-44 years of age)</b>
White	17.6
Hawaiian	17.6
Filipino	18.0
Japanese	7.2
Other	28.3
Overall	15.1
Source: Hawai'i State Department of Health, Office of Health Status Monitoring, Vital Statistics Records.; Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics Reports.; U.S. Census Bureau, Population Division.	

<sup>4</sup> Source: Hawai'i State Department of Health, Office of Health Status Monitoring, Vital Statistics Records.; Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics Reports.; U.S. Census Bureau, Population Division.

### Low Birth Weight

Since 2000, the proportion of LBW (birth weight of <2,500 grams as reported on the birth certificate) births in Hawai'i has remained relatively stable, ranging from 7.4% in 2000 to 8.6% in 2004. LBW births accounted for 8.4% of all births in 2008, and do not meet the HP 2010 objective of 5.0%.

**Chart 3-2 Low Birth Weight, State of Hawai'i: 2000 - 2008**

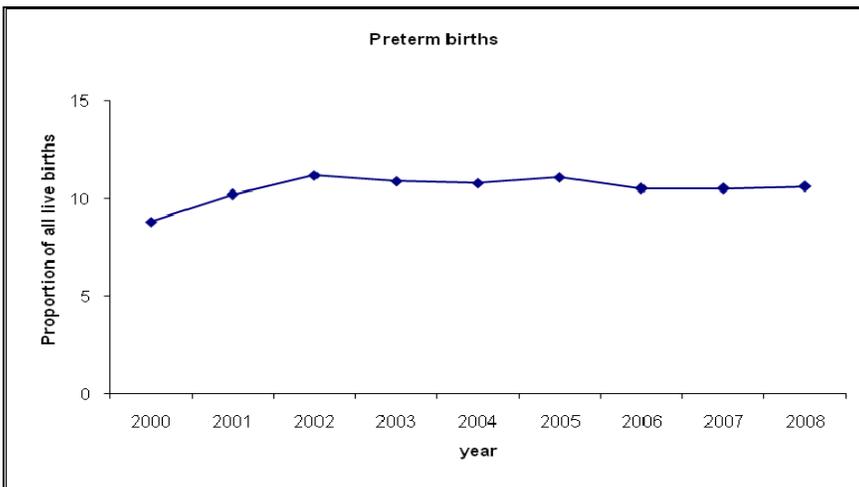


Source: Hawai'i State Department of Health, Office of Health Status Monitoring, Vital Statistics Records

### Preterm Births

In Hawai'i, the rate of preterm delivery (delivery before 37 weeks based on clinical estimate of gestational age as reported on the birth certificate) has remained relatively stable at 10-11% since 2002 remaining above levels found in 2000 and 2001. In 2008, 10.6% of all births in Hawai'i were considered preterm.

**Chart 3-3 Preterm Births, State of Hawai'i: 2000 - 2008**



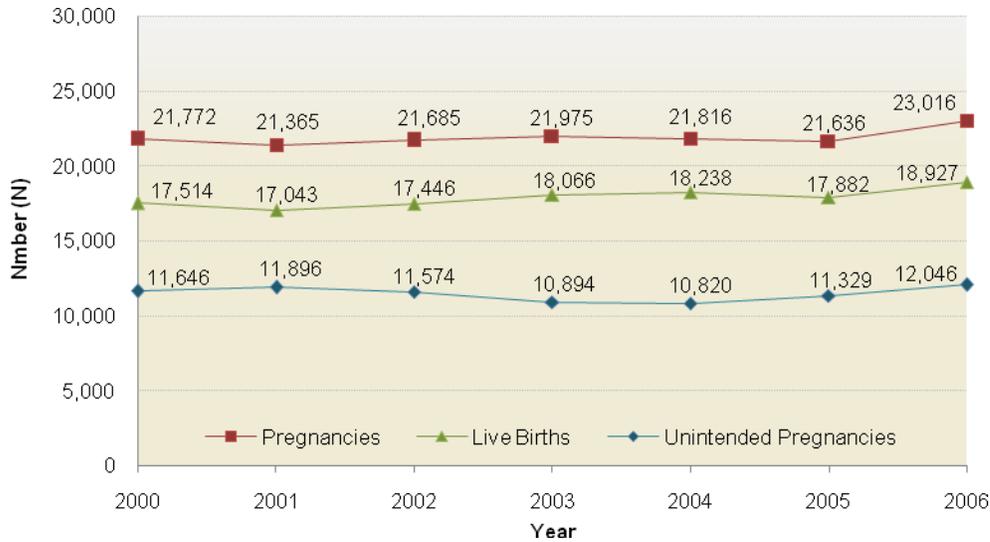
Source: Hawai'i State Department of Health, Office of Health Status Monitoring, Vital Statistics Records

### Unintended Pregnancy

The consequences of unintended pregnancy are serious. Research has shown that unintended pregnancy is a risk factor for inadequate prenatal care, low birth weight, exposure of the fetus to harmful substances like tobacco, alcohol and other drugs, neonatal death, domestic violence and child abuse. Unintended pregnancy is associated with economic hardship, marital dissolution, and spousal abuse. In an era when technology should enable couples to have considerable control over their fertility, the rate of unintended pregnancies can be reduced.

An estimated half of all unintended pregnancies in the U.S. end in an abortion.<sup>5</sup> Based on data from the Hawai'i Pregnancy Risk Assessment Monitoring System (PRAMS) combined with vital statistics data on abortions and fetal deaths, the number of pregnancies in Hawai'i was consistent from 2000 to 2005 at around 22,000, but increased in 2006 to 23,016. In 2006, an estimated 52.3% (or 12,046) of pregnancies were unintended with minimal change since 2000 when the proportion was 53.4%. Hawai'i does not meet the HP 2010 objective to have 30% of pregnancies to be unintended.

**Chart 3-4 State of Hawai'i, Unintended Pregnancy, Resident Population: 2000-2006**



Source: Hawai'i State Department of Health, Pregnancy Risk Assessment Monitoring System. Hawai'i State Department of Health, Office of Health Status Monitoring. The rate of unintended pregnancy is derived from estimates from the OHSM birth, fetal death, and Induced Termination of Pregnancy files which were not available for 2007 at time of publication.

<sup>5</sup> U.S. Department of Health and Human Services, Healthy People 2010, Conference Edition. Washington, DC, 2000, p.9-3

Maternal Characteristics

Data for 2008 based on all live births by age and ethnicity is presented in Table 3-5. The majority of births were to women between the ages of 20 and 34 years of age. Approximately 8.0% of all live births were to adolescents under 20 years of age. This percentage has dropped over the past decade. The Hawaiian, Filipino, and Other race groups had the highest proportions of births to those under 20 years of age. The Hawaiian births amounted to 58% of all births under age 18 and 53% of all births at 18 and 19 years of age. Filipinos followed with 18% of all births under age 18, and 15% of all births between 18 and 19 years of age. Those of an Other race group had 15% of all births under age 18, and 16% of all births between 18 and 19 years of age.

<b>Table 3-5. Total Live Births by Race and Age of Mother (residents), Hawai'i 2008</b>								
Race	Under 18 years	18-19 years	20-24 years	25-29 years	30-34 years	35-39 years	40+ years	Total by Race
Caucasian	35	147	1100	1410	1099	613	179	4583
Hawaiian	258	627	1561	1445	937	435	107	5370
Filipino	81	184	750	965	939	522	157	3598
Japanese	8	40	193	384	638	552	146	1961
Other	65	192	963	1067	908	563	147	3905
<b>Total</b>	<b>447</b>	<b>1190</b>	<b>4567</b>	<b>5271</b>	<b>4521</b>	<b>2685</b>	<b>736</b>	<b>19417</b>
Source: Hawai'i State Department of Health, Office of Health Status Monitoring. Annual Report: Statistical Supplement 2008								

The percentage of births to unmarried mothers was significantly higher in the Hawaiian (44%) population when compared with the other ethnic groups. Although about one in five births among Filipino mothers were to unmarried mothers. Families that are formed by first births to single parents, to young mothers, or to mothers with limited education are particularly at risk of facing long-term difficulties, with the risk for poor outcomes increasing when families are formed under all three circumstances. Children in these families tend to grow up in poverty, have below average academic achievement, have lower college aspirations, engage in early sexual activity, and, as adults, have greater risk for divorce.<sup>6</sup>

<sup>6</sup> Center on the Family, Portrait of Hawai'i Families, P. 4.

**Table 3-6. Selected Maternal and Prenatal Care Characteristics (residents), Hawai'i, 2008**

Characteristics	% of total births	% of births to teenage mothers (>19 yrs)	% of births to unmarried mothers	% of mothers starting prenatal care:		% of low birth weight infants
				First trimester	3 <sup>rd</sup> trimester no care	
Caucasian	22.5%	4.9%	10.9%	86.7%	11.3%	6.4%
Hawaiian	27.0%	51.9%	44.4%	94.3%	22.8%	8.8%
Chinese	3.4%	1.1%	1.2%	84.4%	11.6%	8.2%
Filipino	19.3%	24.2%	20.0%	81.2%	15.5%	10.7%
Japanese	12.2%	4.1%	6.4%	85.4%	10.5%	10.1%
Other*	15.6%	13.7%	17.0%	70.1%	25.6%	7.8%

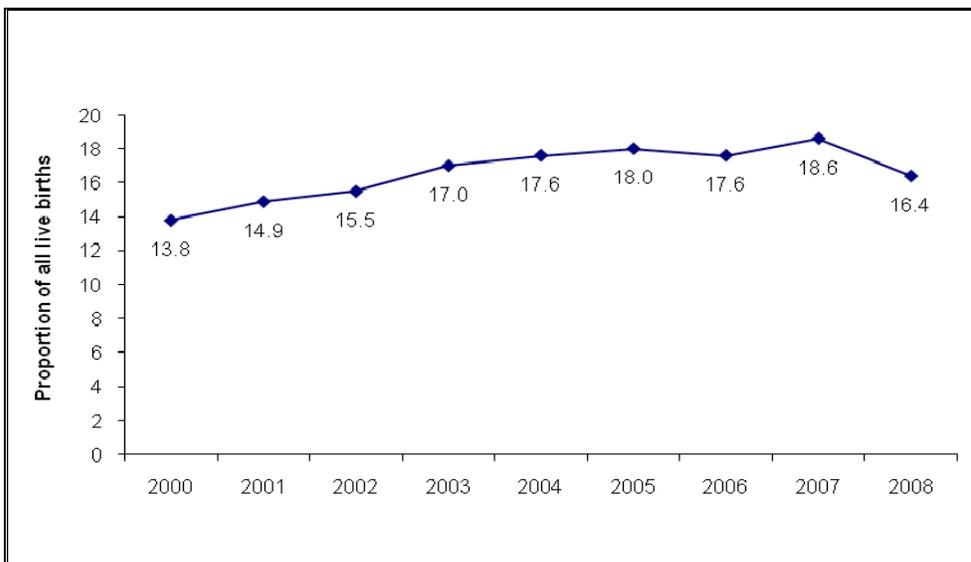
\* "Other" here refers to all remaining births.

Source: Hawai'i State Department of Health, Office of Health Status Monitoring. Annual Report: Statistical Supplement 2008.

### Prenatal Care

Women receiving early and consistent prenatal care tend to have better birth outcomes. Nationally, in 2006, the 32 state aggregate of those who reported unrevised birth certificate data showed that 16.8% of mothers did not have first trimester prenatal care with. In Hawai'i, the proportion of mothers without first trimester prenatal care has increased significantly from 13.8% in 2000 to 18.6% in 2007. In 2008, the proportion decreased to 16.4% of all births and will continued to be monitored as it still does not meet the HP 2010 objective of 10.0%.

**Chart 3-5 State of Hawai'i, Mothers without First Trimester Prenatal Care, Resident Population: 2000-2008**



Source: Hawai'i State Department of Health, Office of Health Status Monitoring.

### Medical & Other Risk Factors

Births to mothers with pre-existing medical conditions may be associated with worse outcomes than those born to mothers without these conditions. In general women are delaying child birth to later years and this is coinciding with increases in chronic conditions (e.g., diabetes, high blood pressure) and their risk factors (e.g., obesity, physical inactivity) among women of reproductive age. This combination stresses the importance of obtaining and providing appropriate care before pregnancy, termed preconception and interconception care, to try and optimize the health of both the mother and the infant resulting from the pregnancy.<sup>7</sup> Analysis of data from 2003-2008 vital records, demonstrated that 44.5% of mothers had a pre-existing medical condition. This particular indicator was determined with the presence of the notation for any of the following pre-existing medical conditions: anemia, cardiac disease, acute or chronic lung disease, diabetes, genital herpes, hydraminos/oligohydraminos, hemoglobinopathy, chronic hypertension, pregnancy-associated hypertension, eclampsia, incompetent cervix, previous infant 4000+ grams, previous preterm or small-for-gestational-age infant, renal disease, Rh sensitization, uterine bleeding, or infectious disease.

### Birth Defects

A birth defect is defined as an abnormality of structure, function or body metabolism present at birth that adversely affects a child's health and development, results in a physical or mental disability, or is fatal. Some conditions are recognized prior to or at birth, while others become apparent shortly thereafter.

Birth defects may be genetically linked, caused by environmental hazards, or adverse life style effects, but most often are of unknown origin. Birth defects are the number one cause of fetal death and infant mortality in Hawai'i with about 800 fetal deaths occur each year in Hawai'i. About 1 in five (20%) of all pregnancies result in spontaneous miscarriage and an average of 1,000 (5.1%) of all babies born each year in Hawai'i are born with some recognizable abnormality, according to the Hawai'i Birth Defects Program.<sup>8</sup>

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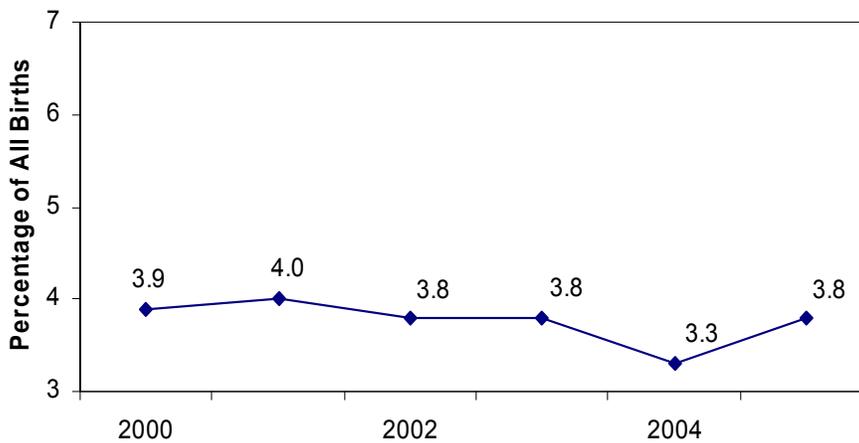
7 D'Angelo D, Williams L, Morrow B, Cox S, Harris N, Harrison L, Posner SF, Hood JR, Zapata L. 2007. Preconception and interconception health status of women who recently gave birth to a live-born infant--Pregnancy Risk Assessment Monitoring System (PRAMS), United States, 26 reporting areas, 2004. MMWR Surveillance Summary. 56(10):1-35.

8 Data from Hawai'i Birth Defects Program, 1986-2004, Statewide Data Surveillance,

The number of babies born in Hawai'i with some type of birth defect in 2005 was 857 (out of 18,875 live births). The proportion of birth defects (expressed as a percent of all births) has been relatively stable over the past years (see Chart 3-3).

Most children have a single defect when born (49.5%), but 10.6% have 5 or more defects. The types of birth defects most commonly encountered are grouped by the body system they affect. Cardiac and circulatory defects (heart and blood vessel problems) are the most common defects, followed by limb and musculoskeletal defects. Among the 4 counties, Oahu has the highest rate of birth defects (527.4 per 10,000 births) while Maui has the lowest rate (427.0). Women over 39 years of age have the highest rate of birth defects (787.1/10,000) followed by women age 35-39 years (595.6).

**Chart 3-6 Proportion of All Birth Defects, Hawai'i, 2000-2005**

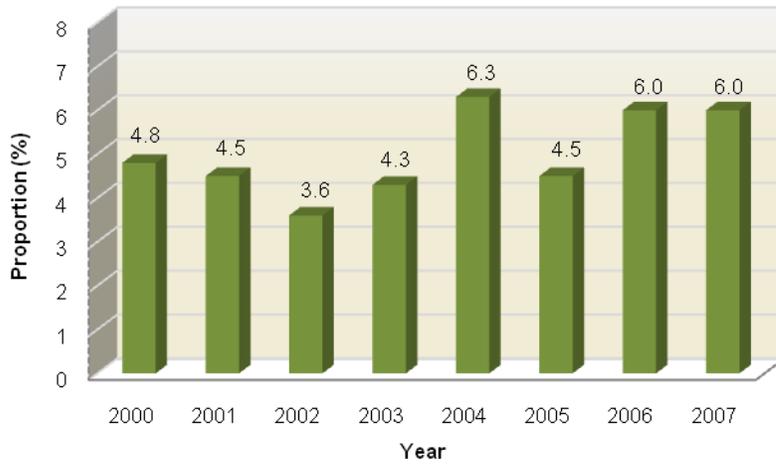


#### Maternal Substance Use

The use of alcohol, tobacco, and illegal substances during pregnancy is a major risk factor for adverse outcomes including LBW infants, preterm delivery, stillbirth (late fetal deaths) and spontaneous abortion. Data for maternal substance use comes from the Hawai'i Pregnancy Risk Assessment Monitoring System (PRAMS), a population based survey of mothers at 2-4 months after child birth. Although the surveys are anonymous, behaviors are likely to be under-reported.

In Hawai'i, approximately 6% of women reported using alcohol during their pregnancy in 2007. This is almost a two-fold increase from 2002, when only 3.6% of women reported using alcohol during their pregnancy.

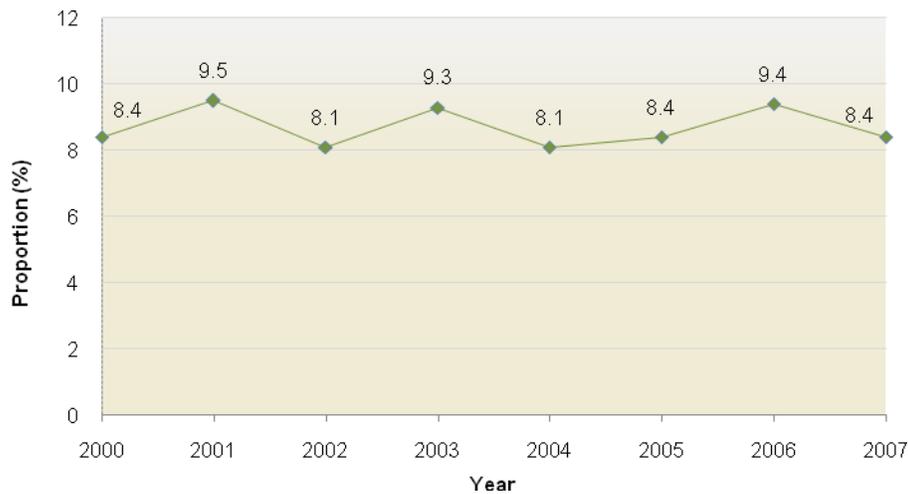
**Chart 3-7 State of Hawai'i, Proportion of Women who Report Alcohol Use during Pregnancy: 2000-2007**



Source: Hawai'i State Department of Health, Family Health Services Division, Maternal and Child Health Branch, Pregnancy Risk Assessment Monitoring System.

There has been little change in self-reported smoking during the last 3 months of pregnancy since 2000. In 2007, an estimated 8.4% of pregnant women Hawai'i reported smoking during the last 3 months of pregnancy.

**Chart 3-8 State of Hawai'i, Smoking during the Last 3 Months of Pregnancy, Resident Population: 2000-2007**



Source: Hawai'i State Department of Health, Family Health Services Division, Maternal and Child Health Branch, Pregnancy Risk Assessment Monitoring System.

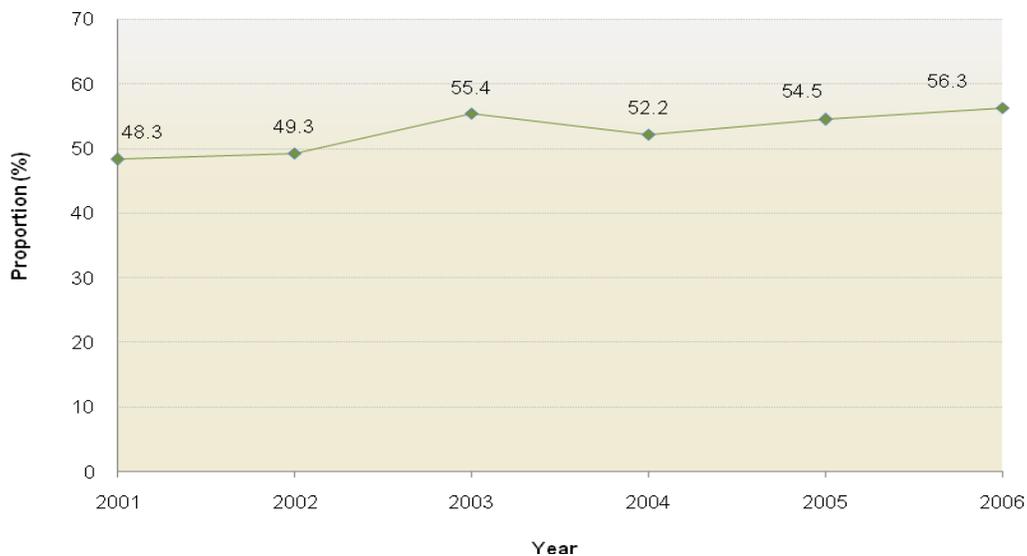
## Breastfeeding

Human milk is the preferred feeding for all infants, including premature and sick newborns. Exclusive breastfeeding is ideal nutrition and sufficient to support optimal growth and development for approximately the first 6 months after birth. The advantages of breastfeeding are indisputable and include nutritional, immunological and psychological benefits to both mother and infant, as well as economic benefits.

In children born in 2001, an estimated 48.3% mothers breastfed their infants for 6 months in Hawai'i. That rate has continued to increase with 56.3% of Hawai'i mothers reported breastfeeding for 6 months who had their infant in 2006, surpassing the national percentage (43.4%), and exceeding the Healthy People 2010 objective of 50%.<sup>9</sup>

Based upon 2007 Breastfeeding report card produced by the CDC, Hawai'i is only one of four states (Maine, Hawai'i, Montana, and Utah) that achieved all three HP 2010 breastfeeding objectives - 75% of mothers initiating breastfeeding, 50% of mothers breastfeeding their infant at 6 months of age, and 25% of mothers breastfeeding their infant at 12 months of age.<sup>10</sup>

**Chart 3-9 State of Hawai'i, Breastfeeding at 6 Months, Resident Population: Birth Cohorts: 2001-2006**



Source: Centers for Disease Control and Prevention. National Immunization Survey, 2001-2006 Birth Cohorts. Provisional Data for Hawai'i. [http://www.cdc.gov/breastfeeding/data/NIS\\_data](http://www.cdc.gov/breastfeeding/data/NIS_data). Accessed July 13, 2010.

<sup>9</sup> Centers for Disease Control & Prevention. National Immunization Survey, 2006 births. [http://www.cdc.gov/breastfeeding/data/NIS\\_data](http://www.cdc.gov/breastfeeding/data/NIS_data) [Accessed 7/13/2010]

<sup>10</sup> Centers for Disease Control & Prevention. National Immunization Survey, 2004 Births. Washington, DC: U.S. Department of Health and Human Services; 2007.

## Outcome Measures

There are five perinatal mortality measures used to assess overall outcomes for the MCH population in the federal MCH Block Grant. Data are presented here along with a discussion of whether the state was able to meet specific targets set for these measures.

The infant mortality rate (IMR) for 2008 was 5.3. Although this rate is nearly 29% lower than it was in 2000 (7.6), because it is based on a relatively small number of deaths, the difference is not statistically significant. The rate is remarkably lower than it has been for the past 3 years.

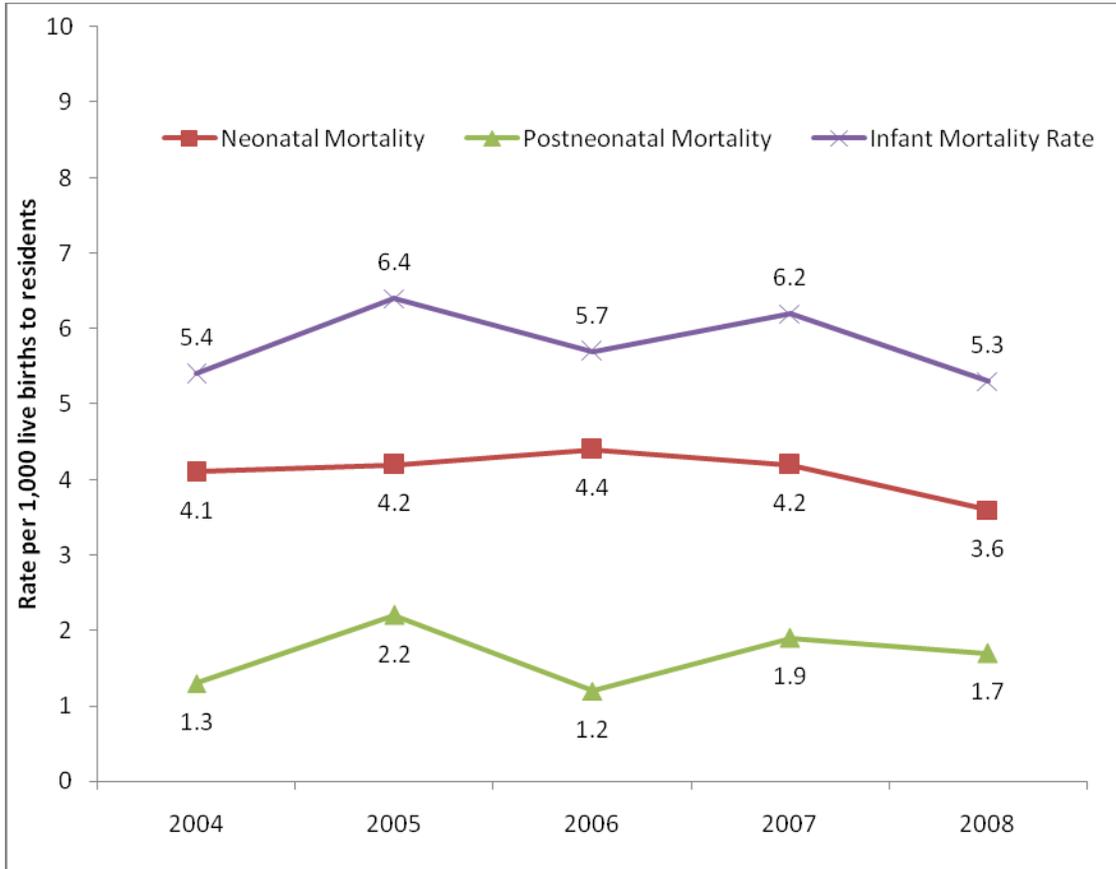
The disparity between racial groups for this health measure is examined nationally by reporting the ratio of black IMR to white IMR. Because of Hawai'i's varied ethnic representation, data collected indicate that for 2008 the ratio of the Black infant mortality rate to the White infant mortality rate was 2.9, whereas for 2003 the ratio was 4.1. The Black population is extremely small in Hawai'i, and an increase or decrease by one or two infant deaths can dramatically affect this ratio. This is reflected in the wide range of infant mortality rates reported (1.3-6.1) for Black infants over the past 5 years. Furthermore, fewer than 25 White and 10 Black infants died in any one of the past 5 years. In Hawai'i the Black/White infant mortality ratio is an unstable measure and is not useful in making decisions about maternal and child health.

The neonatal mortality rate for 2008 was 3.6 per 1,000 live births. However, the 2008 rate is 29% lower than the rate of 5.1 for 2003. Much of the reduction in Hawai'i's infant mortality rate for the past 5 years has been due to a decrease in neonatal deaths. These are the deaths that are first impacted by improvements in rates of prenatal and neonatal care.

The post neonatal mortality rate for 2008 was 1.7 per 1,000 live births. Hawai'i's post neonatal death rate has remained relatively stable over the previous 6 years at ~1.8. To maintain a stable rate of 1.5, the national health objective for post neonatal mortality, FHSD will need to identify factors where improvements in infant care can be achieved. Although the 2008 rate is below the national health objective it is based on a fairly small number of deaths (33).

Perinatal mortality are fetal deaths >28 weeks plus infant deaths <7 days. The perinatal mortality rate for 2008 was 4.6 per 1,000 live births. Hawai'i's perinatal death rate has been relatively stable over the past 5 years, but like the other infant mortality measures are subject to variability due to small numbers. The state infant, neonatal, and post neonatal mortality rates for 2004-2008 are presented in Chart 3-10.

Chart 3-10 Mortality Rates for Infants (residents) 1994-2003



Source: Hawai'i State Department of Health, Office of Health Status Monitoring, Vital Statistics Records

## **DIRECT HEALTH CARE AND ENABLING SERVICES**

### Financial Access to Health Care and Health-related Services

Hawai'i's Prepaid Health Care Act of 1974 is the only act of its kind in U.S. history. Since Jan. 1, 1975, this law has required nearly all employers to provide health insurance to their employees who worked 20 hours or more a week for four consecutive weeks. Employees must maintain the minimum of at least 20 hours a week to remain eligible. This has had a major impact in assuring that a large segment of Hawai'i residents had health insurance coverage.

In the U.S. women of certain ethnic minorities have more difficulty accessing medical care compared to Caucasians. In Hawai'i where everyone is an ethnic minority most access issues focus on Native Hawaiians, Filipinos, Pacific Islanders or new immigrant groups. Women in these ethnic groups generally have worse maternal health and pregnancy outcomes as well as decreased access to prenatal and reproductive health care, than women from the other major ethnic groups. Because members of these groups also tend to reside in rural areas of the state they have limited access to both primary and tertiary care providers.

Furthermore, adolescents in several of these groups are more likely to get pregnant and may not access medical care without adequate psychosocial support. The perinatal system of care is improving in the area of providing psychosocial support services for teens and young women. Coordination between physicians and support services must be improved to provide adequate educational and counseling services to new mothers.

### Geographic accessibility

The majority of tertiary health care facilities and specialty/sub-specialty facilities are located on the island of Oahu. The neighbor island facilities can accommodate routine obstetric care and labor and delivery. The island of Lanai has only one OB/GYN who provides service for one day every month.

The costs of travel to and from the neighbor islands to Oahu for specialized or emergency care can be extremely burdensome for families with limited insurance coverage and income. Expenses include airfare (\$200 or more per roundtrip), food and lodging, plus additional uncovered medical costs.

The availability of quality emergency care can also be an issue for neighbor island residents. Parents have reported that at neighbor island emergency rooms that for infants/children may not be available, a persistent problem on some islands.

Other support and treatment services may be limited on the neighbor islands. For instance the island of Kaua'i has no drug treatment programs for pregnant women. Thus, women seeking treatment must relocate to Oahu for care. On Molokai 65% of deliveries are flown to Oahu and 35% of births on Molokai are delivered by Nurse Midwives. An OB/GYN flies to Molokai every two weeks to provide services and consult with the Nurse Midwives.

### Cultural Acceptability

As mentioned, certain ethnic groups are over-represented in the data with respect to poor pregnancy outcomes, limited use of prenatal care, increased rates of infant mortality, higher rates of domestic violence and substance use/abuse during pregnancy. Many existing health services are focused on reducing the disparity among ethnic groups and various populations.

#### Big Island Perinatal Health Disparities Project (BIPHDP)

The Maternal and Child Health Branch's BIPHDP is a federally funded program to address disparities in perinatal health and birth outcomes among specific populations on the Big Island. Native Hawaiian, other Pacific Island and Hispanic women, and adolescent females residing on the Big Island (regardless of ethnicity) all have poorer overall perinatal health and birth outcomes than do Big Island women of other ethnicities. The BIPHDP provides several support services to pregnant women of the target populations in an effort to eliminate these disparities. This program focuses on high risk groups and the data reflects that the program is targeting an appropriate group in need of services.

The BIPHDP works with four Local Area Consortia (LAC). Each LAC participates in health fairs and other public gatherings within their local communities, providing information on pregnancy, the importance of early prenatal care, as well as describing the services available through the BIPHDP. In addition, the East Hawai'i LAC (servicing the Hilo/Puna communities) recently began to run a series of articles in the Hawai'i Tribune Herald describing the project and the need for prenatal care.

The BIPHDP also provides project participants with risk assessment, case management, health education, home visiting, and anticipatory counseling and guidance to augment and reinforce the medical prenatal care they receive. Examples of how the program increases the number of women accessing services like early prenatal care include assistance with navigating the health insurance application process, finding a prenatal care provider, transportation, and translation services.

#### Perinatal summit

A statewide Perinatal Summit was held on the Big Island of Hawai'i in October 2008 on "Developing Strategies for Healthy Women, Healthy Pregnancy, Healthy Birth Outcomes." The summit was attended by about 175 people and served as a platform to highlight State perinatal data and the areas of perinatal health that need more focus and improvement. Keynote speakers included national leaders in the field of perinatal health research which focused on health disparities including: Dr. Hani Atrash and Dr. Michael Lu who spoke about the importance of preconception and interconceptual health of women to address disparities in birth outcomes. Data presentations also focused on health disparities with a focus on differences by race/ethnicity, income and geography. A compendium of fact sheets covering many issues related to preconception, interconception, and perinatal health was produced by FHSD. Participants also completed surveys to provide input for selection of the Title V needs assessment priorities.

## Availability of Prevention and Primary Care Services Providers

Data on Hawai'i's providers comes from the HMSA Foundation report, Health Trends in Hawai'i. The annual publication is compiled by the Hawai'i Health Information Corporation. HHIC is a private, not-for-profit corporation established in 1994 to collect inpatient discharge records from Hawai'i's 23 acute care hospitals for each year since 1993. Its mission has expanded to collect, analyze and disseminate statewide health information in support of improving the health care system.<sup>11</sup>

There were 4,035 licensed physicians in Hawai'i in 2008 in active practice and providing patient care, a rate of 3.1 per 1,000 population. Hawai'i compares well to the national rate of 2.7, ranking 10th in the U.S.<sup>12</sup> Primary care physicians provide a full range of basic health services to patients and include general practice, pediatricians, obstetrician/gynecologists, family practice physicians, and internists. Most HMOs require each enrollee to select a PCP who provides or arranges for appropriate care. Forty-one (41) percent of active physicians in Hawai'i are PCPs, slightly more than the U.S. percentage of 36. Hawai'i ranks 12th in the percentage of active physicians that are primary care physicians.<sup>13</sup> Like the continental U.S., Hawai'i's physicians are highly concentrated in a small urban area on Oahu. Some of this discrepancy is due to tertiary care service available only on Oahu.

A recent study by the University Medical School on Hawai'i's Physician Supply and Shortages supports the geographic disparity of physician supply between Oahu and the neighbor islands, particularly in Obstetrics/Gynecology. The survey found no shortage of Ob/GYN physicians for Oahu with clear shortages on the neighbor islands (see Table 3.7).

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<sup>11</sup> Hawai'i Health Trends data is available online at [www.healthtrends.org](http://www.healthtrends.org).

<sup>12</sup> Source: American Medical Association. Physician Characteristics and Distribution in the U.S. from Hawai'i Health Information Corporation, Health Trends in Hawai'i.

<sup>13</sup> The Kaiser Family Foundation, <http://www.statehealthfacts.kff.org>. (in Hawai'i/Providers and Service Use/Physicians)

<b>Table 3-7 Hawai'i Physician Workforce: Supply/Demand Status for Primary Care and OB/GYN Physicians, Hawai'i 2010</b>			
Area	Status	Primary Care	Ob/GYN
Honolulu County	2010 Supply	677	137
	2010 Demand	862	130
	2010 Shortage	185	0
Hawai'i County	2010 Supply	128	18
	2010 Demand	171	27
	2010 Shortage	43	9
Maui County	2010 Supply	108	16
	2010 Demand	136	22
	2010 Shortage	28	6
Kauai	2010 Supply	49	5
	2010 Demand	63	9
	2010 Shortage	14	4
State	2010 Supply	962	176
	2010 Demand	1232	188
	2010 Shortage	270	19
Source: Withy K, Sakamoto D. Act 219, SLH 2007, Draft Hawai'i Physician Workforce Assessment Project, February 2010.			

Like many areas around the U.S., Hawai'i is facing a shortage of doctors due to rising malpractice costs. One of the critical shortage areas for women and infant health is obstetrics. In the field of obstetrics, the number of doctors who handle infant deliveries and provide care to the mother dropped by 9% to 146 statewide from 2002 to 2004 according to an informal survey conducted by the Hawai'i chapter of the American College of Obstetricians and Gynecologists.<sup>14</sup> Moreover, 42% of Hawai'i Ob-GYN physicians reported plans to quit obstetrics, with 29% planning to stop delivering babies in the next 5 years.

The neighbor island situation is particularly grave: 67% plan to quit by 2009. The majority cited the risk of getting sued as the main reason for curtailing their practice. Tort reform bills have been introduced at the state Legislature over the past three years, championed by the Hawai'i Medical Association to address the potential shortages, but have been unsuccessful.

#### Facilities

There are twenty-five acute care facilities statewide, one of which is Tripler Army Medical Center which supplies integrated services to all three military service branches. Fourteen of the 25 hospitals are

<sup>14</sup> American College of Obstetricians and Gynecologists Hawai'i Chapter, Report on ACOG Physician Survey, May 2005.

considered major community hospitals. Twelve are former state hospitals, now organized under the Hawai'i Health Systems Corporation. Ten major community hospitals are located on Oahu. There are 6 Critical Access Hospitals serving remote areas.

There are 14 community health centers on three of the seven islands. These community centers provide Primary Care (usually inclusive of perinatal health care) services for the uninsured.

#### Access to Specialty Care when Needed

Tertiary care centers are located only on the island of Oahu. There is limited access to specialty obstetric care on the neighbor islands and in rural Oahu for high-risk pregnant women. All high-risk deliveries are scheduled at Level III hospitals on Oahu or flown in by air ambulance in an emergency.

Kapiolani Medical Center for Women and Children (KMCWC) a private, non-profit, tertiary care facility specializing in gynecological, obstetrical, newborn and pediatric care has the largest delivery service in Hawai'i located on the island of Oahu. KMCWC is the only hospital providing Level III-B care in the western Pacific region with a 46 bed Neonatal Intensive Care Unit (NICU). According to KMCWC certificate of need application, approved in May 2009 by the Statewide Health Coordinating Council, proposed plans for 24 additional NICU beds to 70 will accommodate the community's long term needs. The increase of NICU beds are necessary as part of the overall plan to create single-rooms for the NICU. The proposed state-of-the-art technologically advanced care NICU for the premature and critically ill infant will be completed by December 2015.

Located in Honolulu County, KMCWC provides services to the rest of the State, including Kaiser and Tripler Army Medical Center (TAMC), for infants requiring specialized procedures not available at the respective facilities. Kaiser Medical Center - which provides services only to subscribers of its health plan, and TAMC that provides obstetrical care for the military population on the island of Oahu as well as referral for care for military and civilian patients from the Pacific island and Asia, both report a Level III NICU. TAMC has a 16 bed NICU which admits approximately 300 infants annually.

The KMCWC Neonatal transport Program is responsible for managing the transport of infants from other hospitals on Oahu and on other islands, as well as from Hawai'i to the Mainland. Specially trained transport nurses and respiratory therapists accompanied by a neonatologist or fellow for critically ill infants are on each team and work collaboratively with the air ambulance service.

Table 3-8 shows the number and percentage of resident births in eleven labor and delivery facilities spread throughout the state in 2008. The majority of the facilities are located in Honolulu County which coincides with the largest proportion of all births. It appears that most high-risk deliveries, particularly those born of Very Low Birth Weight (VLBW) are being handled at the major tertiary (Level III) care facilities in the state. Very low birth weight infants are more likely to survive and thrive if they are born/cared for in an appropriately staffed and equipped facility with a high volume of high risk admissions. The percentage of VLBW infants delivered at tertiary care centers was 85% in 2008.

The Hawai'i Air Ambulance came under new management in 2006 and combined services with AirMed Hawai'i with services renamed, Hawai'i Life Flight. Hawai'i Life Flight provides air ambulance

medical transport from all neighbor island hospitals to Oahu, including obstetrical emergencies requiring a Level III NICU. There is an air ambulance and medical crew based strategically across the State to transport medical emergencies within 20 minutes of a call. The air ambulance bases are located in Hilo, Waimea and Kona of the Big Island, Lihue, Kauai, and Kahului, Maui. The Maui base serves Molokai and Lanai as well. The main base for Hawai'i Life Flight is on Oahu, which can dispatch extra services to the neighbor islands and from rural areas of Oahu as needed.

<b>Table 3-8 Birth Weights at Tertiary delivery Locations (residents), Hawai'i, 2008.</b>								
Facility	All Births		Very Low Birth Weight		Low Birth Weight		Normal Birth Weights	
	No.	% of all live births	No.	% of all VLBW	No.	% of all LBW	No.	% of all normal weight
	<b>Honolulu</b>							
Kapi`olani Medical Center Level III Facility	6450	33%	140	60%	781	59%	5663	32%
Tripler Army Medical Center Level III Facility	2724	14%	31	13%	194	15%	2527	14%
Queen's medical Center	2277	12%	5	2%	119	9%	2158	12%
Kaiser Foundation Hospital Level II Facility	1642	8%	28	12%	138	10%	1504	8%
Castle	822	4%	1	0%	19	1%	801	4%
<b>Hawai'i</b>								
Hilo	1201	6%	5	2%	81	6%	1120	6%
North Hawai'i	662	3%	4	2%	24	2%	638	4%
Kona	563	3%	4	2%	29	2%	534	3%
<b>Kauai</b>								
Wilcox	593	3%	9	4%	53	4%	539	3%
Kauai Veteran's	272	1%	2	1%	8	1%	264	1%
<b>Maui</b>								
Maui Memorial Medical Center	1842	9%	6	3%	98	7%	1744	10%
<b>Total</b>	<b>19416</b>		<b>235</b>		<b>1332</b>		<b>17838</b>	
Source: Hawai'i State Department of Health, Office of Health Status Monitoring. Vital Statistics Data. 2008								

## **PROGRAMS/SERVICES**

### WIC Services

The Special Supplemental Nutrition Program for Women, Infants & Children (WIC) is a federally funded short-term intervention program designed to establish good nutrition and health behaviors through nutrition education, breastfeeding promotion, a monthly food prescription allotment and access to maternal, prenatal and pediatric health-care services. WIC serves low-income pregnant and post-partum women and children up to age 5 nutritionally at-risk through purchase-of-service (POS) and state-run agencies. WIC contracts with seven community health centers, one Native Hawaiian Health Care Center and one hospital to provide services, resulting in greater integrated health service delivery than the eight state-run agencies. During FFY 2009, Hawai'i WIC served a monthly average of 36,320 individuals, an increase of 6.7% from 34,050 individuals in 2008. The mix is approximately 25% women, 25% infants and 50% children. The new WIC food packages effective October 2009 (with reduced fat milk, fruits/vegetables, whole grains, baby foods and soy alternatives) aligns with messages to increase intake of fruits/vegetables and whole grains/fiber, decrease intake of fat and juices, and breastfeed babies. The gradual change to a more paraprofessional delivery model continues as does the emphasis on participant-centered services.

Because a major goal of the WIC Program is to improve the nutritional status of infants, WIC mothers are encouraged to breastfeed their infants as the optimal infant feeding choice. Mothers receive information, counseling, incentives, and on-going support (including breast pumps) while breastfeeding. Breastfeeding mothers are eligible to participate in WIC six months longer than non-breastfeeding mothers. Mothers who exclusively breastfeed their infants receive an enhanced food package.

WIC has expanded its breastfeeding peer counselor training program to increase the number of trained WIC peer counselors that can provide effective breastfeeding information and support to their clients. WIC also provides information on the Hawai'i Mothers Breastfeeding Act to all local service agencies. The Act protects women's ability to breastfeed and express milk at work during regular break times, encourages employers to establish policies to accommodate those activities, and protects the women's right to breastfeed in public places.

### State Perinatal Health Support Services

This perinatal support service program (PSS) is designed to work with high risk pregnant women and provide case management through pregnancy and then six months interconception to support healthy outcomes for these women and their infants. Services are provided by 9 community based providers including 6 community health centers. Pregnant women are screened for social, health and medical conditions and receive individual or group health education to address high risk factors that contribute to poor birth outcomes including preterm birth and low-birth weight infants. The section also administers funding for the federal Healthy Start Big Island Perinatal Health Disparities Grant which provides services to Hawaiian, other Pacific Islander, Hispanic, Filipino and adolescent pregnant women during pregnancy and two years interconception.

### State Family Planning Program

Title X federal funds that are administered by the Family Planning Program (FPP) provide greater access to contraception and other FP services through thirty-five clinics (with 18 satellite sites) on 6 islands often located in underserved geographical areas statewide. Target populations are individuals from low-income families, uninsured and underinsured; men and women; adolescents; those with limited English proficiency; disparate groups such as homeless, and substance users. The DOH as the Title X grantee for Hawai'i contracts with 11 community health centers, 4 community college health centers, and 3 community-based nonprofit organizations in rural areas for subsidized FP quality clinical services not limited to reproductive life planning, pregnancy and std testing, contraceptive services including health education and counseling with all service provision. Annually the FPP completes a provider survey to assure maximum client service availability and a broad array of contraceptive methods and related services are available. This information is then used to subsequently address barriers to access to care (e.g. training needs, supply issues or service limitations).

### Early Head Start program

The Early Head Start program is funded through the U.S. Department of Health and Human Services to provide support services to low-income families, particularly teens, while they are pregnant until their child reaches the age of three. Families are encouraged to register with the regular Head Start programs, which service low-income families with children 3-5 years. Early Head Start staff includes outreach workers, educational specialists and social workers.

### Male Achievement Network (MAN) Project-Oahu

This project is implemented by the Waikiki Health Center Youth Outreach Program. It provides clinical, outreach and educational counseling services to males most likely to engage in risky sexual behaviors including incarcerated youth, homeless youth, runaway youth, and those attending alternative schools for at-risk youth. This agreement through 2/10 is also focused on testing key program evaluation recommendations to support development of lesson plans to be used for male services statewide and promote healthy reproductive decision making and use of contraception to high risk men.

### Path Clinic

This Honolulu based clinic provides comprehensive perinatal clinical and counseling services to women who are past or current substance users. Funding for this program has come by the Tobacco Prevention and Control Trust fund and Hawai'i Community Foundation.

### GRADS (Graduation Reality and Dual Skills)

The GRADS program in the public high schools provides support to pregnant and parenting teens by enhancing the students' regular classes with life skills learning, such as budgeting, parenting, cooking, and other issues.

### Hawai'i Healthy Start

The Family Health Services Division, Maternal Child Health Branch administers the Hawai'i Healthy Start (HHS) program which is a home visiting service that strengthens families and promotes positive parent-child relationships. It began as a demonstration project in July, 1985. By 2001, Healthy Start had expanded statewide and included universal screenings and assessments in all civilian birthing hospitals. However due to poor economic performance and reduced state revenues the program was subjected to severe budget restrictions. Today the program is limited to two (2) program sites and it has eliminated its statewide universal screening and assessment services in hospitals, and eliminated its inclusion in the IDEA (Individuals with Disabilities Education Act) Part C services for care coordination. The program currently enrolls families with children ages 0 to 3 years of age and is located on the islands of Oahu and Hawai'i.

In October, 2008 the DOH, Family Health Services Division was awarded a \$500,000.00 grant per year for 5 years by the Department of Health and Human Services, Administration for Children and Families. The grant was awarded to "Support Infrastructure Needed for the Widespread Adoption, Implementation and Sustaining of Evidence-Based Home Visitation (EBHV) Programs."

Although the EBHV grant funding has since been significantly impacted, the project has continued to move forward with its planned enhancements for program fidelity and quality assurance initiatives.

### Effect of Recent State Budget Cuts on State Contracted Perinatal Services

State budget cuts and restrictions have impacted numerous programs overseen by the Department of Health Family Health Services Division and include:

- Total elimination of the **Baby Safe Substance Free Environment (S.A.F.E)** Program. This program had focused on all types of substance abuse including alcohol. This resulted in \$633,505 in purchase of service contracts to the Big Island, Maui and Waianae communities ending which had provided outreach, case management and support to enter treatment services to approximately 500 pregnant clients annually.
- 12% reduction (\$94,229) of funding to the **PSS Program**. This resulted in service discontinuation at one rural site and substantially less funding for service delivery to other PSS providers and high risk pregnant women in need of services.
- 40% reduction (\$503,229) in funding for **Family Planning Program**. This will impact service delivery and resources required for clinical services and supplies. In addition, Temporary to Needy Families Funding for the community based health educator positions was discontinued. This has resulted in 14 community-based educators at 50% rather than full-time equivalency which will impact information and access to family planning services and education which promote early identification of pregnancy and risk assessment such as alcohol use during pregnancy.
- Abolishment of 1 full-time Program Coordinator position supporting the prevention of Fetal Alcohol Spectrum Disorder.

## POPULATION-BASED SERVICES

### Healthy Mothers, Healthy Babies Coalition

HMHB distributes educational materials for pregnant women and provides leadership for advocacy efforts by overseeing quarterly meetings of perinatal providers, and addressing related statutes and policies impacting perinatal health including those related to substance use and its impact on healthy individuals, babies and communities. HMHB oversees the Title V phone line Mothers Care toll-free statewide hotline for information and referrals to prenatal care and other services required. HMHB also maintains a website that provides perinatal information and referral. Most recently HMHB has taken the lead to promote Text4baby to promote text health education and information throughout a pregnancy and expected due date also supporting healthy behaviors and choices for women who participate.

### Hawai'i's Newborn Metabolic Screening Program

The Newborn Metabolic Screening Program (NBMSp) was established within the Children with Special Health Needs Branch in 1986 with the passage of HRS §321-291. NBMSp has statewide responsibilities for ensuring that infants born in the State of Hawai'i are satisfactorily tested for 32 disorders since 2003. These disorders can cause mental and growth retardation, severe health problems, and even death, if not detected and treated early in the newborn period. NBMSp tracks and follows-up to ensure that the infants with specified diseases are detected and provided with appropriate and timely treatment.

Hawai'i's Newborn Metabolic Screening Program is administered through the FHSD Children with Special Health Needs Branch (CSHNB). and assures all infants receive testing and that infants with the specified diseases are 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 2008, 99.7% of newborns were screened statewide.

### Newborn Hearing Screening Program

The Newborn Hearing Screening Program (NHSP) began in 1990 through a law mandating that the DOH develop methodology to establish a statewide program for screening of infants and children age 0-3 years for hearing loss. Screening began in 2 hospitals in 1992, was provided in all birthing facilities by 1999, and is now part of standard newborn care in Hawai'i.

Amendment of the law in 2001 mandated screening all newborns for hearing loss and reporting screening results to the DOH. In 2003, NHSP began outreach to homebirth families statewide through midwives. Hearing screening is now available to families statewide, regardless of birth location. As of

November 2006, all hospitals have both otoacoustic emissions and auditory brainstem response screening capability and have backup equipment. In 2008 98.9% of infants were screened for hearing loss.

#### State Family Planning Program

Title X federal funds that are administered by the Family Planning Program (FPP) also help provide population-based services including statewide FP community health educators that work to increase awareness of reproductive health, healthy decision making and improve access to family planning providers for those individuals in need of these services. Activities to promote this increased knowledge and awareness of family planning services include presentations, comprehensive sex education curricula in schools and community organizations, distribution of educational materials, and health fairs. The FPP HE Program with its community-based health educators is in the process of selecting a curriculum for Title X educators to use and teach brief lessons related to Title X and reproductive health care that can be used in the schools and community. This will be shared with the Department of Education for approval and use.

#### Hawai'i Immunization Coalition

The Hawai'i Immunization Coalition is a statewide, community-based coalition of public and private agencies, which ensures that all of Hawai'i's children are appropriately immunized against vaccine-preventable diseases. Activities include data collection, statewide distribution of educational materials, and review of policies that affect immunizations. The Coalition also coordinates training for health professionals and organizations on current immunization issues and works in collaboration with community partners to address concerns regarding access to care for at-risk populations. The Coalition is supporting Department of Health efforts to develop a statewide immunization registry.

#### Fetal Alcohol Spectrum Disorders (FASD) Task Force

The FASD Task Force is facilitated by a part-time FASD coordinator located in the Title V agency. The Task Force is co-facilitated by Vivian Aiona, the State Lt. Governor's wife, and a parent advocate. The Task Force promotes abstinence of drinking any alcohol while pregnant in prevention and awareness activities and plans awareness activities for International FASD Awareness Day annually in September every year. The TF is also working to collaborate with other agencies to develop and deliver training/education to local communities and professionals on the screening of pregnant women, and identification, diagnosis, and treatment of children with FASD. Currently, the clinical group is working with the Department of Human Services, Child Welfare Services Foster Care program on a screening and diagnosis pilot, and hopes to increase Foster Care referrals.

### People Attentive to Children (PATCH)

PATCH tracks the available roster of all licensed childcare providers for the general public to access services. The agency also provides training for the providers to maintain their licenses. With so many working mothers in Hawai'i access to safe and reliable childcare services is vital to reduce infant mortality and morbidity.

### Hawai'i Women's Health Week

In alignment with National Women's Health Week, Hawai'i celebrated the 2010 Hawai'i Women's Health Week from May 9-15, 2010. Through a collaborative community-based partnership known as the Hawai'i Women's Health Week Committee, various statewide women's health related activities were planned to encourage all women, with support from others in their life, to take advantage of preventive healthcare services, including blood pressure checks, mammograms, tests for diabetes, cholesterol, HIV/STD, and cancer, such as Pap smears and other appropriate tests. Bus placards promoting 2010 Hawai'i Women's Health Week were placed in all county public buses operating in the islands of Oahu and Maui, and Hawai'i County during the entire month of May 2010. Women's Health Screening guides will also developed and distributed statewide to major Supermarkets and Pharmacies, community health centers, Native Hawai'i Health Care organizations, libraries, health care providers, churches, and other health related events. The Women's Health Screening Guides provided general guidelines for preventive health screenings, risk factor information, and websites for healthcare information.

## **INFRASTRUCTURE BUILDING SERVICES**

### Domestic Violence Fatality Review

The Maternal and Child Health Branch has implemented a Domestic Violence Fatality Review which is a legislative initiative intended to reduce the incidence of preventable deaths related to domestic violence. The DOH is the lead agency to administer statewide team reviews and through this process the MCHB is collaborating with key agencies involved in Domestic Violence. The hope is that thru this collaboration the MCHB can participate in advocacy efforts improve the systems of care and interventions related to intimate partner violence.

### Domestic Violence, Sexual Assault Special Fund And Sexual Violence/Rape Prevention And Education

The Maternal and Child Health Branch has a Centers for Disease Control Grant to address Sexual Violence and Rape Prevention Education. This grant provides needed prevention dollars to address this critical issue. The Maternal and Child Health Branch also oversees the Domestic Violence and Sexual Assault Special Fund established by the legislature. This fund and the programs related to domestic violence/intimate partner violence and sexual violence prevention provides opportunity for the MCHB to expand its efforts toward violence prevention. The Branch is looking at ways to expand the surveillance

capacity in these areas and ways to collaborate with other women's health initiatives within the branch, such as family planning and the perinatal programs to assure that women are screened and able to access violence prevention information and services as needed through these service delivery points. As state funding and staffing diminished the branch continues to find ways to look at ways to coordinate and collaborate and to integrate where there are shared outcomes.

#### Family Health Services Surveillance Data

The Family Health Services Division is responsible for administering several surveillance systems to monitor the health of the maternal and child population:

#### Pregnancy Risk Assessment Monitoring System

The Hawai'i Pregnancy Risk Assessment Monitoring System (PRAMS) is a population-based surveillance system designed to identify and monitor maternal experiences, attitudes, and behaviors before, during and just after pregnancy. The program is funded by the Centers for Disease Control and Prevention (CDC). Hawai'i PRAMS provides ongoing monitoring of maternal behaviors to determine how to reduce infant deaths, decrease low birth weight and how to improve the overall health of the population in Hawai'i. Data is self-reported from a sample of recent mothers through a survey conducted by mail with telephone follow-up. Every year, about 2,000 women who deliver a live infant in Hawai'i are randomly selected to participate.

#### Birth Defects Monitoring System

The Birth Defects Monitoring System (BDMS) program is a population-based surveillance system that collects demographic, diagnostic, and health risk information on infants up to one year of age with specific birth defects and pregnancies resulting in adverse reproductive outcomes. Over 1,000 CDC mandated congenital anomalies are identified in approximately every 17,000 births annually. The program provides data and information on incidence, trends, and clustering, which contribute toward identifying genetic factors, environmental hazards, and other causes or risk factors.

#### Pediatric Nutrition Surveillance and Pregnancy Nutrition Surveillance System

The Pediatric Nutrition Surveillance System (PedNSS) and the Pregnancy Nutrition Surveillance System (PNSS) are public health surveillance systems that monitor the nutritional status of low-income pregnant mothers and their children in federally funded maternal and child health programs. Data on birth weight, breastfeeding, anemia, short stature, underweight, and overweight are collected for children who attend public health clinics for routine care, nutrition education, supplemental food, trimester of prenatal care entry, weight, and weight changes over the pregnancy, smoking, and alcohol use, and other factors are collected in these surveillance systems. In Hawai'i, data collected is from the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) participants.

### Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System is a national surveillance tool coordinated by the Centers for Disease Control (CDC) to gather state specific data on health risk behaviors through monthly telephone interviews with randomly selected adult residents. Data on women's health generated from the survey is used to identify women's health, perinatal and family planning health needs in the state.

Hawai'i Youth Services Network (HYSN)/Healthy Youth Hawai'i (HYH)

HYH is an initiative of HYSN, a 501 (c)(3) non-partisan, statewide organization operating exclusively for charitable purposes. Specifically, HYH's mission is "Creating networks and promoting effective programs for Hawai'i's youth that support healthy and informed choices." In partial fulfillment of this mission, HYH serves as an advisory organization to teen pregnancy prevention projects of HYSN and supports science based curricula and other youth health initiatives, especially reduction of teen unintended pregnancies.

### State Family Planning Program

Title X federal funds that are administered by the Family Planning Program (FPP) also help provide infrastructure building services including performing family planning needs assessments in rural and low socio-economic communities and providing professional training and technical assistance to providers through annual conferences that feature updates on research, methods and practices for family planning.

### March of Dimes

This organization continues to advocate and address perinatal issues including the prevention of low birth weight, pre-term births and other neonatal issues such as alcohol use during pregnancy

## **Standards of Care/Guidelines/Monitoring/Evaluation**

All State Perinatal Support Services purchase-of-service contracts are monitored. Providers are required to give periodic reports to assure progress of the contract performance. Technical assistance is provided to contractors as needed.

Title V and Title X funding require annual reporting on a series of perinatal performance measures that incorporate national Healthy People 2010 objectives (HP 2020 objectives when they become available). Services and interventions are evaluated and revised based on annual performance measure indicators.

Federal grant funding for specific projects also require routine reporting and evaluation of both client outcomes and service provision. Many perinatal programs also maintain performance measures that are evaluated annually.

Standardized quality of care measures are used by Hawai'i's largest public and private insurance providers. Thus data is available regarding the vast majority of health consumers on customer satisfaction and specific perinatal health outcomes. HEDIS measures which support integration of preconception/interconception care and promote women's health may be considered as potential contract performance measures in the future.

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**CHAPTER 4:**

**CHILDREN WITH SPECIAL  
HEALTH CARE NEEDS**

## Introduction

The Hawai'i Title V needs assessment includes a focus on the six core outcomes for children with special health care needs (CSHCN):

1. Families of CSHCN partner in decision-making at all levels and are satisfied with the services they receive.
2. CSHCN receive coordinated, ongoing, comprehensive care within a medical home.
3. CSHCN have adequate private and/or public insurance to pay for the services they need.
4. Children are screened early and continuously for special health care needs.
5. Community-based service systems are organized so families can use them easily.
6. Youth with special health care needs receive the services necessary to transition to adult life, including adult health care, work, and independence.

CSHCN are defined as children who have or are at risk for a chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally (definition from the federal Maternal and Child Health Bureau). Due to the complexity of their health needs, it is essential to assure access to comprehensive, coordinated, community-based services.

### Priority Needs

The State of Hawai'i has recognized the need for improved health services for CSHCN to assure healthy outcomes for the future. As part of the commitment to the health of this population in the state, a CSHCN Workgroup was convened as a component of the Title V Needs Assessment. The Workgroup identified three key health issues based on a review of the existing CSHCN priorities, stakeholder input, and compilation of research and data. Using a set of prioritization criteria, two final priorities were identified for the CSHCN population group:

- Promote the identification of children with developmental delay
- Promote the transition of adolescents with special health care needs to adult health care

### Data Sources

The data presented in this report is not a comprehensive compilation of all CSHCN data, but is a summary of key health data to assess the overall population health and identify health issues. Data sources for this report include:

- Hawai'i data from the National Survey of CSHCN, 2005-2006.
- Hawai'i CSHCN data from the National Survey of Children's Health, 2007.
- Hawai'i Title V/CSHCN Needs Assessment Survey – 2009. This was a DOH Children with Special Health Needs Branch (CSHNB) survey of family and community/providers to identify areas of biggest challenges/problems for CSHCN in Hawai'i.
- Data and information from state and community agencies and programs.
- Data and information from DOH/CSHNB programs.

## POPULATION DATA AND HEALTH STATUS

### Prevalence

- The Hawai'i prevalence of CSHCN age 0-17 years is 12.0%, based on Hawai'i data from the National Survey of CSHCN, 2005-2006 (Table 4-1). The Hawai'i prevalence is significantly lower than that for the U.S. (13.9%).
- The Hawai'i CSHCN prevalence is significantly lower for age 0-5 years (8.3%), compared to that for ages 6-11 years (14.2%) and age 12-17 years (13.8%).
- The Hawai'i prevalence is significantly higher for males (14.0%) compared to females (9.9%).
- The Hawai'i prevalence is higher in White (non-Hispanic), Native Hawaiian/Pacific Islander (non-Hispanic), and Hispanic populations, compared to the Black and Asian populations (no statistical information available). The prevalence is similar across income levels.

	Hawai'i % CSHCN	U.S. % CSHCN	
CSHCN prevalence among children age 0-17 years	12.0	13.9	<sup>1</sup>
CSHCN prevalence by age			
Age 0-5 years	8.3 <sup>2</sup>	8.8 <sup>2</sup>	
Age 6-11 years	14.2 <sup>2</sup>	16.0 <sup>2</sup>	
Age 12-17 years	13.8 <sup>2</sup>	16.8 <sup>2</sup>	<sup>1</sup>
CSHCN prevalence by sex			
Male	14.0 <sup>3</sup>	16.1 <sup>3</sup>	<sup>1</sup>
Female	9.9 <sup>3</sup>	11.6 <sup>3</sup>	<sup>1</sup>
CSHCN prevalence by ethnicity/race			
Non-Hispanic			
White	11.4	15.0	
Black	13.1	15.5	
Asian	9.6	15.0	
American Indian/Alaskan Native	8.9	6.3	
Native Hawaiian/Pacific Islander	+	14.5	
Multiple races	11.2	11.5	
Hispanic	12.9	17.9	
Hispanic	15.5	8.3	
CSHCN prevalence by poverty level			
0-99% FPL	13.3	14.0	
100-199% FPL	12.0	14.0	
200-399% FPL	11.9	13.5	
400% FPL or more	11.3	14.0	<sup>1</sup>

<sup>1</sup>Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates.  
<sup>2</sup>Statistical difference at the 95% confidence interval between rates for age 0-5 year and 6-11 years, and between age 0-5 years and 12-17 years.  
<sup>3</sup>Statistical difference at the 95% confidence interval between males and females.  
+Prevalence less than 5% of children.  
Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from [www.cshcndata.org](http://www.cshcndata.org).

**Types of Special Health Needs**

- The types of health needs for CSHCN in Hawai'i are similar to those for CSHCN in the U.S (Table 4-2) (no statistical differences). These health needs are qualifying conditions for the identification of CSHCN in the National Survey of CSHCN.
- The types of health needs in Hawai'i are prescription medication (75.5%); elevated use of medical and related services (35.8%); emotional, developmental, or behavioral conditions (29.7%); functional limitations (21.5%); and specialized therapies (15.1%).

<b>Table 4-2. Health Needs – Qualifying Conditions for CSHCN: Comparison of Hawai'i and U.S. Rates, 2005-2006*</b>		
	<b>Hawai'i % CSHCN</b>	<b>U.S. % CSHCN</b>
Prescription medication use due to health conditions lasting 12 months or longer	75.5	78.4
Elevated need or use of medical care, mental health or education services due to health conditions lasting 12 months or longer	35.8	38.5
Functional limitations due to health conditions lasting 12 months or longer	21.5	21.3
Need or use of special therapy such as occupational, physical, or speech therapy due to health conditions lasting 12 months or longer	15.1	17.5
Ongoing emotional, developmental, or behavioral conditions that require treatment or counseling	29.7	28.4
*No statistical differences between Hawai'i and U.S. rates. Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcn.org">www.cshcn.org</a> .		

**Health of CSHCN**

- CSHCN in Hawai'i are similar to CSHCN in the U.S. regarding health conditions impacting daily activities, school attendance, number of health care provider visits, and participation in social and other activities (Table 4-3).
- CSHCN in Hawai'i have significantly fewer emergency room visits (13.8%) compared to CSHCN in the U.S. (19.3%). This may be due to due to more adequate insurance coverage in Hawai'i (see Table 4-12).

<b>Table 4-3. Health of CSHCN: Comparison of Hawai'i and U.S. Rates, 2005-2006</b>			
	<b>Hawai'i</b> % CSHCN	<b>U.S.</b> % CSHCN	
Health conditions consistently and often greatly affect daily activities	23.5	24.0	1
Health care needs change all the time	5.6	6.2	1
Missed 11 or more school days due to illness in past 12 months	12.8	14.3	1
Had 6 or more visits to a doctor or other health care provider in past 12 months	35.3	36.4	1
Had 2 or more emergency room visits in past 12 months	13.8	19.3	1*
Health conditions interfere with activity and social participation, age 6-17	33.0	31.3	2
*Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates. Source: <sup>1</sup> 2005/06 <i>National Survey of CSHCN</i> , Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> . <sup>2</sup> 2007 <i>National Survey of Children's Health</i> , Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.nschdata.org">www.nschdata.org</a> .			

### Functional Difficulties

- CSHCN in Hawai'i have a significantly higher rate of difficulties with breathing or other respiratory problems (51.0%), compared to CSHCN in the U.S (42.7%) (Table 4-4). This may be related to higher asthma rates in Hawai'i (see Table 4-5).
- CSHCN in Hawai'i have a significantly lower rate of difficulties with seeing, chronic pain, self-care activities, and making/keeping friends, compared to CSHCN in the U.S.

	<b>Hawai'i % CSHCN</b>	<b>U.S. % CSHCN</b>	
Experiences difficulty with:			
Seeing (without glasses or contact lenses)	18.2	28.3	*
Hearing (without hearing aids)	6.4	5.0	
Breathing or other respiratory problems, such as wheezing or shortness of breath	51.0	42.7	*
Swallowing, digesting food, or metabolism	8.5	10.3	
Chronic physical pain, including headaches	13.3	17.5	*
Self-care activities, such as eating, dressing, and bathing	8.1	11.9	*
Coordination or movement	14.3	14.2	
Using hands	9.3	10.9	
Learning, understanding, or paying attention	36.5	41.0	
Speaking, communicating, or being understood	20.2	22.6	
Feeling anxious or depressed	24.9	28.7	
Behavior problems, such as acting-out, fighting, bullying, or arguing	26.1	28.3	
Making and keeping friends	16.5	20.4	*
Difficulties caused by health problems are moderate/severe	36.7	41.6	

\*Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates.  
 Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website.  
 Retrieved May 2010 from [www.cshcndata.org](http://www.cshcndata.org).

## Health Conditions

- CSHCN in Hawai'i have a significantly higher rate of asthma (52.9%), compared to CSHCN in the U.S. (38.8%) (Table 4.5).
- Compared to U.S. CSHCN, Hawai'i CSHCN have significantly lower rates of attention deficit disorder or attention deficit hyperactivity disorder; depression, anxiety, eating disorder or other emotional problem; epilepsy or other seizure disorder; learning disability; mental retardation or developmental delay; and migraine and frequent headaches.
- Hawai'i and U.S. CSHCN have similar health risks for oral health, overweight/obesity, and secondhand smoke exposure.

<b>Health Conditions</b>	<b>Hawai'i % CSHCN</b>	<b>U.S. % CSHCN</b>	
Allergies (any type)	49.7	53.0	<sup>1</sup>
Allergies – eczema or skin allergy	25.7	22.3	<sup>2</sup>
Allergies – food or digestive allergy	13.4	11.8	<sup>2</sup>
Allergies – hay fever or other respiratory allergy	35.0	37.1	<sup>2</sup>
Arthritis or other joint problem	3.4	4.2	<sup>1</sup>
Asthma	52.9	38.8	<sup>1*</sup>
Attention deficit disorder or attention deficit hyperactivity disorder	25.0	29.8	<sup>1*</sup>
Autism or autism spectrum disorder	4.2	5.4	<sup>1</sup>
Blood problem such as anemia or sickle cell disease	2.3	2.3	<sup>1</sup>
Cerebral palsy	2.6	1.9	<sup>1</sup>
Depression, anxiety, eating disorder or other emotional problem	16.8	21.1	<sup>1*</sup>
Epilepsy or other seizure disorder	2.0	3.5	<sup>1*</sup>
Heart problem, including congenital heart disease	3.5	3.5	<sup>1</sup>
Learning disability	18.2	25.7	<sup>2*</sup>
Mental retardation or developmental delay	8.3	11.4	<sup>1*</sup>
Migraine or frequent headaches	10.4	15.1	<sup>1*</sup>
Stuttering, stammering, or other speech problem, age 2-17	9.5	12.4	<sup>2</sup>
<b>Other Health Concerns</b>			
Condition of child's teeth is excellent/very good (age 1-17)	75.4	64.7	<sup>2</sup>
Child is overweight or obese, based on Body Mass Index ( BMI)	30.6	36.3	<sup>2</sup>
Child lives in households where someone smokes	29.6	30.3	<sup>2</sup>
*Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates. Source: <sup>1</sup> 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> . <sup>2</sup> CSHCN data from 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.nschdata.org">www.nschdata.org</a> .			

### Family, School, and Neighborhood Impact on Families of CSHCN

- Significantly fewer Hawai'i families of CSHCN pay \$1,000 or more out-of-pocket in medical expenses per year (11.1%) and have financial problems due to their child's health conditions (11.0%), compared to U.S. families (20.0% and 18.1%, respectively) (Table 4-6). This may be due to more adequate insurance coverage in Hawai'i (see Table 4-12).
- Families of CSHCN are impacted in other ways, including reducing work hours to care for their child, and needing respite care, genetic counseling, and/or mental health care/counseling.

	<b>Hawai'i % CSHCN</b>	<b>U.S. % CSHCN</b>	
Families pay \$1,000 or more out-of-pocket in medical expenses per year	11.1	20.0	*
Child's health conditions cause financial problems for family	11.0	18.1	*
Families spend 11 or more hours per week providing and/or coordinating child's health care	11.3	9.7	
Child's health conditions cause family members to cut back or stop working	22.1	23.8	
Family need for respite care	6.5	4.5	
Family need for genetic counseling for advice about inherited conditions related to the child's health conditions	7.5	5.7	
Family member needed mental health care or counseling related to the child's health conditions	11.3	12.3	

\*Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates.  
 Source: \*2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website.  
 Retrieved May 2010 from [www.cshcndata.org](http://www.cshcndata.org).

### CSHCN Activities, School, and Neighborhood

- Significantly more CSHCN in Hawai'i participate in organized activities outside school (87.8%), compared to CSHCN in the U.S. (77.2%) (Table 4-7).
- CSHCN in Hawai'i are similar to CSHCN in the U.S. regarding their families reading, singing, and telling stories to them every day. They are also similar in their watching TV or videos, consistent engagement in school, and exhibiting positive social skills.
- Significantly more CSHCN in Hawai'i live in neighborhoods with a park, library, and community center (69.8%), compared to CSHCN in the U.S. (47.9%). CSHCN in Hawai'i are similar to CSHCN in the U.S. in living in neighborhoods that are supportive and safe.

**Table 4-7. CSHCN Activities, School, and Neighborhood: Comparison of Hawai'i and U.S. Rates, 2007**

	Hawai'i % CSHCN	U.S. % CSHCN	
Children whose families read to them every day (age 0-5 )	63.1	56.2	
Children whose families sing or tell stories to them every day (age 0-5)	65.7	65.4	
Children usually watch more than one hour of TV or videos on an average weekday (age 1-5)	50.0	60.0	
Children are consistently engaged in school ( <i>based on caring about doing well in school and doing all required homework</i> ) (age 6-17)	70.4	69.5	
Children participate in organized activities outside of school (age 6-17)	87.8	77.2	*
Children exhibit positive social skills ( <i>e.g., respect for teachers and neighbors; gets along well with other children; tries to understand other people's feelings; tries to resolve conflicts with classmates, family, friends</i> ) (age 6-17)	88.9	87.7	
Live in neighborhoods with a park, sidewalks, a library, and a community center	69.8	47.9	*
Live in neighborhoods that contain poorly kept or dilapidated housing	21.8	17.7	
Live in neighborhoods that families describe as supportive	86.7	80.4	
Live in neighborhoods or communities that families feel are usually/always safe	85.9	84.4	

\*Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates.  
 Source: CSHCN data from 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from [www.nschdata.org](http://www.nschdata.org).

**Family Partnership in Decision-Making and Satisfaction (CSHCN Outcome #1)**

- 59.3% of CSHCN in Hawai'i achieved the outcome that families of CSHCN are partners in decision-making at all levels and are satisfied with the services they receive (Table 4-9). This rate is similar to that for CSHCN in the U.S. (57.4%).
- Hawai'i CSHCN with medical homes have significantly higher rates of partnership in decision-making and satisfaction with services (85.0%), compared with those without medical homes (40.1%) (Table 4-10).
- Hawai'i CSHCN with functional limitations have a significantly lower rate of partnership in decision-making and satisfaction with services (43.8%), compared with CSHCN managed by prescription medications only (69.4%).
- Hawai'i CSHCN with emotional/behavioral/developmental issues have a significantly lower rate of partnership in decision-making and satisfaction with services (41.9%), compared with CSHCN without these issues (66.5%).

<b>Table 4-8. Family Partnership and Satisfaction – CSHCN Outcome #1: Comparison of Hawai'i and U.S. Rates, 2005-2006*</b>		
	<b>Hawai'i % CSHCN</b>	<b>U.S. % CSHCN</b>
<b>Families of CSHCN are partners in decision-making at all levels and are satisfied with the services they receive (CSHCN Outcome)+</b>	<b>59.3</b>	<b>57.4</b>
Doctors usually/always make the family feel like a partner	87.9	87.7
Family is very satisfied with services received	62.2	59.8
+Outcome measure is derived from the indicators in the table. *No statistical differences between Hawai'i and U.S. rates. Source: Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Progress Toward Implementing Community-Based Systems of Services for CSHCN: Summary Tables from the National Survey of CSHCN, 2005-2006, December 2007. 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website; retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .		

<b>Table 4-9: Family Partnership and Satisfaction – Factors Impacting Successful Achievement of Outcome, Hawai'i, 2005-2006</b>				
	<b>% CSHCN successfully achieving outcome that: Families of CSHCN are partners in decision-making at all levels and are satisfied with the services they receive</b>			
<b>All CSHCN</b>	<b>59.3</b>			
Age	0-5 years <b>68.9</b>	6-11 years <b>55.2</b>	12-17 years <b>57.2</b>	
Family Structure	Two-parent (biological/adoptive) household <b>62.3</b>	Two-parent stepfamily household <b>61.9</b>	Mother only household (no father present) <b>51.7</b>	Other types of family structure <b>58.9</b>
Household income	0 - 99% FPL <b>48.1</b>	100 - 199% FPL <b>60.3</b>	200 -399% FPL <b>59.8</b>	≥400% FPL <b>65.2</b>
Health insurance – type	Private insurance only <b>61.8</b>	Public insurance only <b>61.5</b>	Both private and public insurance <b>40.2</b>	Uninsured <b>+</b>
Health insurance – consistency	Insured entire year <b>59.9</b>		1 or more periods uninsured, past year <b>51.0%</b>	
Type of special health needs	Functional limitations <b>43.8<sup>1</sup></b>	Managed by Rx medications <b>69.4<sup>1,2</sup></b>	Above routine need/use of services <b>48.5<sup>2</sup></b>	Rx medications and service use <b>58.7</b>
Emotional/behavioral/developmental (EBD) issues	One or more EBD issues <b>41.9<sup>1</sup></b>		No qualifying EBD issues <b>66.5<sup>1</sup></b>	
Presence of medical home	CSHCN with medical home <b>85.0<sup>1</sup></b>		CSHCN without medical home <b>40.1<sup>1</sup></b>	
FPL = Federal Poverty Level Rx = prescription +Estimate based on sample size too small to meet standards for reliability or precision. <sup>1</sup> Statistical difference at the 95% confidence interval for items in a row. <sup>2</sup> Statistical difference at the 95% confidence interval for items in a row. Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .				

**Medical Home (CSHCN Outcome #2)**

- 45.2% of Hawai'i CSHCN achieved the outcome of receiving coordinated, ongoing, comprehensive care within a medical home (Table 4-10). This rate is similar to that for U.S. CSHCN (47.1%).
- A significantly higher proportion of Hawai'i families usually/always gets sufficient help coordinating care if needed (76.0%), compared to U.S. families (67.4%).
- Hawai'i CSHCN with functional limitations have a significantly lower medical home rate (36.0%), compared with CSHCN managed by prescription medications only (52.7%) (Table 4-12).
- Hawai'i CSHCN with emotional/behavioral/developmental issues have a significantly lower medical home rate (29.5%), compared with CSHCN without these issues (51.6%).

	<b>Hawai'i % CSHCN</b>	<b>U.S. % CSHCN</b>	
<b>CSHCN receive coordinated, ongoing, comprehensive care within a medical home (CSHCN Outcome)+</b>	<b>45.2%</b>	<b>47.1</b>	
Child has a usual source of care ( <i>derived</i> )	91.9	92.9	
Child has a usual source for sick care	93.2	94.4	
Child has a usual source for preventive care	97.7	97.1	
Child has a personal doctor or nurse	94.0	93.5	
Child has no problems obtaining referrals when needed	78.6	78.9	
Child receives effective care coordination ( <i>derived</i> )	60.9	59.2	
Family is very satisfied with doctors' communication with each other	61.5	63.8	
Family is very satisfied with doctors' communication with other programs	51.4	52.1	
Family usually/always gets sufficient help coordinating care, if needed	76.0	67.4	*
Child receives family-centered care ( <i>derived</i> )	64.4	65.8	
Doctors usually/always spend enough time	77.5	78.7	
Doctors usually/always listen carefully	88.9	88.8	
Doctors are usually/always sensitive to values and customs	90.8	88.9	
Doctors usually/always provide needed information	82.4	83.1	
Doctors usually /always make the family feel like a partner	87.9	87.7	
+Outcome measure is derived from the indicators in the table.			
*Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates.			
Source: CDC, NCHS, Progress Toward Implementing Community-Based Systems of Services for CSHCN: Summary Tables from the National Survey of CSHCN, 2005-2006, December 2007.			
2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website; retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .			

**Table 4-11: Medical Home – Factors Impacting Successful Achievement of Outcome, Hawai'i, 2005-2006**

	<b>% CSHCN successfully achieving outcome that: CSHCN receive coordinated, ongoing, comprehensive care within a medical home</b>			
<b>All CSHCN</b>	<b>45.2.3</b>			
Age	0-5 years <b>41.9</b>	6-11 years <b>47.7</b>	12-17 years <b>44.9</b>	
Family Structure	Two-parent (biological/adoptive) household <b>49.6</b>	Two-parent stepfamily household <b>53.6</b>	Mother only household (no father present) <b>36.7</b>	Other types of family structure <b>33.9</b>
Household income	0 - 99% FPL <b>41.6</b>	100 - 199% FPL <b>41.1</b>	200 -399% FPL <b>45.8</b>	≥400% FPL <b>50.7</b>
Health insurance – type	Private insurance only <b>47.7</b>	Public insurance only <b>42.0</b>	Both private and public insurance <b>30.5</b>	Uninsured  +
Health insurance consistency	Insured entire year <b>45.5</b>		1 or more periods uninsured, past year <b>34.5</b>	
Type of special health needs	Functional limitations <b>36.0<sup>1</sup></b>	Managed by Rx medications <b>52.7<sup>1,2</sup></b>	Above routine need/use of services <b>35.0<sup>2</sup></b>	Rx medications and service use <b>43.6</b>
Emotional/behavioral/ developmental (EBD) issues	One or more EBD issues <b>29.5<sup>1</sup></b>		No qualifying EBD issues <b>51.6<sup>1</sup></b>	
FPL = Federal Poverty Level Rx = prescription +Estimate based on sample size too small to meet standards for reliability or precision <sup>1</sup> Statistical difference at the 95% confidence interval for items in a row <sup>2</sup> Statistical difference at the 95% confidence interval for items in a row Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .				

**Adequate Health Insurance (CSHCN Outcome #3)**

- 73.5% of Hawai'i CSHCN achieved the outcome of having adequate private and/or public insurance to pay for needed services (Table 4-12). This rate is significantly higher than that for U.S. CSHCN (62.0%).
- Hawai'i CSHCN, compared to U.S. CSHCN, have a significantly higher rate for having public/private insurance (99.1% Hawai'i vs. 96.5% U.S.), insurance meeting child's needs (91.0% Hawai'i vs. 87.3% U.S.), reasonable costs when not covered by insurance (79.8% Hawai'i vs. 72.0% U.S.), and insurance permitting child to see needed providers (94.4% Hawai'i vs. 90.7% U.S.).
- Hawai'i CSHCN age 0-5 years have a significantly higher rates of adequate insurance (82.8%), compared with those age 12-17 years (67.5%) (Table 4-13).
- Having adequate insurance is related to income. Hawai'i CSHCN with a family income  $\geq$ 400% FPL have significantly a higher rate of adequate insurance (80.3%) compared with those with income 0-99% FPL (62.1%).
- Hawai'i CSHCN with a medical home have a significantly higher rate of adequate insurance (84.6%), compared to those without a medical home (65.0%).

<b>Table 4-12. Adequate Health Insurance – CSHCN Outcome #3: Comparison of Hawai'i and U.S. Rates, 2005-2006</b>			
	<b>Hawai'i % CSHCN</b>	<b>U.S. % CSHCN</b>	
<b>Families of CSHCN have adequate private and/or public insurance to pay for the services they need (CSHCN Outcome)+</b>	<b>73.5</b>	<b>62.0</b>	<b>*</b>
Child has public or private insurance at time of interview	99.1	96.5	*
Child has no gaps in coverage during year before the interview	96.7	91.2	*
Insurance usually/always meets the child's needs	91.0	87.3	*
Costs not covered by insurance are usually/always reasonable	79.8	72.0	*
Insurance usually/always permits child to see needed providers	94.4	90.7	*
+Outcome measure is derived from the indicators in the table. *Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates. Source: CDC, NCHS, Progress Toward Implementing Community-Based Systems of Services for CSHCN: Summary Tables from the National Survey of CSHCN, 2005-2006, December 2007. 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website; retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .			

<b>Table 4-13: Adequate Health Insurance – Factors Impacting Successful Achievement of Outcome, Hawai'i, 2005-2006</b>				
	<b>% CSHCN successfully achieving outcome that: Families of CSHCN have adequate private and/or public insurance to pay for the services they need</b>			
<b>All CSHCN</b>	<b>73.5</b>			
Age	0-5 years <b>82.8<sup>1</sup></b>	6-11 years <b>73.6</b>	12-17 years <b>67.5<sup>1</sup></b>	
Family Structure	Two-parent (biological/adoptive) household <b>77.9<sup>1</sup></b>	Two-parent stepfamily household <b>75.5</b>	Mother only household (no father present) <b>63.1<sup>1</sup></b>	Other types of family structure <b>78.6</b>
Household income	0 - 99% FPL <b>62.1<sup>1</sup></b>	100 - 199% FPL <b>68.5</b>	200 -399% FPL <b>77.0</b>	≥400% FPL <b>80.3<sup>1</sup></b>
Health insurance – type	Private insurance only <b>76.3</b>		Public insurance only <b>70.3</b>	Both private and public insurance <b>72.40</b>
Type of special health needs	Functional limitations <b>67.9</b>	Managed by Rx medications <b>77.2</b>	Above routine need/use of services <b>65.8</b>	Rx medications and service use <b>76.6</b>
Emotional/behavioral/developmental (EBD) issues	One or more EBD issues <b>66.2</b>		No qualifying EBD issues <b>76.6</b>	
Presence of medical home	CSHCN with medical home <b>84.6<sup>1</sup></b>		CSHCN without medical home <b>65.0<sup>1</sup></b>	
FPL = Federal Poverty Level Rx = prescription <sup>1</sup> Statistical difference at the 95% confidence interval for items in a row. Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .				

#### **Early and Continuous Screening (CSHCN Outcome #4)**

- 69.7% of Hawai'i CSHCN achieved the outcome of early and continuous screening for special health care needs (Table 4-14). This rate is significantly higher than that for U.S. CSHCN (63.8%). Outcome is based on children's receiving routine medical and dental preventive care.
- Hawai'i CSHCN have a significantly higher rate of receiving routine preventive dental care (86.6%), compared to the U.S. rate (78.5%).
- Hawai'i CSHCN who have consistent health insurance coverage for the entire year have a significantly higher rate of early and continuous screening (70.7%), compared with CSHCN who had periods of being uninsured (45.6%) (Table 4-16).
- The need for screening is indicated by 59.3% families of Hawai'i CSHCN having concerns about child's physical, behavioral or social development, and 50.2% CSHCN age 4 months-5 years being at moderate/high risk for developmental or behavioral problems (not statistically different from U.S. rates) (Table 4-16). Only 33.6% families reported that their children (age 10 months-5

years) received a standardized screening for developmental or behavioral problems during a health care visit.

	Hawai'i % CSHCN	U.S. % CSHCN	
<b>Children are screened early and continuously for special health care needs (CSHCN Outcome)+</b>	<b>69.7</b>	<b>63.8</b>	*
Child has received routine preventive medical care in the past year	79.5	77.1	
Child has received routine preventive dental care in the past year	86.6	78.5	*
+Outcome measure is derived from the indicators in the table. *Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates. Source: CDC, NCHS, Progress Toward Implementing Community-Based Systems of Services for CSHCN: Summary Tables from the National Survey of CSHCN, 2005-2006, December 2007. 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website; retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .			

	% CSHCN successfully achieving outcome that: Children are screened early and continuously for special health care needs			
<b>All CSHCN</b>	<b>69.7</b>			
Age	0-5 years <b>68.3</b>	6-11 years <b>70.0</b>	12-17 years <b>70.3</b>	
Family Structure	Two-parent (biological/adoptive) household <b>72.5</b>	Two-parent stepfamily household <b>72.4</b>	Mother only household (no father present) <b>61.8</b>	Other types of family structure <b>72.8</b>
Household income	0 - 99% FPL <b>70.3</b>	100 - 199% FPL <b>59.0<sup>1</sup></b>	200 -399% FPL <b>71.2</b>	≥400% FPL <b>77.7<sup>1</sup></b>
Health insurance – type	Private insurance only <b>73.0</b>	Public insurance only <b>62.7</b>	Both private and public insurance <b>61.9</b>	Uninsured <b>+</b>
Health insurance – consistency	Insured entire year <b>70.7<sup>1</sup></b>		1 or more periods uninsured, past year <b>45.6<sup>1</sup></b>	
Type of special health needs	Functional limitations <b>73.0</b>	Managed by Rx medications <b>70.3</b>	Above routine need/use of services <b>65.6</b>	Rx medications and service use <b>67.6</b>
Emotional/behavioral/developmental (EBD) issues	One or more EBD issues <b>66.8</b>		No qualifying EBD issues <b>70.9</b>	
Presence of medical home	CSHCN with medical home <b>72.3</b>		CSHCN without medical home <b>67.5</b>	
FPL = Federal Poverty Level Rx = prescription +Estimate based on sample size too small to meet standards for reliability or precision. <sup>1</sup> Statistical difference at the 95% confidence interval for items in a row Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .				

<b>Table 4-16. Early and Continuous Screening – Additional Indicators: Comparison of Hawai'i and U.S. Rates, 2007*</b>		
	<b>Hawai'i % CSHCN</b>	<b>U.S. % CSHCN</b>
Doctor or other health care provider asked about concerns about child's learning, development, or behavior, during past 12 months, age 0-5 years	62.5	55.4
Children who received a standardized screening for developmental or behavioral problems during a health care visit, age 10 months-5 years	33.6	23.9
Parental concerns about child's physical, behavioral or social development, age 4 months-5 years	59.3	60.2
Children at moderate/high risk for developmental or behavioral problems, age 4 months-5 years (based on parental concerns scored using the method of the Parents Evaluation of Developmental Status [PEDS] screening tool)	50.2	45.4
*No statistical differences between Hawai'i and U.S. rates. Source: CSHCN data from <i>2007 National Survey of Children's Health</i> , Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.nschdata.org">www.nschdata.org</a> .		

#### **Community-Based Service Systems are Easy to Use (CSHCN Outcome #5)**

- 88.8% of Hawai'i CSHCN achieved the outcome that their services are organized so families can use them easily (Table 4-17). This rate is similar to that for U.S. CSHCN (89.1%).
- Hawai'i CSHCN age 0-5 years have a significantly higher rate of their services being easy to use (96.1%), compared with children age 6-11 years (85.9%) and age 12-17 years (87.0%) (Table 4-18).
- Hawai'i CSHCN with medical homes have a significantly higher rate of their services being easy to use (97.2%), compared to those without medical homes (82.0%).
- Hawai'i CSHCN with functional limitations issues have a significantly lower rate of their services being easy to use (67.9%), compared with those managed by prescription medications only (98.4%).
- Hawai'i CSHCN with emotional/developmental/behavioral issues have a significantly lower rate of their services being easy to use (72.5%), compared with CSHCN without those issues (95.6%).
- Families of CSHCN have various difficulties in trying to use needed services (Table 4-19). Reasons include not getting services when needed, not finding providers with necessary skills, not getting needed information, problems with communication between service providers, and services not available in area.
- 13.3% of Hawai'i CSHCN have unmet needs for specific health care services, and 5.6% have unmet need for family support services (Table 4-20).

**Table 4-17. Community-Based Service System – CSHCN Outcome #5: Comparison of Hawai'i and U.S. Rates, 2005-2006\***

	Hawai'i % CSHCN	U.S. % CSHCN
<b>Community-based service systems are organized so families can use them easily (CSHCN Outcome)+</b>	<b>88.8</b>	<b>89.1</b>
Child's family has experienced no difficulties using services	88.8	89.1
+Outcome measure is derived from the indicators in the table. *No statistical differences between Hawai'i and U.S. rates. Source: CDC, NCHS, Progress Toward Implementing Community-Based Systems of Services for CSHCN: Summary Tables from the National Survey of CSHCN, 2005-2006, December 2007. 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website; retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .		

**Table 4-18: Community-Based Service System – Factors Impacting Successful Achievement of Outcome, Hawai'i, 2005-2006**

	% CSHCN successfully achieving outcome that: Community-based service systems are organized so families can use them easily			
<b>All CSHCN</b>	<b>88.8</b>			
Age	0-5 years <b>96.1<sup>1,2</sup></b>	6-11 years <b>85.9<sup>1</sup></b>	12-17 years <b>87.0<sup>2</sup></b>	
Family Structure	Two-parent (biological/adoptive) household <b>88.7</b>	Two-parent stepfamily household <b>90.9</b>	Mother only household (no father present) <b>86.3</b>	Other types of family structure <b>94.7</b>
Household income	0 - 99% FPL <b>89.2</b>	100 - 199% FPL <b>82.4</b>	200 -399% FPL <b>90.4</b>	≥400% FPL <b>92.3</b>
Health insurance – type	Private insurance only <b>89.4</b>	Public insurance only <b>89.7</b>	Both private and public insurance <b>83.9</b>	Uninsured <b>72.2</b>
Health insurance – consistency	Insured entire year <b>89.1</b>		1 or more periods uninsured, past year <b>78.7</b>	
Type of special health needs	Functional limitations <b>67.9<sup>1,2</sup></b>	Managed by Rx medications <b>98.4<sup>1,2</sup></b>	Above routine need/use of services <b>86.5<sup>1</sup></b>	Rx medications and service use <b>88.5<sup>2</sup></b>
Emotional/behavioral/developmental (EBD) issues	One or more EBD issues <b>72.5<sup>1</sup></b>		No qualifying EBD issues <b>95.6<sup>1</sup></b>	
Presence of medical home	CSHCN with medical home <b>97.2<sup>1</sup></b>		CSHCN without medical home <b>82.0<sup>1</sup></b>	
FPL = Federal Poverty Level Rx = prescription <sup>1</sup> Statistical difference at the 95% confidence interval for items in a row <sup>2</sup> Statistical difference at the 95% confidence interval for items in a row Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .				

**Table 4-19. Community-Based Service System – Difficulties of CSHCN/Families in Using Needed Services: Comparison of Hawai'i and U.S. Rates, 2005-2006\***

	Hawai'i % CSHCN	U.S. % CSHCN	
Difficulties in trying to use needed services during past 12 months:			
Could not get needed info	7.1	6.7	
Too much paperwork required	4.1	2.7	
Not able to pay for services	3.9	4.3	
Problems with transportation	2.1	2.2	
Could not get services when needed	8.0	7.2	
Long waiting lists	3.4	3.3	
Problems with communication between service providers	6.7	5.5	
Language or cultural problems	1.8	1.4	
Could not find providers with necessary skills	7.1	4.5	*
Services were not available in area	5.6	4.4	
Services were available but child was not eligible	4.6	4.8	
Did not have time to figure it out	2.0	2.7	

\*Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates.  
Source: CDC, NCHS, Progress Toward Implementing Community-Based Systems of Services for CSHCN: Summary Tables from the National Survey of CSHCN, 2005-2006, December 2007.  
2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website; retrieved May 2010 from [www.cshcndata.org](http://www.cshcndata.org).

**Table 4-20. Community-Based Service System – Additional Indicators: Comparison of Hawai'i and U.S. Rates, 2005-2006\***

	Hawai'i % CSHCN	U.S. % CSHCN	
Delayed or went without needed health care in past 12 months	5.2	8.3	*
Unmet need for specific health care services	13.3	16.1	
Unmet need for family support services	5.6	4.9	
Child age 0-2 years receives Early Intervention Services	46.0	22.6	
Children age 2-17 receives Special Education Services	27.0	28.5	

\*Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates.  
Source: CSHCN data from 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from [www.nschdata.org](http://www.nschdata.org).

**Transition to Adult Life (CSHCN Outcome #6)**

- 39.4% of Hawai'i youth with special health care needs (YSHCN) achieved the outcome of receiving the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence (Table 4-21). This rate is similar to that for U.S. YSHCN (41.2%).
- Hawai'i YSHCN have a significantly higher rate of their doctors discussing future insurance needs (46.9%), compared to the U.S. rate (34.1%).
- Hawai'i YSHCN with functional limitations have significantly lower rates of receiving the services necessary to transition to adult life (22.8%), compared to YSHCN with conditions managed by prescription medications only (44.7%) (Table 4-22).
- Hawai'i families of YSHCN indicated a need for a discussion with their doctors about doctors who treat adults, adult health care needs, and maintaining health insurance (Table 4-23).

	<b>Hawai'i % CSHCN</b>	<b>U.S. % CSHCN</b>	
<b>Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence (CSHCN Outcome)+</b>	<b>39.4</b>	<b>41.2</b>	
Child receives anticipatory guidance in the transition to adulthood (derived)	36.9	38.2	
Doctors have discussed shift to adult provider, if necessary	36.1	42.0	
Doctors have discussed future health care needs, if necessary	62.4	62.5	
Doctors have discussed future insurance needs, if necessary	46.9	34.1	*
Child has usually/always been encouraged to take responsibility for his or her health care needs	79.6	78.0	
+Outcome measure is derived from the indicators in the table. *Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates. Source: CDC, NCHS, Progress Toward Implementing Community-Based Systems of Services for CSHCN: Summary Tables from the National Survey of CSHCN, 2005-2006, December 2007. 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website; retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .			

**Table 4-22: Transition to Adult Life – Factors Impacting Successful Achievement of Outcome, Hawai'i, 2005-2006**

<b>% CSHCN age 12-17 years successfully achieving outcome that: Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence</b>				
<b>All CSHCN</b>	<b>39.4</b>			
Family Structure	Two-parent (biological/adoptive) household <b>45.7</b>	Two-parent stepfamily household <b>49.9</b>	Mother only household (no father present) <b>30.1</b>	Other types of family structure <b>+</b>
Household income	0 - 99% FPL <b>++</b>	100 - 199% FPL <b>40.6</b>	200 -399% FPL <b>40.2</b>	≥400% FPL <b>43.3</b>
Health insurance – type	Private insurance only <b>41.8</b>	Public insurance only <b>34.5</b>	Both private and public insurance <b>+</b>	Uninsured <b>+</b>
Health insurance – consistency	Insured entire year <b>40.8</b>		1 or more periods uninsured, past year <b>+</b>	
Type of special health needs	Functional limitations <b>22.8<sup>1</sup></b>	Managed by Rx medications <b>44.7<sup>1</sup></b>	Above routine need/use of services <b>31.6</b>	Rx medications and service use <b>46.6</b>
Emotional/behavioral/ developmental (EBD) issues	One or more EBD issues <b>37.1</b>		No qualifying EBD issues <b>40.5</b>	
Presence of medical home	CSHCN with medical home <b>47.8</b>		CSHCN without medical home <b>33.5</b>	
FPL = Federal Poverty Level Rx = prescription +Estimate based on sample size too small to meet standards for reliability or precision <sup>1</sup> Statistical difference at the 95% confidence interval for items in a row Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a> .				

**Table 4-23. Transition to Adult Life – Additional Indicators: Comparison of Hawai'i and U.S. Rates, 2005-2006\***

	<b>Hawai'i</b> % CSHCN age 12-17	<b>U.S.</b> % CSHCN age 12-17
Discussion about doctors who treat adults is needed but has not yet happened	21.3	16.6
Discussion about adult health care needs is needed but has not yet happened	29.7	28.2
Discussion about maintaining health insurance is needed but has not yet happened	37.0	42.0
*No statistical differences between Hawai'i and U.S. rates. Source: CSHCN data from 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.nschdata.org">www.nschdata.org</a> .		

### Urban-Rural Comparison of Outcome and Indicators

- A comparison of CSHCN living in urban (island of Oahu) and rural (Neighbor Islands) areas of Hawai'i show that CSHCN in rural areas appear to have greater needs related to child health, health insurance coverage, access to care, family-centered care, and impact on the family (statistical information not available) (Table 4-24).
- The comparison also shows that CSHCN in rural areas appear to have generally lower rates of achieving the CSHCN outcomes of family partnership, medical home, adequate health insurance, screening, and transition to adult life (statistical information not available).

<b>Table 4-24. Outcomes and Indicators: Urban-Rural Comparison, Hawai'i, 2005-2006*</b>			
	<b>Urban Oahu<sup>1</sup> % CSHCN</b>	<b>Rural Neighbor Islands<sup>2</sup> % CSHCN</b>	<b>Hawai'i Statewide % CSHCN</b>
<b>Child Health</b>			
CSHCN whose conditions affect their activities usually, always, or a great deal	22.4	26.0	<b>23.5</b>
CSHCN with 11 or more days of school absences due to illness	12.1	14.5	<b>12.8</b>
<b>Health Insurance Coverage</b>			
CSHCN without insurance at some point in past year	2.5	5.2	<b>3.3</b>
CSHCN without insurance at time of survey	0.7	1.9	<b>0.9</b>
Currently insured CSHCN whose insurance is inadequate	22.2	28.9	<b>24.3</b>
<b>Access to Care</b>			
CSHCN with any unmet need for specific health care services	9.3	21.9	<b>13.3</b>
CSHCN with any unmet need for family support services	4.7	7.5	<b>5.6</b>
CSHCN needing a referral who have difficulty getting it	20.3	23.8	<b>21.4</b>
CSHCN without a usual source of care when sick (or who rely on the emergency room)	5.1	10.5	<b>6.8</b>
CSHCN without any personal doctor or nurse	6.2	5.3	<b>6.0</b>
<b>Family Centered Care</b>			
CSHCN without family-centered care	33.9	41.0	<b>36.1</b>
<b>Impact on Family</b>			
CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	10.3	13.1	<b>11.1</b>
CSHCN whose conditions cause financial problems for the family	8.6	16.2	<b>11.0</b>
CSHCN whose families spend 11 or more hours per week providing or coordinating child's health care	8.9	16.6	<b>11.3</b>
CSHCN whose conditions cause family members to cut back or stop working	21.4	23.6	<b>22.1</b>
<b>CSHCN Outcomes</b>			
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	61.6	54.0	<b>59.3</b>
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	48.7	37.6	<b>45.2</b>

CSHCN whose families have adequate private and/or public insurance to pay for the services they need	76.3	67.5	<b>73.5</b>
CSHCN who are screened early and continuously for special health care needs	72.9	62.6	<b>69.7</b>
CSHCN whose services are organized in ways that families can use them easily	89.5	87.2	<b>88.8</b>
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	40.4	36.7	<b>39.4</b>
<p>*Confidence intervals were not available.  <sup>1</sup>Urban=combined data for "urban core" and "suburban". Based on the map location, all urban areas were on the island of Oahu.  <sup>2</sup>Rural=combined data for "large town" + "small town/rural". Based on the map location, all rural areas were on the Neighbor Islands.            Source: 2005/06 National Survey of CSHCN, Data Resource Center for Child and Adolescent Health website. Retrieved May 2010 from <a href="http://www.cshcndata.org">www.cshcndata.org</a>.</p>			

## Other Hawai'i Data on Health Conditions and Disabilities

### Acquired Immunodeficiency Syndrome (AIDS)

- For the period 1983-2008, of the 3,071 reported cases of AIDS in Hawai'i, there were 17 children under age 13 years, with the last case diagnosed in 2003; and 12 youth age 13-19 years, with the last case diagnosed in 2006. At the end of 2007, of the estimated 1,316 persons living in Hawai'i with AIDS, three were children under age 13 years.<sup>1</sup>
- To increase HIV testing by health care providers, Hawai'i Revised Statute (HRS) §325-16 was amended in 2009 to remove the requirement for health care providers to obtain written informed consent and offer pretest HIV (Human Immunodeficiency Virus) counseling before doing a HIV test. A national estimate is that approximately 25% of infected individuals have not been tested or know that they have HIV.<sup>2</sup>
- The DOH STD/AIDS Prevention Branch provides education, risk reduction, prevention, case management, medical management, and surveillance for HIV/AIDS.<sup>3</sup>

<sup>1</sup> Hawai'i DOH HIV/AIDS Surveillance Program, "HIV/AIDS Surveillance Semi-Annual Report, Cases to December 31, 2008", [http://hawaii.gov/health/healthy-lifestyles/std-aids/aboutus/prq-aids/aids\\_rep/2h2008.pdf](http://hawaii.gov/health/healthy-lifestyles/std-aids/aboutus/prq-aids/aids_rep/2h2008.pdf).

<sup>2</sup> Hawai'i DOH News Release, "New State Law Encourages Health Care Providers to Test for HIV, 8/10/09). <http://hawaii.gov/health/healthy-lifestyles/std-aids/pdfs/aboutus/Press%20Release.pdf>

<sup>3</sup> CDC, HIV/AIDS Surveillance Report – Cases of HIV Infection and AIDS in the U.S. and Dependent Areas, 2007, Vol.19. <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2007report/>

## Asthma<sup>4</sup>

- The asthma prevalence among Hawai'i children under age 18 years is 11.6%. The prevalence is higher for children who are male (14.2%), living in Hawai'i County, age 5-9 years (15.1%), and Native Hawaiian (18.0%).
- The DOH/Hawai'i State Asthma Control Program (HSACP) is addressing asthma from a public health perspective, through surveillance, education, coalition and workgroup building, advocacy, interventions, and evaluation. HSACP workgroups have developed specific, evidence-based activities aligned to the Hawai'i Asthma Plan to meet the needs of Hawai'i communities throughout the state.

## Autism Spectrum Disorders (ASD)

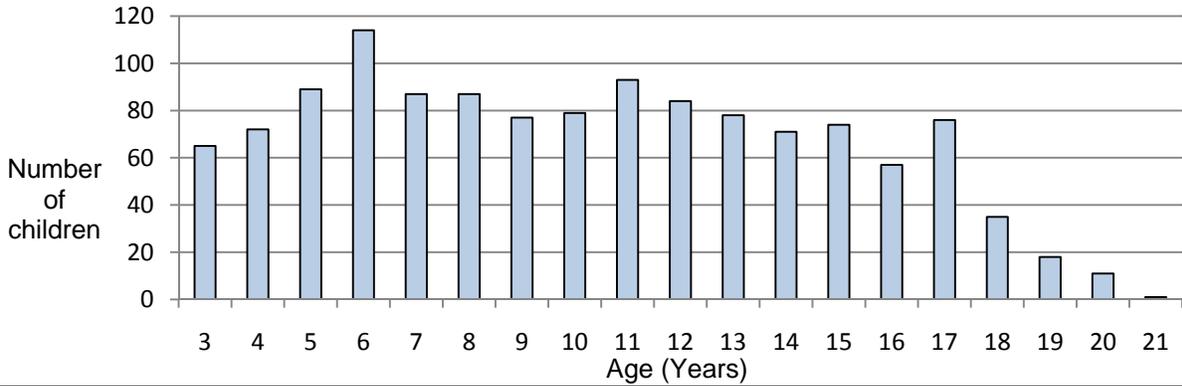
- In 2009, the number of children age 0-3 years with ASD served by the DOH/CSHNB/Early Intervention Section (EIS) was 165 (Table 4-25).
- In 2009, the number of children age 3-21 years with ASD served by the Department of Education (DOE) Special Education was 1,268. The majority are Asian/Pacific Islander. Most children receive services until high school graduation, with only a small number receiving services until age 21 years (Graph 4-1). The number of children with ASD receiving DOE services increased over the period 2005-2009 (Graph 4-2), possibly due to increased awareness and identification of children with ASD.
- Needs regarding the system of services for children/youth with ASD relate to all six CSHCN outcomes (Table 4-26).
- 

Age (years)	# Children & Youth with ASD	Race/ethnicity				
		American Indian/ Alaska Native	Asian/ Pacific Islander	Black (not Hispanic)	White (not Hispanic)	Hispanic
0-3 <sup>1</sup>	165	-	-	-	-	-
3-5 <sup>2</sup>	226	0 (0%)	141 (62.4%)	5 (2.2%)	68 (30.1%)	12 (5.3%)
6-21 <sup>2</sup>	1,042	11 (1.1%)	700 (67.2%)	27 (2.6%)	271 (26.0%)	33 (3.2%)
<b>Total</b>	<b>1,433</b>	-	-	-	-	-

Source: <sup>1</sup>Hawai'i DOH Early Intervention Section, May 2010 (for children with ASD).  
<sup>2</sup>Hawai'i Department of Education, Report of Children with Disabilities Receiving Education, Part B, IDEA, as Amended, 2009. [http://doe.k12.hi.us/reports/specialeducation/idea\\_part\\_b\\_data\\_reports/index.htm](http://doe.k12.hi.us/reports/specialeducation/idea_part_b_data_reports/index.htm)

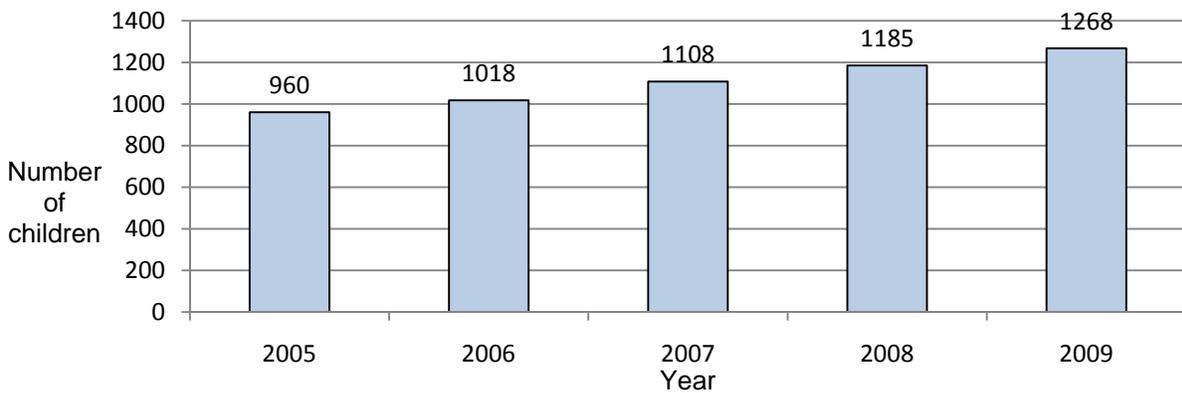
<sup>4</sup> Hawai'i DOH Asthma Control Program, <http://hawaii.gov/health/family-child-health/chronic-disease/asthma/index.html>, and "State of Asthma, Hawai'i 2009", <http://hawaii.gov/health/family-child-health/chronic-disease/asthma/downloads/doh.asthmaburden.2009.pdf>.

**Chart 4-1. Autism Spectrum Disorders: Children in DOE Special Education with ASD, by Age, 2009**



Source: Hawai'i Department of Education, Report of Children with Disabilities Receiving Education, Part B, IDEA, as Amended, 2009.  
[http://doe.k12.hi.us/reports/specialeducation/idea\\_part\\_b\\_data\\_reports/index.htm](http://doe.k12.hi.us/reports/specialeducation/idea_part_b_data_reports/index.htm)

**Chart 4-2. Autism Spectrum Disorders: Children in DOE Special Education with ASD, Age 3-21 Years, 2006-2009**



Source: Hawai'i Department of Education, Report of Children with Disabilities Receiving Education, Part B, IDEA, as Amended, tables 2006-2009.  
[http://doe.k12.hi.us/reports/specialeducation/idea\\_part\\_b\\_data\\_reports/index.htm](http://doe.k12.hi.us/reports/specialeducation/idea_part_b_data_reports/index.htm)

**Table 4-26. Autism Spectrum Disorders – Needs by the CSHCN Outcomes, 2010**

CSHCN Outcomes		Needs	
<b>Community Services Easily Used</b>	<b>Family-Professional Partnership</b>	<ul style="list-style-type: none"> <li>▪ A statewide parent to parent resource center with specialized ASD support and information for families of children/youth with ASD</li> <li>▪ Information materials on ASD for families that are culturally appropriate and in different languages</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increased statewide public awareness/outreach activities about ASD and available services and resources</li> <li>▪ Education and information on evidence-based best practices in identification and treatment of ASD for families and professionals</li> <li>▪ ASD resource directory and training on services and resources for ASD, for professionals and families</li> <li>▪ Training materials on ASD, ASD referral algorithm, coordination of benefits, clinical follow-up, and community resources, for coordinators of Medicaid-funded program services</li> <li>▪ Evaluation/quality monitoring tools for IBS services for children age 0-3 years with ASD, and integration of IBS with other early intervention services</li> </ul>
	<b>Medical Home &amp; Screening</b>	<ul style="list-style-type: none"> <li>▪ Education/training for PCPs on ASD screening and follow-up</li> <li>▪ Community-based ASD referral algorithm to assist the medical home in appropriate referrals</li> <li>▪ Increased knowledge of medical homes on the management of ASD, evidence-based best practices, community resources, and their role in integrating/coordinating care</li> <li>▪ Quality improvement activities related to access to care for children/youth with ASD/DD</li> </ul>	
	<b>Health Insurance</b>	<ul style="list-style-type: none"> <li>▪ Health insurance coverage of evidence-based, medically necessary screening, evaluation and treatment of ASD</li> </ul>	
	<b>Transition to Adult Health Care</b>	<ul style="list-style-type: none"> <li>▪ ASD transition guide on adult health care, work, and independence to supplement individualized service planning process</li> </ul>	
<p>Source: Hawai'i DOH CSHNB and Family Voices of Hawai'i needs assessment on ASD and other developmental disabilities, June 2010.</p>			

**Birth Defects**

- Birth defects surveillance data for 1986-2005 (Table 4-27) show that 4.4% of all infants/fetuses delivered in Hawai'i have moderate-severe birth defects (Centers for Disease Control and Prevention [CDC] categories), and that 5.1% of all infants/fetuses delivered in Hawai'i had adverse reproductive outcomes (CDC plus additional categories).
- The most common birth defects are cardiac & circulatory, limb & musculoskeletal, and genital & urinary conditions.
- Birth defects surveillance is conducted by the DOH/CSHNB/Hawai'i Birth Defects Program using an active surveillance system.
- Congenital anomalies were the cause of 17/148 (11.5%) of deaths for children/youth under age 18 years in 2008 (Table 4-28).

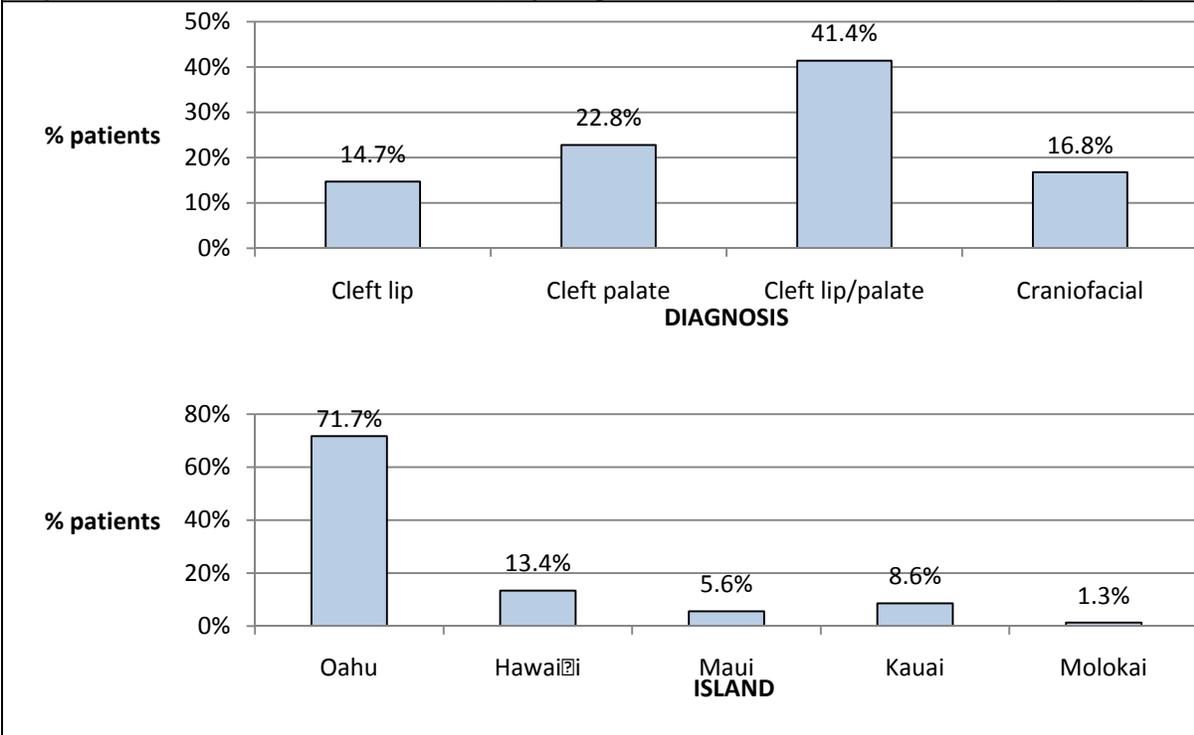
	<b>Rate % births</b>		<b>Rate Per 10,000 births</b>
<b>Birth Defects Rate<sup>1</sup></b>	<b>4.4%</b>	Major CDC birth defects categories:	
<b>Adverse Reproductive Outcomes Rate<sup>2</sup></b>	<b>5.1%</b>	Cardiac & circulatory	179.9
		Limb & musculoskeletal	124.9
		Genital & urinary	103.8
		Skin & integument	58.3
		Orofacial & gastrointestinal	56.5
		Chromosome & syndrome	52.9
		Eye, ear, face, & neck	48.0
		Brain & nervous system	39.1
		Respiratory	23.8
		Major non-CDC categories:	
		Maternal substance abuse	82.3
		Neoplasms	9.6
		Congenital infection	6.8
<sup>1</sup> Birth defects rate includes moderate-severe birth defects as defined by the Centers for Disease Control and Prevention (CDC). <sup>2</sup> Adverse reproductive outcomes rate includes the major CDC categories of birth defects plus additional non-CDC categories. Source: DOH Hawai'i Birth Defects Program. Data analysis by the DOH/Children with Special Health Needs Branch, 2010.			

<b>Infant deaths</b>	<b>Deaths (N=103)</b>		<b>Leading causes of death for children under age 18 years</b>	<b># Deaths (N=148)</b>	
	<b>#</b>	<b>%</b>		<b>#</b>	<b>%</b>
Diseases of the digestive system	5	4.9%	Perinatal conditions	57	38.5%
Maternal complications of pregnancy	14	13.6%	Congenital anomalies	17	11.5%
Complications of placenta, cord, and membrane	6	5.8%	Symptoms, signs, and ill-defined conditions, including sudden infant death syndrome (SIDS)	15	10.1%
Short gestation	13	12.6%	Other accidents and adverse effects	13	8.8%
Sudden infant death syndrome	5	4.9%	Motor vehicle accidents	5	3.4%
All other causes	60	58.3%	Malignant neoplasms	5	3.4%
			All other diseases	36	24.3%
Source: Hawai'i DOH/Office of Health Status Monitoring, Vital Statistics Report – 2008 ( <a href="http://hawaii.gov/health/statistics/vital-statistics/vr_03/index.html">hawaii.gov/health/statistics/vital-statistics/vr_03/index.html</a> ).					

### Cleft Lip/Palate and other Craniofacial Conditions

- The rate of oral clefts in Hawai'i is 18.7 per 10,000 births for the period 1986-2005. This rate includes isolated cleft palate (7.0 per 10,000 births) and cleft lip ± cleft palate (11.7 per 10,000 births). (Source: DOH/CSHNB/ Hawai'i Birth Defects Program, 2010.)
- The care for children with cleft lip/palate and other craniofacial conditions may be complex. The Kapiolani Cleft and Craniofacial Center (KCCC), which began in 2007, addressed a previous unmet need for comprehensive coordinated care for children with craniofacial conditions. The center has a multidisciplinary team that includes craniofacial surgeon, oral surgeon, pediatrician, geneticist, developmental and behavioral specialists, audiologist, speech therapist, occupational therapist, otolaryngology physician, pediatric dentist, orthodontist, and nurse coordinator.
- Most children served by KCCC have cleft lip and/or palate conditions (78.9%) (Graph 4-3). Children served included both Oahu (71.7%) and Neighbor Islands (28.3%).
- CSHNP assists families as needed with access to KCCC services (including Neighbor Island travel), financial assistance for orthodontic services not covered by health insurance, and coordination of community-based services.

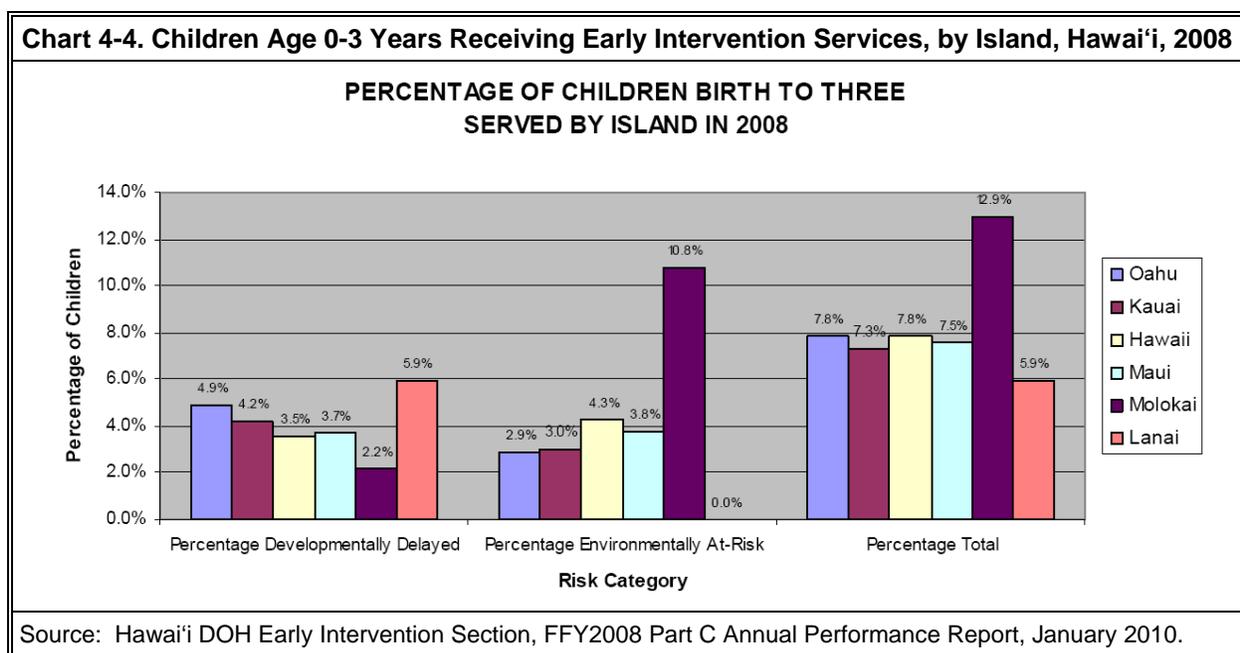
**Chart 4-3. Children with cleft lip/palate and other craniofacial conditions receiving services at Kapiolani Cleft and Craniofacial Center, by diagnosis and island, as of March 2010 (N=232)**



Source: University of Hawai'i/ Department of Pediatrics, May 2010.

### Developmental Delay – Children Age 0-3 Years Receiving Early Intervention Services

- Children age 0-3 years with or at risk for developmental delays are served through the DOH Early Intervention Section (lead agency for Part C of Individuals with Disabilities Education Act [IDEA]).
- Data for 2009 show that 3.77% of the population age 0-3 years received early intervention (EI) services due to developmental delay or biological risk.<sup>5</sup>
- Graph 4-4 shows the variation in percentage of children receiving EI services, by island in 2008.
- EI services have been impacted by the state’s economic crisis. In May 2009, the eligibility definition for Part C EI services was revised to only include children age 0-3 years who are experiencing developmental delays or have a biological risk; children at environmental risk were no longer eligible. A proposed change to the eligibility criteria for children with developmental delays is now under consideration.



### Disabilities – Children Age 3-21 Years in School (Part B of IDEA)<sup>6</sup>

- Children and youth age 3-21 years with disabilities are served under Part B of IDEA by the Hawai'i State Department of Education (DOE). In December 2009, there were 21,913 students receiving services and educational supports under IDEA and Section 504 of the Rehabilitation Act of 1973. Of that total, 92% were IDEA eligible and 8% were Section 504 eligible. The number of students receiving services under special education and related services under the IDEA is approximately 12% of the overall student enrollment.

<sup>5</sup> Hawai'i DOH Early Intervention Section, FFY 2008 Part C Annual Performance Report, January 2010.)

<sup>6</sup> Hawai'i DOE, "Performance Report – Performance Period July 2009-December 2009.

[http://165.248.6.166/data/felix\\_archive/report/Report2009Jul-Dec/index.htm](http://165.248.6.166/data/felix_archive/report/Report2009Jul-Dec/index.htm)

- It is estimated that 5.39% of the population age 3-5 years, 9.41% of the population age 6-17 years, and 0.98% of the population age 18-21 years are served under Part B of IDEA (Table 4-29).
- For children age 3-5 years receiving services under IDEA, the most common disabilities are developmental delay (72%), autism (9%), and speech/language impairment (7%) (Table 4-30). For children/youth age 6-21 years, the most common disabilities are specific learning disabilities (48%), other health impairments (15%), emotional disturbance (8%), mental retardation (7%), developmental delay (7%), and autism (6%),

Age Group	# Children/Youth in Part B	Est. Population	% Population Served Under IDEA
Age 3-5 years	2,477	45,966	5.39%
Age 6-17 years	17,320	184,154	9.41%
Age 18-21 years	644	65,446	0.98%

Source: Data Accountability Center, Data Tables for OSEP State Reported Data, [http://www.ideadata.org/arc\\_toc9.asp#partbCC](http://www.ideadata.org/arc_toc9.asp#partbCC)

	Children and Youth with Disabilities Age 3-5 Years		Children and Youth with Disabilities Age 6-21 Years	
	#	%	#	%
Mental Retardation	16	1%	1,244	7%
Hearing Impairments	51	2%	314	2%
Speech or Language Impairments	173	7%	598	3%
Visual Impairments	12	0%	58	0%
Emotional Disturbance	18	1%	1,420	8%
Orthopedic Impairments	28	1%	71	0%
Other Health Impairments	92	4%	2,664	15%
Specific Learning Disabilities	7	0%	8,393	48%
Deaf-Blindness	2	0%	5	0%
Multiple Disabilities	58	2%	457	3%
Autism	226	9%	1,042	6%
Traumatic Brain Injury	8	0%	69	0%
Developmental Delay	1,764	72%	1,167	7%
<b>TOTAL</b>	<b>2,455</b>	<b>100%</b>	<b>17,502</b>	<b>100%</b>

Source: Hawai'i Department of Education, "Report of Children with Disabilities Receiving Special Education, Part B, IDEA, As Amended, 2009."  
[http://doe.k12.hi.us/reports/specialeducation/idea\\_part\\_b\\_data\\_reports/index.htm](http://doe.k12.hi.us/reports/specialeducation/idea_part_b_data_reports/index.htm)

### Disabilities – Supplemental Security Income (SSI) Recipients Age 0-17 Years

- Of Hawai'i children/youth receiving SSI payments, children are of all age groups, there are more males (64.3%) than females (35.7%), and about 16.8% are not living in their parent's household (Table 4-31). Eligible children/youth are those who have limited income/resources and have a chronic physical and/or mental condition that results in "marked and severe functional limitations".
- U.S. data on conditions for children and youth age 0-17 years receiving SSI payments include: mental retardation (14.1%), other mental disorders (51.6%), nervous system and sense organs (8.1%), congenital anomalies (5.2%), respiratory system (2.7%), blood and blood-forming organs (1.1%), neoplasms (1.1%), and other conditions (16.1%). Source: Social Security Administration. SSI Annual Statistical Report, 2008.

	# CSHCN	% CSHCN		# CSHCN	% CSHCN
<b>Age (years)</b>			<b>Sex</b>		
0-1	90	5.3%	Male	1,091	64.3%
2-3	142	8.4%	Female	606	35.7%
4-5	177	10.4%	<b>Living arrangements</b>		
6-7	202	11.9%	Own household	149	8.8%
8-9	200	11.8%	Another's household	112	6.5%
10-11	201	11.8%	Parent's household	1,412	83.2%
12-13	206	12.1%	Medicaid institution	25	1.5%
14-15	241	14.2%			
16-17	238	14.0%	<b>Total</b>	1,697	100%

Source: Social Security Administration. Social Security Record (Characteristic Extract Record format), 100% data. Table produced by SSA/ORDP/ORES/DSSA, 2010.

### Fetal Alcohol Spectrum Disorders (FASD)

- Prior to pregnancy, 18% of Hawai'i women reported binge drinking. During pregnancy, 6% of women drank alcohol and 1% binge drank.<sup>7</sup>
- Dr. Ira Chasnoff's data from "The First 1,000 Women, Perinatal Substance Use on Hawai'i Island" reported that 34.6% of pregnant women screened drank alcohol in the month before they knew they were pregnant.
- In Hawai'i, 90 children were diagnosed with fetal alcohol syndrome, 1986-2005.<sup>8</sup>
- In the United States, FASD occurs in about 10 per 1,000 live births, or 40,000 babies per year.<sup>9</sup>

<sup>7</sup> Schempf A, Hayes D, Fuddy L. "Perinatal Substance Use Fact Sheet." Honolulu, HI: Hawai'i DOH Family Health Services Division; September 2008.

<sup>8</sup> Hawai'i DOH Hawai'i Birth Defects Program, 2010.

<sup>9</sup> Substance Abuse and Mental Health Services Administration (SAMHSA), "The Physical Effects of Fetal Alcohol Spectrum Disorders" fact sheet, 2007.

- An alcohol exposed pregnancy is a leading cause for birth defects and developmental disabilities in the United States and is preventable through abstinence from drinking alcohol during pregnancy. Adverse birth outcomes and developmental/behavioral problems including stillbirth, low birth weight, preterm delivery, birth defects, mental retardation, and fetal alcohol syndrome are associated with prenatal use of alcohol.
- Key issues contributing to a poor birth outcome due to alcohol exposed pregnancy.<sup>10</sup>
  - Women are not well informed of alcohol effects to a developing fetus and the importance to abstain from alcohol use during pregnancy.
  - A high percentage of unintended pregnancies (41.9%, 2008 Hawai'i PRAMS), in combination with alcohol use, increases the chances of giving birth to a child with birth defects and FASD.
  - A higher use of alcohol in a short period of time, or binge drinking, during pregnancy increases the rate of severity to the fetus.
  - Not all physicians and clinical providers incorporate screening of alcohol use for women who are pregnant, nor are they all in agreement about advising pregnant women to abstain from drinking alcohol during pregnancy.
  - Lack of documentation of mother's use of alcohol during pregnancy significantly decreases the chances of a child receiving a correct diagnosis and treatment plan. Currently this information may not be noted in the child's school and/or agency files.
- The DOH FHSD, with the FASD Task Force, is increasing awareness of FASD in the general public and in at-risk populations, and facilitating development and implementation of a comprehensive, statewide system of care for the prevention, identification, surveillance, and treatment of FASD.
- A Hawai'i geneticist is collaborating with other agencies to improve screening and assessments so more children with FASD can be identified and receive appropriate treatment in a timely manner.

### **Hearing Loss – Young Children**

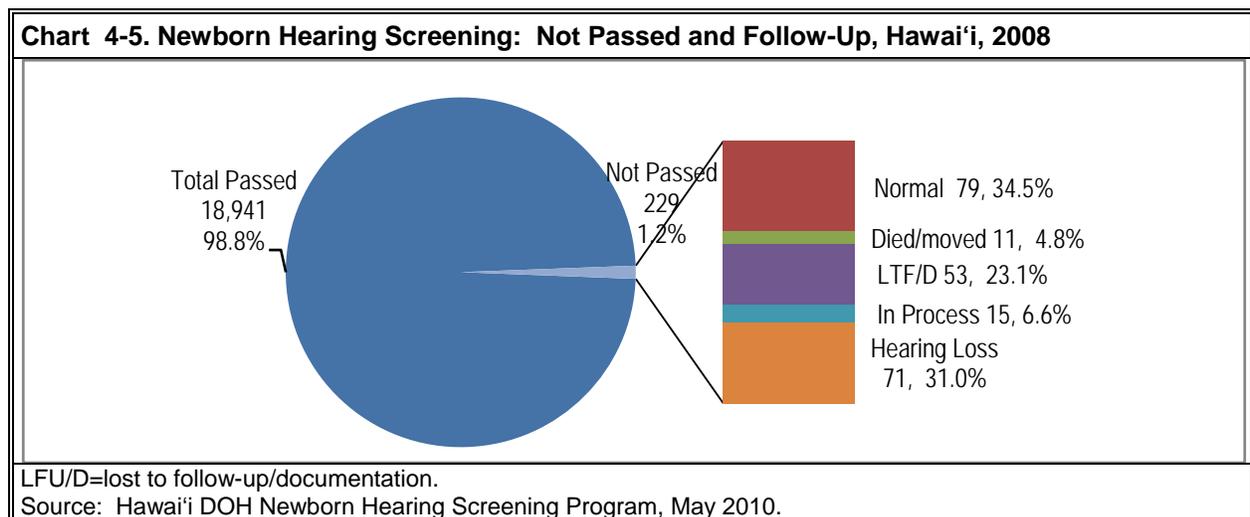
- The Newborn Hearing Screening Program (NHSP) began in 1990 through a law that mandated that the DOH develop methodology to establish a statewide program for screening of infants and children age 0-3 with hearing loss. Screening began in 2 hospitals in 1992, was provided in all birthing facilities by 1999 and is now part of standard newborn care in Hawai'i. Each birthing facility has a newborn hearing screening program. The law was amended in 2001 to mandate screening of all newborns for hearing loss and reporting screening results to the DOH.
- In 2008, 98.8% of newborns were screened for hearing loss (Graph 4-5). Of those that did not pass, 31.0% were identified with hearing loss, and 23.1% were lost to follow-up/documentation (LFU/D).

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<sup>10</sup> Hawai'i DOH FASD Office, 2010.

- All children should have hearing screening by age 1 month, those not passing should have diagnostic audiological evaluation by age 3 months, and children with hearing loss should receive early intervention (EI) services by age 6 months. Hawai'i data for 2008 show that 97.3% were screened by age 1 month, 41.3% were evaluated by age 3 months, and 59.0% received EI services by age 6 months (Table 4-32). Data for the period 2005-2008 show that the LFU/D rates for screening, evaluation, intervention have fluctuated, with no clear trend in improvement.
- In 2008, there were 65 children identified with permanent congenital hearing loss (Table 4-33), of which 32% had unilateral and 68% had bilateral hearing loss (Table 4-33). The majority of children had sensorineural hearing loss. Severity of hearing loss ranged from mild to profound.
- A comparison of Hawai'i and U.S. rates shows that the prevalence of hearing loss in Hawai'i (3.7 per 1000 screened) is greater than that for the U.S. (1.2 per 1000 screened) (Table 4-34).
- DOH NHSP is responsible for the oversight and development of the newborn hearing screening and follow-up system in Hawai'i.
- The following are issues for newborn hearing screening and follow-up:
  - Inadequate newborn hearing screening for homebirths. Outreach to educate midwives on newborn hearing screening is needed to increase screening rates for homebirths.
  - Need to increase the percentage of children meeting early hearing detection and intervention timelines, especially diagnostic audiological evaluation by age 3 months and referral to early intervention services by age 6 months.
  - Need to reduce the percentage of children lost to follow-up/lost to documentation (LFU/D).
  - Need to improve access to diagnostic audiological evaluation especially on the Neighbor Islands. Difficulties include lack of or limited availability of diagnostic equipment and audiological services on several Neighbor Islands.

(Source: Hawai'i DOH Newborn Hearing Screening Program, 2010.)



**Table 4-32. Newborn Hearing Screening, Evaluation, and Intervention, Hawai'i, 2005-2008**

	2005	2006	2007	2008
<b>Screening</b>				
% screened by age 1 month	97.6%	98.3%	98.1%	97.3%
% LFU/D at screening stage	0.9%	0.9%	0.8%	1.1%
% births out-of-hospital (homebirths) LFU/D at screening stage	68.1%	60.7%	43.1%	72.7%
<b>Evaluation</b>				
% evaluated by age 3 months	48.9%	50.2%	39.1%	41.3%
% LFU/D at evaluation stage	42.7%	31.9%	44.8%	41.3%
<b>Intervention</b>				
% receiving early intervention by age 6 months	81.0%	72.6%	72.6%	59.0%
% LFU/D at intervention stage	1.6%	3.7%	3.2%	1.6%

LFU/D=lost to follow-up/documentation.

Source: Hawai'i DOH/Newborn Hearing Screening Program, May 2010.

**Table 4-33. Type and Severity of Permanent Congenital Hearing Loss, Hawai'i, 2008**

Unilateral Hearing Loss Total 21 Children			Bilateral Hearing Loss Total 44 Children		
	# ears (N=21)	% ears		% ears (N=88)	% ears
Type			Type		
Sensorineural	10	48%	Sensorineural	58	66%
Conductive	6	29%	Conductive	7	8%
Mixed (conductive + sensorineural)	2	10%	Mixed (conductive + sensorineural)	17	19%
Unknown	3	14%	Unknown	6	7%
Severity			Severity		
Mild	6	29%	Mild	21	24%
Moderate	8	38%	Moderate	31	35%
Severe	4	19%	Severe	27	31%
Profound	0	0%	Profound	3	3%
Unknown	3	14%	Unknown	6	7%

Source: Hawai'i State Department of Health, Newborn Hearing Screening Program, October 2009

<b>Table 4-34. Newborn Hearing Screening and Hearing Loss: Comparison of Hawai'i and U.S. Rates, 2007</b>		
	<b>Hawai'i</b>	<b>U.S.*</b>
Total births	19,147	3,449,300
Total screened (%)	18,867 (98.5%)	3,345,629 (97.0%)
Total not passed (%)	271 ( 1.4%)	65,339 ( 2.1%)
Total hearing loss (%)	69 (25.5%)	3,364 ( 5.2%)
Prevalence of hearing loss	3.7 per 1000 screened**	1.2 per 1000 screened
* 47 states and 2 territories (Guam, CNMI)		
** Highest in U.S.		

### **Metabolic Disorders (Newborn)**

- Newborns in Hawai'i are now screened for 32 disorders. In 1997, the number of disorders screened increased from 2 disorders (phenylketonuria, congenital hypothyroidism) to 7 disorders (with the addition of biotinidase deficiency, congenital adrenal hyperplasia, galactosemia, hemoglobinopathies, and maple syrup urine disease). In 2003, the newborn screening panel expanded to 31 disorders, with the addition of 24 disorders (amino acid, urea cycle, organic acid, and fatty acid disorders) screened using tandem mass spectrometry. In 2007, the newborn screening testing panel expanded to 32 disorders, with the addition of cystic fibrosis screening.
- In 2009, 99.7% of eligible newborns received metabolic screening. Of infants confirmed with metabolic disorders, 100% infants received appropriate follow-up. All confirmed cases are under medical supervision and none have been lost to follow-up.
- Congenital hypothyroidism (1/2,403), congenital adrenal hyperplasia (1/20,968), and hemoglobinopathies (1/20,065) are the most common disorders identified through newborn screening in Hawai'i (Tables 4-35, 4-36, 4-37). Compared with the U.S. rate, the incidence in Hawai'i appears greater for congenital hypothyroidism (Hawai'i 1/2,403 vs. U.S. 1/4,000), maple syrup urine disease (Hawai'i 1/46,130 vs. U.S. 1/250,000), and biotinidase deficiency (Hawai'i 1/38,442 vs. U.S. 1/70,000).
- The DOH Newborn Metabolic Screening Program (NBMSPP) is responsible for the oversight and development of the newborn metabolic screening and follow-up system in Hawai'i.
- The following are emerging issues for newborn screening:
  - *Addition of Severe Combined Immunodeficiency (SCID) to the list of the disorders screened:* In January 2010, the Advisory Committee on Heritable Disorders in Newborns and Children recommended the addition of SCID to the uniform newborn screening panel. SCID is a group of disorders characterized by the absence of an immune system, causing infants with SCID to develop recurrent infections, leading to death in early childhood. Treatment in the first months after birth can prolong life and prevent infections. NBMSPP must study the incidence of SCID in Hawai'i, cost for screening and follow-up, feasibility of follow-up, etc., and then present information to the Hawai'i

Newborn Screening Advisory Committee to determine whether or not SCID should be added to the newborn screening panel.

- *Retention and use of dried blood spot specimens after newborn screening:* This is a national issue due to privacy concerns raised by parents about the retention of their children's DNA by government programs. In Hawai'i, the residual dried blood spots are kept for one year under the contract with the regional laboratory and are used for quality assurance/improvement activities but not research purposes. In consultation with the community and the Hawai'i Newborn Screening Advisory Committee, NBMSP must address developing procedures and standards for retaining residual dried bloodspot specimens, with consideration for existing federal regulations, state laws, professional guidelines, ethical and legal precedents, and the consent process for newborn screening.
- *Emergency preparedness/contingency planning for newborn screening:* Newborns with conditions that may be identified through newborn screening are vulnerable during disasters, and therefore it is critical to keep newborn screening operational. Problems may include disruption in screening, specimen transport, laboratory testing, diagnostic confirmation, communication with providers/consultants, and treating/managing infants with disorders. Due to the isolation of our state, it is vitally important to develop and maintain an emergency plan for newborn screening.
- *Implementation of new guidelines for newborn screening of preterm, low birth weight, sick, and at-risk newborns:* Newborns who require neonatal intensive care are at greater risk for missed, unreliable, or incomplete newborn screening than normal newborns, due to multiple factors associated with the mother, infant, or treatments. Best practices now include the serial collection of three specimens (in contrast to the current single specimen) to ensure that newborns at risk receive reliable/timely screening and early treatment if needed. Implementation in Hawai'i will require the development of guidelines, new screening laboratory forms, new contractual arrangements with the regional laboratory, education for health care providers and birthing facilities, and potentially higher fees for newborn screening.

(Source: DOH Newborn Metabolic Screening Program, 2010.)

**Table 4-35. Incidence of Newborn Metabolic Screening Disorders in Hawai'i and U.S., July 1997-March 2010**

	Phenylketonuria	Congenital hypothyroidism	Congenital adrenal hyperplasia	Maple syrup urine disease	Galactosemia	Biotinidase deficiency	Hemoglobinopathies
Incidence -U.S.	1/18,000	1/4,000	1/15,000	1/250,000	1/60,000	1/70,000	1/15,000 Gen. Pop.
Incidence – Hawai'i (7/97-3/10)	1/46,130 3 classic 2 hyperphe	1/2,403 96 primary	1/20,968 5 salt-wasters 6 virilized	1/46,130 4 classic 1 intermediate	1/115,325 2 classic 21 Duarte Variants	1/38,442 4 partial 2 profound	1/20,065 5 SC Disease 5 SS Disease

Source: Hawai'i DOH Newborn Metabolic Screening Program, May 2010.

**Table 4-36. Incidence of Tandem Mass Newborn Screening Disorders in Hawai'i and U.S., September 2003-March 2010**

Disorder	MCADD	VLCADD	3MCC	Holocarb o-xylase	?CPT I Variant	IVA	GA-1	SCADD
Incidence - U.S.	1/15,000	1/120,000	1/50,000	1/87,000	?	1/230,000	1/40,000	?
Incidence – Hawai'i (9/03-3/10)	1/30,891 4 cases	1/24,713 5 cases 9 variants	1/41,188 3 cases	1/123,565 5 1 case	1/17,652 7 cases	1/61,783 2 cases	1/123,565 5 1 case	1/123,565 5 1 case

MCADD Medium Chain Acyl-CoA Dehydrogenase Deficiency  
 VLCADD Very Long Chain Acyl-CoA Dehydrogenase Deficiency  
 3 MCC DEFICIENCY 3 Methylcrotonyl CoA Carboxylase Deficiency  
 HOLOCARBOXYLASE Holocarboxylase Synthetase Deficiency  
 CPT I Carnitine Palmitoyl Transferase I  
 IVA Isovaleric Acidemia  
 GA-1 Glutaric Acidemia Type 1  
 SCADD Short Chain Acyl-Co-A Dehydrogenase Deficiency

Source: Hawai'i DOH Newborn Metabolic Screening Program, May 2010.

**Table 4-37. Incidence of Cystic Fibrosis in Hawai'i and U.S., September 2007-March 2010**

Disorder	Cystic Fibrosis
Incidence -U.S.	1/4,000
Incidence –Hawai'i (9/03- 3/10)	1/49,249 1 case (meconium ileus)

Source: Hawai'i DOH Newborn Metabolic Screening Program, May 2010.

## **Hawai'i Title V/CSHCN Needs Assessment Survey – 2009**

The DOH Children with Special Health Needs Branch (CSHNB) developed family and community-provider surveys to identify areas of biggest challenges/problems for CSHCN in Hawai'i. This was part of the needs assessment required every five years by Title V Maternal and Child Health Block Grant.

Survey tools were developed by a CSHCN Workgroup with representatives of FHSD, CSHNB, District Health Offices, and Family Voices of Hawai'i. Questions were based on national CSHCN outcomes, Healthy People 2010 goals, and FHSD/CSHCN goals. Surveys were developed for families of CSHCN and for the community and providers (including advocates and health providers/professionals). Surveys were distributed statewide during February-April 2009, in person and by mail, to professional and community organizations, clinics, health centers, committees, DOH staff, families of CSHCN age 0-21 years, and other groups. While results from this selected sample may not be representative of the state, survey data and comments provide information on stakeholder priorities that may be used in determining CSHCN priorities.

### *Survey results:*

- Table 4-38 shows the 535 respondents by island and group. By island, 61.3% were from Oahu, and 37.0% were from Neighbor Islands. By group, there were 45.8% families, 43.6% health providers/professionals, 1.1% advocates, and 5.4% other.
- Topics of biggest concern were: lack of specialists/services (54.8%), development-behavior (46.9%), lack of pediatric specialists on Neighbor Islands (35.0%), developmental-behavioral screening (34.2%), and lack of adequate insurance (33.8%) (Graph 4-6).
- Families identified the following topics as the biggest concerns: development-behavior (59.6%), lack of specialists/services (48.6%), developmental-behavioral screening (45.7%), lack of adequate insurance (35.9%), and coordinated services (28.6%) (Table 4-39). Community-provider respondents identified the following topics as biggest concerns: lack of specialists/services (60.0%), lack of pediatric specialists on Neighbor Islands (41.4%), development-behavior (36.2%), lack of adequate insurance (32.1%), and family support services (31.4%).
- Oahu respondents identified the following topics as biggest concerns: lack of specialists/services (54.9%), development-behavior (50.3%), developmental-behavioral screening (34.5%), lack of adequate insurance (32.9%), and social-emotional (30.5%) (Table 4-40). Neighbor Island respondents identified the following topics as biggest concerns: lack of pediatric specialists on the Neighbor Islands (63.8%), lack of specialists/services (54.6%), development-behavior (41.6%), lack of adequate insurance (35.3%), and developmental-behavioral screening (33.8%).

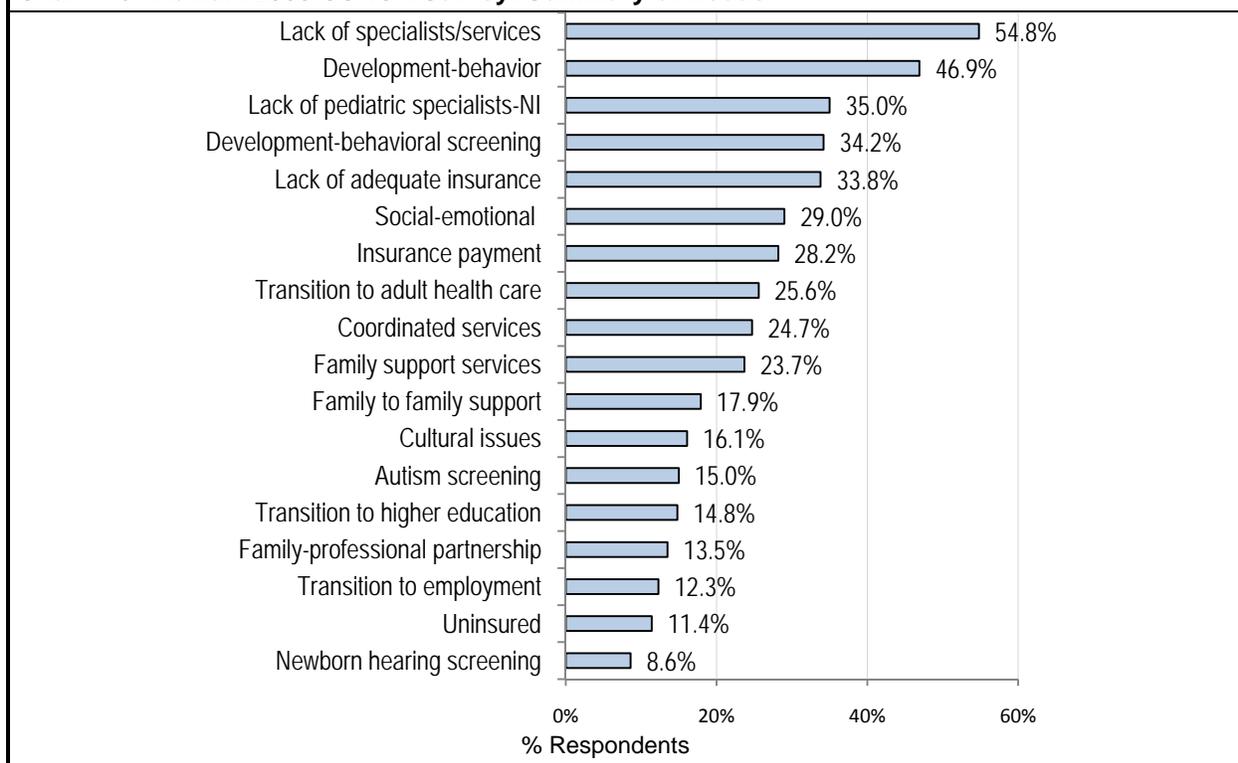
**Table 4-38. Hawai'i 2009 CSHCN Survey Respondents, By Island and Group**

Island	Family	Advocate	Health provider/ professional	Other	Unknown	Total
Oahu	151	*	153	10	12	328 (61.3%)
Hawai'i	37	*	36	10	0	84 (15.7%)
Maui	13	*	19	9	*	47 ( 8.8%)
Molokai/Lanai	*	-	*	0	*	5 ( 0.9%)
Kauai	38	-	24	0	0	62 (11.6%)
Unknown	*	-	0	0	6	9 ( 1.7%)
Total	245 (45.8%)	6 (1.1%)	233 (43.6%)	29 (5.4%)	22 (4.1%)	535 (100%)

\* <5 respondents

Source: Hawai'i DOH Children with Special Health Needs Branch, 2009.

**Chart 4-6. Hawai'i 2009 CSHCN Survey: Summary of Needs**



Source: Hawai'i DOH Children with Special Health Needs Branch, 2009.

**Table 4-39. Hawai'i 2009 CSHCN Survey: Comparison of Needs Identified by Families and Community-Providers**

TOPIC	Percent of responders identifying topic as one of biggest concerns		
	Families (N=245 )	Community-Providers (N=290)	
<b><i>Unmet health care needs</i></b>			
Development-behavior	59.6%	36.2%	+
Social-emotional	26.9%	30.7%	
Lack of specialists/services	48.6%	60.0%	+
<b><i>Health insurance</i></b>			
Uninsured	2.0%	19.3%	+
Lack of adequate insurance	35.9%	32.1%	
Insurance payment	26.5%	29.7%	
<b><i>Access to care</i></b>			
Lack of pediatric specialists on Neighbor Island	27.4%	41.4%	+
Cultural issues	2.9%	27.2%	+
Coordinated services	28.6%	21.4%	
<b><i>Screening and follow-up</i></b>			
Newborn hearing screening	14.3%	3.8%	+
Development-behavioral screening	45.7%	24.5%	+
Autism screening	11.8%	17.6%	
<b><i>Family support</i></b>			
Family to family support	18.0%	17.9%	
Family support services	14.7%	31.4%	+
Family-professional partnership	15.9%	11.4%	
<b><i>Transition to adult life</i></b>			
Transition to adult health care	24.1%	26.9%	
Transition to higher education	19.2%	11.0%	+
Transition to employment	8.6%	15.5%	++

+ Statistically different, P<0.01, between Families and Community-Providers

++ Statistically different, P<0.05, between Families and Community-Providers

Source: Hawai'i DOH Children with Special Health Needs Branch, 2009.

TOPIC	Percent of responders identifying topic as one of biggest concerns					
	Oahu (N=328 )	Neighbor Islands (N=198)	Hawai'i (N=84)	Maui, Molokai, Lanai (N=52)	Kauai (N=62)	
<b>Unmet health care needs</b>						
Development-behavior	50.3%	41.6%	31.0%	46.0%	53.2%	++
Social-emotional	30.5%	26.6%	25.0%	36.0%	30.0%	
Lack of specialists/services	54.9%	54.6%	65.5%	42.0%	51.6%	
<b>Health insurance</b>						
Uninsured	11.6%	11.1%	6.0%	14.0%	11.3%	
Lack of adequate insurance	32.9%	35.3%	35.7%	38.0%	29.0%	
Insurance payment	25.6%	32.4%	40.5%	18.0%	30.7%	
<b>Access to care</b>						
Lack pediatric specialists on Neighbor Islands	16.8%	63.8%	76.2%	52.0%	61.3%	+
Cultural issues	15.6%	16.9%	28.6%	8.0%	9.7%	
Coordinated services	28.7%	18.4%	21.4%	12.0%	19.4%	+
<b>Screening and follow-up</b>						
Newborn hearing screen	8.2%	9.2%	8.3%	2.0%	16.1%	
Developmental-behavioral screening	34.5%	33.8%	32.1%	42.0%	30.7%	
Autism screening	17.7%	10.6%	10.7%	16.0%	6.5%	++
<b>Family support</b>						
Family to family support	17.7%	18.4%	16.7%	14.0%	25.8%	
Family support services	25.9%	20.3%	14.3%	30.0%	19.4%	
Family-professional partnership	11.9%	15.9%	21.4%	20.0%	6.5%	
<b>Transition to adult life</b>						
Transition to adult health care	26.2%	24.6%	29.8%	12.0%	30.7%	
Transition to higher education	13.4%	16.9%	11.9%	28.0%	12.9%	
Transition to employment	10.4%	15.5%	11.9%	30.0%	8.1%	
+ Statistically different, P<0.01, between Oahu and Neighbor Islands.						
++ Statistically different, P<0.05, between Oahu and Neighbor Islands.						
Source: Hawai'i DOH Children with Special Health Needs Branch, 2009.						

## DIRECT HEALTH CARE

Primary care providers, including private physicians and community health centers, are available on all islands. Community health centers, located in underserved areas on all islands of Hawai'i, serve individuals/families with limited access to other primary care services. Most physicians practice on the island of Oahu (3.6 physicians per 1000 population), with fewer physicians in the rural counties of Hawai'i, Kauai, and Maui (2.1 physicians per 1000 population). (Source: Health Trends in Hawai'i, [http://www.healthtrends.org/resources\\_overview.aspx](http://www.healthtrends.org/resources_overview.aspx))

Access to community-based pediatric subspecialty care on Neighbor Islands and in rural Oahu is a problem. Issues include:

- Specialists tend to practice in urban or suburban areas, primarily on Oahu, thereby creating a barrier to care for residents living in rural Oahu and on the Neighbor Islands. Difficulties for

specialists located in rural areas may include inadequate patient volume to sustain a specialty care practice or to maintain professional competency, excessive and uncompensated on-call coverage, and insufficient opportunities for continuing education and professional collaboration/interaction.

- Neighbor Island residents who need to travel to Oahu for specialty services may have financial difficulties, since some health insurance plans may not include airfare, ground transportation, and lodging as covered benefits. Insurance may cover the travel costs for a Neighbor Island child to travel to Oahu for specialty services, but may not cover the travel cost for the accompanying caregiver. The airfare cost between a Neighbor Island and Oahu now ranges from \$135-340 per round-trip. Parents may incur lost wages due to the time it takes to travel inter-island.
- Some Neighbor Island families have difficulty traveling to health services on their own island, due to factors such as long distances, long travel times, high gasoline costs, and lack of public transportation system.
- There is a national shortage of physicians in some specialty fields, adding to the difficulty in recruiting physician specialists to Hawai'i.

CSHNB provides or supports pediatric cardiology, neurology, genetics, and hematology/thalassemia clinics on Oahu and Neighbor Islands, with resources from the Children with Special Health Needs Program (CSHNP), Genetics Program, and Newborn Metabolic Screening Program. Clinics are provided or supported to improve access to care in areas where they are otherwise not available. CSHNP assists eligible families in getting services from providers who are willing to accept program fees or insurance payment without the co-payment from families; and assists eligible Neighbor Island families with airfare, ground transportation, and lodging as needed to access specialty services on Oahu. CSHNP also provides financial assistance for laboratory tests, procedures such as X-rays and EKG, prescription medications, and hearing aids and related services.

Shriners Hospital for Children in Honolulu provides orthopedic services for children under age 18 years in Hawai'i and from the Pacific Basin. It provides medical and rehabilitative services to children with congenital deformities, diseases of the musculoskeletal system, and problems from orthopedic injuries.

Tertiary health care facilities are located on Oahu, with none on the Neighbor Islands. Kapiolani Medical Center for Women and Children (KMCWC), the only pediatric tertiary center in Hawai'i, has inpatient and outpatient services, including pediatric intensive care, neonatal intensive care, 24-hour emergency room, and specialty clinics including cleft and craniofacial, behavioral developmental, neonatal intensive care follow-up, neurodevelopmental, genetics, and rheumatology clinics. It also has specialized teams to transport critically ill infants and children from Neighbor Islands to Oahu, and from Oahu to mainland hospitals for specialized care not available in Hawai'i.

Hawai'i Community Genetics (HCG) demonstrates a unique collaboration. HCG was created as a collaborative effort of the DOH, Hawai'i Medical Services Association, Kapiolani Medical Center for Women and Children (KMCWC), Queen's Medical Center, and the University of Hawai'i John A. Burns

School of Medicine. HCG provides pediatric and adult clinical genetic services. Special multidisciplinary clinics include Hemoglobinopathy and Metabolic Clinics.

## **ENABLING SERVICES**

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Providers of enabling services for CSHCN in Hawai'i include:

- DOH Children with Special Health Needs Program (CSHNP) provides information/referral, outreach, and service coordination for CSHCN age 0-21 years. Service coordinators include nurses, social workers, audiologist, and nutritionist on Oahu, and social workers on the islands of Kauai, Maui, and Hawai'i. Financial assistance for medical specialty services is provided as a "safety net" and "last resort" for eligible children who have no other resources. CSHNP assists eligible families in getting services from providers who are willing to accept program fees or insurance payment without the co-payment from families; and assists eligible Neighbor Island families with airfare, ground transportation, and lodging as needed to access specialty services on Oahu. CSHNP also provides financial assistance for laboratory tests, procedures such as X-rays and EKG, prescription medications, and hearing aids and related services.
- DOH Early Intervention Section care coordinators (social workers/human services professionals) provide care coordination services for children age 0-3 years with developmental delay or with a diagnosed physical or mental condition has a high probability of resulting in a developmental delay.
- DOH Public Health Nurses (PHNs) provide nursing services for children with complex medical care such as multiple medical conditions, medications, medical specialists, and/or hospitalizations. PHNs provided families with assistance in coordinating health services, family support, education about the child's conditions, referrals to community resources, and developmental monitoring.
- DOH Developmental Disabilities Division case managers assist individuals with developmental disabilities or mental retardation through a person-centered process based on the individual's desires, dreams, and goals. Services include identifying the supports necessary to assure the individual's health, safety, and well-being; assisting individuals in developing a plan to support them in their desired life; and assisting individuals in obtaining needed supports and services.
- The Medicaid managed care health plans (QUEST and QUEST Expanded Access) enabling services include coordinating services, arranging services, and/or referrals to community resources.

Kapiolani Cleft and Craniofacial Center (KCCC) is a collaboration of KMCWC with CSHNP. A CSHNP nurse and social worker are members of the KCCC team and provide nursing and social work assessments, coordinate services, coordinate with insurance regarding cleft lip/palate services and supplies, and assist with referrals to community providers (e.g., primary care providers, Early Intervention, CSHNP services).

## POPULATION-BASED SERVICES

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### **Newborn Metabolic Screening**

State role: The Newborn Metabolic Screening Program (NBMSp), in the Children with Special Health Needs Branch of the Family Health Services Division, DOH, has statewide responsibilities for assuring that all infants born in Hawai'i are screening for 32 mandated disorders. These disorders are phenylketonuria, congenital hypothyroidism, congenital adrenal hyperplasia, galactosemia, sickle cell and other hemoglobinopathies, biotinidase deficiency, maple syrup urine disease, cystic fibrosis, and other amino acid, urea cycle, organic acids, and fatty acid disorders.

NBMSp has oversight over the newborn metabolic screening system, including obtaining blood specimens at hospitals, specimen transport, central laboratory testing, physician notification, and tracking. NBMSp staff track all infants who are diagnosed with metabolic and other disorders, have abnormal and unsatisfactory screening results, transfer to another facility, or are not screened. For infants who confirmed with disorders, NBMSp identifies the medical home, links the medical home with the metabolic consultants, and follows-up with the medical home to ensure timely treatment.

To assist in quality assurance, monthly newborn metabolic screening practice profiles are sent to birthing facilities and submitters. These profiles include errors in transit time, timing of specimen collection, specimen quality, and reporting of demographic information. NBMSp staff identify infants who did not receive newborn screening, based on "Specimen Not Obtained" forms and Hospital Monthly Newborn Screening Reports from birthing facilities, and try to get these infants screened. NBMSp staff provide education to health care providers, midwives, public health nurses, childbirth educators, and the general public about expanded newborn metabolic screening.

State's coordination with other agencies and organizations: 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 DOH representatives) from the private and public sectors. The advisory committee's purposes are to 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.

Geographic availability: Screening is available statewide at all birthing facilities. Screening is also available at outpatient laboratories through midwives.

Funding: Newborn Metabolic Screening Special Fund provides funding for NBMSp staff, laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, and other NBMSp expenses. NBMSp collects fees for specimen collection kits, which include filter paper, screening test, and any needed diagnostic testing. Payment from birthing facilities for specimen collection kits are deposited into the Newborn Metabolic Screening Special Fund. Birthing facilities obtain reimbursement for newborn metabolic screening from health insurance. NBMSp staff has provided

information and education to midwives, and have made screening kits available through midwives for families who are unable to afford the cost of screening.

### **Newborn Hearing Screening**

State role: The Newborn Hearing Screening Program (NHSP), in the Early Intervention Section of the Children with Special Health Needs Branch of the Family Health Services Division, DOH, has statewide responsibilities for assuring that all infants born in Hawai'i are screened for hearing.

Screening began in two Honolulu hospitals in 1992, and all birthing facilities in Hawai'i were screening by the end of 1999. Newborn hearing screening is now part of the standard of care for newborns.

NHSP works with birthing facilities, primary care providers, medical specialists, audiologists, parents, early interventionists, and others to implement the program. NHSP provides assistance with follow-up for infants who need rescreening or referrals for audiological assessments. NHSP continues to work with hospitals and primary care providers to assure that follow-up is provided. NHSP provides outreach to homebirth families through midwives.

Updated HI\*TRACK software, technical assistance and software support are provided to birthing hospitals to support efficient data reporting of newborn hearing screening results to NHSP.

NHSP monitors hospital inpatient and outpatient newborn hearing screening rates and provides technical assistance to address barriers to screening.

NHSP continues to develop and disseminate public awareness materials to inform parents, early intervention providers, physicians, and other health care professionals about universal newborn hearing screening and the importance of early intervention services for infants with hearing loss.

State coordination with other agencies and organizations: The Early Hearing Detection and Intervention (EHDI) Advisory Committee advises NHSP, with its Baby Hearing Evaluation and Access to Resources and Services (HEARS) Project. The committee includes parents, AAP-Hawai'i Chapter EHDI Champion, Hospital Newborn Hearing Screening Coordinator, DOH (EIS, Genetics Program, Newborn Metabolic Screening Program, and CSHNB Chief and Research Statistician), community agencies, and pediatric audiologists.

Training is provided for hospital newborn hearing screening staff, audiologists, physicians and early intervention providers to improve the quality of newborn hearing screening and audiological follow-up in Hawai'i. NHSP works closely with the American Academy of Pediatrics-Hawai'i Chapter EHDI Champion to increase awareness regarding early hearing detection and intervention.

Geographic availability: Screening is available statewide at all birthing facilities and at various outpatient locations.

Funding: NHSP staff positions are state funded. Currently NHSP receives Universal Newborn Hearing Screening grant funding from the Maternal and Child Health Bureau for a Baby Hearing Evaluation and Access to Resources and Services (HEARS) project to further improve newborn hearing screening and follow-up in Hawai'i. Grant funding supports educational materials, continuing education,

newborn hearing screening equipment for birthing facilities, and other program expenses. Birthing facilities obtain reimbursement for newborn hearing screening from health insurance.

## **INFRASTRUCTURE-BUILDING SERVICES**

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### **STANDARDS, GUIDELINES, MONITORING, EVALUATION, QUALITY IMPROVEMENT**

**Children with Special Health Care Needs:** The Hawai'i data from the National Survey of CSHCN and the National Survey of Children's Health have been the best sources for population-based data applicable to all CSHCN, related to the core outcomes. CSHNB analyzes these national and other local data sources as available. As needed, surveys on selected topics for a specific population group are also conducted.

**Newborn Metabolic Screening:** The Newborn Metabolic Screening Program (NBMS) standards are established in the Hawai'i Administrative Rules and in the Hawai'i Practitioner's Manual. Standards include specified diseases required to be screened; hospital, birth attendant, and physician responsibilities; specimen collection; parental notification and refusal; home and non-institutional births; laboratory responsibility; fees; and special fund. NBMS monitors monthly data for 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. NBMS periodically provides these data to each birthing facility and assists them as needed to improve newborn screening practices.

**Newborn Hearing Screening:** The Newborn Hearing Screening Program (NHSP) guidelines are in its Hawai'i Practitioner's Manual for Early Hearing Detection and Intervention. NHSP monitors hospital inpatient and outpatient newborn hearing screening and follow-up rates, e.g., percent screened by age 1 month (statewide and by individual hospital), percent receiving diagnostic audiological evaluation by age 3 months, and enrollment in early intervention services by age 6 months. As needed, NHSP provides assistance to address barriers to screening, such as outdated screening equipment or lack of backup equipment. NHSP continues to work with hospitals and primary care providers to assure that follow-up is provided.

**Early Intervention:** The Early Intervention Section's quality assurance has two focuses: 1) to assure that all children under age 3 years with developmental delays and their families are provided the necessary early intervention (EI) services to meet their needs and that all services conform with federal IDEA Part C and state requirements; and 2) to assure that all programs that serve Part C eligible children meet compliance with Part C. Routine monthly monitoring is provided for provision of timely services, timely compliance with comprehensive developmental evaluations, timely compliance with Individualized Family Support Plan development, complete transition plans, transition notices, and timely transition conferences. Data are collected on child/family outcomes to determine the effectiveness of EI services in supporting outcomes of children and their families; data compare children enrolled in EI programs with their typically developing peers, at entry into and exit from services. Families are surveyed to determine their satisfaction with EI and whether EI supports their ability to support their children's development.

External Reviews provide the opportunity for an objective observation of a child's and family's progress and the extent that the EI system supports the child and family.

**Setting standards through law:** The following are Hawai'i laws that pertain to CSHCN. They had originated as legislative bills drafted by CSHNB.

- 1996 Amendment to newborn metabolic screening law. A special fund was established to provide program funding (H.R.S. §321-291).
- 1997 Genetic information non-discrimination in health insurance coverage (H.R.S. §431:10A-118, 432:1-607, §432D-26).
- 1999 Mandated insurance coverage for medical foods and low-protein modified food products for metabolic disorders (H.R.S. §346-67, §431:10A-120, §432:1-609, §432D-23).
- 2001 Amendment to the newborn hearing screening law to mandate newborn hearing screening for all infants, require the reporting of screening results to the DOH, and allowed the DOH to develop rules regarding screening (H.R.S. §321-361-363).
- 2002 Genetic information non-discrimination in health insurance coverage (H.R.S. §431:10A-404.5, §432:2-404.5). Genetic information non-discrimination in employment (H.R.S. §378:1).
- 2002 Establishment of a birth defects program in the DOH, funded by a special fund of \$10 of each marriage license fee (deposited into a special fund (H.R.S. §321-421).

Legislative activities included drafting bills and justifications, drafting testimony, and involving key partners such as other consumers, family advocacy organizations, professional organizations, community agencies, and others. Recent proposed legislative bills had included changes to the membership of the Hawai'i Early Intervention Coordinating Council, and mandated insurance coverage for early intervention services.

## **FOUR CONSTRUCTS OF A SERVICE SYSTEM**

### **State Program Collaboration with Other State Agencies and Private Organizations**

The Title V CSHCN program participates in a network of coalitions, advisory groups and coordination efforts ***Department of Health (DOH)***

Within the DOH, Title V CSHCN works with the District Health Offices and various Divisions/programs including Community Health Division, Developmental Disabilities Division, Dental Health Division, Child and Adolescent Mental Health Division, Office of Health Status Monitoring, Maternal and Child Health Branch, WIC Services Branch, Public Health Nursing Branch. Areas of collaboration include early childhood comprehensive systems development, oral health, craniofacial disorders, nutrition for CSHCN, care coordination for early intervention services, linkage of birth records with newborn hearing and metabolic screening data, and access to specialty services on Neighbor Islands.

### ***Department of Education (DOE)***

CSHNB/Early Intervention Section (EIS) works collaboratively with the DOE in several areas:

- EIS and DOE develop transition materials and regularly provide joint training to early interventionists, DOE staff, families, and other community members.

- Depending on the availability of funds, EIS supports the continuation of early intervention services for DOE-eligible children with Autism Spectrum Disorder who turn 3 during the summer months until their DOE school year starts.
- The State Interagency Quality Assurance Committee provides oversight and leadership for the quality assurance system that monitors the quality and effectiveness of services for children and youth with special needs. Members include the DOE, DOH (FHSD, EIS, Child and Adolescent Mental Health Division, Developmental Disabilities Division, and Alcohol and Substance Abuse Division), DHS, Family Court, and Hawai'i Families as Allies.

### ***Department of Human Services (DHS)***

DHS houses programs critical to the health and welfare of the state MCH population including Medicaid EPSDT, Temporary Assistance to Needy Families (TANF), Food Stamps, Child Welfare Services, Disability Determination, Vocational Rehabilitation, Child Care Services, and Youth Services Programs.

**DHS Med-QUEST Division (MQD)** provides reimbursement to DOH for early intervention services for QUEST-eligible infants and toddlers who are developmentally delayed or biologically at risk.

MQD has updated the EPSDT examination form, which includes immunizations, screening, referrals, and care coordination needs. The standardized form provides providers with clear guidelines about the required examination components, and provides information on screenings and immunizations by various ages. FHSD provided input to DHS on this form. MQD is assuring diverse community participation and expert advising regarding EPSDT through methods such topical meetings with specific stakeholders.

**DHS Benefit, Employment and Support Services Division (BESSD)** provides funding for Healthy Child Care Hawai'i to the UH Department of Pediatrics. This collaborative project also involves the American Academy of Pediatrics-Hawai'i Chapter and CSHNB. The project promotes the health and safety of young children in child care, based on the national health and safety performance standards in child care settings.

**DHS Vocational Rehabilitation and Services for the Blind Division (DVR)** is a state-federal program for individuals with disabilities which provides vocational rehabilitation services to enable eligible individuals with disabilities to achieve gainful employment and economic self-sufficiency. The Children with Special Health Needs Program refers clients as necessary for DVR services. CSHNB participated in the DVR needs assessment.

**DHS Disability Determination Branch (DDB)** which is part of DVR, determines whether Hawai'i applicants for SSI disability benefits meet the required medical and/or psychiatric/psychological and vocational criteria to be found disabled. DDB refers children under age 16 years with disabilities who are medically eligible for Supplemental Security Income (SSI) to the Children with Special Health Needs Program (CSHNP). CSHNP provides outreach, assessment, information/referral, and/or service coordination as needed, regarding the SSI beneficiary's medical, education, and social needs.

### ***Public and Private Collaboration***

**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 DOH 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 special needs, early intervention providers, state legislator, and representatives for personnel preparation, special education preschool services, Medicaid program, Office of the Governor, provision/payment of early intervention services, Head Start/Early Head Start, child care, foster care, regulation of health insurance, education of homeless children, children's mental health, family advocacy, military, and community preschools.

**Newborn Metabolic Screening Advisory Committee** consists of consumers and professionals from the private and public sectors, including physicians, laboratory personnel, nurses from various birthing facilities, medical insurance plan representatives, parents, and other DOH representatives.

**Hawai'i Birth Defects Program (HBDP) Advisory Committee** is composed of representatives from the community, medical, university, and public and private sectors.

**Early Hearing Detection and Intervention (EHDI) Advisory Committee** advises the DOH Newborn Hearing Screening Program and its Baby Hearing Evaluation and Access to Resources and Services Project (Baby HEARS). The committee includes parents, AAP-Hawai'i Chapter EHDI Champion, Hospital Newborn Hearing Screening Coordinator, DOH (EIS, Genetics Program, Newborn Metabolic Screening Program, and CSHNB Chief and Research Statistician), community agencies, and pediatric audiologists.

**State Genetics Advisory Committee** consists of representatives from public health, health care organizations, consumers, laboratories, insurance, policy makers, and other interested organizations such as the March of Dimes. The Committee advises the DOH about genetics activities and helps disseminate information about these activities.

**Hawai'i Community Genetics (HCG)** is a partnership of DOH/CSHNB Genetics Program, Kapiolani Medical Center for Women and Children, Queen's Medical Center, and UH School of Medicine on clinical genetics and metabolic services in Hawai'i. HCG has a full-time geneticist for clinical services. Clinical genetics services are provided statewide with regular in-person Neighbor Island clinics and telemedicine visits. HCG also provides clinical and newborn screening follow-up services for Guam.

A core team of CSHNB, Family Voices (Hilopa'a Family to Family Health Information Center), UH/School of Medicine/Department of Pediatrics (with MCH Leadership Education in Neurodevelopmental and Related Disabilities), and American Academy of Pediatrics-Hawai'i Chapter, with other key state/community partners, continues to work closely together in various areas toward achieving the six core outcomes for CSHCN.

The DOH FHSD Medical Director is the Title V representative on the State Council on Developmental Disabilities. Act 175 of the 2001 Legislature required that the Council's membership include a Title V representative. The Council's responsibilities include: development of the state plan which guides the development and delivery of services for persons with developmental disabilities, coordination of

departments and private agencies, evaluation, and advocacy.

The Special Education Advisory Council is an advisory committee to the Superintendent of Education for policies regarding the education of students with disabilities. Membership includes representative of consumer advocate groups, parents, individuals with disabilities, regular and special education personnel, DOH, DHS, and UH. EIS is a representative on SEAC.

### **State Support for Communities**

Different State programs provide community supports related to the program focus. CSHNB (EIS, CSHNP), Public Health Nursing Branch, Developmental Disabilities Division, and Child and Adolescent Mental Health Division have staff/programs/offices located in communities throughout the state. CSHNP arranges neurology, cardiology, and nutrition clinics on the Neighbor Islands. The Genetics Program arranges and supports genetics clinics on the Neighbor Islands. EIS provides early intervention programs on all islands through state programs or contracted services through community agencies, and provides technical assistance, education/training, and common protocols and data collection. The Newborn Hearing Screening and Newborn Metabolic Screening Programs provide guidelines, technical assistance, and training/education at community birthing facilities. Financial support for travel is provided by various programs for attendance by Neighbor Island staff and community members at Oahu educational conferences, training, or meetings of task forces, advisory committees, etc.

### **Coordination of Health Components of Community-Based Systems, and Coordination of Health Services with Other Services at the Community Level**

Health and other services at the community level are coordinated in part by physicians/medical homes and community service coordinators/case managers. 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.

On the Neighbor Islands, the DOH FHSD Coordinators for the Counties of Hawai'i, Maui, and Kauai, have key roles in coordinating services in their county.

## SUMMARY OF NEEDS

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**Family-Professional Partnership** ▪ Efforts to involve family leaders at program/policy levels and in decision-making (e.g., participation of family members in advisory committees) need to continue.

**Medical Home**

- Increased developmental screening using standardized developmental and autism screening tools is needed (*see below*).
- Improved access of Neighbor Island families to community-based specialty services is needed.
- Additional supports are needed for families of children with functional limitations and emotional/behavioral/developmental issues, who have more difficulty with family-professional partnership, medical home, and transition to adult life.
- The medical home partnership of the Kapiolani Cleft and Craniofacial Center with the DOH CSHNP should be continued. CSHNP assists in the coordination of community-based services and assists families in accessing services,

**Adequate Health Insurance**

- Areas of inadequate insurance coverage need to be addressed. These areas include: orthodontic services for children with cleft lip/palate, Neighbor Island transportation to Oahu when specialty services are not available on a child's island, hearing aids, developmental screening, autism screening, 1:1 intervention services for ASD, habilitative services for children with developmental delays.
- "Safety net" services need to continue, to support families of CSHCN who are uninsured or whose services are not adequately covered by insurance.
- The impact of health reform on health insurance coverage in Hawai'i needs to be monitored.

**Early and Continuous Screening**

- Developmental delay must be identified early to assure that young children receive care and resources to promote optimal development. Developmental screening tests are an important part of preventive health care. (*TITLE V STATE PRIORITY*)
- Increased autism screening by primary care providers is needed.
- Health insurance coverage for autism and other screening and adequate payment to health care providers is needed.
- Emerging issues for newborn metabolic screening include addition of Severe Combined Immunodeficiency (SCID) to the panel of disorders, retention/use of dried blood spot specimens, and emergency preparedness/contingency planning.

- Improvements are needed in the follow-up after newborn hearing screening, to ensure diagnostic audiological evaluation by age 3 months, and early intervention services by age 6 months.

**Community Services Easily Used**

- The system of EI services is changing, with a possible revision in eligibility requirements for EI services, use of standardized evaluation tools, and possible implementation of a sliding fee scale. As the system changes, it is important to ensure that the EI system is easy to access.
- Increased supports/services are needed for the Neighbor Islands, who have greater needs related access to care, medical home, adequate health insurance, screening, community-based services, and transition to adult life, compared to urban areas.
- Improvement is needed for the system of services for children with Autism Spectrum Disorders (ASD), where needs include family support, training for medical homes on autism screening and a community-based ASD referral algorithm, health insurance coverage for screening, and education/information for families and professionals on evidence-based best practices in the identification and treatment for ASD.
- Efforts need to continue to build and maintain partnerships with other state and community agencies, professional and family organizations, policy-makers, health care providers, and others, to further develop the system of services for CSHCN.

**Transition to Adult Health Care**

- The transition from pediatric to adult health care is a significant issue for youth with special health care needs. Youth need assistance over a period of time to assume their new role as informed health care consumers. They also need developmentally appropriate support to understand and manage their condition and to negotiate the changes as they move from pediatric to adult health care systems. *(TITLE V STATE PRIORITY)*

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**CHAPTER 5:**

**CHILD**

**AND**

**ADOLESCENT**

## **Introduction**

The health of Hawai'i's children remained relatively stable over the past decade despite a decade of economic hardship for the state. Across a broad spectrum of major social and health indicators, statewide trends have varied with improvements in some areas. Examples of progress include declines in teen pregnancy and smoking rates, increasing child immunization rates and insurance coverage. When compared with the United States as a whole Hawai'i's children are as healthy as or better than the nation. While Hawai'i's children are not the healthiest in the nation, they are definitely healthier than average in many respects.

The national Kids Count annual assessment of child health, ranked Hawai'i 13<sup>th</sup> in 2008 which is an improvement over a 24<sup>th</sup> ranking in 2005.<sup>1</sup> In the 2008 report, Hawai'i ranks in the top 9 states for five of the 10 key indicators. Trend data in the report showed improvement in Hawai'i for 6 areas (infant mortality rate, teen death rate, teen birth rate, teens not attending school and not working, percent of children living in families where no parent has full time employment, percent of children living in poverty), and worsening in the other four (low birth weight, child death rate, high school dropouts, and single parents) compared to 2000 data.

Significant health challenges remain to prevent any further erosion of children's health in the state. A recent downturn in the state economy may make it more difficult for families in Hawai'i particularly among those with disparities in health such as among Native Hawaiians and other Pacific Islander subgroups. There are alarming trends appearing regarding childhood overweight and adolescent Chlamydia in Hawai'i. Furthermore, there are still thousands of children in the state that continue to need assistance with basic health needs because they remained uninsured.

## **Priority Needs**

The State of Hawai'i has recognized the need for improved health services for children to assure healthy outcomes for the future. As part of the commitment to the health of this population in the state, a Child and Adolescent (CA) Work Group was convened as a component of the Title V Needs Assessment. The work group identified five key health issues based on a review of the existing MCH priorities, stakeholder input, and compilation of research and data. Using a set of prioritization criteria, four final priorities were identified for the CA population group:

- Reduce the rate of child abuse and neglect with special attention on ages 0-5 years
- Reduce the rate of overweight and obesity in young children ages 0-5
- Prevent bullying behavior among children with special attention on adolescents age 11-18

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<sup>1</sup> 2008 Kids Count Data Book. Annie E. Casey Foundation. Baltimore, MD: 2008. Available online at <http://www.aecf.org>.

## **Health Status**

Improving the health and well-being of children is the primary goal of the child health care system. To assess the achievement of this goal, it is important to develop a clear picture of the health of children and youth in Hawai'i. However, childhood is a period of dependency and development with unique characteristics that make monitoring health challenging both conceptually and methodologically.

Because children are in a developmental stage of life, they generally do not develop the symptoms of chronic disease found in adults. The assumption is that childhood is generally a healthy period of life (with the exception of children who have serious congenital problems). But, poor health behaviors adopted in childhood or living in unhealthy environments clearly lay the foundation for poor health outcomes in adolescence and later as adults.

Furthermore, children's health is extremely dependent on the care they receive from their families and communities and to a lesser extent on the direct healthcare they receive. Thus, the definition of child health used in this report is very broad and includes social, behavioral and environmental factors that can affect a child's well-being and determine whether the child is adopting healthy lifestyles and habits. For purposes of this assessment, the child and youth population is defined as 1 to 19 years of age. Since this period of life is characterized by continual and rapid physical, cognitive, emotional and social development, the manifestations of potential health problems change with age. Data on children is often classified by age groupings in recognition of these rapid developmental changes. However, there are no uniform age categories used to collect and report health data on youth. Thus, the data reported herein may vary considerably by health issue and data source.

## **Data Sources**

The data presented in this report is not a comprehensive compilation of all child health data, but merely a summary of the key health data reviewed to assess the overall population health to help identify the priority health issues. Socio-economic and household data can be found in Chapter 2. Most of the data will focus on the three health priority areas for the population. As the needs assessment work continues over the next 5 years additional data review and analysis will be conducted to develop a greater understanding of the population's health and develop strategies to improve child health in the state.

For adolescents, Hawai'i participates in the national for High School grades 9-12 and Middle School grades. 6-8. Participants must secure parental consent. The survey does not include dropouts or students with poor attendance. Because this is a national surveillance instrument comparable data is available for the U.S. and Hawai'i for High School only. Both surveys are conducted every two years.

For younger children of elementary school age (5-11 years), data was generated from the National Survey on Children's Health. An FHSD data publication is forthcoming based on more detailed analysis of the data.

Analysis of childhood obesity among children entering kindergarten in 2002 by the Hawai'i Department of Health is included as a more current final report is not yet available.

### General Description of the Child Population

There are approximately 319,159 children aged 0-19 years residing in Hawai'i, comprising 25.4% of the total state population. The distribution of children by county closely follows that for the state with 25% of each county population consisting of children 0-19 years of age except for Honolulu County which has about the same or 26% of its population consisting of children. The challenge for the state is to provide adequate access to services and infrastructure for all children despite geographic barriers.

	County							
	Hawai'i		Honolulu		Kauai		Maui	
	No.	%	No.	%	No.	%	No.	%
Children 0-19 years	43,603	13.7	224,673	70.4	15,742	4.9	35,141	11.0

Source: Hawai'i State Department of Health, Vital Statistics, Hawaii Household Survey, 2008

In 2007, there were less children living in families with incomes below the federal poverty level (FPL) in Hawai'i (10.8%) compared to that for the nation (18.0%). However, there are disparities within the state by county with 18.1% of those in Hawai'i County living below the FPL and 12.5% of those in Kauai.

National	State of Hawai'i	Honolulu	Hawai'i	Kauai	Maui
18.0	10.8	9.5	18.1	12.5	9.8

Source: U.S. census Bureau, Small Area Income and Poverty Estimates (SAIPE).

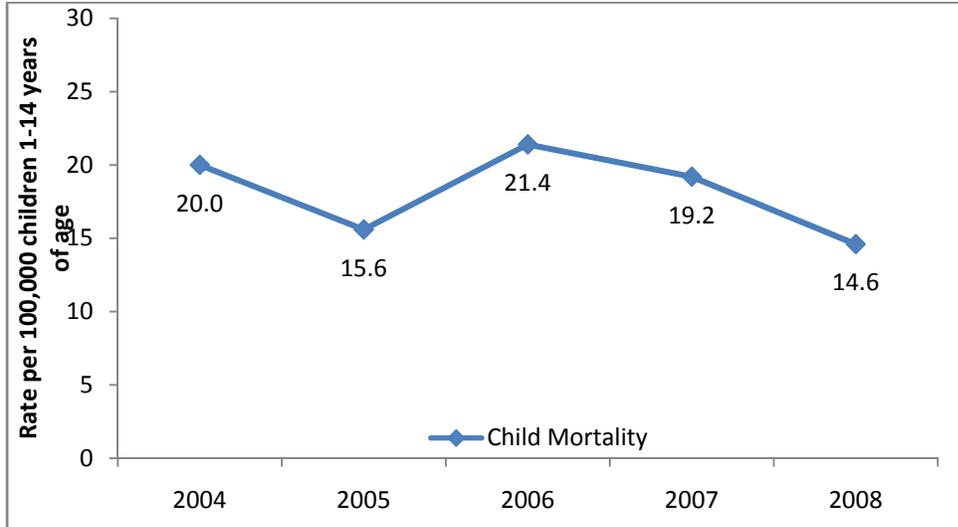
### Child Mortality

Mortality is unusual in childhood but examination of death trends supplies important information about risks to children. Data from 2008 indicate there were 32 deaths of resident children ages 1-14, a rate of 14.6 per 100,000 children.<sup>2</sup> This represents a reduction of 27% in the child death rate since 2004 (20.0 deaths per 100,000 children). Hawai'i's child death rate also compares well to the U.S. rate overall with both 19 per 100,000 in 2007.<sup>3</sup>

<sup>2</sup> Hawai'i State Department of Health, Vital Statistics. <http://www.Hawai'i.gov/doh/stats>.

<sup>3</sup> Kids Count Data Center. <http://datacenter.kidscount.org>.

**Chart 5-1. Child Mortality Rate in Hawai'i, 2004-2008**



Source: Hawai'i State Department of Health, Vital Statistics

**Leading Causes of Death**

The highest risk of death from injury occurs in the first few years of life. Table 5-3 shows the leading causes of death by age group. The majority of deaths for infants in the neonatal period are due to perinatal conditions and congenital anomalies. For the post-neonatal period ill-defined/unspecified, SIDS, and unintentional injuries are predominant. After the first year of life, unintentional injuries and malignant neoplasm (cancer) are common. Suicide was reported for 30 deaths in those over 10 years of age, particularly in the 16-18 year age group in which suicide was documented in 22 deaths placing it second only to unintentional injuries as the leading cause of death.

<b>Table 5-3. Hawai'i Leading Causes of Death by Age Group, 2004-2008</b>	
<b>Age Group</b>	<b>Leading Causes of Death</b>
Under 1 month	Perinatal conditions Congenital Anomalies Ill-defined/Unspecified
1 to 4 years	Unintentional injuries Congenital Anomalies Malignant neoplasms (cancer)
5 to 9 years	Malignant neoplasms (cancer) Unintentional injuries Diseases of the Heart
10 to 15 years	Unintentional injuries Malignant neoplasms (cancer) Congenital Anomalies Suicide

16 to 18 years	Unintentional injuries Suicide Malignant neoplasms (cancer) Homicide
Source: Hawai'i State Department of Health, Injury Prevention & Control Program. Dan Galanis. Report on Childhood injury in Hawai'i, 2004-2008	

### Fatal Injuries

In Hawai'i, the leading cause of injury related death among infants were related to suffocation, homicide, and possible homicide. Among all age groups, a motor vehicle related event accounted for the majority of deaths for children ages. Also of note is that a drowning death was the second or third leading cause of death due to injury among all age groups after infancy. Whereas, suicide became the second leading cause of death due to injury among those 10 years of age and older, behind motor vehicle related. Motor vehicle and drowning related deaths are highly preventable and have been the focus of major initiatives by the Hawai'i State Department of Health, Injury Prevention & Control program. Table 5-4 shows the leading injury deaths for several age categories from birth to 18 years compiled by the Injury Prevention and Control Program.

<b>Table 5-4. Hawai'i Leading Causes of Death due to Injury by Age Group, 2004-2008</b>	
<b>Age Group</b>	<b>Leading Causes of Death</b>
Under 1 year	Suffocation Homicide Possible Homicide Motor Vehicle
1 to 4 years	Motor Vehicle Drowning Suffocation
5 to 9 years	Homicide Drowning Motor Vehicle
10 to 15 years	Motor Vehicle Suicide Drowning
16 to 18 years	Motor Vehicle Suicide Drowning Homicide Poisoning
Source: Hawai'i State Department of Health, Injury Prevention & Control Program. Dan Galanis. Report on Childhood injury in Hawai'i, 2004-2008	

## Non-Fatal Injury

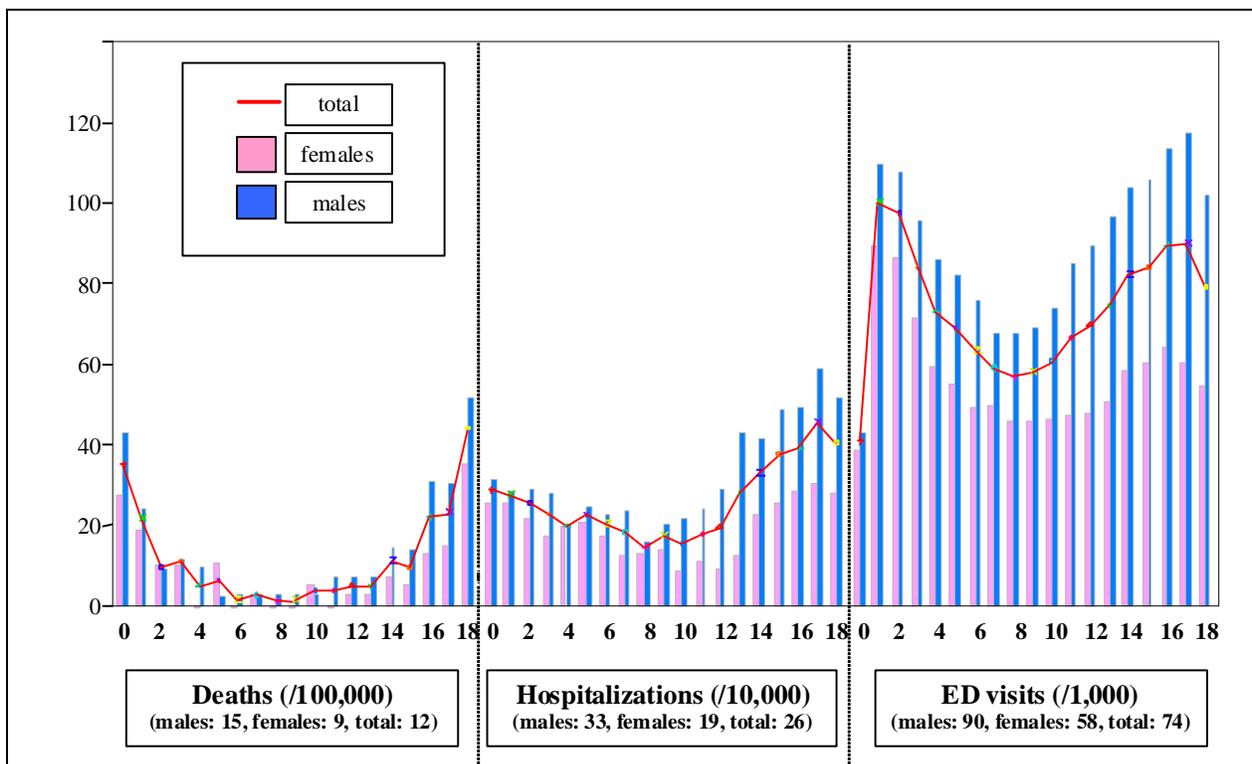
Far more injuries are nonfatal than fatal, but the causes and incidence of nonfatal injury are less well documented than those of fatal injury. Among injuries to children in Hawai'i, it was estimated based on data from 2004-2008, that for every death in the state due to an injury, there were 22 non-fatal injuries resulting in hospitalizations and 610 non-fatal injuries resulting in emergency room visits.<sup>4</sup> The prevention of child deaths should consider the larger picture and focus on preventing all injuries. Table 5-5 lists the leading causes of non-fatal injuries that required hospitalization by age group. Falls were a leading cause among all age groups, and motor vehicle related injuries were common in those 5 years and over. The most specifically coded "striking" injuries were "struck accidentally by objects or persons in sports" (42%). Another 8% of patients were "struck accidentally by falling object".

Age Group	Leading Causes
Under 1 year	Falls Assault Suffocation
1 to 4 years	Falls Poisoning Fire/Burn
5 to 9 years	Falls Motor Vehicle Striking
10 to 15 years	Falls Motor Vehicle Striking
16 to 18 years	Motor Vehicle Falls Suicide
Source: Hawai'i State Department of Health, Injury Prevention & Control Program. Dan Galanis. Report on Childhood injury in Hawai'i, 2004-2008	

<sup>4</sup> Hawai'i State Department of Health, Injury Prevention & Control Program. Dan Galanis. Report on Childhood injury in Hawai'i, 2004-2008

For 2004-2008, the average number of hospitalizations for non-fatal injuries among children were 800 per year, and the average number of emergency department visits among children were 22,569 per year for non-fatal injuries. The rate of hospitalizations among males (33 per 10,000 males 0-18) is nearly twice that of females (19 per 10,000 females 0-18) with a similar pattern seen in non-fatal injuries that resulted in an emergency room visit (900 per 10,000 males 0-18 vs. 580 per 10,000 females 0-18).

**Chart 5-2. Annual Rates of Injuries among young residents of Hawai'i by severity, gender, and age, 2004-2008**



Source: Hawai'i State Department of Health, Injury Prevention & Control Program. Dan Galanis. Report on Childhood injury in Hawai'i, 2004-2008

### Intentional Injury

Intentional injuries are defined as injuries resulting from interpersonal violence, including homicide and the self-directed violence of suicide. Homicide is largely found among infants and young children due to child abuse and neglect. Homicide in adolescence is likely due to an increase in violent behavior and exposure to violent situations. Child homicide rates for Hawai'i are generally lower than those found nationally.

Although rates for suicide deaths among youth are relatively low compared to the U.S., self-reports of suicide attempts have been consistently higher than U.S. averages. Table 5-5 reports the latest data from the YRBS on suicide behavior. The elevated behavior is even seen among our younger students in middle school when compared to the national high school estimates.

<b>Behavioral Description</b>	<b>Hawai'i Middle School</b>	<b>Hawai'i High School</b>	<b>U.S. High School</b>
Seriously considered attempting suicide	20.1	18.9	13.8
Made a suicide plan	12.2	16.0	6.9
Attempted suicide one or more times	6.6	12.8	6.3
Attempted suicide & had to be treated by a doctor or nurse	2.6	4.5	1.9
Source: Hawai'i High and Middle School Youth Behavioral Risk Surveillance System, 2009.			

## **Oral Health**

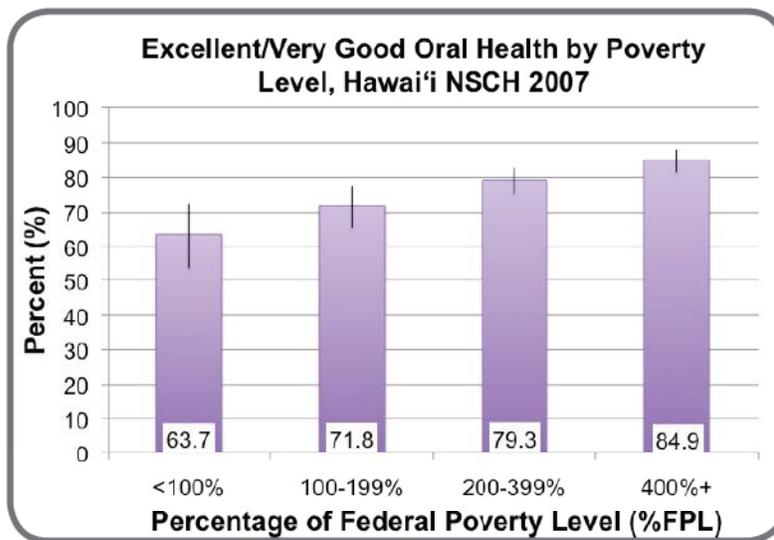
Poor oral health is a national public health concern for children, especially in Hawai'i where children suffer from some of the worst oral health in the U.S. The consequences of poor oral health can be severe. Children suffering from dental problems have difficulty eating, are distracted in learning and playing, and experience reduced self-esteem from an unattractive appearance. Nationally, almost 52 million school hours - equivalent to 850,000 school days - are missed each year because of dental concerns. The cost for treatment of dental disease can be substantial and pose a major financial hardship for families without insurance coverage. The tragedy is poor oral health is largely preventable. Children aged 6-8 years are at a critical stage of dental development. Their permanent teeth are erupting in their mouths. Maintaining optimal oral health for these children is important for the short-term and for the remainder of their lives.

Generally, children from families with low or modest incomes have the greatest dental needs, yet they receive the least dental care. Access to oral health care is often a problem for low-income children. Publicly funded health insurance programs have strong potential to provide and assure necessary dental care for these children, but have substantially failed to do so. Oral health is also closely linked to nutrition. Establishment of health promoting behaviors including wise food choices early in life can also have a major impact on the oral health of children. Child nutrition will be addressed in relation to overweight and

obesity.

A recent National Survey of Children's Health sponsored by the federal Maternal and Child Health Bureau in partnership with the Centers for Disease Control and Prevention was conducted in 2007. Results have been recently published for children 1-17 years of age including data on oral health. State and national comparisons are provided. Parents in Hawai'i report the overall condition of their children's teeth is generally better than what is reported by parents nationally. Nearly, 77% of Hawai'i parents report their child's oral health to be excellent or very good as compared to 71% of parents nationally. Only 4.3% of parents report that their children's oral health was fair or poor, compared to 8.4% for the rest of the nation. Further analysis demonstrated variation by age, race, and federal poverty levels. A report of excellent or very good oral health in their children steadily increased with household federal poverty level with only 63.7% of children in families below 100% FPL compared to 84.9% in families with 400% FPL and above.

**Chart 5-3 Excellent/Very Good Oral Health among Children in Hawai'i by Federal Poverty Level, 2007**



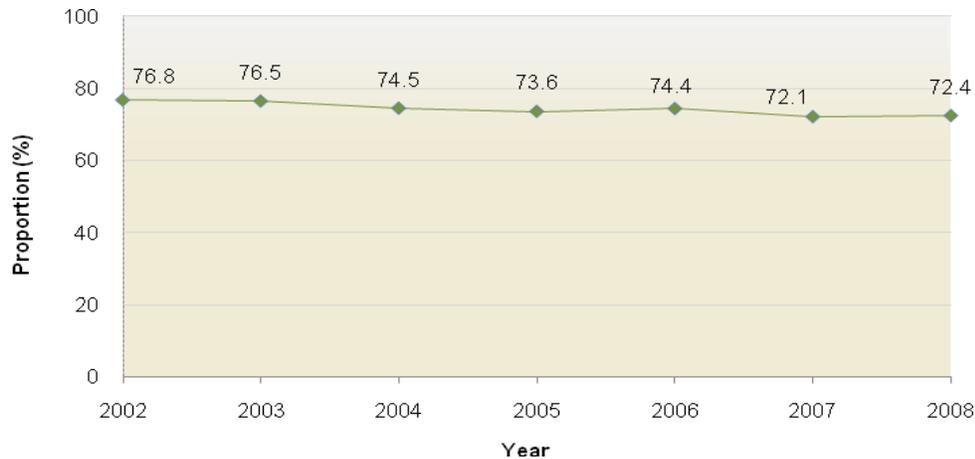
Source: Hawai'i Department of Health, Family Health Services Division. 2007 National Survey of Children's Health.

In contrast to the self report of oral health in children by parents, children in Hawai'i tend to have higher rates of dental caries compared to the rest of the nation. Dental caries refer to decay in one or more teeth. It is the single most common chronic disease of childhood, occurring 5 to 8 times as frequently as asthma, the second most common chronic disease in children. Results from the 2003-2004 National Health and Nutrition Examination Survey (NHANES), using oral health assessments, indicate that 53 percent of children aged 6 to 8 years had dental caries.<sup>5</sup> Estimates of children in Hawai'i with

<sup>5</sup> Centers for Disease Control, Chronic Disease Prevention and Health Promotion <http://www.cdc.gov/NCCdphp/publications/factsheets/Prevention/oh.htm>

dental caries has declined since 2002 with 72.4% having caries in 2008. This rate in 2008 exceeds the Healthy People 2010 objective of 42% as well as that found nationally in 2003-2004 when the rate in Hawai'i ranged from 74.5% to 76.5%.

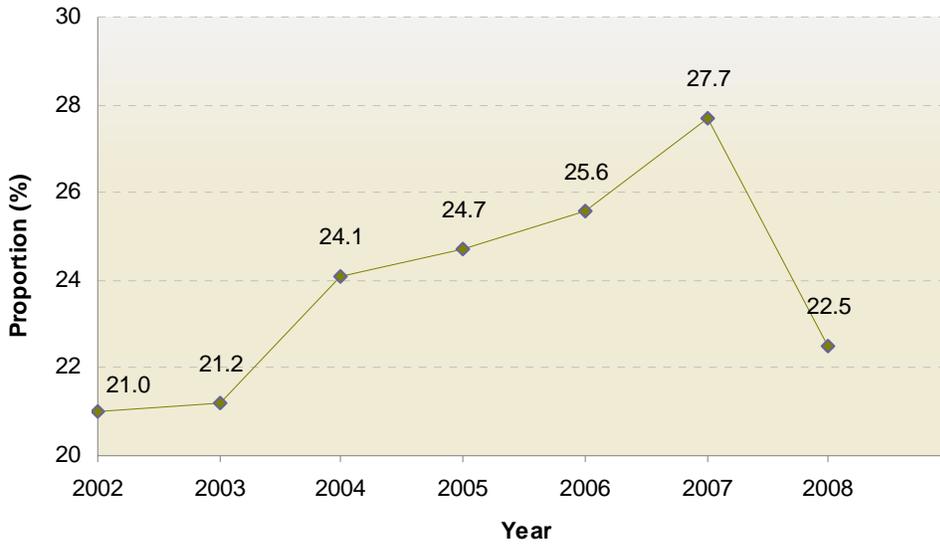
**Chart 5-4 State of Hawai'i, Dental Caries in Primary and Permanent Teeth among Children 6-8 Years of Age: 2002-2008**



Source: Hawai'i State Department of Health , Dental Health Division, Dental Hygiene Branch.

Another indicator for dental service utilization is the number of dental sealants found in the molars of third graders. Based on DHD assessments, dental sealant rates have increased from 21% in 2002 to nearly 28% in 2008, but then decreased in 2008 to just 22.5% of children. It will be concerning to see if this pattern of decline in use of sealants continues and impacts the gains seen recently in less dental caries.

**Chart 5-5 State of Hawai'i, Percent of Third Grade Children who received Protective Sealants on at least one permanent molar tooth: 2002-2008**



Source: Hawai'i State Department of Health, Dental Health Division, Dental Hygiene Branch.

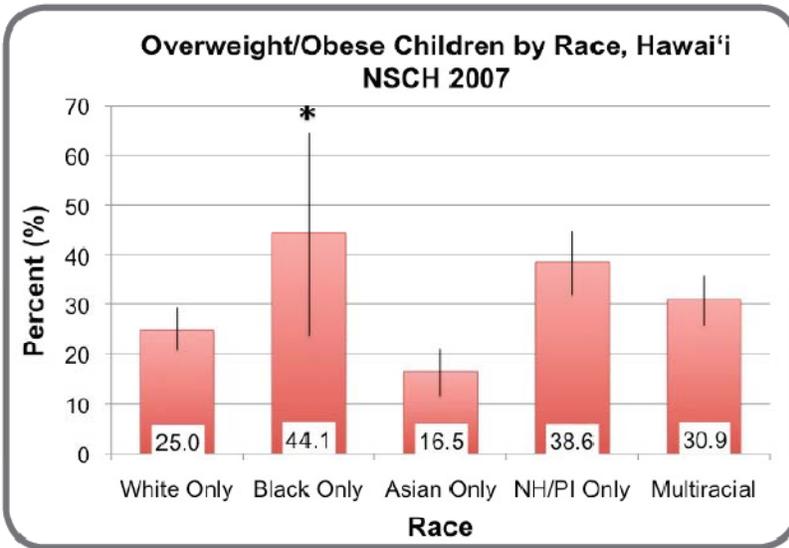
### Overweight/Obesity

Childhood obesity in the U.S. has risen dramatically in the past few decades. Many diseases are associated with overweight and obesity including high blood pressure, Type 2 diabetes, coronary heart disease, stroke, gallbladder disease, osteoarthritis, sleep apnea, respiratory problems, and some types of cancer. The affects of these diseases can often be reduced through weight loss. Inactivity and poor diet combined contribute to obesity and the related chronic disease risk factors. It is estimated that the cost of obesity is almost \$100 billion dollars a year, or approximately 8% of the national health care budget.<sup>6</sup>

The National Survey of Children's Health sponsored by the federal Maternal and Child Health Bureau in partnership with the Centers for Disease Control and Prevention was conducted in 2007. Parents in Hawai'i report the height and weights for their children from which a calculation of body mass index is made. It estimated that 28.5% of children aged 10-17 years were overweight or obese (defined as 85% or above), which was lower than the rate for the rest of the nation (31.7%) in 2007. There was variation by race groups with overweight or obese in 44% of blacks, 39% of Native Hawaiian or Other Pacific Islanders, 31% of those who report more than one race, and in 25% of white children.

### Chart 5-6 Overweight/Obese Children 10-17 years of age by Race in Hawai'i, 2007

<sup>6</sup> D Satcher, 2000. Speech by the U.S. Surgeon General, Getting Physical: Exercising our Demons, Sedentary Lifestyles and Fatty Foods Leave Americans Overweight and Unhealthy.



Source: Hawai'i Department of Health, Family Health Services Division. 2007 National Survey of Children's Health. Data Note: \*Reflects Relative Standard Error >30% and caution should be used in interpretation.

In 2004, the Hawai'i State Department of Health (DOH) in conjunction with the Hawai'i State Department of Education (DOE) examined School Health Records required for the entry of all 4 and 5 year olds into school. The forms contain information on height, weight and gender. Analysis of the data revealed Hawai'i 4 & 5 year olds entering public schools have high proportions of overweight and at-risk for overweight, 28.5% overall: 14.4% overweight and another 14.1% at risk for overweight.<sup>7</sup> This percentage is similar to other states where comparable data are available.

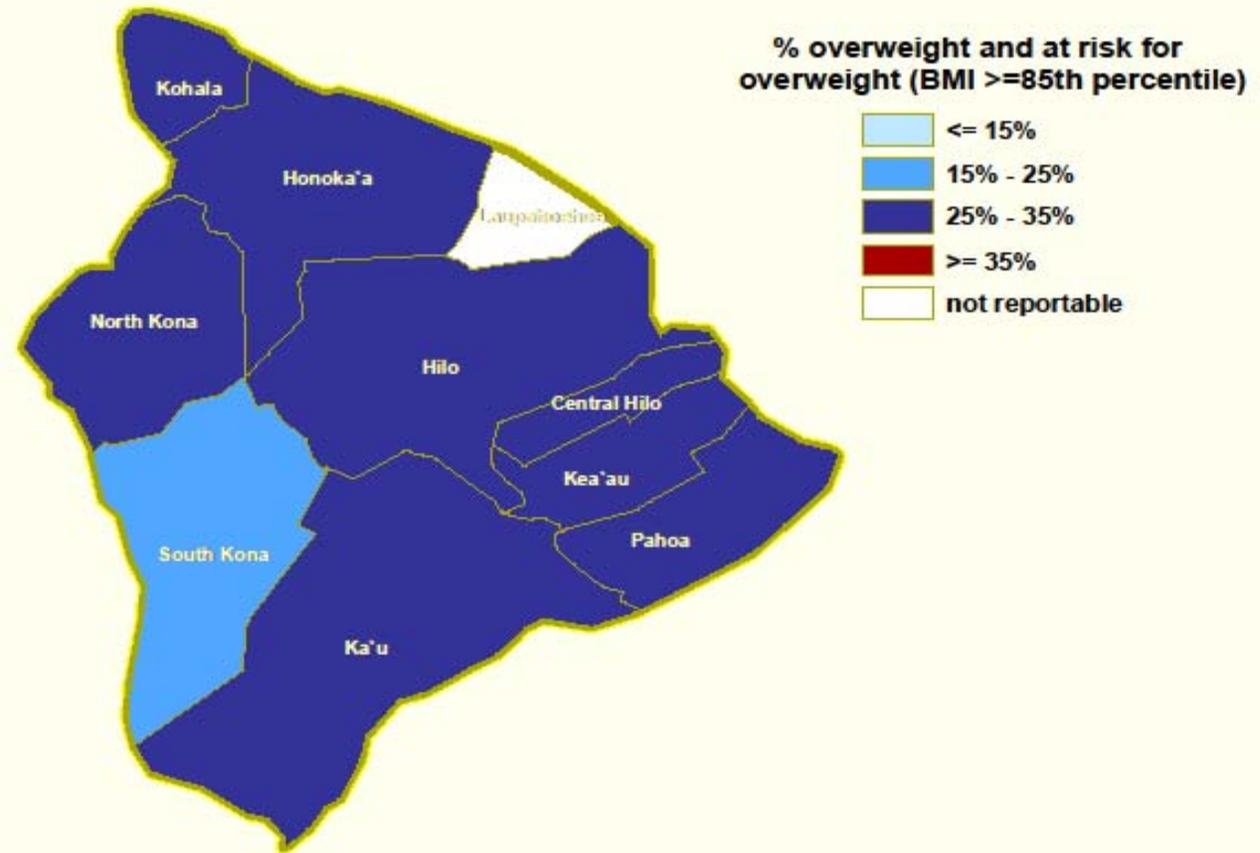
Boys were more likely to be overweight than girls, and girls more likely to be at risk for overweight. There were some slight differences by age, with 4 year olds more likely to be overweight and at risk for overweight than 5 year olds, among both boys and girls.

The data was mapped by the University of Hawai'i Center on the Family (see following maps) by school complex (a high school and all its feeder elementary and middle schools). The problem of overweight appears to be more serious on the neighbor islands and in rural areas including rural areas of Oahu.

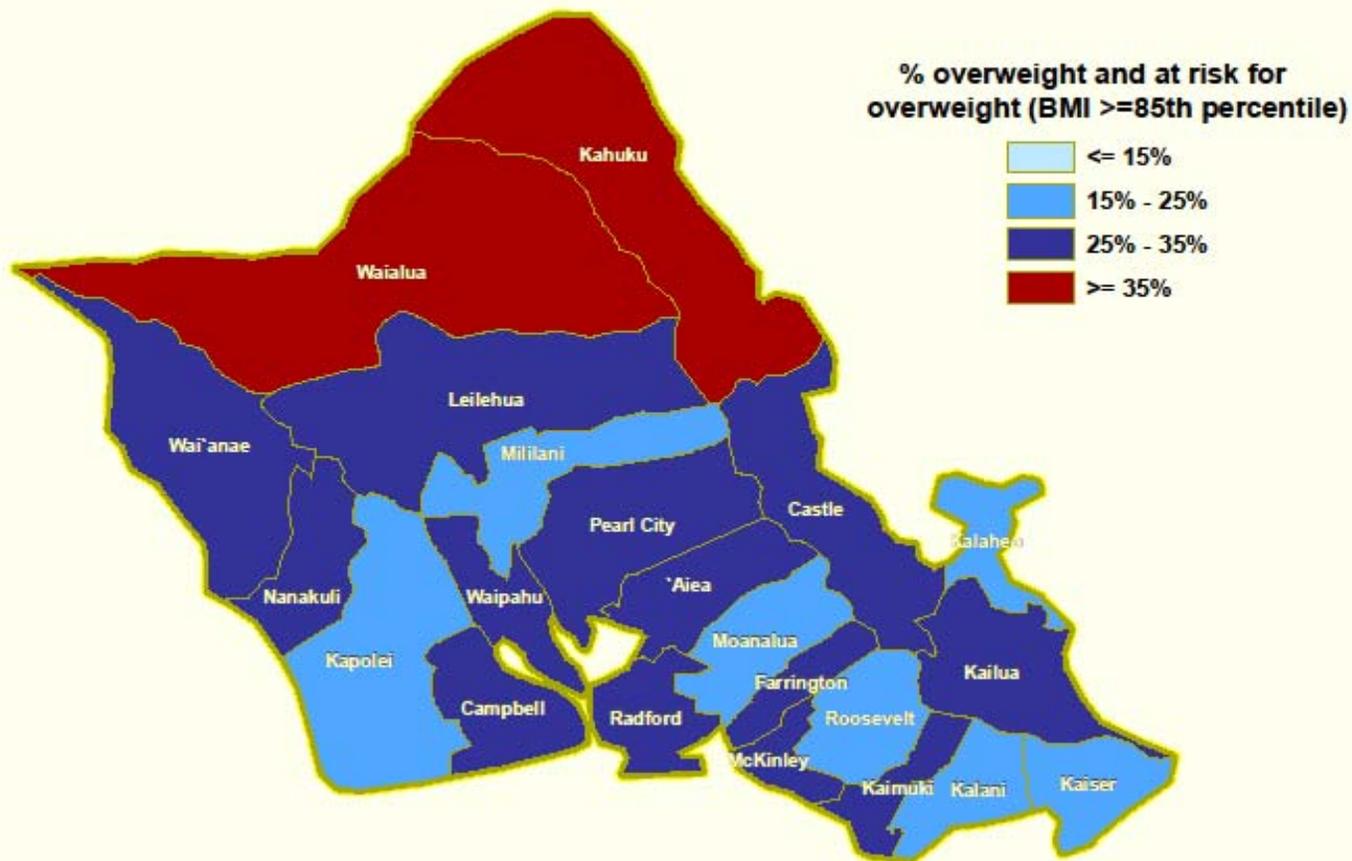
The implications are disturbing. The problem of childhood overweight clearly begins before children get to school at a very young age and exists in many communities throughout Hawai'i. DOH is working with the DOE to secure additional demographic data from the school health records for further analysis and develop a process to continue surveillance on childhood overweight.

<sup>7</sup> Ann Pobutsky, Jack Huang, Olga Geling, R. Hirokawa and L. Zou, Community level correlates of overweight among public school students entering kindergarten in Hawai'i. Presentation at the Pacific Global Health Conference, June 15-17, 2005.

**Percent Overweight And At Risk for Overweight, Public School Students Entering Kindergarten By School Complex, Hawai`i County, 2002 - 2003**



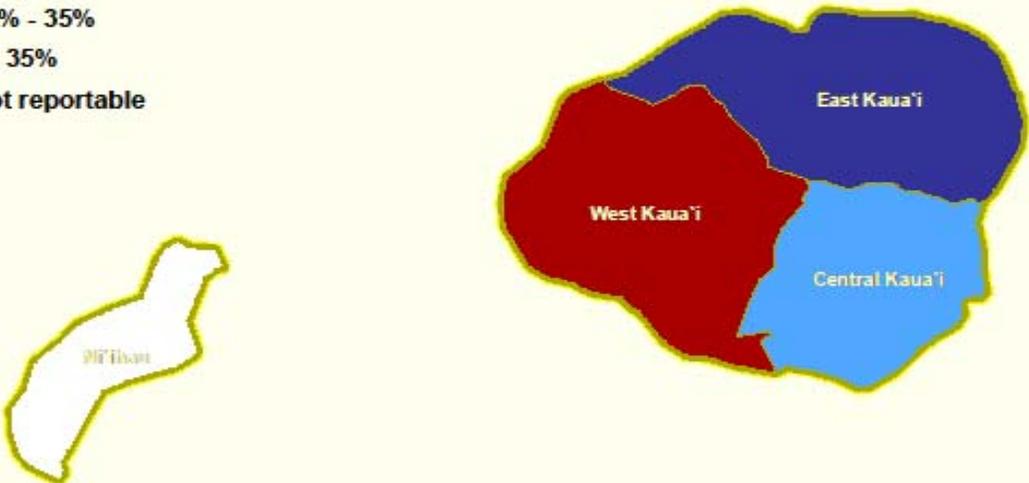
**Percent Overweight And At Risk for Overweight, Public School Students Entering Kindergarten By School Complex, Honolulu County, 2002 - 2003**



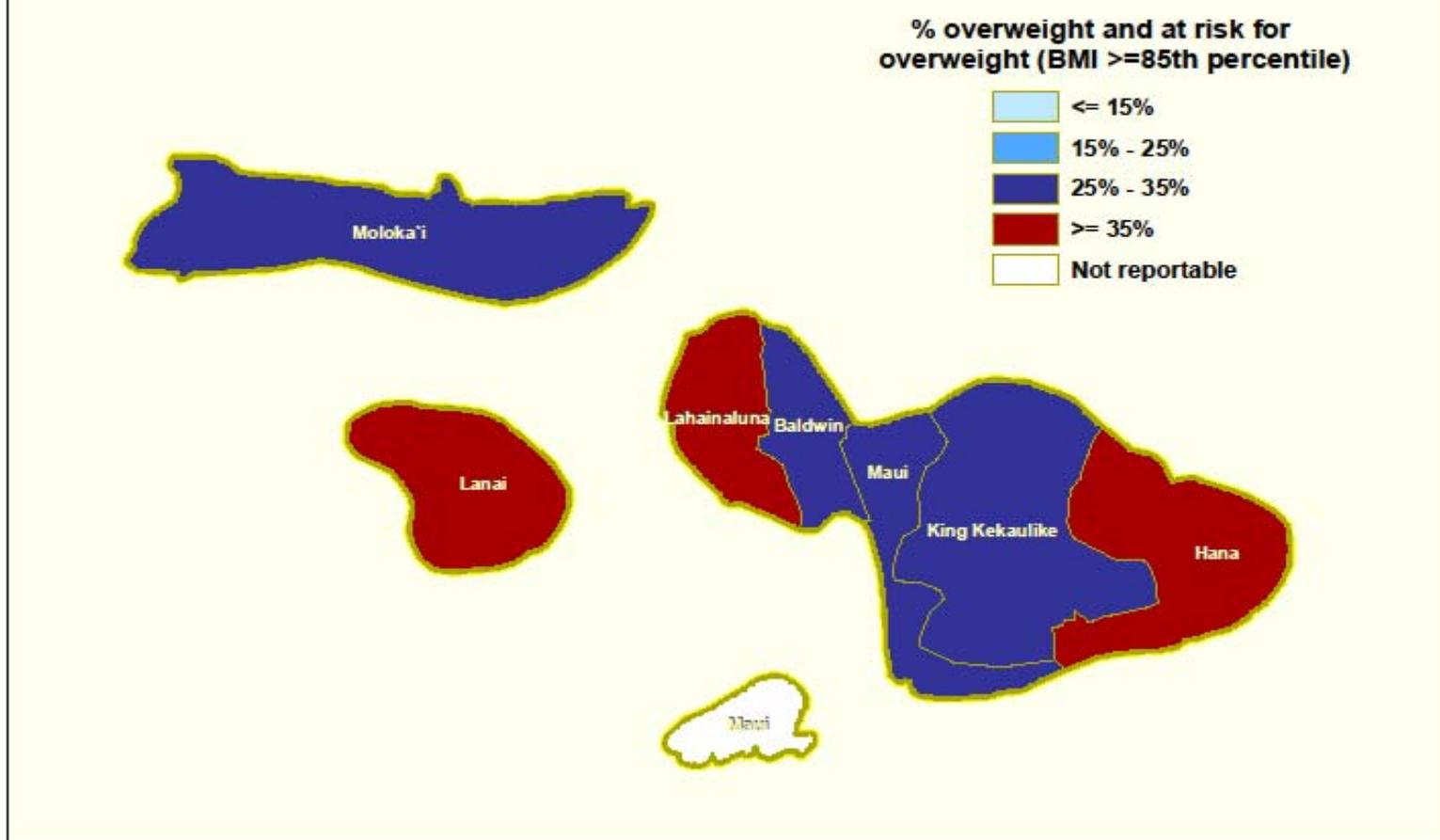
### Percent Overweight And At Risk for Overweight, Public School Students Entering Kindergarten By School Complex, Kaua'i County, 2002 - 2003

% overweight and at risk for overweight (BMI  $\geq$ 85th percentile)

- $\leq$  15%
- 15% - 25%
- 25% - 35%
- $\geq$  35%
- Not reportable

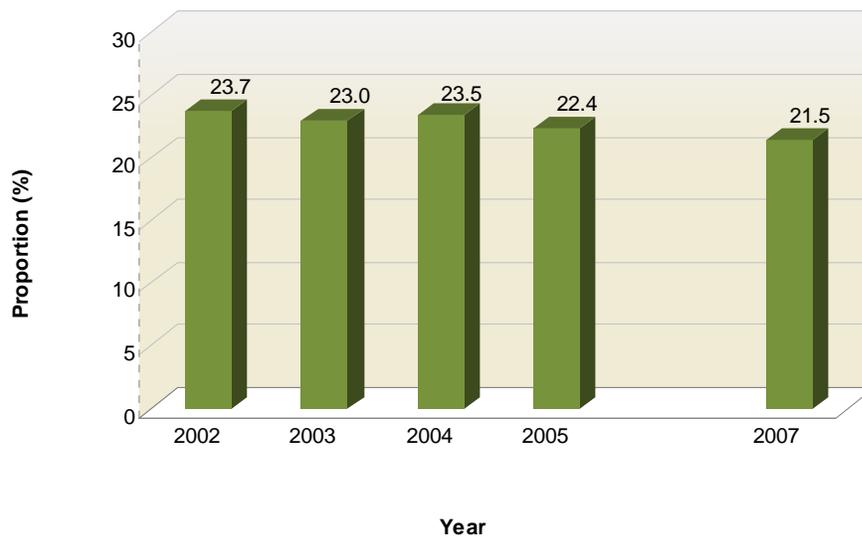


**Percent Overweight And At Risk for Overweight, Public School Students Entering Kindergarten By School Complex, County of Maui, 2002 - 2003**



The Women, Infants and Children (WIC) Supplemental Nutrition Program is a federally funded program which provides nutritious supplemental foods, nutrition counseling, breastfeeding counseling, and referrals to low-income residents. Services are limited to women who are pregnant, breastfeeding or postpartum, and to infants or children under 5 years of age. WIC staff monitor length and weight on infants and children up to age 2 and height/weight ratios (Body Mass Index) on all 2 to 5-year-olds to assess whether they are in a healthy range. WIC dietitians and certified staff counsel on the risk of childhood weight gain and explore ways to make recommended changes in diet and activity with caregivers. In 2007, 21.5% of WIC children 2-5 years of age in Hawai'i were at-risk of being overweight or obese. Although this represents a small decrease from 2005, the estimate in Hawai'i remains significantly lower than the average of 31.2% in all those in PedNSS.<sup>8</sup> The significance of this recent decline in Hawai'i in the light of increased rates shown in other data sources is uncertain and will be monitored.

**Chart 5-7 At Risk for Overweight and Obese among Children 2-5 years of Age receiving WIC services 2002-2005, 2007**



Source: Hawai'i State Department of Health, Family Health Services Division, Women, Infants and Children (WIC) Services Branch, PedNSS. No data was available for 2006.

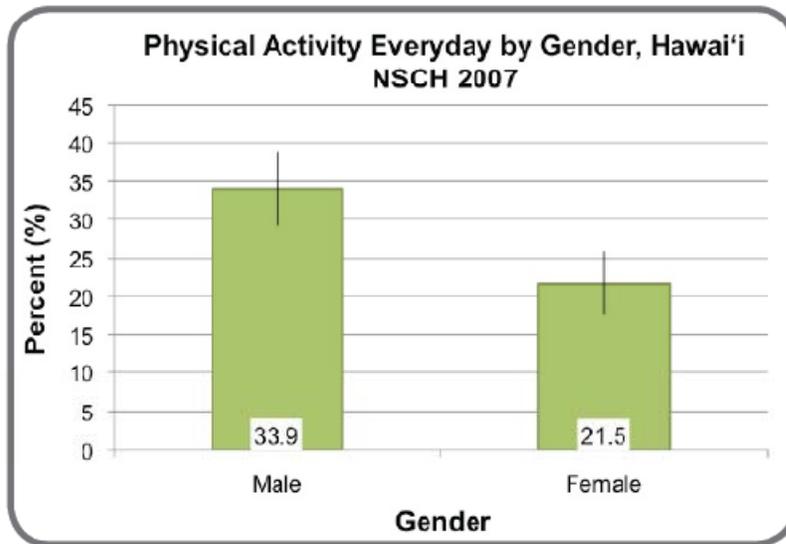
<sup>8</sup> Centers for Disease Control & Prevention. 2007 Pregnancy Nutrition Surveillance. Center for Disease Control. Accessed 4/10/2009  
[http://www.cdc.gov/PEDNSS/pnss\\_tables/pdf/national\\_table6.pdf](http://www.cdc.gov/PEDNSS/pnss_tables/pdf/national_table6.pdf) [Accessed 4/23/09]

Nutrition and Physical Activity

The most effective way to maintain a healthy weight is to eat a balanced diet that includes several servings of fruits and vegetables and to exercise regularly. Unfortunately, less than one-quarter of high school students eat five or more servings of fruits and vegetables a day. Physical activity throughout life is important for maintaining a healthy body, enhancing psychological well-being, and preventing premature death. Physical activity among children and adolescents provides tremendous health benefits and establishes healthy lifestyle habits that are more likely to continue into adulthood. Inactivity may be primarily responsible for the dramatic increase in child and adolescent obesity rates in the U.S. during the past decade.

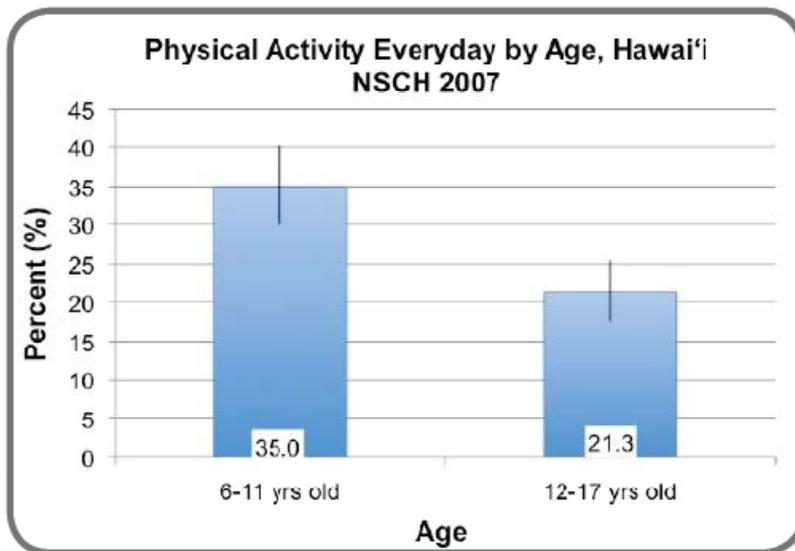
Data from the National Survey of Children's Health estimates that 28.0% of children aged 6-17 years were physically active every day of the week in Hawai'i, similar to the proportion (29.9%) for the rest of the nation in 2007. There was variation by age groups with 35.0% of those 6-11 years of age reporting daily physical activity, compared to 21.3% of those 12-17 years of age. Females were also less likely to report daily physical activity with 21.5% of females compared to 33.9% of males.

**Chart 5-8 Daily Physical Activity among Children 6-17 years of age by Gender in Hawai'i, 2007**



Source: Hawai'i Department of Health, Family Health Services Division. 2007 National Survey of Children's Health.

**Chart 5-9 Daily Physical Activity among Children 6-17 years of age by Age Group in Hawai'i, 2007**



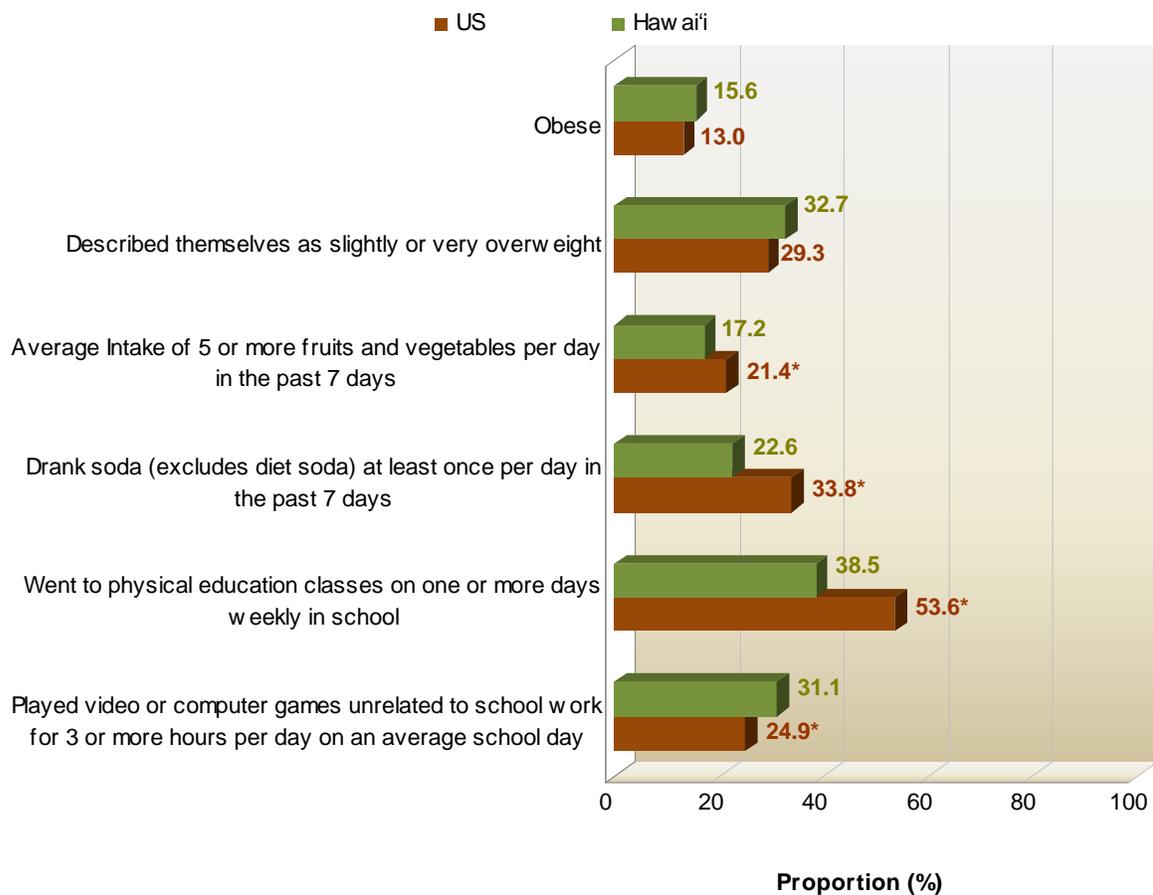
Source: Hawai'i Department of Health, Family Health Services Division. 2007 National Survey of Children's Health.

Schools are an effective means to provide physical activity and fitness instruction because they reach most children and adolescents. Participation in school physical education ensures a minimum amount of physical activity and provides a forum to teach physical activity strategies and activity that can continue through a child's life. Research has shown that schools that offer intense physical activity programs have shown: positive effects on academic achievement, including increased concentration; improved mathematics, reading and writing test scores; and reduced disruptive behaviors, even when the physical education reduces the time for academics.

Unfortunately, schools are eliminating physical education classes often replacing them with more sedentary classroom and computer activities. The State Department of Education follows the national standards for PE and requires: 120 minutes of PE per week for K-3rd grade, 90 minutes of PE per week in grades 4-6, and 200 minutes of PE per week in middle and high school. However, PE is an elective in middle school, and only one year is required for high school graduation.

In 2009, the Youth Risk Behavior Survey (YRBS), based on self-reported data among high school students, estimated similar estimates of obesity (>95% for BMI by age and sex) and describing themselves as being at least slightly overweight nationally and in Hawai'i public high school students. Hawai'i public high school students were less likely to eat 5 or more fruits and vegetables daily and were less likely to attend physical education classes compared to high school students nationally. Students in Hawai'i were more likely to spend time on the computer than the rest of the nation. Hawai'i data suggests that students in the state are generally doing better than the rest of the US.

**Chart 5-10 Obesity, Physical Activity, and Nutrition among Hawai'i Public School Students vs. U.S. High School Students: 2009**



Source: University of Hawai'i, Curriculum Research and Development Group (CDRG). Hawai'i Youth Risk Behavior Survey (YRBS). Data Note: \* Denotes a significant statistical difference at p=0.05.

Table 5-6 presents selected physical activity measures for middle and high school students from Hawai'i compared to U.S. high school students. There are fewer Hawai'i high school students that attend P.E. classes and exercise for 60 or minutes in P.E. class than the U.S. average. There is some decrease in Hawai'i in all measures when comparing Hawai'i middle school students and Hawai'i high school students.

<b>Behavioral Description</b>	<b>Hawai'i Middle School</b>	<b>Hawai'i High School</b>	<b>U.S. High School</b>
Attended in P.E. class at least once a week	69.9	43.8	56.4
Attended P.E. class daily	19.0	11.4	33.3
60 or more minutes of exercise in P.E. class	44.8	34.4	37.0

Source: Hawai'i High and middle School Youth Behavioral Risk Surveillance System, 2009

Establishing healthy dietary and physical activity behaviors needs to begin at childhood. Research suggests that parents can influence children's eating behaviors as preschoolers, but have less influence on the choices of school-age children. Some of the environmental factors which contribute to a decrease in physical activity include lack of physical education in schools, sedentary after school activities and day care activities, lack of accessible low cost community physical activity programs, absence of organized sport opportunities for non-athletes in schools, and neighborhoods which are unsafe for unsupervised play. In Hawai'i, participation in youth physical activity programs is often costly and therefore, not accessible to families with little disposable income. Working parents may also not have time to drive their children to various activity centers.

### **Violence & Safety**

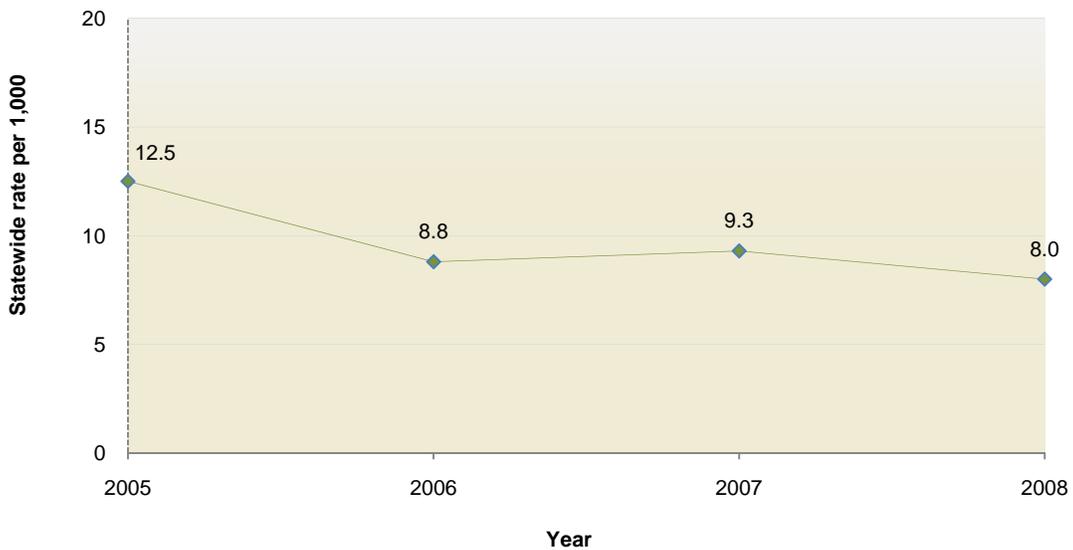
Children need a safe and nurturing environment for healthy development. Yet, violence in the U.S. is pervasive and can change the quality of children's lives. Over the past 30 years, all major causes of childhood death from injury and disease have declined, except one—violence. Homicide of young children has nearly doubled, and homicide and suicide of older children have nearly tripled.<sup>9</sup> Maltreated children are at high risk for such problems as developmental delays, school-related problems, drug abuse, and physical and emotional problems throughout their lives. Youth in detention facilities frequently report histories of physical and sexual abuse. Research also suggests a link between child sexual abuse and teen pregnancy. Teens who are victimized as children tend to engage in sexual intercourse earlier, and are less likely to use contraceptives, than non-abused teens.

<sup>9</sup> Health Resources and Services Administration, Office of Minority Health, National Family and Intimate Partner Violence Prevention Initiative, 1997

Child Abuse

Children under the age of five are the most vulnerable for child abuse and neglect (CAN). For children 0-5 in Hawai'i in 2008, the rate of CAN was 8.0 (per 1,000 children 0-5 years of age) which is a 36% relative decrease since 2005 when the rate was 12.5. There were no comparable national estimates for this particular age group. In 2007 for all children, the national rate of confirmed CAN reports was 10.1 (per 1,000 children, aged 0-17 years) compared to 7.1 in the State of Hawai'i. There was some variation by county with Hawai'i County having the highest rate. Although the CAN rates reflect this slight decline since 2005 many experts believe that increased family stress due to the state's poor economy may result in a rise in cases of family violence including CAN. It should be noted that the definition of a "confirmed" CAN case has changed over time. Also new policies have resulted in reported cases receiving early intervention services to divert families from entering into the child protection system. These two factors may lead to an under reporting of the "true" CAN rate.

**Chart 5-11 Hawai'i rate of Child Abuse and Neglect Ages 0-5 year, 2005-2008 (rate per 1,000 children)**



Source: Hawai'i State Department of Human Services, Management Services Office, accessed through the University of Hawai'i Center on the Family Data Center available at [http://uhfamily.Hawai'i.edu/Cof\\_Data/cfi/family\\_indicators.asp](http://uhfamily.Hawai'i.edu/Cof_Data/cfi/family_indicators.asp)

Table 5-7 summarizes the YRBS for safety and violence questions. Relative to the U.S., more Hawai'i students report feeling unsafe at school, physically hurt by boyfriend/girlfriend, and physically forced to have sexual intercourse. Rates are generally lower for physical fights in Hawai'i compared to U.S. High school students. Middle school students in Hawai'i public schools being involved in a physical fight on school property 1 or more times in the past 12 months. Youth continue to be involved in violent activity as both perpetrators and victims of violence. Generally, physical fighting is more prevalent at middle school and goes down in high school.

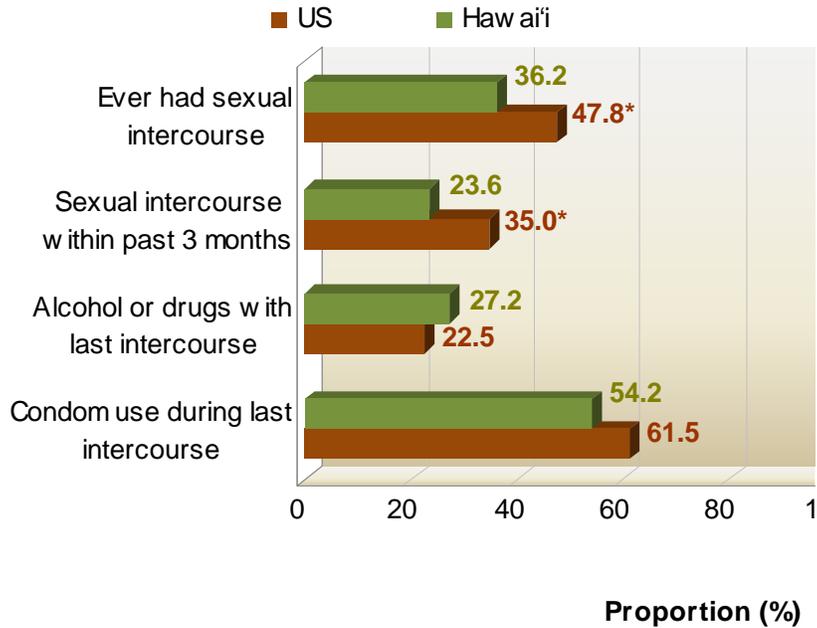
<b>Behavioral Description</b>	<b>Hawai'i Middle School</b>	<b>Hawai'i High School</b>	<b>U.S. High School</b>
Felt unsafe at school & did not go	9.2	7.9	5.0
Threatened/Injured with weapon at school	6.9	7.7	7.7
Physical fight 1+ times on school property	20.7	10.2	31.5
Physically hurt by boyfriend/girlfriend	4.0	13.0	9.8
Physically forced to have sexual intercourse	5.1	10.3	7.4

Source: Hawai'i High and Middle School Youth Behavioral Risk Surveillance System, 2009.

### **Sexual activity**

Sex and sexuality pervade many aspects of today's popular culture. Despite the promotion of sexual imagery in the mass media and resulting fascination with sexual matters, Americans are generally uncomfortable about discussing sex and sexuality as a normal human function. Thus, becoming a sexually healthy and responsible person can be a difficult outcome for young adolescents. Yet, learning and practicing sexually responsible attitudes and behaviors is a key developmental task of adolescence. Unsafe sex can result in unintended pregnancies and sexually transmitted diseases, including HIV/AIDS. In 2007, 36.2% of high school students in Hawai'i reported being currently sexually active compared to the 47.8% nationally. Public high school students in Hawai'i report lower estimates of sexual intercourse, current sexual activity than other high school students nationally. Among those that are sexually active, more than a half didn't use a condom at last sexual intercourse. More than a quarter of those sexually active report using alcohol or other drugs just prior to last sexual intercourse.

**Chart 5-12 Sexual Activity among Hawai'i Public High School Students vs. U.S. High School Students: 2007**

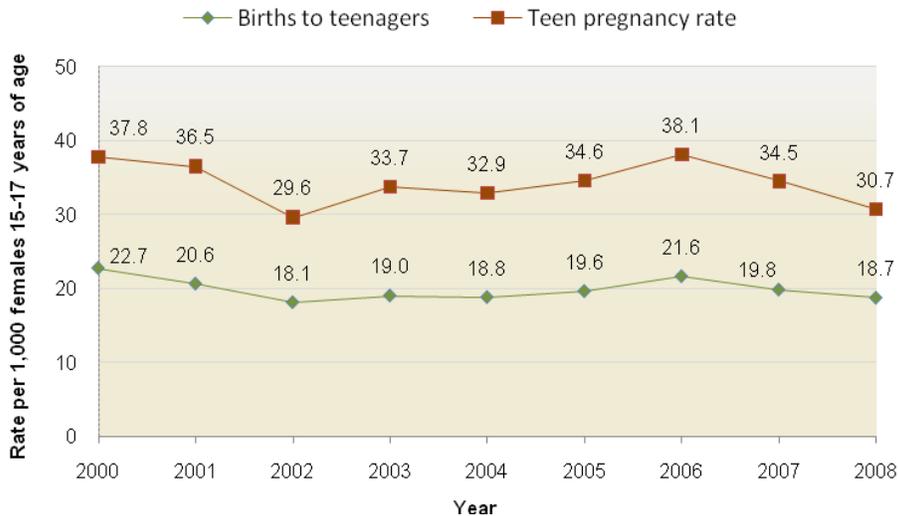


Source: University of Hawai'i, Curriculum Research and Development Group (CDRG). Hawai'i Youth Risk Behavior Survey (YRBS).

Pregnancy Rates

Since 2000 Hawai'i's teen pregnancy rates have fluctuated but has generally declined from 37.8 per 1,000 females 15-17 years of age in 2000 to 30.7 per 1,000 females 15-17 years of age in 2008. The proportion of births to females 15-17 years of age has also generally declined from 22.7% in 2000 to 18.7% in 2008. Although the overall decreasing trend in teen pregnancy and birth rates is positive, several significant disparities exist. Teen pregnancy rates overall tend to be lower in urban than in rural areas. Pregnancy rates for the rural neighbor islands are much higher than for urban Honolulu County.

**Chart 5-13 State of Hawai'i, Pregnancy and Birth Rates among Females 15-17 Years of Age: 2000-2008**



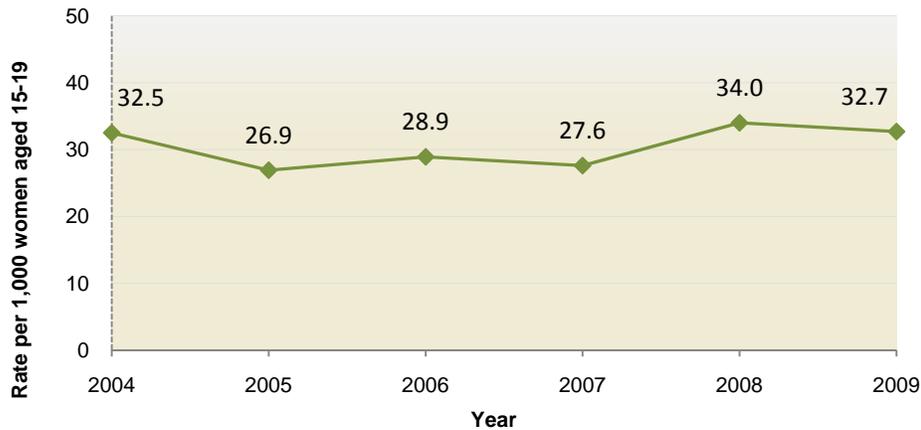
Source: Hawai'i State Department of Health, Office of Health Status Monitoring. Birth data file, Fetal death data file, ITOP data file. Note: U.S. Census Bureau, Population Division, SC-EST2008-agesex-res-Hawai'i, Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2008 (May 14, 2009.)

Sexually transmitted disease

Sexually transmitted diseases (STDs) are a common threat to the health of adolescents ages 15-19 years. Chlamydia can impact reproductive health and is among the most frequently reported communicable disease in the US. Chlamydia is often asymptomatic, thus is more likely to go untreated. It is a major cause of pelvic inflammatory disease and infertility in women. Screening for Chlamydia is important to women's reproductive health. High rates are found in sexually active adolescents and young adults, particularly in those 15-19 years of age. In Hawai'i, the number and rate of reported cases of Chlamydia among women aged 15 to 19 has remained stable with a rate of 32.7 per 1,000 women aged 15-19 years in 2009. This indicator has varied from 26.9 in 2005 to 34.0 in 2008 over the past 6 years. The higher rates recently may be due to an increased awareness and screening efforts in the population or other factors.<sup>10</sup>

<sup>10</sup> Hawai'i Title V Block Grant application for 2010

**Chart 5-14 State of Hawai'i, Rate per 1,000 women aged 15 through 19 years with a reported case of Chlamydia: 2004-2009**



Source: Hawai'i State Department of Health (DOH), Communicable Disease Division, STD/AIDS Prevention Services Branch. Reported positive cases primarily reflect chlamydia infections identified during screening of asymptomatic women. Population data based on U.S. Census Bureau, Population Estimates Program, "Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: July 1, 2008" (SC-EST2007-AGESEX\_RES) (May 1, 2009). Estimates for the 2009 population were not available from the Census bureau at time of this report so the prior year estimate was used in the determination of the indicator.

## **Substance Abuse**

### Tobacco

Cigarette smoking is the single most preventable cause of disease and death in the United States. Smoking results in more deaths each year in the U.S. than AIDS, alcohol, cocaine, heroin, homicide, suicide, motor vehicle crashes, and fires combined. Smoking tobacco causes heart disease, several kinds of cancer, and chronic lung disease.

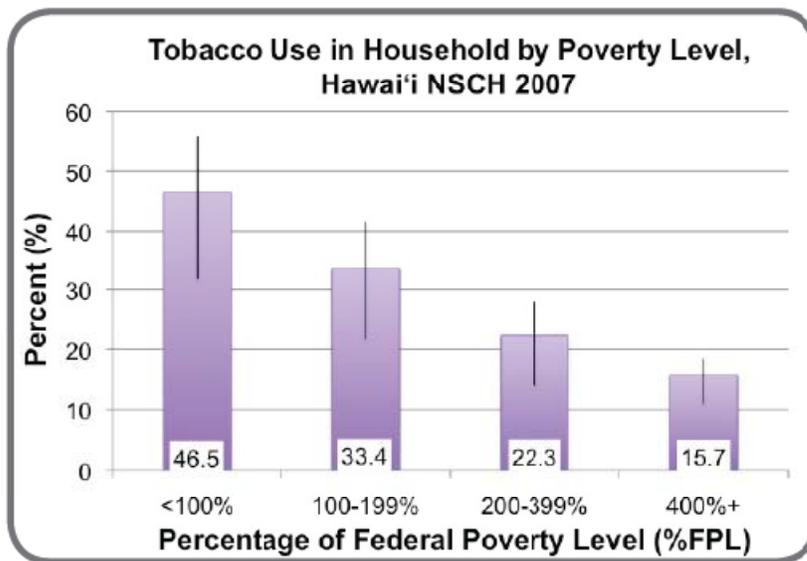
Smoking among children and adolescents has severe, lifelong consequences for each generation because a large proportion of those who begin smoking as youth will likely continue to smoke for the rest of their lives. The nicotine found in tobacco can create a life long addiction to smoking that is difficult to treat.

Hawai'i tobacco prevention efforts have been successful in reducing smoking among youth. Tobacco sales to minors have dropped substantially since 1996 to the fourth lowest rates in the nation due to aggressive enforcement of law prohibiting the sale of tobacco to minors. Bolstered by Tobacco Settlement funding, smoking prevention efforts are beginning to show results among the state's youth. YRBS data indicates teen smoking has dropped from 27.9% in 1999 to 15.2% in 2009. Nationally, there has been an increased interest in the use of other tobacco forms. Data from YRBS in 2009 shows that 4.9% of Hawai'i High School students report using chewing tobacco in the past 30 days, compared to 8.9% for U.S. high school students.

<b>Behavioral Description</b>	<b>Hawai'i Middle School</b>	<b>Hawai'i High School</b>	<b>U.S. High School</b>
Smoked cigarettes in past 30 days	8.2	15.2	20.0
Used chewing tobacco, snuff, or dip on at least 1 day in past 30 days	--	4.9	8.9
Source: Hawai'i High and Middle School Youth Behavioral Risk Surveillance System, 2009.			

Data from the National Survey of Children's Health shows that among children 0-17 years of age, 26.3% of children in Hawai'i live in a home with someone that smokes tobacco which is not significantly different from the 26.2% for the rest of the nation. The presence of smokers in the household decreased with household federal poverty level with 46.5% of children in families below 100% FPL compared to 15.7% in families with 400% FPL and above.

**Chart 5-14 Children Living in Households with Smokers in Hawai'i, 2007**



Source: Hawai'i Department of Health, Family Health Services Division. 2007 National Survey of Children's Health.

## Alcohol

Alcohol is the most popular drug of choice for adolescents in Hawai'i, as well as throughout the nation. Commonly recognized as a gateway drug, the continued use of alcohol often leads to illicit drug use. Each year about 100,000 deaths in the U.S. are related to alcohol consumption.<sup>11</sup> Alcohol use has been linked with a substantial proportion of injuries and deaths from traffic accidents, falls, fires, and drowning. It can also be a factor in suicide, homicide, violent behavior, reduced school performance, and high-risk sex. Like tobacco use, adolescent use of alcohol increases the likelihood of continued adult use, potential abuse and associated alcohol-related problems. The perceived acceptance of alcohol consumption among family, peers, and society influences an adolescent's decision to use or avoid the substance. The perception that alcohol use is socially acceptable correlates with the fact that more than 80% of youth in the United States consume alcohol before their 21<sup>st</sup> birthday.

Table 5-8 summarizes the YRBS data on alcohol use for adolescents in Hawai'i and the U.S. All alcohol use data indicates positive trends for Hawai'i students. All but one of the Hawai'i student rates for alcohol use are lower than the U.S.. Although the data looks promising Hawai'i percentages are still remain unacceptably high. Almost 2 out of 5 Hawai'i high school students report current alcohol use, nearly 1 in 4 report binge drinking, and over 28% report drinking alcohol before age 13. The only measure with higher Hawai'i rates was for students who drove in car with someone who had been driving alcohol. The Hawai'i high school rate (12.2%) is higher than the U.S. rate (9.7%), particularly alarming is that the rate is even higher among Hawai'i middle school students in which over a third of them report riding in a car driven by someone who drank alcohol.

<b>Behavioral Description</b>	<b>Hawai'i Middle School</b>	<b>Hawai'i High School</b>	<b>U.S. High School</b>
Had first drink of alcohol before age 11	16.7	--	--
Had first drink of alcohol before age 13	--	28.6	21.1
Ever had alcohol	35.1	68.6	72.5
Current alcohol Use	15.3	37.8	41.8
Binge Drinking	--	22.4	24.2
Rode in car driven by someone who drank alcohol	36.6	12.2	9.7

Source: Hawai'i High and Middle School Youth Behavioral Risk Surveillance System, 2009.

<sup>11</sup> U.S. Department of Health and Human Services, Healthy People 2010, p26-31.

## **DIRECT HEALTH CARE AND ENABLING SERVICES**

### **Financial Access to Health Care and Health-Related Services**

Historically, Hawaii has had a large proportion of its population covered by some form of health insurance. In the 1980s, Hawaii's uninsured population was estimated at 5%, and the state was credited as having the lowest uninsured rate in the U.S. This is a legacy from traditional Hawaiian society; the subsequent plantation era where medical care was provided for workers, and the rise of strong labor unions.

### **Prepaid Health Care Act**

The generally accepted principle of broad or universal access to health care is reflected in the passage of the Hawaii Prepaid Health Care Act of 1974. The Act requires employers to provide a group health plan for employees working at least 20 hours a week for at least four straight weeks and earn at least \$542 a month. The law also mandates a minimum set of benefits that must be provided.

Hawaii is the only State with such a requirement and was successful in obtaining a waiver from the federal Employee Retirement Income and Security Act (ERISA), which prohibits state regulation of self-insured employers. The law does not require employers to cover dependents, so families may be omitted from coverage. Recent large increases in insurance premiums over the past few years have raised concerns about the Act and its impact on businesses in Hawaii.

### Insurance Market

Information on Hawaii's health insurance market is from the Hawaii Health Information Corporation. The latest available data was for 2007.<sup>12</sup> Private and public health insurance covered an estimated 90% of Hawai'i residents in 2007. Private health insurance covered about 56% of residents. Of those people covered by private health plans in Hawai'i, 93% were covered through employment-based plans. The number of residents in public-sponsored insurance programs remained fairly stable between 1995 and 2007 at about 36% of the resident population an increase of 29%. While the percent of individuals covered by private plans increased 2%.

From 1992 to 2007, the proportion of the population with overlapping coverage has increased by 80%. (Overlapping coverage refers to an individual's coverage by more than one insurance plan.) In 2007, 9% of covered individuals, or 1 in 11 individuals, had overlapping coverage.

As in the rest of the nation, the two dominant types of managed care organizations are health maintenance organizations and preferred provider organizations. Nearly 35% of Hawaii residents with insurance were enrolled in an HMO in 2007. Of these HMO enrollees, one out of three participated with one of the QUEST plans. Almost 40% of Hawai'i's residents were enrolled in a

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<sup>12</sup> All information in this section was taken from the Hawaii Health Information Corporation, Health Trends in Hawaii, Health Market online at [www.healthtrends.org](http://www.healthtrends.org), accessed in July 2010.

PPO in 2007.

Traditional fee-for-service coverage declined by 63% between 1992 and 2007, and makes up 11% of covered lives. In 2007, all of the fee-for-service covered lives were covered by public insurance (either Medicare or Medicaid). Both the federal and state governments are in the process of changing coverage for these populations to managed care options so this percentage is expected to change in future reporting.

The financing of health care in Hawaii's private sector is dominated by two health plans: the Hawaii Medical Service Association (HMSA, the Blue Cross and Blue Shield plan) which was founded in 1935, and Kaiser which began operating in Hawaii in 1958. In 2007 HMSA insured 60% of the Hawaii market, while Kaiser covered 20%. The other major insurers in the state as of 2007 were Hawaii Management Alliance Association (HMAA) and University Health Alliance (UHA). All 4 insurers are non-profits and exempt from taxes. A new for-profit insurance plan, Summerlin Life & Health Insurance, began offering services in 2005.

Although there was a significant commercial insurance presence at one time, it has dwindled due to the State's isolation, limited consumer market and aggressive competition from the HMSA and Kaiser. To address Hawaii's shrinking health insurance market and rising health costs, legislation was passed in 2002 to regulate health insurance plans to assure insurance rate increases are not excessive, yet sufficient to keep insurance companies viable in the long term. Hawaii was one of the last states in the U.S. to pass such legislation.

Medicare, the federal government's coverage for the elderly, accounted for 35% of the government program covered lives in 2007; QUEST and Medicaid, state and federally-funded programs, represented 29% and 8% of government funded health plans respectively. TRICARE, the federal government's coverage for military-dependent and military retiree health care, accounted for 28%.

## **MEDICAID<sup>13</sup>**

The Hawaii QUEST Expanded demonstration project is a Medicaid waiver project administered by the Department of Human Services Med-QUEST Division (MQD) that began in August 1994. QUEST is an acronym that stands for: Quality Care, ensuring Universal Access, encouraging Efficient Utilization, Stabilizing Costs, and Transforming the way health care is provided. QUEST has 2 basic objectives: to expand medical coverage to include populations previously ineligible for Medicaid and to contain costs by shifting fee-for-service to a managed care delivery system. Savings realized from such a shift would be used to expand coverage.

In 1996, economic changes led to a tightening of QUEST eligibility. The income requirement was changed from 200 percent of the Federal Poverty Level (FPL) to 100 percent, and enrollment was capped at 125,000 members, down from the high of 160,000. Certain groups are not subject

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<sup>13</sup> Information and data for this section are from the State Department of Human Services, Med-QUEST Division. Enrollment figures are now available directly from the Med-QUEST website at <http://www.med-quest.us/PDFs/queststatistics/2010%20QUEST%20ENROLLMENT.PDF>

to the cap and can enroll at anytime: pregnant women, children under 19 years of age, foster children and children in subsidized adoptions under age 21, adults whose incomes do not exceed the TANF payment limit, and people who apply within 45 days of losing their employer sponsored coverage due to loss of employment.

Through a Medicaid QUEST waiver in 2006 DHS also expanded services by covering more low-income adults. Through the new QUEST-ACE (Adult Coverage Expansion) launched by DHS in March 2007 benefits are provided for inpatient and outpatient care, emergency room visits, mental health services, diagnostic tests, immunizations, alcohol and substance abuse treatments, dental care and prescription drug coverage. Men and women over the age of 19 without dependent children are eligible whose annual earnings are at or below 200% of the FPL. The program is designed to help adults who could not previously qualify for QUEST due to the statewide enrollment cap imposed in 1996. The waiver also allowed the state to continue to make direct payments to hospitals to offset the costs of caring for the uninsured.

Dental coverage is a comprehensive benefit for children but limited to emergency and palliative services for adults and was moved from managed care to fee-for-service in October 2001. In December 2006, DHS reinstated adult dental benefits - including periodic exams and cleanings - to help up to 95,000 men and women eligible for Medicaid. The MQD ended this dental program on August 10, 2009. At this time, the State only pays for emergency dental services, such as tooth extractions for adults.

QUEST allows participants to select medical plans from the three current participating providers: HMSA, Kaiser, and AlohaCare. The three QUEST health plans offer additional services for disease management and some plans will offer health promotion programs for enrollees. Med-QUEST also implemented a new quality assurance program. Plans receive financial incentives for meeting quality performance standards and are assessed penalties if they fail to meet baseline requirements. As of January 2010 HMSA covered 52.1 % of QUEST enrollees, Kaiser 11.8%, and AlohaCare 35.1%, (another 1.0% remain under QUEST FFS). Not all providers are available on each island.

DHS has plans to implement a new economic stimulus program that will increase health care coverage by providing a health insurance premium subsidy to employers who hire unemployed individuals.

### **Medicaid/QUEST Expanded Access**

The Medicaid population of clients 65 years or older and disabled of all ages (commonly called the aged, blind, and disabled (ABD) population) was covered under a separate fee-for-service program. In February 2009, the ABD population transitioned into a managed care system through the new QUEST Expanded Access (QExA) program. MQD designed the QExA program to provide service coordination, outreach, improved access, and enhanced quality healthcare services by health plans through a managed care delivery system to this Medicaid population.

QExA health plans coordinate benefits across the continuum of care to include acute and primary care, behavioral health, and long-term care services. In 2008, DHS awarded the 3-year QExA contracts to two new health plans: Evercare and 'Ohana Health Plan associated with national health insurers United Health Group and WellCare Health.

As of January 2010 the QExA enrollment was 41,671; QUEST enrollment was 205,106 for a total Medicaid enrollment of 249, 875. Due to the state economic downturn, Medicaid programs observed an approximately 13% increase in recipients for two successive years. This unexpected growth of the program with federal restrictions under the American Recovery and Reinvestment Act that prevented states from decreasing eligibility resulted in a budget shortfall and the need to delay two months of health plan capitation payments (one month's for 6 weeks, and a second month's for 2 weeks). DHS earnestly awaits a six-month extension of the increased federal medical assistance percentage.

### **State Children's Health Insurance Program**

The State Children's Health Insurance Program (SCHIP), enacted in August, 1997, provided new incentives for states to extend public health insurance coverage to low-income uninsured children. The federal government offered states a higher federal match and greater flexibility to design their programs than they enjoyed under Medicaid. Hawaii uses Tobacco Settlement revenues to fund the State match for SCHIP.

The Department of Human Services (DHS) is the lead agency in Hawaii for the State Child Health Insurance Program (SCHIP). Hawaii's SCHIP program, a Medicaid expansion, began on July 1, 2000, and covers all children under 19 years of age with family incomes up to 300% of the Federal Poverty Level (FPL) for Hawaii. There is no waiting period for SCHIP eligibility. As of January 2010, 23,621 children were enrolled in SCHIP.

Effective July 1, 2000 Children who are legal immigrants arriving after August 1996, refugees and those born in the Marshall Islands and Federated States of Micronesia and Palau were eligible under both SCHIP and QUEST effective July 1, 2000 under a state funded immigrant program.

In July 2009, MQD used the provisions of Section 214 of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) to amend the Medicaid State Plan retroactive to April 1, 2009. Section 214 of CHIPRA extends federal medical assistance to alien children under nineteen years of age and alien pregnant women who are Legal Permanent Residents or citizens of a Compact of Free Association nation. Effective July 9, 2009, MQD began to convert the children and pregnant women covered in the State-funded programs to the appropriate Section 1115 QUEST Expanded programs. Therefore, as of January 2010, the immigrant child enrollment was 38 since the majority of children in this program (approximately 3,800) were converted to a Medicaid program that received Federal funds.

## **Improving Medicaid Coverage & Services Delivered**

With increased availability of Medicaid insurance, the number of uninsured children has decreased and more children are accessing needed medical services. However, there are still an estimated 6815 children without insurance coverage.

**Hawaii Covering Kids** (HCK) is a statewide initiative that identifies, enrolls and retains eligible children and youths in health insurance programs. HCK collaborates with federal, state and community agencies to conduct outreach activities and works with the Hawai'i State Department of Human Services Med-QUEST Division (DHS Med-QUEST), the state's Medicaid agency, to improve policies and procedures that increase enrollment of children and youths in public health insurance. The Hawaii Primary Care Association began the project in 1999 with Robert Wood Johnson Foundation start-up funding. HCK is currently funded by Hawai'i State Department of Human Services Med-QUEST Division and three foundations.

Over the past 10 years, HCK has been extremely successful in leading and initiating efforts to increase children's enrollment into Medicaid and other private insurance sources through the work of its five task forces (Process Simplification, Media and Public Information, Identification and Outreach, Training and Public Education, and Evaluation) and ad hoc committees. HCK also maintains a user-friendly website with updated eligibility information about children's health insurance programs and DHS Med-QUEST forms. Easy access to updated information includes, Guidelines for QUEST and Medicaid. A web page has been developed specifically for recently Laid-Off Workers. The Child insurance web page, the Facebook page, and advertisement on the Hawaii High School Athletic Association webpage are continuously updated.

HCK outreach activities will utilize a variety of media resources which may also include, movie theater and shopping mall advertising during November-December; radio and television advertising focusing on Asian and Latino immigrants and Pacific Island immigrants; focusing on Pacific migrant service organizations, faith-based groups, and ethnic Chambers of Commerce to continue outreach for newly arrived immigrants and Pacific migrants; and organize pharmacy outreach campaigns.

### Insurance Coverage

Medical insurance coverage is a strong predictor of access to care. Among the uninsured in the U.S., children are the largest group.<sup>14</sup> Children with no medical insurance are less likely to secure care for routine/preventive care or for illness, have a regular source of care, and experience a lower overall standard of care than insured children. Without access to primary care, many are forced into the most expensive ambulatory care setting-hospital emergency departments to obtain routine services.

The percentage of children covered by private health insurance in Hawai'i is higher than for the U.S. in general. This is due largely to the Hawai'i Prepaid Health Act, expansion of Medicaid coverage for children and the efforts of Hawaii Covering Kids. Since 1988, all private insurance policies which provide

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14 John B. Kotch, ed. *Maternal and Child Health: Programs, Problems and Policy in Public Health*. Gaithersburg, Maryland: Aspen Publication, 1997 p. 125.

coverage for sick child care are mandated to provide well child supervision coverage up to the age of 6 years.

Because Hawai'i residents may have the best opportunity to obtain health insurance, the Department of Health annual household health survey showed that in 2008 only 2.4% of all Hawai'i children 0-17 years did not have health insurance (over 8,000 children).<sup>15</sup> The impact of the State's poor economic conditions has resulted in increased unemployment. Because the main source of coverage in Hawaii and the U.S. as a whole is employment-based insurance, the coverage situation has deteriorated as unemployment has risen. Future data may begin to reflect this impact.).<sup>16</sup>

Although many Hawai'i residents have medical insurance, they could be "underinsured," where health plans may not cover needed services or require co-payments which pose a financial burden on families. The data appears to show insurance coverage is relatively high for children. But out-of-pocket financial payments by families for health care services may pose a barrier to accessing care. If families lack the means to pay for care they will likely be low users of preventive services and tend to delay seeking care until conditions require higher levels of service, more costly interventions, or more intensive treatment than if they had entered the care system at an earlier stage.

## **Health Resources**

Another factor affecting access is the availability of health care providers and facilities. Overall Hawai'i has an adequate supply of providers, facilities and equipment. It is their distribution that presents the problems both the location of their practice and the type of insurance or payment they accept. There are significant gaps in the supply of providers in rural areas, particularly on the neighbor islands, and in low-income urban neighborhoods in Honolulu that often include many minority groups.

For certain services like dental care, the centralized location of dental providers and their reluctance to accept publicly insured clients is a serious issue since most dental health services in Hawai'i are delivered through private dental offices. The state health department and a several community health centers provide limited dental services to under-served groups but maintain long waiting lists.

## **Providers<sup>17</sup>**

Hawai'i ranks 8th among states in physicians in patient care per capita. With 3.2 active physicians per 1,000 resident population, Hawai'i has more physicians per capita than the national average (2.8 physicians per 1,000 population). Like their mainland counterparts who are concentrated in urban areas, Hawai'i's physicians are highly concentrated in a small area on Oahu. In 2007, about 80% were practicing on Oahu. Oahu has approximately 3.6 physicians per 1,000 population compared to about 2.1 physicians per 1,000 population in the rural counties of Hawai'i, Kauai, and Maui. While Hawai'i's rural counties have

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<sup>15</sup> Hawai'i State Department of Health, Office of Health Status Monitoring, Hawai'i Health Survey, 2008.

<sup>16</sup> Hawai'i State Department of Health, Office of Health Status Monitoring, Hawai'i Health Survey, 2008.

<sup>17</sup> All information in this section was taken from the Hawaii Health Information Corporation, Health Trends in Hawaii, Health Market online at [www.healthtrends.org](http://www.healthtrends.org), accessed in July 2010

more family practice/general medicine physicians per capita than O'ahu, these rural counties have far fewer specialists available to care for residents.

Hawai'i has more dentists per capita than the nation as a whole. This is largely driven by the high concentration of dentists on Oahu, with 88 per 100,000 population, which is well above the national rate of 64. However, Hawai'i's rural counties experience a shortage of dentists, with about 60 dentists per 100,000. Hawai'i, Kauai, and Maui Counties are each designated Dental Health Professional Shortage Areas by the federal Health Resource and Service Administration (HRSA).

### **Shortage Designation Areas**

Areas with a shortage of health professionals have been identified in the state through a system of designations for underserved areas or populations-at-risk by the Federal Bureau of Health Professions. Health professional shortage designation areas (HPSA) are divided into three major categories according to the type of health professional shortage: primary care, dental and mental health.

Communities may also be designated as Medically Under-Served Areas (MUA) and Medically Under-Served Populations (MUP). Medically under-served area/populations are considered to have a shortage of health services (versus professionals in the HPSA) and where a high proportion of the population is below 100% of poverty, is elderly, exhibits poor health outcomes and has a low ratio of primary care physicians. The designations are important to channel substantial federal resources and grants to underserved communities. Table 5-9 lists all the health professional shortage designation areas (HPSA) and medically under-served areas/populations in Hawaii. Maps of the Hawaii's HPSAs can be found on the DOH website at <http://hawaii.gov/health/doc/pcna2009databook.pdf>.

**Table 5-11. Medically Underserved Area/Population and Health Professional Shortage Area Designations by Area, Type, Score, and Designation Date (as of July 2009)**

Area	MUA/ MUP	Primary Care HPSA	Dental HPSA	Mental Health HPSA	Date of Last HPSA Update		
					Primary Care	Dental	Mental Health
(Census Tract)							
<b>Hawai'i County</b>							
Hawai'i County	MUP		** 12			6-Jun	
Puna (210.01-211)		* (211) 14		* 16	6-Sep		7-Aug
Kau (212)		* 17		* 12	6-Aug		6-Aug
Waikoloa (217.01)		* 8			6-Sep		
North Hawai'i (219-221)				** 9			7-Aug
<b>Honolulu County</b>							
Waikiki (18.01-20.02)	GOV MUP						
Kalihi-Palama (51-62.02)	GOV MUP		** 7			5-Nov	
Kalihi Valley (63.01-66)	MUA		** 7			5-Nov	
Waianae (96.01-98.01)	MUA						
Koolauloa (101-102.02)	MUA						
North Shore (99.01-102.02)				** 10			9-Feb
Waimanalo (113.01-113.02)	GOV MUP						
<b>Kauai County</b>							
Kauai County	GOV MUP			* (408-409) 8			7-Nov
<b>Maui County</b>							
Hana/Haiku (301-302)	GOV MUP	* 14	** 18	* (301) 10	6-Sep	8-Apr	6-Sep
Maui (303.01-315)	MUP		* 12			9-Mar	
Lanai island (316)	MUP						
Molokai Island (317-319)	MUA	* 10	** 12	* 17	8-Nov	8-Apr	7-Apr
<b>Kalawao County</b>							
Kalawao County (319)	MUA			* 17			7-Aug

MUA – Medically Underserved Area requested by Governor  
MUP – Medically Underserved Population  
HPSA – Health Professional Shortage Area designation

GOV MUP – Medically Underserved Area  
X – Approved as an Area designation  
XX – Approved as a Low-Income Population

The Primary Care Office (PCO) is located in the Family Health Services Division and helps to assure access to primary care services for the medically under-served in Hawai'i. The Hawai'i PCO works in close collaboration with federally qualified health center's (FQHC's), primary care contractors, Hawai'i Primary Care Association (HPCA), Hawai'i State Office of Rural Health, Hawai'i Area Health Education

Center, Native Hawaiian Health Scholarship Program, community stakeholders, and other public, private, and voluntary organizations to support the development, maintenance, and expansion of a statewide comprehensive primary health care system for the medically underserved.

Obtaining an accurate picture of our communities' health status and needs is accomplished through our needs assessment process. This process is facilitated by the PCO, and one outcome is publication of a biennial data book, which provides essential data for identifying community, technical assistance, shortage designation, health workforce, and primary care health needs. The PCO is responsible for overseeing the Health Professional Shortage Areas (HPSA), and Medically Underserved Area/Populations (MUA/P) designation applications

#### Primary Care Contracts

An integral part of the PCO program is the provision of high-quality, culturally competent, coordinated, primary care services to the uninsured and under insured through contracts with 16 health centers throughout the state. Medical care, behavioral health, dental treatment, and pharmaceutical services are covered under these contracts. Recent program data demonstrates an ever increasing demand for services.

#### Facilities

There are 14 federally qualified health centers (FHQC) in Hawai'i located in the under-served areas in the state. Six of these CHCs have multiple satellite sites. CHCs serve 80,000 people every year. The majority of CHC clients are low-income.

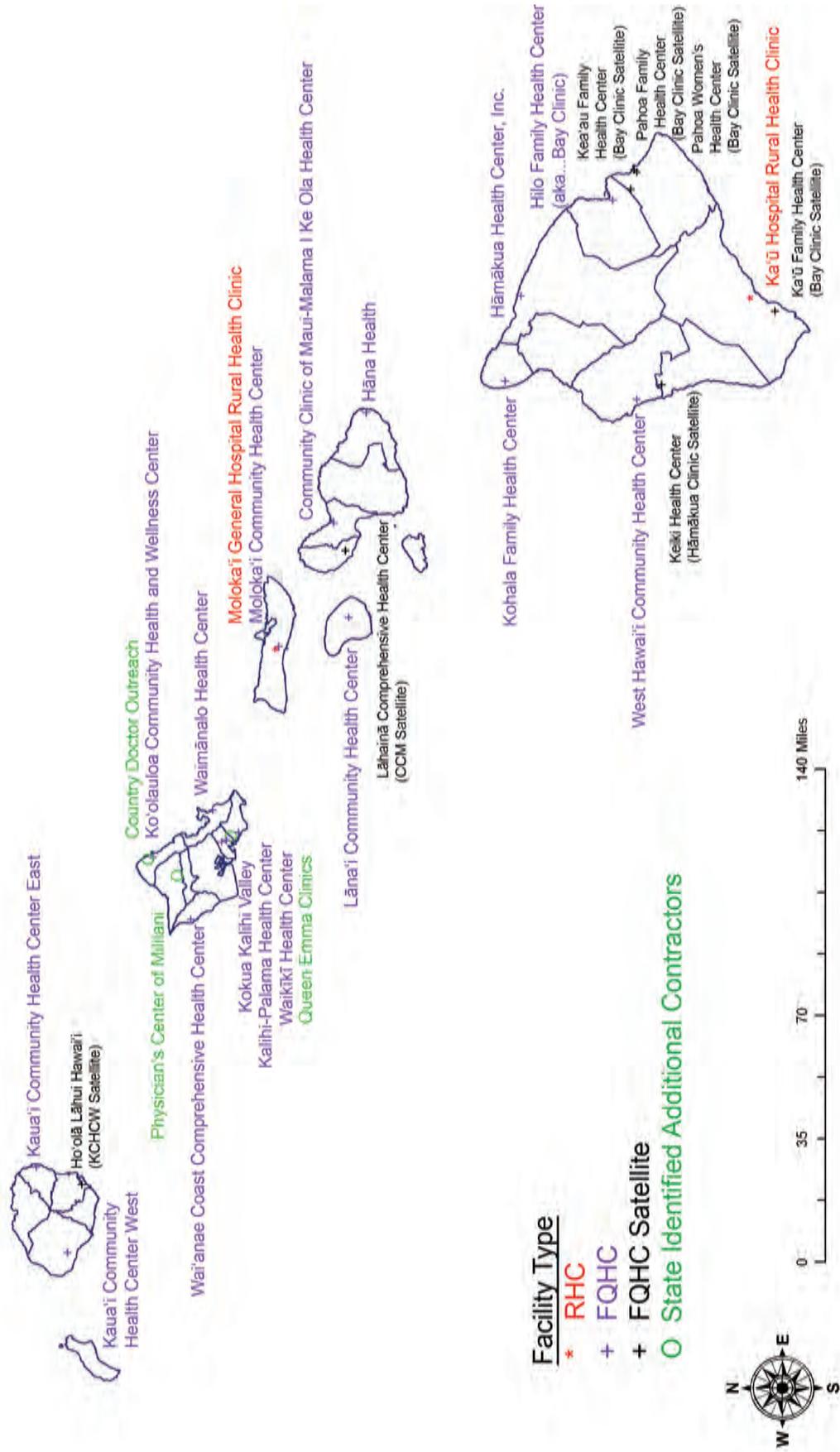
Hawaii has 2 Rural Health Clinics (RHC) intended to increase primary care services for Medicaid and Medicare patients in rural communities. The clinic must be staffed as least half time and must provide the same services that are required of a community health center.

The Department of Health identified the need to provide primary care services to areas that did not meet the requirements for a RHC or FQHC, but were critical in ensuring appropriate access to services. Currently, there are three sites that receive such funding identified through an open and competitive procurement process. These health centers and clinics expand access to primary care services for the medically underserved that are coordinated, culturally sensitive, and focus on health promotion and disease prevention.

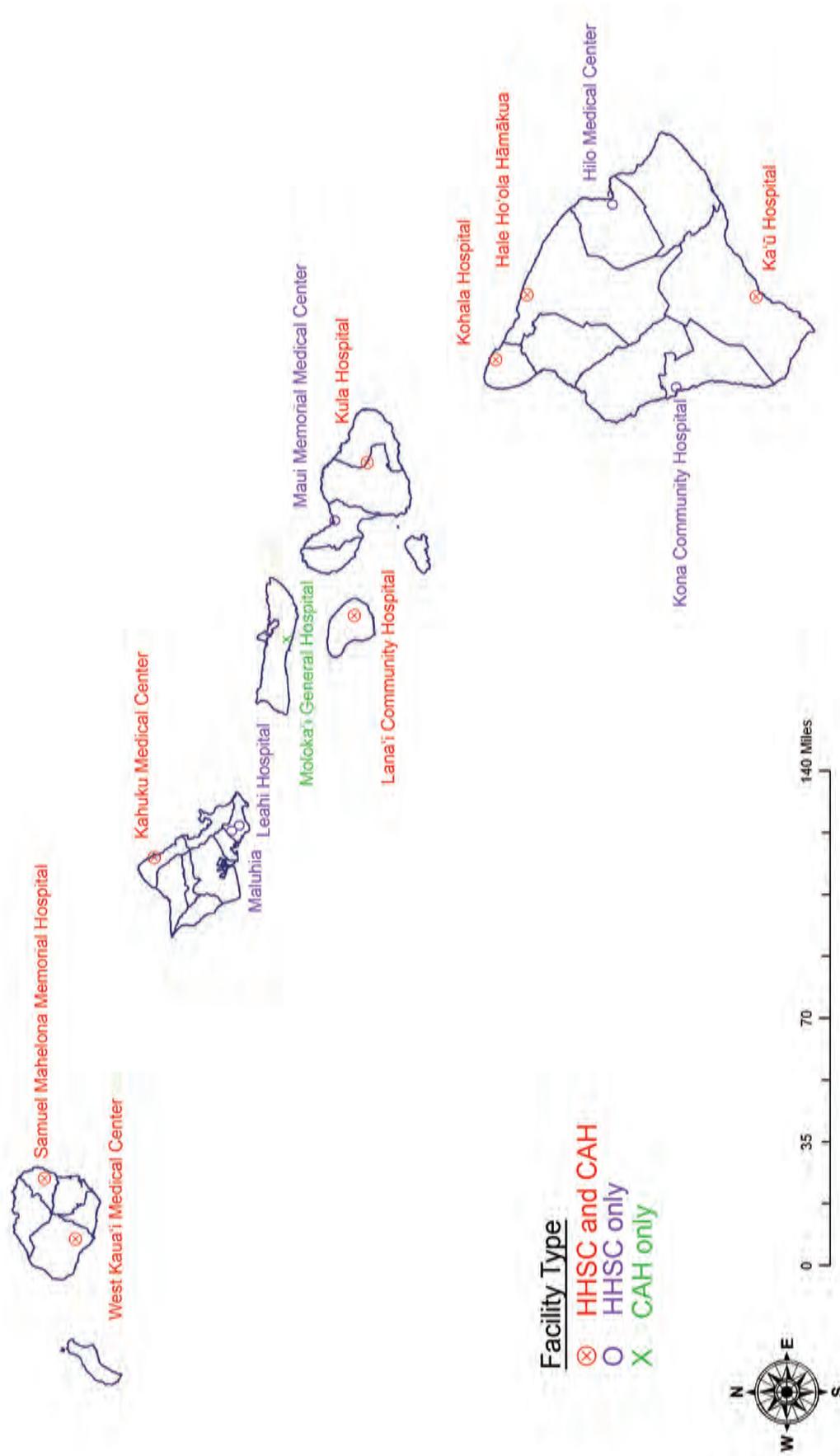
There are 24 civilian acute care hospitals in the state. Tripler Army Medical Center serves the Hawai'i military population. Of the 25 hospitals 14 are considered major community hospitals. Each of the major islands has one hospital with the exception of Niihau. Twelve of the hospitals are located on the Oahu. Twelve of the former state hospitals are now organized under the Hawai'i Health Systems Corporation.

Tertiary care services, or high-risk service centers such as trauma centers, burn centers, and regional perinatal centers that support the statewide population, are centralized on Oahu.

The first map shows the location of the location of the community health centers and clinics. The second map shows the location of the Hawai'i Health Systems Corporation and Critical Access hospitals.



**Map 5-5: Location of Community Health Centers and Clinics**



**Map 5-6: Location of Hawai'i Health Services Corporation and Critical Access Hospitals**

## **Geographic Access to Health Care & Health-related Services**

The network of community health centers in rural and urban under-served areas helps alleviate access issues for children to primary and preventive services. Still major gaps exist, specifically access to dental care. The majority of tertiary health care facilities and specialty and sub-specialty services are located on Oahu with the greatest concentration in the primary urban center of Honolulu. Consequently, Neighbor Island and rural Oahu residents must travel to Honolulu for these services. This is a financial burden for neighbor island residents since the round-trip airfare can vary from \$120 to over \$200.

To address some of the access problems to tertiary care and specialty care for the neighbor islands, a new health care network, the State of Hawai'i Telehealth Access Network (STAN) was created in 1998 to foster telehealth and telemedicine in Hawai'i. STAN links health care providers, educational institutions and related agencies, allowing communication for clinical, financial/management, and educational services. Through the use of electronic video communication, health information and services can be delivered despite long distances to care providers. STAN now links many of the acute care hospitals, Shriners Hospital for Children, the University of Hawai'i, and the community health centers.

## **Access to Primary Care/Barriers to Care: Utilization of Services**

Consumer use of health resources and providers indicate accessibility of the service system. Various measures are reviewed to determine the adequacy of primary and preventive services for children in Hawai'i.

### Immunization

The level of immunizations received by children is an important measure of the delivery of direct services to children. The immunization schedule serves as the basis for routine health maintenance services recommended for preschool children. Vaccines prevent the debilitating and in some cases, fatal effects, of infectious diseases like polio, measles, pertussis, mumps and rubella. In 2008 according to the results of the National Immunization Survey, 78.3% of Hawai'i children 10-35 months of age received the full immunization schedule of vaccines close to the Healthy People 2010 objective of 80% and comparable to the national rate of 78.2% for the same year.<sup>18</sup>

### Primary Care

#### **Medical Home**

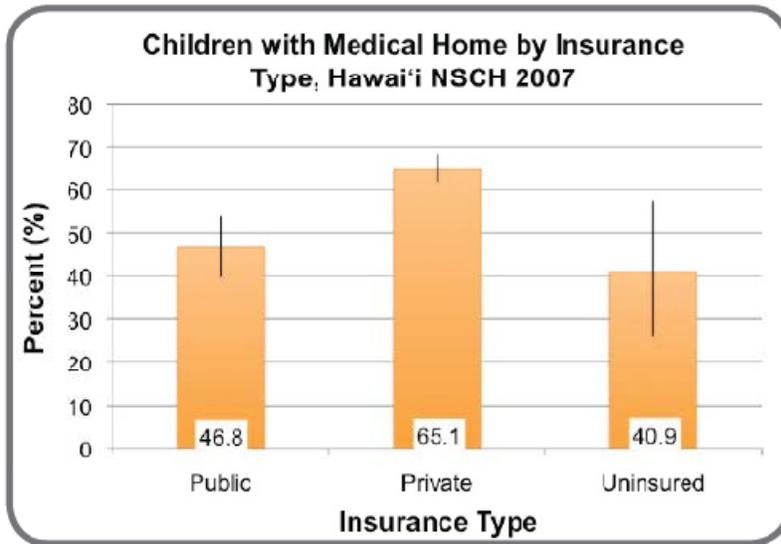
The medical home plays an integral role in early intervention and is essential for services rendered to at-risk youth in order to ensure that appropriate steps are taken for optimal outcomes for every child.<sup>19</sup> Data from the National Survey of Children's Health shows that among children 0-17 years of age, 60.1% of children in Hawai'i have a medical home compared to 57.5% for the rest of the nation. Further analysis revealed disparities by age, federal poverty level, and insurance type. Among those with private insurance, 65.1% had a medical home, compared to 46.8% on public insurance, and 40.9% of those without insurance.

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<sup>18</sup> Data on immunization series 4:3:1:3:3 comes from the U.S. National Immunization Survey (NIS), Centers for Disease Control

<sup>19</sup> Council on Children with Disabilities. Role of the Medical Home in Family-Centered Early Intervention Services. 2007. *Pediatrics*. 120(5):1153-1158.

**Chart 5-15 Children with a Medical Home by Insurance Status in Hawai'i, 2007**



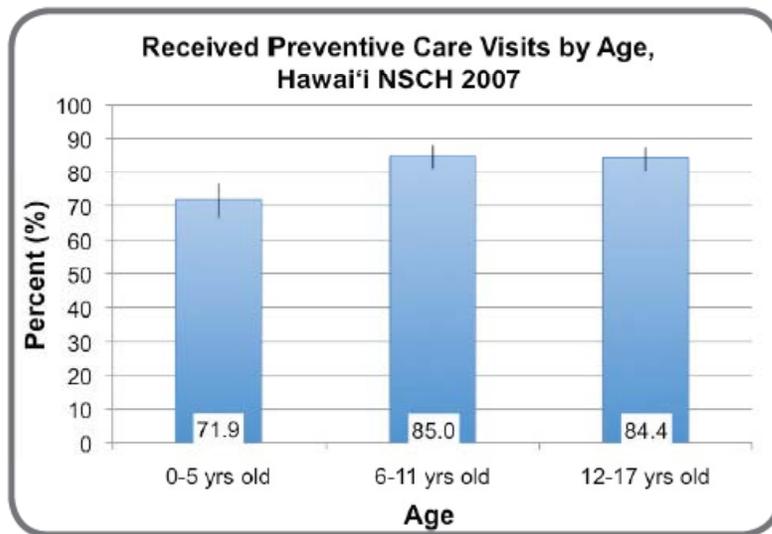
Source: Hawai'i Department of Health, Family Health Services Division. 2007 National Survey of Children's Health.

### **Preventive Care**

Preventive care visits are important for ensuring children are in good medical and oral health. Well-child visits, for instance, help to ensure proper immunizations and screening for delay or other health conditions. Tooth decay is the most common chronic disease of children in the nation, albeit generally avoidable through preventive care visits.<sup>20</sup> Data from the National Survey of Children's Health shows that among children 0-17 years of age, 80.3% of children in Hawai'i received both medical and dental preventive care compared to 71.6% for the rest of the nation. Further analysis revealed there were disparities by age, federal poverty level, and insurance type. Among those aged 0-5 years, only 71.9% received both preventive care visits compared to 85.0% of those 6-11 years of age and 84.4% of those 12-17 years of age.

20 Centers for Medicare and Medicaid Services. U.S. Department of Health and Human Services. Guide to Children's dental care in Medicaid. 2004 update. Available at <http://www.cms.gov/medicaidDentalCoverage/Downloads/dentalguide.pdf>.

**Chart 5-16 Children that Received a Preventive Care Visit by Age group in Hawai'i, 2007**



Source: Hawai'i Department of Health, Family Health Services Division. 2007 National Survey of Children's Health.

### **Early and Periodic Screening Diagnosis and Treatment**

Poverty is one of the best predictors of child health status. Childhood poverty has a strong association with poor child health due to the economic disadvantages and stressors experienced by these families. Medical care can mitigate some of the adverse effects of poverty and other risk factors associated with this vulnerable population. Recognizing the effectiveness of preventive primary care for children, Congress enacted the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) to assure low-income children have access to a comprehensive package of preventive care. Through implementation of the EPSDT program, child health could be vastly improved. Unfortunately, since its inception the program's success in screening and treating eligible children has not met expectations.

Utilization rates for EPSDT are reported annually. The percentage of Medicaid eligible children in Hawai'i who have received a service paid by the Medicaid program was 41.3% in 2000. The low percentage, however, reflects the decline of service utilization rates for older children. A review of the data by age groups reveals that those children requiring increased screening are in fact utilizing services: Infants (89.1%), ages 1-2 years (78.1%), 3-5 years (60.0%), 6-9 years (31.5%), 10-14 (33.3%), 15-18 years (28.9%), 19-20 (10.5%).

Other problems with EPSDT concern the quality of visits. Exams may occur without completed lead testing, developmental assessments, and vision/hearing screening.

## Family Support

Assuring parenting support and information is made available to all families and children is an important mandated service for the federal Title V Block Grant. FHSD funds a free, statewide telephone **Parent Line**.

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

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. Referral systems are in place within facilities providing different levels of services (e.g. medical centers that provide both outpatient and inpatient services).

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 Hawai'i. The team includes neonatologists/pediatricians, nurses, and respiratory therapists.

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

FHSD, the Title V agency, partners with numerous community stakeholders to assure children have access to primary care. These stakeholders include other Divisions within the Department of Health (Dental Health, Health Promotion, Public Health Nursing, and Emergency Services) as well as other government departments (Human Services responsible for administration of Medicaid, Department of Health, and Judiciary). FHSD also partners with purchase of service contractors to provide an array of direct and enabling services to ensure vulnerable populations in the state have access to health services.

## **Services/Programs**

### **Women, Infant and Children**

The Special Supplemental Nutrition Program for Women, Infants & Children (WIC) is a federally funded short-term intervention program designed to establish good nutrition and health behaviors through nutrition education, breastfeeding promotion, a monthly food prescription allotment and access to maternal, prenatal and pediatric health-care services. WIC serves low-income pregnant and post-partum women and children up to age 5 nutritionally at-risk through purchase-of-service (POS) and state-run agencies. WIC contracts with seven community health centers, one Native Hawaiian Health Care Center and one hospital to provide services, resulting in greater integrated health service delivery than the eight state-run agencies. During FFY 2009, Hawaii WIC served a monthly average of 36,320 individuals, an increase of 6.7% from 34,050 individuals in 2008. The mix is approximately 25% women, 25% infants and 50% children. The new WIC food packages effective October 2009 (with reduced fat milk, fruits/vegetables, whole grains, baby foods and soy alternatives) aligns with

messages to increase intake of fruits/vegetables and whole grains/fiber, decrease intake of fat and juices, and breastfeed babies. The gradual change to a more paraprofessional delivery model continues as does the emphasis on participant-centered services. Over 12% of the trained state WIC staff (14 of the 113.5 FTEs) was replaced in some cases with higher salaried more senior staff during the 2009 RIF process; further vacancies exist for qualified nutritionists due to two hiring freezes. Some POS agencies have accepted additional caseload and funds, but furloughs for state employees have impacted potential caseload and spending. ARRA funding will be used to plan the replacement of the 11-year old information technology system.

### **Family Planning Program**

The Family Planning Program (FPP) in the Maternal and Child Health Branch (MCHB) ensures access to affordable birth control and reproductive health services to all individuals of reproductive age with a priority on low income and hard-to-reach individuals including adolescents. Services are offered free or at low cost, including education, counseling, cervical and breast exams, provision of appropriate contraceptive methods, testing for pregnancy and sexually transmitted infections. In FY 2008 there were 2,582 women under 18 and 2,692 women 18-19 years of age that received direct services through FPP contracts.

### **Healthy Start Program**

The Healthy Start Program reaches families experiencing multiple stresses when a child is born. This community based program helps strengthen family functioning and promote child development. Program components include daily chart screening at targeted hospitals to identify high risk families utilizing a nationally recognized screening tool. Voluntary paraprofessional home visitation is offered to qualifying families. These home visits focus on improving parent-child interaction and bonding. Services are contracted through private agencies. FHSD routinely evaluates the contracts to assure program integrity.

### **Parenting Support Programs**

Parenting Support Programs administered through FHSD include: **HomeReach**- short-term home visitation services to resolve a parenting concern or family crisis, **Mobile Outreach**- activities and programs to isolated or homeless families that promote age-appropriate parent-child interaction, communication, and positive discipline, **Community-based Parent Support Groups** (via The Baby Hui)- parenting and appropriate child development/guidance support through volunteer led peer parent groups, **Respite Services**- care giving relief, parent education and support on Oahu to high risk families having crises or difficulties with parenting and family stress, Services for **Children who have Witnessed Violence** (via The Family Peace Center)- intended to help children cope with their emotional responses to violence and by helping the family create a safe, stable, and nurturing environment for the child by teaching parents to have age-appropriate expectations and an awareness of the effects of violence on children. State funding for Services for Children who have Witnessed Violence was eliminated by the 2009 Legislature due to state revenue shortfalls.

### **Head Start Dental Health Initiative**

Hawaii is now one of 27 states that have launched a Head Start Dental Home Initiative, developed in partnership between the Office of Head Start and the American Academy of Pediatric Dentistry, since 2008. The project goal is to ensure that all children enrolled in Head Start and Early Head Start (approximately 3,200 low-income children in Hawaii) have dental homes and access to comprehensive, continuous oral health care through a network of pediatric dentists and general dentists.

The Hawaii Head Start initiative was launched in May 2009, in conjunction with the annual meeting of the APPD held in Honolulu. Since that time, the following activities have been conducted: informational meetings have been held with dental hygienists and dentists on Hawaii Island, and with dental directors of Community Health Centers; a DVD that focuses on promoting parent awareness about the importance of starting oral health practices early has been produced and will soon be replicated and available for distribution to Head Start/Early Head Start programs to use in parent workshops; plans are being developed to partner Lutheran Pediatric Dental Residents with HS/EHS programs around dental screenings and oral health education activities; and a grant from the Hawaii Dental Services Foundation has been secured to purchase copies of Brush'um and dental starter packs for all HS/EHS enrolled children, statewide. State team meetings are convened quarterly, and Head Start staff attend Neighbor Island Oral Health Task Force meetings to share information and participate in other oral-health related activities.

### **Hawai'i Healthy Start**

Hawai'i Healthy Start (HHS) program is a home visiting service that strengthens families and promotes positive parent-child relationships. It began as a demonstration project in July, 1985. By 2001, Healthy Start had expanded statewide and included universal screenings and assessments in all civilian birthing hospitals. However due to reduced state revenues the program was subjected to severe budget restrictions. Today the program is limited to two (2) program sites and it has eliminated its statewide universal screening and assessment services in hospitals, and eliminated its inclusion in the IDEA (Individuals with Disabilities Education Act) Part C services for care coordination. The program currently enrolls families with children ages 0 to 3 years of age and is located on the islands of Oahu and Hawaii.

In October, 2008 the DOH, Family Health Services Division was awarded a \$500,000.00 grant per year for 5 years by the Department of Health and Human Services, Administration for Children and Families to "Support Infrastructure Needed for the Widespread Adoption, Implementation and Sustaining of Evidence-Based Home Visitation (EBHV) Programs." Although the EBHV grant funding has since been significantly impacted, the project has continued to move forward with its planned program enhancements for program fidelity and quality assurance initiatives.

## **POPULATION-BASED SERVICES**

### **Safe Sleep Hawaii**

Safe Sleep Hawaii's goal is to reduce the numbers of deaths through an awareness campaign targeting parents, caregivers, and health care providers. This will be done through: existing programs serving young families, a public awareness campaign, and hospitals with birthing facilities. The committee has begun an outreach campaign using informational packets, PSA's, DVDs, and educational sessions. Many agencies that service young families are represented on the Committee which functions as a sub-committee of the Keiki Injury Prevention Coalition.

### **Hawai'i Immunization Coalition**

Hawai'i Immunization Coalition is a statewide, community-based coalition of public and private agencies that ensure all of Hawai'i's children are appropriately immunized against vaccine-preventable diseases. Activities include dispersing current information and resources, distributing educational materials to the community, under taking statewide vaccination campaigns, and developing policies that affect immunizations. Training for health professionals and organizations on the latest immunization information and issues is an important function. The Coalition also works to address access issues and barriers to care for at-risk populations. The Coalition is also considering the feasibility of developing an immunization registry to secure more accurate and timely data regarding immunization levels for children in the state.

### **The Parent Line**

The Parent Line is a free, statewide telephone warm line that provides support, encouragement, informal counseling, information, and referral to over 5,000 callers a year. The usage demonstrates a substantial interest and need for these services. Due to limited funds, the Parent Line is in operation for only limited hours during the week. 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. Usually, these families have not accessed any other social service; and this phone call is experiencing concerns about their initial entry to service providers and can be a first line of prevention for child abuse, neglect, and early referral to ongoing services.

### **Cultural Acceptability of Health Care & Health-Related Services**

With over one million residents, there is no one ethnic group in Hawai'i that comprises a majority. Caucasians, Japanese, Filipino, and Native Hawaiians are the four largest ethnic groups, and together make up about three-quarters of the population. The remaining residents are Chinese, Korean, Vietnamese, Samoan, Pacific Islanders, Black, Laotian, American Indian, Eskimo, Aleut, or Tongan.

Language is sometimes a barrier, particularly for recent immigrants. Two growing immigrant populations especially on the neighbor islands are the Micronesians and Mexicans drawn to the islands to work in the

agricultural industry. Hawai'i has many ethnic groups whose first language is not English and who have limited English proficiency including Filipinos, Vietnamese, Laotian, Japanese and Chinese. Culture may also influence an individual's definition of health and illness, belief about disease causation, child's development and 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, informational materials, and interventions; and education/training to develop cultural competence and awareness. Efforts are also made to provide informational materials in various languages or who have issues regarding family stresses or questions on community resources. Short term home visitation services have been incorporated into the Parent Line.

The Parent Line Office also publishes and distributes: Keiki 'O Hawaii which is an early childhood developmental newsletter distributed in the hospitals to first-time parents, the Teddy Bear Post parent education newsletters, distributed to families of preschool age children, the Keiki 'O Hawaii - which gives parents information on accessing services and is distributed to parents of young children and to agencies helping them, and the A Happy Start brochure distributed to parents of children who are preparing to enter kindergarten.

### **Blueprint for Change**

Blueprint for Change through its system of Neighborhood Places and partners in the community, is working for positive change to reduce environmental and social risk factors and increasing protective factors by providing access to resources; building the capacity of at risk families to provide for the safety of their children; and serves as a neutral hub in their communities for service coordination and community building.

### **Prevent Child Abuse Hawaii**

Prevent Child Abuse Hawaii (PCAH) is a private non-profit organization dedicated to the prevention of child abuse and to ensure that all children in the state are able to grow up in a safe and nurturing environment. Programs are designed to promote positive parenting and healthy families through education, public awareness and advocacy. Programs are designed for the general public and promote positive parenting and healthy families where children are valued and loved. PCAH maintains an informational website of statewide events at <http://www.preventchildabusehawaii.org>.

## **INFRASTRUCTURE-BUILDING SERVICES**

### **Early Childhood Comprehensive Systems**

The Early Childhood Comprehensive Systems grant is designed to coordinate state efforts to develop a system of care to support the physical, social, emotional and learning environments for young children. A 2- year planning process resulted in a 3-year implementation plan scheduled to begin at the end of 2005.

### **Children's Trust Fund**

(HCTF) was established by statute to support family strengthening programs aimed at preventing CAN and promoting healthy child development. HCTF is a public/private partnership between the DOH and the Hawaii Community Foundation to assure a network of primary prevention services that support and strengthen families to prevent child abuse and neglect through community-based grants and public awareness.

### **Keiki Injury Prevention Coalition**

Keiki Injury Prevention Coalition (KIPC) is an organization of over 60 private and public partners in the community, including KIPC chapters on Kauai, Maui, and Hawai'i. FHSD staff continues to provide leadership and participate in statewide activities to address issues related to childhood injury prevention. KIPC supports data analysis and assessment of injury incidence and causation, 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.

### **Healthy Hawai'i Initiative**

Launched in 2000, HHI is a statewide effort to encourage healthy eating, physically active and tobacco free lifestyles and prevention-oriented public health programs that contribute significantly to the development of chronic disease. HHI is supported by a portion of the Tobacco Settlement Funds. HHI takes a multifaceted approach to improving health in the state by focusing on: a Coordinated School Health Program, community programs and projects, public and professional education, and surveillance.

### **Coordinated School Health Program**

Recognizing the critical role of schools in the development of healthy children, HHI, the Department of Education, and the University of Hawaii and other external stakeholders have formed a partnership to facilitate improvements in school health through policy development, environmental and systems change. Accomplishments include the adoption of statewide Wellness Guidelines which contains standards for nutrition

education, food and beverages, physical activity, physical education and health education. From 2000-2009, HHI funding training over 8,000 teachers and school staff in health and physical education.

### **Good Beginnings Alliance**

Good Beginnings Alliance (GBA) is the state's public/private partnership to create a coordinated early childhood education care system. The Alliance provides technical assistance and recommendations for policy development and funding to partners at the local and state level to support activities that will lead to improved outcomes for young children from birth through the first five years of life. A major focus has been the assurance of quality child care services for children under the age of five. GBA has created a master plan for early childhood systems and works at the local level through four County Councils and at the state level through an Interdepartmental Council consisting of the five State Cabinet members and the Office of the Governor. The master plan aims to increase community engagement in early childhood issues, assess needs, coordinate data collection, create system financing strategies, attract private funding, and create a financial aid system to access early childhood services.

### **The State Early Childhood Comprehensive Systems**

The State Early Childhood Comprehensive Systems grant is funded by the Maternal and Child Health Bureau (MCHB) in recognition of the fact that the early childhood systems building work of the federal, State, and local governments and private foundations over the last 15 years has been impressive, although, the proliferation of early childhood programs from diverse and unconnected service systems left significant gaps between the services that need to be addressed. ECCS is a systems' building grant that supports collaborative partnerships to align early childhood service systems priorities and integrating their funding streams in order to maximize health, mental health, early care and education, parenting education and family support benefits to the children, families, and communities served. Hawaii's ECCS grant continues to partner with state and federal agencies including the Housing and Urban Development (HUD), Departments of Education and Human Services, Aloha United Way, Blueprint for Change, Good Beginnings Alliance, Hawaii Association for the Education of Young Children, Head Start Association of Hawaii, Head Start State Collaboration Office, Medical Home Works!/Community Pediatrics Institute, University of Hawaii Center on the Family.

In 2007, ECCS became one of eight state cohorts with the **Center on the Social and Emotional Foundations for Early Learning (CSEFEL)**. CSEFEL provided training and technical assistance to Hawai'i in building the professional development of early childhood practitioners working with children's challenging behaviors and to develop the infrastructure for social emotional development of young children. In 2008-2009, 95 Early Childhood practitioners from over 30 programs have been trained in the CSEFEL Pyramid Model approach and the Parent Modules.

ECCS and the **Hawai'i Mental Health Transformation State Incentive Grant** partners to convene an annual Early Childhood Mental Health Leadership Summit. Leaders from the early childhood and mental health communities attended representing various agencies. The outcome of the meetings help consensus on working

definitions of early childhood mental health, infant mental health, and natural supports for families in Hawai'i.

### **Hawai'i Child Death Review Council**

Death in childhood is often preventable yet the exact causes and circumstances surrounding death, which may generate important data and strategies, are incomplete when simply examining vital statistics. To address this problem, Hawai'i's Child Death Review Council, a voluntary public-private partnership, was established in 1996 to develop 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 Department of Health to conduct child death reviews through standardized procedures to identify causes of death and recommend policies and strategies to prevent future deaths. Currently, the Council is finalizing a report based on the review of cases for years 2001-2006.

### **The Child Safety Collaborative**

The Child Safety Collaborative (CSC) is a public-private partnership to promote a safe and nurturing environment for children and youth. This group works toward creating a child safety system that is coordinated, effective, and well-funded; and to create an informed public around prevention issues. Its purpose is to be a voice to speak for the safety of children/youth and their families through public awareness, education, advocacy, and action. The CSC provides leadership for system change; assuring a comprehensive/effective service system; policy development; and provides a forum for communication and collaborative action.

### **Hawaii Partnerships to Prevent Underage Drinking (HPPUD)**

Hawaii Partnerships to Prevent Underage Drinking (HPPUD) Coalition was created to coordinate efforts to address the problem of underage drinking in Hawaii. The members of the partnership represent county, state, and federal agencies, non-profit organizations, private businesses, and community residents concerned with the health of Hawaii's youth. The current structure of HPPUD includes a Statewide Advisory Council, and four county coalitions. HPPUD's Strategic Plan was completed in 2009.

### **Asian Pacific Islander Youth Violence Prevention Center (APIYVPC)**

The APIYVPC is one of ten National Academic Centers of Excellence on Youth Violence Prevention and is a university-community resource center that conducts research, provides training and technical assistance, and engages in community mobilization and capacity-building efforts. The APIYVPC has shared their literature, research, activities, and toolkits on violence prevention. Although focused to work primarily with one community in Hawai'i, the Center may be able to provide clearinghouse information, technical assistance, training, and consultation on issues related to youth violence prevention.

### **Prevent Suicide Hawai'i Taskforce (PSHTF)**

The PSHTF is a state, public, and private partnership of individuals, organizations, and community groups working in collaboration to provide leadership, set goals and objectives, develop strategies, coordinate activities, and monitor progress of suicide prevention efforts in Hawai'i. The PSHTF collaborates with the Department of Health's (DOH) Injury Prevention and Control Program (IPCP) in planning and implementing these activities. "Prevent Suicide Hawai'i" is the brand name for the overall movement to reduce the incidence of suicides and suicide attempts in Hawai'i.

### **School Based Survey**

The Youth Risk Behavior Survey (YRBS), the Youth Tobacco Survey (YTS), and the Alcohol, Tobacco, and Other Drugs (ATOD) have collaborated to administer one survey every other year in the school. A goal of this collaboration is to increase the sample size administered so that estimates can be obtained at the county level and for other subgroups. In addition to providing county level estimates, the standardization of questions related to specific topics will better inform the public. The details of this collaboration are still being determined, but this single survey will continue to allow the monitoring of health risk behaviors among youth and young adults in Hawaii middle and high schools.

### **Assess from the State perspective how local delivery systems meet the population's health needs**

Hawai'i, because of the state's high rate of insured children, fares well compared to the rest of the U.S. in meeting the health care needs of children. An obvious area for improvement relates to assurance of dental health care both preventive and remedial. Hawai'i is one of the last states to fluoridate its water. While Medicaid covers child dental health utilization rates are extremely low.

Services for children experiencing mental health disability problems are still a concern for Hawai'i. The state is still under a court-decree for failure to provide appropriate services to address these critical health needs for children.

### **Standards, guidelines, monitoring, evaluation, quality improvement**

Through the Purchase of Service system, FHSD is able to monitor and evaluate services provided throughout the community. Performance measures are identified that focus on both the service delivery and client outcomes. Reporting on the measures is required as part of the contracted services. Many FHSD programs utilize customer satisfaction surveys for evaluation of services.

Standardized quality of care measures are used by Hawai'i's largest public and private insurance providers. Thus data is available regarding the vast majority of health consumers on customer satisfaction and health outcomes. The measures and data will be reviewed and analyzed to assess the quality of care received in the state.

# Appendices

A-0 Family Health Services Division & State Priorities

A-1 Reports on Stakeholder surveys

A-2 CSHN Issue Reclassification for Priority Setting

A-3 Prioritization criteria

A-4 Health Issue Workgroup Process

A-5 Health Issue Problem Maps

A-6 Health Issue Fact Sheets (drafts)

A-7 Health Issue Performance Measures



## **Family Health Services Division**

### **Mission Statement**

**The mission of Family Health Services Division is:**

- 🍌 to improve the health of women, infants, children and adolescents and other vulnerable populations and their families by**
- 🍌 increasing public awareness and professional education about the importance of a life course perspective**
- 🍌 advocating for systemic changes that address health equity and the social determinants of health and**
- 🍌 assuring a system of health care that is family/patient centered, community based, and prevention focused with**
- 🍌 early detection and treatment, habilitative and rehabilitative services for those with chronic conditions**

### **Vision Statement**

**The vision of Family Health Services Division is:**

**To assure that systems are in place to address the full continuum of care throughout the life cycle from preconception to birth to adolescents to adulthood for Hawaii's population and address the health and safety needs of vulnerable individuals, children and youth, with particular attention to children with special health needs.**

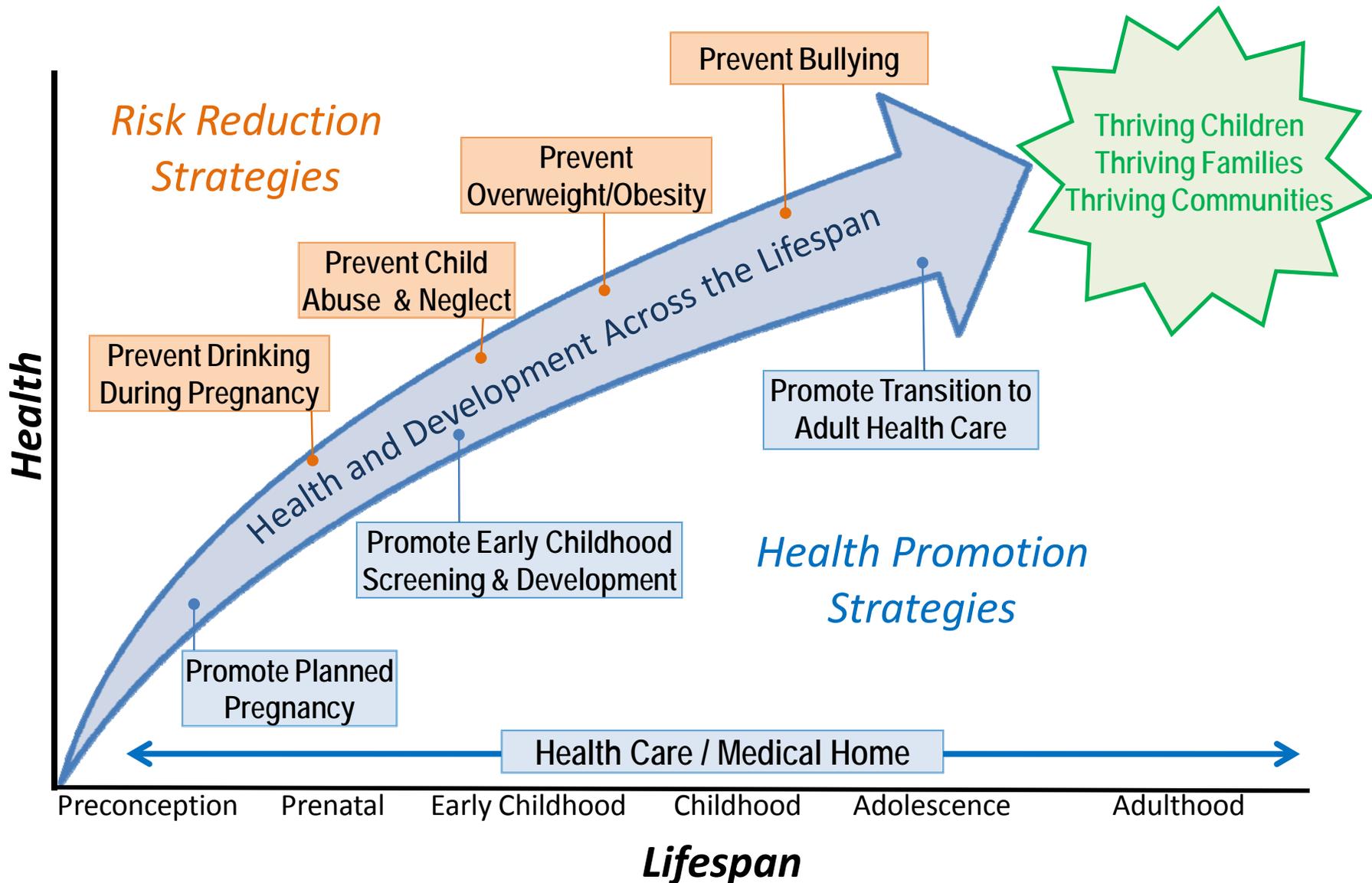


## Family Health Services Division Goals & State Priorities

- Pregnancy/conception shall occur by choice and under circumstance of lowest risk.** (State Priority: Prevention of Unintended Pregnancy)
- Every woman will utilize appropriate services and engage in health behaviors to optimize health outcomes.** (State Priority: Prevent Alcohol Use During Pregnancy)
- All families will have a safe and nurturing environment, free of violence and will engage in behaviors to promote optimum health.** (State Priority: Prevention of Child Abuse & Neglect; Prevention of Bullying)
- All infants, children and adolescents, including those with special health care needs, will receive appropriate services to optimize health, growth and development.** (State Priority: Promotion of Early Child Developmental Screening; Childhood Obesity Prevention)
- Access to quality health care shall be assured through the development of a comprehensive, coordinated community-based, patient/family-centered, culturally competent system of care.** (State Priority: Children Special Health Needs Transition to Adulthood)
- FHSD will have the necessary infrastructure to support the implementation of core public health functions.** (Commitment to staff training).



# Hawai'i State Title V Priorities to Strengthen Lifelong Health



# 2008 Perinatal Summit Needs Assessment Survey Results

Presented by  
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Division of Reproductive Health, Centers for Disease Control & Prevention  
Family Health Services Division  
Needs Assessment Training  
January 14/15 2009  
Honolulu, Hawai'i

**2008 PERINATAL SUMMIT NEEDS ASSESSMENT SURVEY**

Thank you for participating in this brief survey to identify the priority health needs affecting perinatal and women's health in Hawai'i.

**What are the three most important health issues in Perinatal and Women's Health for Hawai'i? (CHECK THREE)**

<input type="checkbox"/> Unintended Pregnancy	<input type="checkbox"/> Oral Health
<input type="checkbox"/> Teen Pregnancy	<input type="checkbox"/> Breastfeeding
<input type="checkbox"/> Alcohol Substance Use	<input type="checkbox"/> Intimate Partner Violence
<input type="checkbox"/> Tobacco Substance Use	<input type="checkbox"/> Access to Care
<input type="checkbox"/> Illegal Substance Use	<input type="checkbox"/> Depression/Post-Traumatic Stress Disorder
<input type="checkbox"/> Infant Sleep Position	<input type="checkbox"/> Low Birth Weight/Prematurity
<input type="checkbox"/> Infant Health Care	<input type="checkbox"/> Chronic Disease (Specify) _____
<input type="checkbox"/> Other: _____	

**What is the reason you selected the three issues above?**

<input type="checkbox"/> Unintended Pregnancy	<input type="checkbox"/> Oral Health
<input type="checkbox"/> Teen Pregnancy	<input type="checkbox"/> Breastfeeding
<input type="checkbox"/> Alcohol Substance Use	<input type="checkbox"/> Intimate Partner Violence
<input type="checkbox"/> Tobacco Substance Use	<input type="checkbox"/> Access to Care
<input type="checkbox"/> Illegal Substance Use	<input type="checkbox"/> Depression/PTSD
<input type="checkbox"/> Infant Sleep Position	<input type="checkbox"/> LBW/Prematurity
<input type="checkbox"/> Infant Health Care	<input type="checkbox"/> Chronic Disease (Specify) _____
<input type="checkbox"/> Other: _____	

**Describe what would be the most effective ways for addressing the three issues you selected (Feel free to use back of survey)**

<input type="checkbox"/> Unintended Pregnancy	<input type="checkbox"/> Oral Health
<input type="checkbox"/> Teen Pregnancy	<input type="checkbox"/> Breastfeeding
<input type="checkbox"/> Alcohol Substance Use	<input type="checkbox"/> Intimate Partner Violence
<input type="checkbox"/> Tobacco Substance Use	<input type="checkbox"/> Access to Care
<input type="checkbox"/> Illegal Substance Use	<input type="checkbox"/> Depression/PTSD
<input type="checkbox"/> Infant Sleep Position	<input type="checkbox"/> LBW/Prematurity
<input type="checkbox"/> Infant Health Care	<input type="checkbox"/> Chronic Disease (Specify) _____
<input type="checkbox"/> Other: _____	

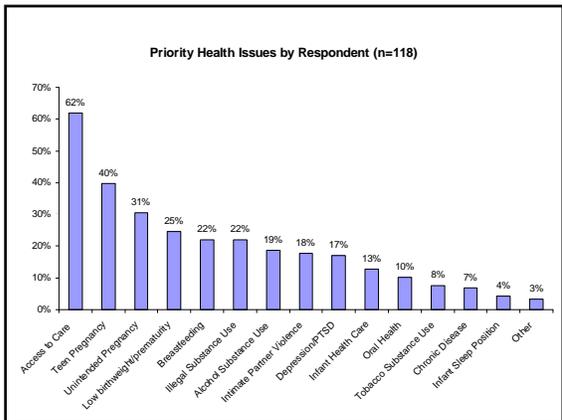
From: (Department of Health)

**2008 PERINATAL SUMMIT NEEDS ASSESSMENT SURVEY**

Thank you for participating in this brief survey to identify the priority health needs affecting perinatal and women's health in Hawai'i.

**What are the three most important health issues in Perinatal and Women's Health for Hawai'i? (CHECK THREE)**

<input type="checkbox"/> Unintended Pregnancy	<input type="checkbox"/> Oral Health
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<input type="checkbox"/> Alcohol Substance Use	<input type="checkbox"/> Intimate Partner Violence
<input type="checkbox"/> Tobacco Substance Use	<input type="checkbox"/> Access to Care
<input type="checkbox"/> Illegal Substance Use	<input type="checkbox"/> Depression/Post-Traumatic Stress Disorder
<input type="checkbox"/> Infant Sleep Position	<input type="checkbox"/> Low Birth Weight/Prematurity
<input type="checkbox"/> Infant Health Care	<input type="checkbox"/> Chronic Disease (Specify) _____
<input type="checkbox"/> Other: _____	



- ## Leading Health Issues
- Access to Care
  - Teen Pregnancy
  - Unintended Pregnancy
  - Low birthweight/prematurity
  - Breastfeeding
  - Alcohol and Drug use
  - Intimate Partner Violence
  - Depression/PTSD

**Describe what would be the most effective ways for addressing the three issues you selected (Feel free to use back of survey)**

<input type="checkbox"/> Unintended Pregnancy	<input type="checkbox"/> Oral Health
<input type="checkbox"/> Teen Pregnancy	<input type="checkbox"/> Breastfeeding
<input type="checkbox"/> Alcohol Substance Use	<input type="checkbox"/> Intimate Partner Violence
<input type="checkbox"/> Tobacco Substance Use	<input type="checkbox"/> Access to Care
<input type="checkbox"/> Illegal Substance Use	<input type="checkbox"/> Depression/PTSD
<input type="checkbox"/> Infant Sleep Position	<input type="checkbox"/> LBW/Prematurity
<input type="checkbox"/> Infant Health Care	<input type="checkbox"/> Chronic Disease (Specify) _____
<input type="checkbox"/> Other: _____	

Issue	Grouped Reasons	How to Address
Access to Care	<ul style="list-style-type: none"> <li>• Policies that restrict providers</li> <li>• Restricted Access to Rural Areas</li> <li>• Not enough Doctors</li> <li>• Lack of Medical Care</li> <li>• Shortage of OB's</li> </ul>	<ul style="list-style-type: none"> <li>• Increase # of providers</li> <li>• Tort Reform</li> <li>• Increase midwives</li> </ul>
Teen pregnancy	<ul style="list-style-type: none"> <li>• Lack of maturity</li> <li>• Lack of education</li> <li>• Socio economic risks</li> </ul>	<ul style="list-style-type: none"> <li>• Teach at an earlier age</li> <li>• Prevention education</li> <li>• More emphasis in middle school</li> </ul>
Unintended pregnancy	<ul style="list-style-type: none"> <li>• Social disintegration</li> <li>• No protection</li> <li>• No prenatal care</li> </ul>	<ul style="list-style-type: none"> <li>• More education on risk factors</li> <li>• Preventative brochures</li> <li>• Places to get condoms</li> <li>• More free family planning</li> </ul>
Low birth weight / Prematurity	<ul style="list-style-type: none"> <li>• Need more OB's</li> <li>• Lifelong costs/quality of life</li> <li>• Big problem in HI</li> </ul>	<ul style="list-style-type: none"> <li>• Group team approach to prenatal care delivery</li> <li>• Access to prenatal care</li> </ul>
Breastfeeding	<ul style="list-style-type: none"> <li>• Under-supported by medical staff</li> <li>• Leads to healthier children</li> </ul>	<ul style="list-style-type: none"> <li>• Education and training</li> <li>• Baby friendly institutions</li> </ul>

Issue	Grouped Reasons	How to Address
Illegal substance use	<ul style="list-style-type: none"> <li>• Harmful to fetus</li> <li>• Affects women and infants</li> </ul>	<ul style="list-style-type: none"> <li>• Increase education</li> <li>• More clinics</li> <li>• Use local resources</li> </ul>
Alcohol Substance use	<ul style="list-style-type: none"> <li>• Effects on fetus</li> <li>• Multiple negative consequences</li> </ul>	<ul style="list-style-type: none"> <li>• Change social norms</li> <li>• More education</li> </ul>
Intimate partner violence	<ul style="list-style-type: none"> <li>• Impacts women and baby</li> <li>• Too much of it</li> <li>• Need for better advocacy</li> </ul>	<ul style="list-style-type: none"> <li>• Education</li> <li>• Increase financial support for programs</li> <li>• Family counseling</li> </ul>
Depression/PTSD	<ul style="list-style-type: none"> <li>• Lack of healthy life style and coping</li> </ul>	<ul style="list-style-type: none"> <li>• Group support</li> <li>• Public awareness</li> </ul>
Infant health care	<ul style="list-style-type: none"> <li>• Many young moms don't know how</li> <li>• Prevention needs</li> </ul>	<ul style="list-style-type: none"> <li>• Social health programs</li> <li>• Education</li> </ul>
Oral Health	<ul style="list-style-type: none"> <li>• Lack of access to oral care</li> <li>• Need to remain on island not travel to Oahu</li> </ul>	<ul style="list-style-type: none"> <li>• Regular clinics</li> <li>• Better access to dental services</li> <li>• Interagency cooperation</li> </ul>
Tobacco substance use	<ul style="list-style-type: none"> <li>• Not enough programs for smoking cessation</li> </ul>	<ul style="list-style-type: none"> <li>• More programs</li> <li>• Adult counseling on risk factors</li> </ul>
Chronic Disease	<ul style="list-style-type: none"> <li>• Overweight/obese</li> <li>• Racial disparities</li> </ul>	<ul style="list-style-type: none"> <li>• Self education start young</li> <li>• Make priority for politicians</li> </ul>
Infant sleep position	<ul style="list-style-type: none"> <li>• Education</li> </ul>	<ul style="list-style-type: none"> <li>• Education</li> </ul>

### Summary of Solutions

- Education, promoting awareness, and primary prevention were the major solutions for the health issues identified
- Education targeting
  - Individuals
  - Community Leaders
  - Political and Societal level

- Acknowledgements
  - Loretta Fuddy, FHSD Chief
  - Annette Mente, FHSD Planner
  - Steven Wong, MCHB Research Statistician
  - Candice Calhoun, MCHB Section Chief

# **Children and Youth 2010 Needs Assessment Survey Results**

## **Introduction**

The Hawaii State Department of Health Family Health Services Division developed the Children and Youth Survey to identify priority health issues for children and youth in the State. The survey was conducted as part of a Needs Assessment required every five years by Title V (Maternal and Child Health Block Grant). Title V is funded by the Health Resources and Services Administration and is the key federal program for promoting and improving the health of women and children.

## **Methods**

The Department of Health staff commenced planning for the survey in the spring of 2009 which included survey design and identification of stakeholders to receive the survey. Twelve core issues were identified and formed the basis of the survey. Participants were asked to select three priority issues and to identify the reason(s) why the issue should be addressed. The survey also allowed participants to write in an issue that the survey did not address.

The surveys were distributed by a link to Survey Monkey, an online resource, with 439 stakeholders statewide that were initially identified to receive the survey. However, some of these surveys were forwarded to additional stakeholders through electronic dissemination on list serves and through other avenues so a true response rate could not be calculated. The number of people who responded to the survey was 240 for a return rate of approximately 55 percent based on the original 439 stakeholders identified which is likely an overestimate of the true response due to the electronic dissemination. The total number of possible selections totaled 720 (which is the number of people who responded multiplied by three).

## Results

Table 1 illustrates the total number of selections for each issue and is arranged in descending order.

<b>Issue</b>	<b>Response Count</b>	<b>Percentage</b>
Abuse & Neglect	171	<b>23.8%</b>
Access to Care	107	<b>14.9%</b>
Obesity	99	<b>13.8%</b>
Oral (Dental) Health	66	<b>9.2%</b>
Suicide	56	<b>7.8%</b>
Dating Violence	45	<b>6.3%</b>
Underage Drinking	43	<b>6.0%</b>
Other *	43	<b>5.9%</b>
Bullying/Cyberbullying	42	<b>5.8%</b>
Infant sleep related death	15	<b>2.1%</b>
Pedestrian Injuries	14	<b>1.9%</b>
Teen Driving	12	<b>1.7%</b>
Adolescent Chlamydia	7	<b>1.0%</b>

\*The top three issues mentioned in this category were teen pregnancy, drug abuse, and domestic violence.

Table 2 shows the reason(s) selected for each issue. The survey allowed participants to select up to six reasons why the issue should be considered a priority. The reasons for selecting the issues varied. This table does not include the reasons for other issues since this category covered a wide range of responses.

<b>Table 2. Reason(s) Selected for the Issue</b>						
<b>Issue</b>	Limited Healthcare Services	Life Threatening	Debilitating Consequences	Economic Consequences	Disparate Population	Need for Education/ Public Awareness
Abuse & Neglect	38	114	104	92	64	100
Access to Care	69	42	50	51	46	50
Obesity	32	54	64	44	38	59
Oral (Dental) Health	42	12	32	26	18	28
Suicide	13	42	29	15	19	38
Dating Violence	10	32	23	20	14	31
Underage Drinking	7	30	28	20	13	28
Bullying/ Cyberbullying	4	11	21	5	5	27
Infant Sleep Related Death	2	8	4	1	2	8
Pedestrian Injuries	n/a	11	10	5	2	11
Teen Driving	2	9	9	3	2	10
Adolescent Chlamydia	2	n/a	2	1	1	4

Figure 1 shows that the largest group of participants represented individuals or organizations who service the County of Maui. Maui County composes 11% of the State population and 31% of the respondents from the survey service Maui County. Similarly, Hawaii County composes nearly 14% of the population and 21% of the respondents service Hawaii County. Kauai County composes 5% of the population and 10% of the respondents service Kauai County. Although Honolulu County composes a little over 70% of the population, only 20% of the respondents service Honolulu County. It was noted that a large number of surveys in Maui County were forwarded to additional stakeholders via various public forums.

**Figure 1. Geographical Service Area**

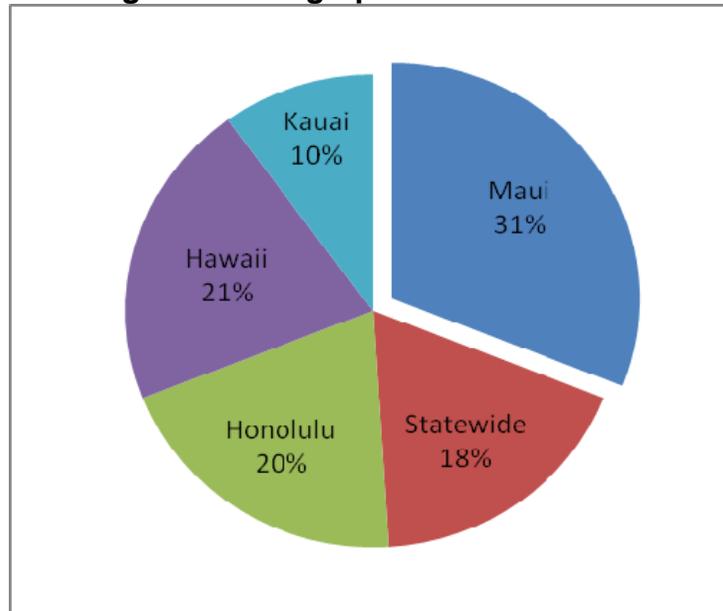
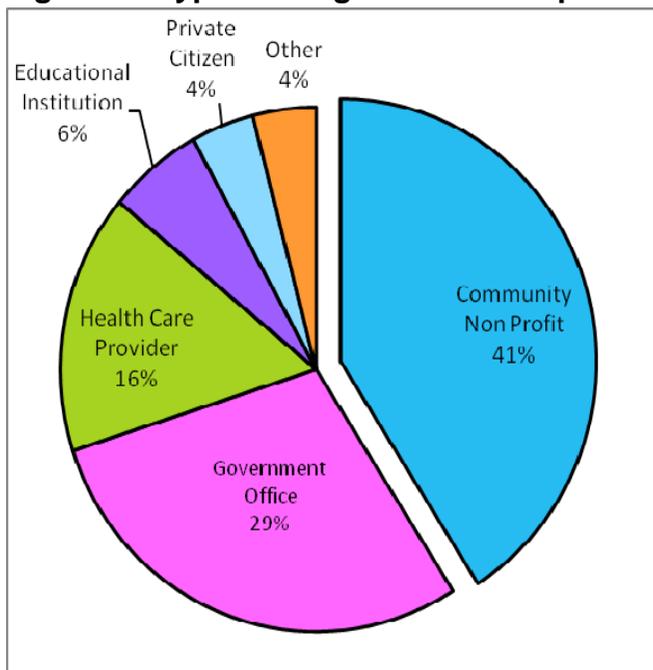


Figure 2 and Table 3 show that the participants in the survey represented a wide range of organizations and positions held within those organizations. 41% of the respondents represented community non-profit organizations, 29% represented State government, 16% represented health care providers, and 14% represented other organizations. Positions held within the organization ranged from management to service providers.

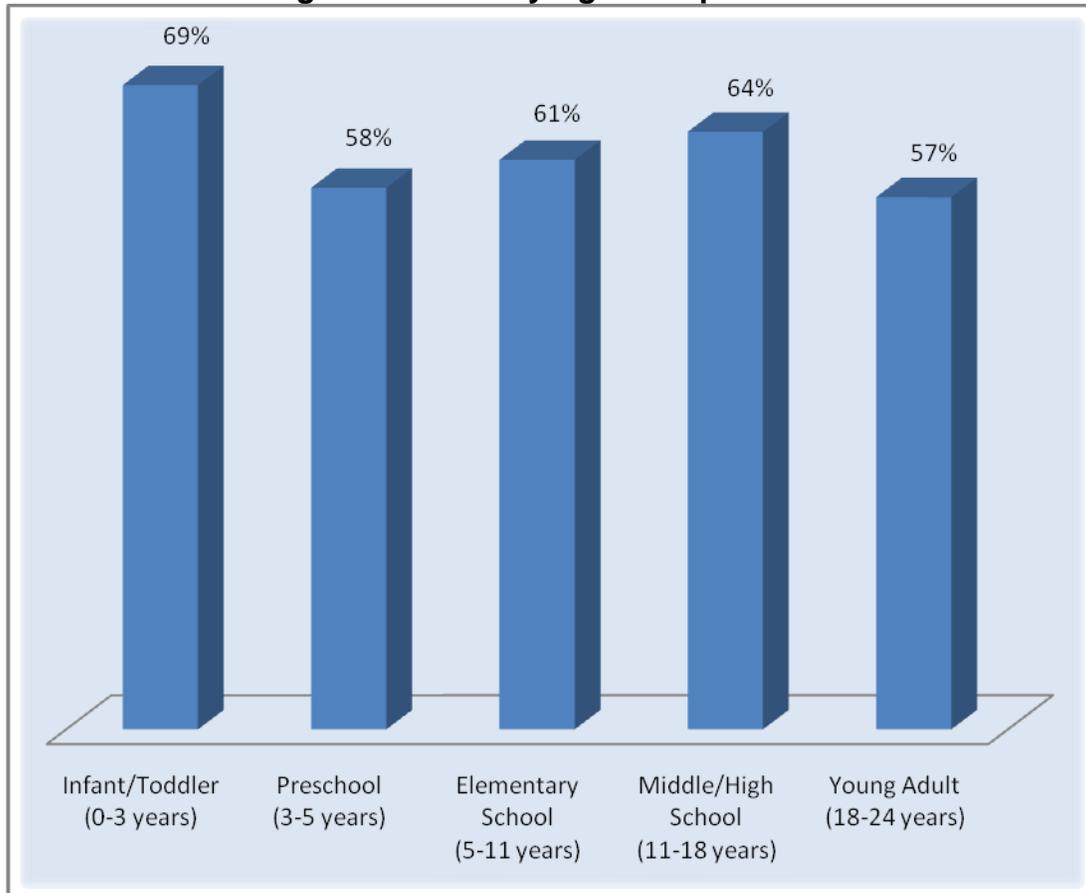
**Figure 2. Types of Organizations Represented**



<b>Table 3. Position Within Organization</b>	
<b>Position</b>	<b>Percentage</b>
Professional/Paraprofessional	23%
Management/Supervisory	19%
Other	17%
Health Care Provider	16%
Executive	9%
Administrative	9%
Health Educator	7%

Figure 3 shows that respondents were allowed to select more than one category for primary age group served. The respondents serviced all age groups and each age group was well represented.

**Figure 3. Primary Age Group Served**



### **Limitations**

The survey is not representative of the State and reflects the opinions of the stakeholders who completed the survey. We were also limited by the inability to conduct systematic follow up of those who did not return the survey due to the nature of dissemination.

### **Conclusion**

An on-line survey was done to assess the priority needs of children and youth in the community. The top three issues selected were abuse and neglect, access to care, and obesity. The participants represented a wide variety of organizations and positions within the organization. All the age groups served were well represented. Almost one-third of the participants serviced Maui County. These results were used in the identification of priority areas to promote and improve the health of children and youth in Hawaii.

## **Hawai'i Children with Special Health Care Needs Survey April 2009**

*Family Health Services Division  
Hawai'i State Department of Health*

The Hawai'i State Department of Health (DOH) /Family Health Services Division (FHSD) developed family and community-provider surveys to identify areas of biggest challenges/problems for children with special health care needs (CSHCN) in Hawai'i. This was part of the needs assessment required every five years by Title V (Maternal and Child Health Block Grant). Survey data will assist FHSD in identifying its priorities for federal fiscal years 2010-2015.

### **SURVEY DESCRIPTION**

*Purpose:* Identify areas of biggest challenges/problems for CSHCN in Hawai'i, related to unmet health care needs, health insurance coverage, access to care, screening and follow-up, family support, and transition for youth.

*Survey development:* Survey tools were developed by a CSHCN Workgroup, which included representatives of the DOH FHSD; DOH Children with Special Health Needs Branch (CSHNB); DOH District Health Offices of Hawai'i, Maui, and Kauai; and Hilopa'a Family to Family Health Information Center. Priority topics were discussed at FHSD meetings on November 14, 2008, and January 15, 2009, and at the CSHCN Workgroup meeting on February 5, 2009. Survey topics were then identified and clustered, with consideration for FHSD goals<sup>1</sup> and the six outcomes for CSHCN<sup>2</sup>.

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<sup>1</sup> Family Health Service Division goals include:

- Assure that systems are in place to address the full continuum of care throughout the life cycle from preconception to birth to adolescence to adulthood for Hawaii's population.
- Address the health and safety needs of vulnerable individuals, children and youth, with particular attention to children with special health needs.
- Assure that all infants, children, and adolescents, including those with special health care needs, will receive appropriate services to optimize health, growth, and development.
- Assure access to quality health care through the development of a comprehensive, coordinated, community-based, family centered, culturally competent system of care.

<sup>2</sup> As part of the national agenda for CSHCN, the MCH Bureau has established six core outcomes for CSHCN:

- Families of CSHCN partner in decision-making at all levels and are satisfied with the services they receive.
- CSHCN receive coordinated, ongoing, comprehensive care within a medical home.
- CSHCN have adequate private and/or public insurance to pay for the services they need.
- Children are screened early and continuously for special health care needs.
- Community-based service systems are organized so families can use them easily.
- Youth with special health care needs receive the services necessary to transition to adult life, including adult health care, work, and independence.

Surveys (*see Attachments 1 and 2*) were developed for families and for the community and providers (including advocates and health providers/professionals) on the same topics but with the language and focus appropriate for the group.

*Target group:* Families of CSHCN age 0-21 years and community-provider representatives involved in the system of services for CSHCN.

*Survey dates:* February 20 to April 3, 2009.

*Survey distribution:* Surveys were distributed by Workgroup members to:

Oahu: American Academy of Pediatrics-Hawai‘i Chapter meeting and conference, Children with Special Health Needs Program (CSHNP) families, Early Intervention Section (EIS) families, Fetal Alcohol Spectrum Disorder Task Force, Kapiolani Medical Center for Women and Children/Metabolic Clinic and Oral Cleft Clinic, Kardiac Kids, Hospital Newborn Hearing Screening Coordinators, Pediatric Gastrointestinal Clinic, Public Health Nurses, State Traumatic Brain Injury Advisory Board, Transition Fair-Kailua.

Hawai‘i: CSHNP families, EIS families.

Maui: Maui District Quality Assurance Team (MDQAT), IMUA, Maui Family Support Services (MFSS)-Early Head Start/Healthy Start/Enhanced Healthy Start, Maui Economic Opportunity (MEO)-Head Start, Maui Case Management and Information Services (CMIS)-DOH, CSHNP families, Nutrition Clinic-Maui.

Molokai: Molokai Community Health Center–Ikaika.

Lanai: Lanai Community Health Center.

Kauai: Home/office visits, Neurology Clinic, by mail to families and physicians, Early Intervention, Public Health Nurses, Community Services for the Developmentally Disabled, Family Health Services staff.

*Data analysis:* The CSHNB Research Statistician developed the database, entered survey data into the database, and analyzed survey data by group (family and community) and by island/county. The family group also included families that completed the Community-Provider Survey.

*Data limitation:* The extent to which the survey data represents all families of CSHCN or the community is not known. However, the survey distribution in various locations to different groups statewide indicates input from a broad group of stakeholders.

## SURVEY QUESTIONS

Surveys on the same topics were developed for families (Attachment 1) and for community and providers (Attachment 2). The questions by topics are shown in Table 1.

**Table 1: Survey Topics and Questions**

	TOPIC	QUESTIONS In Community-Provider Survey	QUESTIONS In Family Survey
	<b><i>Unmet health care needs</i></b>	<i>Unmet health care needs</i>	<i>Things I need for my child's health</i>
1	<b>Development-behavior</b>	Developmental-behavioral needs	Help with my child's growing and learning
2	<b>Social-emotional</b>	Social-emotional needs	Help with my child's feelings
3	<b>Lack of specialists/services</b>	Lack of specialists or services for some conditions	Special doctors who know about my child's needs
	<b><i>Health insurance</i></b>	<i>Health insurance coverage</i>	<i>Health insurance</i>
4	<b>Uninsured</b>	Lack of insurance	No insurance for my child
5	<b>Lack of adequate insurance (underinsured)</b>	Inadequate insurance	Insurance doesn't pay for everything my child needs
6	<b>Insurance payment</b>	Inadequate payment to providers	Paying out of pocket
	<b><i>Access to care</i></b>	<i>Access to care</i>	<i>Getting the care my child needs</i>
7	<b>Lack of pediatric specialists on Neighbor Islands</b>	Lack of pediatric specialists on Neighbor Islands	Not enough doctors on Neighbor Islands
8	<b>Cultural issues</b>	Cultural issues limiting care	Health workers don't know my culture
9	<b>Coordinated services</b>	Services are not coordinated	Help in getting my child's services to work together
	<b><i>Screening and follow-up</i></b>	<i>Screening and follow-up</i>	<i>Health checks</i>
10	<b>Newborn hearing screening</b>	Newborn hearing screening	Baby's hearing
11	<b>Development-behavioral screening</b>	Screening for development and behavior	How my child grows and behaves
12	<b>Autism screening</b>	Screening for autism	Checking for autism
	<b><i>Family support</i></b>	<i>Family support</i>	<i>Day-to-day living</i>
13	<b>Family to family support</b>	Lack of family to family support	Not enough family to help or talk to
14	<b>Family support services</b>	Lack of family support services	Not enough friends to help or talk to
15	<b>Family-professional partnership</b>	Families and professionals are not partners in the child's care	Not enough help from doctors, nurses, or other workers
	<b><i>Transition to adult life</i></b>	<i>Transition for youth</i>	<i>Growing older with special needs</i>
16	<b>Transition to adult health care</b>	Difficulty transitioning to adult health care	Helping my child find an adult doctor for his or her needs
17	<b>Transition to higher education</b>	Difficulty transitioning to higher education	Helping my child go from high school to college
18	<b>Transition to employment</b>	Difficulty transitioning to employment	Helping my child find and keep a job

# SURVEY FINDINGS

## Description of Respondents

There were 535 completed surveys. Table 2 shows the respondents by island and group.

**Table 2: Description of Survey Respondents**

Island	Number of Respondents By Group					Total
	Family	Advocate	Health provider/ professional	Other	Unknown	
Oahu	151	2	153	10	12	<b>328</b>
Hawaii	37	1	36	10	0	<b>84</b>
Maui	13	3	19	9	3	<b>47</b>
Molokai	2	-	1	0	0	<b>3</b>
Lanai	1	-	0	0	1	<b>2</b>
Kauai	38	-	24	0	0	<b>62</b>
Unknown	3	-	0	0	6	<b>9</b>
<b>Total</b>	<b>245</b>	<b>6</b>	<b>233</b>	<b>29</b>	<b>22</b>	<b>535</b>

## Summary of Survey Responses

Table 3 shows a summary of all survey responses on the topics of biggest concerns.

**Table 3. Summary of Survey Responses**

TOPIC	Responders identifying topic as one of their biggest concerns	
	# Responders (N=535)	Percent
<b><i>Unmet health care needs</i></b>		
Development-behavior	251	46.9%
Social-emotional	155	29.0%
Lack of specialists/services	293	54.8%
<b><i>Health insurance</i></b>		
Uninsured	61	11.4%
Lack of adequate insurance	181	33.8%
Insurance payment	151	28.2%
<b><i>Access to care</i></b>		
Lack of pediatric specialists on Neighbor Islands	187	35.0%
Cultural issues	86	16.1%
Coordinated services	132	24.7%
<b><i>Screening and follow-up</i></b>		
Newborn hearing screening	46	8.6%
Development-behavioral screening	183	34.2%
Autism screening	80	15.0%
<b><i>Family support</i></b>		
Family to family support	96	17.9%
Family support services	127	23.7%
Family-professional partnership	72	13.5%
<b><i>Transition to adult life</i></b>		
Transition to adult health care	137	25.6%
Transition to higher education	79	14.8%
Transition to employment	66	12.3%

## Survey Responses by Group

Table 4 shows survey responses by families and community-providers (including advocates and health providers/professionals).

**Table 4. Summary of Survey Responses by Group**

TOPIC	Percent of responders identifying topic as one of their biggest concerns		
	Families (N=245 )	Community-Providers <sup>3</sup> (N=290)	
<b><i>Unmet health care needs</i></b>			
Development-behavior	59.6%	36.2%	+
Social-emotional	26.9%	30.7%	
Lack of specialists/services	48.6%	60.0%	+
<b><i>Health insurance</i></b>			
Uninsured	2.0%	19.3%	+
Lack of adequate insurance	35.9%	32.1%	
Insurance payment	26.5%	29.7%	
<b><i>Access to care</i></b>			
Lack of pediatric specialists on Neighbor Islands	27.4%	41.4%	+
Cultural issues	2.9%	27.2%	+
Coordinated services	28.6%	21.4%	
<b><i>Screening and follow-up</i></b>			
Newborn hearing screening	14.3%	3.8%	+
Development-behavioral screening	45.7%	24.5%	+
Autism screening	11.8%	17.6%	
<b><i>Family support</i></b>			
Family to family support	18.0%	17.9%	
Family support services	14.7%	31.4%	+
Family-professional partnership	15.9%	11.4%	
<b><i>Transition to adult life</i></b>			
Transition to adult health care	24.1%	26.9%	
Transition to higher education	19.2%	11.0%	+
Transition to employment	8.6%	15.5%	++

+ Statistically different, P<0.01, between Families and Community-Providers.

++ Statistically different, P<0.05, between Families and Community-Providers.

<sup>3</sup> Includes Advocates, Health Providers/Professionals, Other, and Unknown groups.

## Survey Responses by Island

Table 5 shows survey responses for the islands of Oahu, Hawai‘i, Maui/Molokai/Lanai, and Kauai.

**Table 5. Summary of Survey Responses by Island**

TOPIC	Percent of responders identifying topic as one of their biggest concerns					
	Oahu (N=328)	Neighbor Islands (combined) <sup>4</sup> (N=198)	Hawai‘i (N=84)	Maui, Molokai, Lanai <sup>5</sup> (N=52)	Kauai (N=62)	
<b>Unmet health care needs</b>						
Development-behavior	50.3%	41.6%	31.0%	46.0%	53.2%	++
Social-emotional	30.5%	26.6%	25.0%	36.0%	30.0%	
Lack of specialists/services	54.9%	54.6%	65.5%	42.0%	51.6%	
<b>Health insurance</b>						
Uninsured	11.6%	11.1%	6.0%	14.0%	11.3%	
Lack of adequate insurance	32.9%	35.3%	35.7%	38.0%	29.0%	
Insurance payment	25.6%	32.4%	40.5%	18.0%	30.7%	
<b>Access to care</b>						
Lack of pediatric specialists on Neighbor Islands	16.8%	63.8%	76.2%	52.0%	61.3%	+
Cultural issues	15.6%	16.9%	28.6%	8.0%	9.7%	
Coordinated services	28.7%	18.4%	21.4%	12.0%	19.4%	+
<b>Screening and follow-up</b>						
Newborn hearing screening	8.2%	9.2%	8.3%	2.0%	16.1%	
Development-behavioral screening	34.5%	33.8%	32.1%	42.0%	30.7%	
Autism screening	17.7%	10.6%	10.7%	16.0%	6.5%	++
<b>Family support</b>						
Family to family support	17.7%	18.4%	16.7%	14.0%	25.8%	
Family support services	25.9%	20.3%	14.3%	30.0%	19.4%	
Family-professional partnership	11.9%	15.9%	21.4%	20.0%	6.5%	
<b>Transition to adult life</b>						
Transition to adult health care	26.2%	24.6%	29.8%	12.0%	30.7%	
Transition to higher education	13.4%	16.9%	11.9%	28.0%	12.9%	
Transition to employment	10.4%	15.5%	11.9%	30.0%	8.1%	

+ Statistically different, P<0.01, between Oahu and Neighbor Islands (*combined*).

++ Statistically different, P<0.05, between Oahu and Neighbor Islands (*combined*).

<sup>4</sup> The Neighbor Islands (*combined*) include all islands except Oahu.

<sup>5</sup> The number of responders for Molokai and Lanai were too small to provide responses as separate groups.

## Survey Comments<sup>6</sup>

### 1. Development-behavior

Oahu	Neighbor Islands
<p><b>Family:</b>            Kids who aren't severe get left behind and have to wait for services too long - cognitive delays.            Want to learn skills to help my child.            Need more qualified pediatric specialist to reduce waiting for important follow-up appointments.            Adolescence issues.            Helping her get along with other children.            Help him to expand his vocabulary. Getting him to perform at the same level of his peers.            Access to Head Start or similar. Getting enough service time. More social situations for child.            Pay attention/speaking.            Interactions with other children.            Child needs more focus on learning, during activities, and on public outings.            No speech.            I think my child has a speech delay.            Lack of self confidence</p>	<p><b>Family:</b>            Feeding.            Educational type learning problems.            Speech delay help.</p>
<p><b>Community-Provider:</b>            Cuts to PA (personal assistance) services have had negative impact.            More education for parents.            Patients age out of early intervention services, DOE does not pick up, so patient remains delayed.            Lack of therapy services esp. for 3-5 years.            Discipline techniques with 0-3.            Due to shortage of providers.            Sometimes wait-listed or delay for evaluation or services.            Need services for children and families.            Late referrals from pediatricians to EI.            Difficulty finding services for children 3-5 who have disabilities and do not qualify for DOE services.            Residential substance abuse for teens.</p>	<p><b>Community-Provider:</b>            Harsh parenting styles.            Parenting issues/skill to learn how to handle behaviors related to DD/MR.            Autism and ASD resources.            Behavioral issues could use additional services. These concerns are best handled before school starts.            Treatment for aggressive/violent children and teens.</p>

### 2. Social-emotional

Oahu	Neighbor Islands
<p><b>Family:</b>            My child is young and doesn't know how to explain her cleft to her friends at school.            How to control temper tantrums with 5 year old.            Need to discuss his feelings with 3rd party.            Talking with other kids with needs.            Be able to help my son tell or express his feelings or talking about this.            Trying to better understand her needs.</p>	<p><b>Family:</b>            Lack of understanding/implementation of preventive/proactive measures for caregivers.            Discipline techniques not working, starting to hit adults, needs behavior modification, but can't get help learning how to do that.            Hard to determine how a child should feel with a seizure disability. Would be nice to get more info.</p>

<sup>6</sup> Selected comments are listed, as applicable to the topic. Where comments are grouped, the topic is *italicized*. Comments that may identify the respondent were edited. Comments are color-coded as follows: **Red**→Family on Oahu, **Blue**→Family on Neighbor Island, **Green**→Community-Provider on Oahu, and **Purple**→Community Provider on Neighbor Island.

<p><b>Community-Provider:</b>  Behavior.  Need Psych and counseling services.  Due to deployments with military families. High stress in family.  Sometimes families feel professionals don't believe them or are only looking at deficits and not strengths.  Isolated families can't get to playgroups.  Bonding with a handicapped child. Chronic sorrow non-acceptance of condition affecting ability to follow through.  There is more focus on "remedies" than prevention.  Focus on our keiki, and we won't have to focus on prisons, remedial ed. Etc.  Socialization opportunities / groups for 0-3.</p>	<p><b>Community-Provider:</b>  More in home services beyond 0-3.  Especially for immigrants.  Lots of psychiatric issues  Therapist who specialize in kids, teenagers and parents of these children. Right now services in a school setting - child must demonstrate such great need.  More legal "teeth" re: families who do not support children's emotional, behavioral needs.</p>
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### 3. Lack of specialists/services

Oahu	Neighbor Islands
<p><b>Family:</b>  Psychological assistance for delay.  Cleft/craniofacial.  So few (GI) specialists available on Oahu.  Some specialists are not covered under Ohana but child's medical needs require services.  Not knowing about my son's condition and special needs.  It would be nice if all the doctors know more about autism.  Only two special doctors know his medical problems truly.  Specialists that accept QUEST insurance.  Not enough pediatric ENT. Hard to make an appointment.  Helping with finding a specialty doctor for my son.  Our previous (GI) specifically told me she was leaving for a position in California because she was on call 24/7.</p>	<p><b>Family:</b>  ~~ Syndrome.  My daughter still needs a diagnosis ... may be sent to another hospital in the mainland?  Challenging when there aren't enough specialist available to provide adequate support when child's situation gets out of control due to health decline.  For his ~~ syndrome.  It's really hard to find a pediatrician on the Big Island.  Not enough facilities for children in need of surgery on the islands, to help the families travel and other expenses.  Lack of understanding by insurance on difficulty arranging visits, transportation, and lodging.</p>
<p><b>Community-Provider:</b>  Infants/children with feeding concerns.  For care of TBI (traumatic brain injury).  Not available on Leeward coast.  Dentists skilled to work with handicapped children.  Many times they have to fly to Oahu to obtain specialty care.  <b>Need for physical therapy (6 comments)</b>  <b>Need for occupation therapy (5 comments) Includes need for sensory integration</b>  <b>Need for speech therapy (13 comments) Includes service for those who do not qualify for DOE services</b>  <b>Need for hearing specialists (3 comments)</b>  <b>Need for vision specialists (5 comments)</b>  <b>Need for intensive behavioral support (5 comments)</b></p>	<p><b>Community-Provider:</b>  Very few pediatric behavioral health specialists in the Big Island.  Not enough Psychiatrists, Neurologists, Neurosurgeons, Orthopedic, Dermatologists.  More clinic visits from Oahu specialists would help.  Limited access to nutrition services for birth to three.  Hearing specialist, Pediatric professionals: Physical Therapy, Occupational Therapist, speech therapist, vision.  Kona needs OT and Hearing specialist and speech therapist. (Signing teacher) for 0-3.  Pediatric neurology services delayed, poor follow-up, feeding clinics, hearing specialist, signing, speech, OT.  Outer islands, rural communities.  On the big island we have limited resources.  Only 1 endocrinologist in Hawai'i.  Lack of Speech Therapy services.</p>

<p><i>Includes service for children with autism or behavioral concerns</i></p> <p><b>Need for special instruction</b> (3 comments)</p> <p><b>Need for pediatric Specialists:</b>  Gastroenterologists.  Open heart surgeries.  Neurology  Cleft/Craniofacial</p> <p><b>Need for mental health services</b> (2 comments)  Includes services for youth and adolescents.</p> <p><b>Need for psychiatric/psychological services</b> (7 comments)</p>	<p>Genetics, Pediatric Gastroenterologist, Endocrinologist, neurologist.  Psychiatry.  Need Psychiatrists on the outer islands.  No place for uninsured to have a free/low cost physical for school requirement.  Cannot get kids into developmental team on Oahu - months delay.  Psychiatric.  Psychology for over 3 years.  Psychiatrists, Hematology/Oncology.  Related to inadequate insurance and no specialists on neighbor islands.  MMC needs more neonatal/pediatric equipment.</p>
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**4. Uninsured**

<b>Oahu</b>	<b>Neighbor Islands</b>
<p><b>Community-Provider:</b>  Many families in gap group and cannot access insurance.  Family applied for QUEST but have to wait a long time to be informed if they are approved.  Insurance companies limit funds. Don't want to pay for care.  Not everyone covered, could be parents not doing all the paperwork, or could be eligibility requirements.</p>	<p><b>Community-Provider:</b>  Makes it hard for families to access care and hard for caregivers to provide it. We're losing professionals instead of gaining them.  To get an appointment, diagnosis, meds, etc.</p>

**5. Lack of adequate insurance**

<b>Oahu</b>	<b>Neighbor Islands</b>
<p><b>Family:</b>  Therapeutic equipments; Less expensive special need stroller versus ten thousand dollar wheelchair.  Insurance rather pay for expensive wheelchair.  Insurance very limited for speech, physical, and occupational therapy.  Cost is very high, travel expenses, gas etc.  We went through some trouble to get approval for one of her surgeries.  Insurance cuts and not covered prescriptions.  Special nutritional requirements are not covered by insurance.  Elecare/expensive formula.  Pays for most except deductibles.  If my child is born with a developmental delay, insurance won't cover specialists or equipment even though it will benefit my child.  For specialized equipment.  More financial support for children with special needs or agency.</p>	<p><b>Family:</b>  Dental.  Oxygen and supplies.  Rental cars because taxis don't have car seats.  Having trouble getting a car seat, he climbs out of his current booster seat.  Vision checks.  <b>Travel to Oahu:</b>  I could use extra help with traveling to another island to see my son's specialists.  Flights to Oahu</p>
<p><b>Community-Provider:</b>  High premiums, not qualify for Quest/Medicaid.  Insurance premiums are too high for many individuals/families.  Dental.  Insurance providers don't cover equipment costs, recommended therapies, etc.</p>	<p><b>Community-Provider:</b>  Health insurance denies, does not quickly approve specialists or PMD medications or recommendations.  No providers taking Quest.  Dental care.  Also related to providers not accepting</p>

<p>Services needed but does not meet medical criteria so cannot tap insurance. Costly for parents.  Insurance does not cover supplies for medical condition. Parents have private insurance and do not qualify for Medicaid.  Cumbersome process to obtain medications, specifically with ~- insurance company  Obesity evaluation.  No coverage for vision, hearing, autism screening, PPD testing  Reimbursement for paperwork/school PE sports forms, telephone calls. No reimbursement for vision/hearing screen for PEs.  Autism related.  Coverage for speech/language therapy  <b>Lack of or inadequate reimbursement for vaccines</b>  (3 comments)</p>	<p>insurance/clients due to low pay rate.</p>
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## 6. Insurance payment

Oahu	Neighbor Islands
<p><b>Family:</b>  On fixed income.  Linked to lack of available specialists.  Some meds has high copay even with insurance.  Becomes burdensome with all the appointment.  How much the surgeries will cost.  Lack of financial support.</p>	<p><b>Family:</b>  We pay a great deal for vitamins supplements, eye treatment. Etc.  Contributes to doctors not wanting to participate in Quest - too much paperwork, too little reimbursement.    <b>Travel to Oahu:</b>  Travel to Oahu  Only one parent is covered for travel (to Oahu).  Travel costs for care on Oahu.  High out of pocket costs.</p>
<p><b>Community-Provider:</b>  Copayment is too high even with insurance.  Discrepancies in coverage/payment.  Inadequate reimbursements to providers. Limit the numbers they'll see. Families trying to find a medical home within reasonable distance from their home.  Insurance companies won't cover much.  Pays very little and takes a long time to get paid  Some services done in our office are not compensated properly.  Lowest payment of any plans.  Especially Medicaid.  Families live on limited resources.  Many specialists, especially behavioral health.  Not good payment from Medicaid compared to other plans.  Better coverage to specialists/MDs from Medicaid.</p>	<p><b>Community-Provider:</b>  Providers stop offering service due to inadequate or lack of payment.  Our health care system is broken, care becomes costlier, continues decreased reimbursements to providers will decrease providers which in turn will increase work loads of remaining providers.  Which directly leads to inadequate amount of providers on the islands.  No providers on island.</p>

## 7. Lack of pediatric specialists on Neighbor Islands

Oahu	Neighbor Islands
	<p><b>Family:</b>            Is there a plastic surgeon that visits Hilo?            Cleft palate specialist.            Big Island needs more specialists.            Takes months to find a doctor willing to take your child – a waitlist for care?            Need local ENT.            Pediatric Endocrinologist for Kauai.            No Medicaid dentists on Maui.</p> <p><b>Travel to Oahu:</b>            Travel to Oahu can be stressful and difficult at times when child is sick.            Travel for 1 parent =personal \$.            Flying back and forth with him is kind of hard.</p>
<p><b>Community-Provider:</b>            Rural communities all islands.            Even on Oahu, there aren't enough developmental pediatricians, Geneticists, Pediatric Neurologists, Pediatric ENT (long wait to get appointment).            All rural areas on all islands.            Pediatric dentists are needed.            On Hawaii, Kauai.            No ENT takes new clients.</p>	<p><b>Community-Provider:</b>            No OT or good PT for children within 1 hour travel time.            Big issues in the Big Island.            Psychiatric care, dental care.            Families travel to Oahu for special services.            Pediatric neurologist.            Difficult for families to travel, get good follow-up.            Specialist comes from Oahu sometimes does not meet family time frame.            Families who have pediatrician at times cannot get an appointment - going to urgent care more.            Also pediatricians.            Need to travel to Oahu for care – takes too much time.            No Pediatrician to provide physicals to uninsured kids for school and sport access.            Need more quality subspecialty pediatric clinics.            Need child psychiatrists and psych nurse practitioner with Rx primer.            Psychiatrists.            There is no incentive for doctors, specialists or generalists to move to the outer islands.            The distance is far enough that need North Hawaii as well as Kona and Hilo based to be effective and realistic.            Children with Quest have only very limited dental options. Many need to go to Oahu.</p>

## 8. Cultural issues

Oahu	Neighbor Islands
<p><b>Community-Provider:</b>            Being unaware of services available.            Care is not provided in family language, cultural barriers/beliefs sometimes not addressed.            Korean speaking services needed.            Some issues that are observed in patient are thought to be normal in some cultures.            Many local people feel shame to get psychiatric help.            Challenges with pacific islander populations            Sometimes seems as though there's no follow through with strategies and lack of concern for some other</p>	<p><b>Community-Provider:</b>            Increased Marshallese/Micronesian population with language barriers.            Language barriers - need translators.            Need competent interpreters. At risk families may have some difficulty 'connecting' or trusting professionals, and may give professionals the impression they do not need help - but in reality they need it.            Translators needed.            Need language interpreters.</p>

<p>developmental and health concerns. Some people see surgery/hospital interventions as health care. They don't see what they do every day as that important. Multi-family homes, transportation, view on therapy/special needs.</p> <p><b>Micronesians:</b> Micronesian population Especially for Micronesian families. Lack of interpreters (i.e., Micronesians) Micronesian translators at no charge.</p>	<p>Lack of translators, multi ethnic providers. Education needed for COFA (Compact of Free Association)<sup>7</sup> population. COFA populations. Translated materials, translators. Caregivers not culturally competent. Translators for "relevant" languages in neediest populations. Increasing Marshallese population – sometimes have cultural or language barriers.</p>
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## 9. Coordinated services

Oahu	Neighbor Islands
<p><b>Family:</b> Knowing about services Would like pediatrician to be more involved or at least refer us to other resources. Would appreciate test results as soon as possible and answers or possible answers to child's health concerns. Between EI, Medicaid, and CWS It would be good if my child's specialists would get together to review their observations and come to a consensus on a diagnosis. Left hand doesn't know what right hand is doing.</p>	<p><b>Family:</b> On Island resource was very helpful to have. It's harder to deal with needs without the on island contact.</p>
<p><b>Community-Provider:</b> DOH/DOE Lack of care coordination. Sometimes families are unaware of services. Physician coordination needs to be better Often difficult to get updated info from other providers. Sometimes communication breaks down. Past problems in accessibility and support between professionals providing health care. Patients fail to make specialist appointments. No coordinators other than the general pediatrician.</p> <p><b>Related to early intervention:</b> Services between agencies (Hospitals/clinics/early intervention programs) not coordinated. Too many therapists seeing child especially with intensive behavior support services. Contracted fee-for-service providers (5 comments)</p>	<p><b>Community-Provider:</b> Hard to coordinate between agencies. No continuity, follow-up for well care and immunizations scanty due to lack of providers, families lost to follow-up due to inability to find parents.</p>

## 10. Newborn hearing screening

Oahu	Neighbor Islands
<p><b>Community-Provider:</b> Missed screens for inpatient. Follow-up concerns, identifying missed babies and early intervention services before aged out. A baby with hearing loss is difficult to swallow. In the past I have had a family not come back.</p>	<p><b>Community-Provider:</b> Follow-up hearing screening not available in a timely period.</p>

<sup>7</sup> Republic of Palau (ROP), Federated States of Micronesia (FSM), and Republic of the Marshall Islands (RMI).

### 11. Developmental-behavioral screening

Oahu	Neighbor Islands
<p><b>Family:</b>            Teach or talk about everyday behaviors            My child is medically challenged and we need assistance to be sure he receives all needed therapy.            Social interaction.            Speech development.</p>	<p><b>Family:</b>            Is my son behaving his age?            Speech.            Help with development in school.            Can't find him the physical therapy he needs, he's 4 and can't run, legs turn out.</p>
<p><b>Community-Provider:</b>            Inadequate staffing.            Limited providers.            Sometimes behaviors overlooked or evaluators think child is too young to test.            Diagnosis made too quickly.            Catch them early, help them in the long run.</p>	<p><b>Community-Provider:</b>            Why screen if there is no good f/u available?            Doctors are not consistently picking up on these areas within their well baby checks.            Qualified trained professionals who have experience should be doing screening, and not just a 1-2 day workshop in training school.</p>

### 12. Autism screening

Oahu	Neighbor Islands
<p><b>Family:</b>            Child has too much energy to learn faster.            Autism communication resources.</p>	<p><b>Family:</b>            Autism runs in our family so I am concerned.</p>
<p><b>Community-Provider:</b>            Many families with concerns about lack of services/screening for autistic youth.            Autism - sometimes hard to test.            Not enough qualified screeners make for less than timely assessments.            The spectrum is so broad that it's difficult to really diagnose this condition early.            None available.            Diagnosis made too quickly for certain providers, disorders not taken into account.</p> <p><b>Follow-up services</b>            Primarily for follow-up services for children with spectrum disorders - need more qualified IBS (Intensive Behavior Support) providers who are skilled in working with an early intervention team and work collaboratively.            Appropriate in-school autism program.            With increased diagnosis, improvement needed in staffing, medical/psychologist.            Lack of services &amp; support for identified patients.</p>	<p><b>Community-Provider:</b>            DOE not meeting needs for kids with autism.</p>

### 13. Family to family support

Oahu	Neighbor Islands
<p><b>Family:</b>            Coordinated Family gatherings with other families with kids that have special needs.            More of group with other children helps a lot.</p>	
<p><b>Community-Provider:</b>            Family not willing/too busy etc. to help.</p>	<p><b>Community-Provider:</b>            Families seem to be relying on agencies for services -</p>

<p>Support groups for infants/children who may need g-tube placements</p> <p>How to get families to participate in group</p> <p>Without center-based services; families don't have a built-in support services. The group families have that support from each other.</p> <p>Home visits sort of isolate families.</p> <p>Confidentiality concerns.</p> <p>Problem solving emotionally and creatively with others who have similar problems.</p> <p>Limited EI parent networking</p> <p>Due to cultural differences, other family members do not support family training.</p> <p>Family support that is culturally appropriate and sensitive.</p>	<p>poor economy caregivers need to work to make ends meet.</p> <p>Both family/friends don't have time or understanding.</p>
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#### 14. Family support services

Oahu	Neighbor Islands
<p><b>Family:</b></p> <p>We don't usually talk to friends about health problems.</p> <p>Alone on this island.</p> <p>Desperate for respite!</p> <p>Helping child to find good friends to hang out with.</p> <p>Family dynamics.</p> <p>Support (emotional) for family with children with heart disease.</p> <p>Training my child to become an advocate for others with FASD.</p> <p>Neighbors/family understanding special needs of my children.</p> <p>Help with transportation needs for doctors appointments.</p> <p>Extra help for my boys besides school.</p> <p>Housing, bed wetting, self-esteem, be positive.</p>	<p><b>Family:</b></p> <p>Support group with similar families would be nice.</p> <p>Child care assistance when I work.</p> <p>Connecting with other families with similar needs/problems.</p> <p>When child gets medi-vac to Oahu there is limited support for off-island families that are highly stressed. When child is in ICU if you don't have family or income for lodging it can be even more stressful.</p> <p>After school care.</p> <p>Major safety issues at home, need custom 8'X4' tall childgate to keep him out of kitchen. Dangerous cleaning supplies, silverware/knives, not safe.</p>
<p><b>Community-Provider:</b></p> <p>Specifically for child with meningitis at birth.</p> <p>Family not willing/too busy/etc. does not see importance of going to Dr. or learning how to care or work with child.</p> <p>Cost of housing is very high for moderate income families.</p> <p><b>Family counseling/support:</b></p> <p>Family support - domestic violence.</p> <p>Family stressors triggering health conditions - unaddressed or under-addressed in our health care system.</p> <p>Stresses/divorce/counseling/economics.</p> <p>Counseling, mental health therapy.</p> <p><b>Parent training/education:</b></p> <p>Parenting classes for families.</p> <p>Parent services/training/support.</p> <p>Parent training.</p> <p>More group therapy perhaps? Parent training.</p> <p>Some families need lots of encouragement to work with child.</p> <p><b>Child care/early education:</b></p>	<p><b>Community-Provider:</b></p> <p>Education.</p> <p>Rural community services spread out.</p> <p>Healthy Start services budget cut.</p> <p>Families need to share equal responsibility for their children's needs. The state is not supposed to meet all their child's needs at public expense.</p> <p>Transportation to access services: medical/Therapeutic.</p> <p>Funding limited at this time, for support services.</p> <p>Obesity, diet and exercise program.</p>

<p>Affordable preschools for at-risk children          Inadequate preschools (other than DOE) and funding.          Lack of transitioning options (preschool).          Cost of child care is high if family does not qualify for child care assistance.          Decreased quality and affordable preschool options, concerns related to state funding cuts.</p> <p><b>Respite:</b>          Need more money for respite for families.          Respite for behaviorally challenged families and children.          Need respite/childcare for special education kids.          (Child care center) does not take kids who need extra support during holidays/weekends non-DOE time. Very hard on parents who work.</p>	
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### 15. Family-professional partnership

Oahu	Neighbor Islands
<p><b>Community:</b>          Families do not understand impact of child's delay in future success in life.          Especially as children start transitioning to DOE or if intensive behavioral support services are in place.          Cultural, language barriers.</p>	<p><b>Family:</b>          Our clinic seems too busy and always in a hurry.          Professionals are not always advocating for what's appropriate.</p>

### 16. Transition to adult health care

Oahu	Neighbor Islands
<p><b>Family:</b>          Access to clinics as an adult.</p>	<p><b>Family:</b>          Need to find orthodontic and orthopedic doctor.          2 years from now          Not enough physicians available that have expertise needed to entrust them with child's health and life          Transition out of DOE for medically fragile dependants.          Help child to take more active role in health issues.</p>
<p><b>Community-Provider:</b>          Primary challenge for us.          Limited services.          Not aware of any services.          Especially children with disabilities.          Lack of providers willing to take these children with special health care needs.          Some patients have a hard time leaving their pediatric home.  <b>Difficulty finding internist who are will to take youth</b>          (4 comments)</p>	<p><b>Community-Provider:</b>          No doctors to move on to after pediatricians.          Substance abuse, high risk sexual behavior.          Need medical transition homes on Kauai.</p>

### 17. Transition to higher education

Oahu	Neighbor Islands
<p><b>Family:</b>          Or trade school          My child's constant struggle academically, tutoring needed.          Transitioning from elementary to middle school.</p>	<p><b>Family:</b>          Help teaching or explaining to be more independent.</p>

<p><b>Community-Provider:</b> Families often struggle with the differences between Part C and 619 and beyond. We have known about their struggles but the system has not responded in an effective way.</p>	<p><b>Community-Provider:</b> We need a university in this side of the island. Community College courses limited. So many cannot afford to leave the island to continue higher education or they have to leave the island in order to get the education they want. Unavailability of employment.</p>
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**18. Transition to employment (or adult life)**

Oahu	Neighbor Islands
<p><b>Family:</b> Child demands to live alone at 18. Not capable - what to do? Being older parents who will care for our child if anything happens to us. Transition to working and living independently.</p>	<p><b>Family:</b> Adjustments to future as easy as possible.</p>
<p><b>Community-Provider:</b> He wants to work. Primary challenge for the patient. Difficulty transitioning to any service after 18 or 21. Need 'list' for parents on what issues need to be addressed with child (i.e., catching bus, contraception, money management, specific self-care issues, etc.). Transition services for middle youth years (13-16 years). DOE needs to be more standardized on their approach to working with persons and evaluating children during transition. Obtaining continued services once children exit our program.</p>	<p><b>Community-Provider:</b> Transportation. More technical training needed in the Big Island; skilled trades particularly and lack of vocational training schools. Life skills training is needed, healthy social outlets.</p>

**Other**

Oahu	Neighbor Islands
<p><b>Family:</b> Checking eyes. Concern over baby's progress in gaining weight.</p>	<p><b>Family:</b> Walking, work more with right hand/arm. Equipment so she can be mobile. More nursing care! ~~ syndrome update.</p>
<p><b>Community-Provider:</b> Emergency preparedness. TORT reform. RSV prophylaxis - no system of care. Arrange for a Grand Rounds explaining various health services and program. Drug/alcohol screening at ER. <b>Overweight/nutrition:</b> Overweight/Obesity Diet in the DOE schools Lack of physical activity in schools. Obesity, lifestyle in this culture.</p>	<p><b>Community-Provider:</b> Early childhood caries. No 'floating' therapists to cover when their regular one is ill or on leave. Lack of training. Some therapists aren't comfortable with trans discipline - to incentive or consequence for not practicing transdiscipline. No special shelters for families with medically fragile children during disasters, emergencies, etc.</p>

Possible Options for Combining Related Topics (Workgroup revision 4-20-09)

A – 18 Topics

	% Response*
Lack of specialists/services	54.8%
Development-behavior	46.9%
Lack of pediatric specialists – Neighbor Islands	35.0%
Development-behavioral screening	34.2%
Lack of adequate insurance	33.8%
Social-emotional	29.0%
Insurance payment	28.2%
Transition–adult health care	25.6%
Coordinated services	24.7%
Family support services	23.7%
Family to family support	17.9%
Cultural issues	16.1%
Autism screening	15.0%
Transition–higher education	14.8%
Family-professional partnership	13.5%
Transition–employment	12.3%
Uninsured	11.4%
Newborn hearing screening & follow-up	8.6%

B – 9 Topics

	% Response
<b>Access–health services</b>	
Lack–specialists/services	54.8%
Lack–ped. specialists-NI	35.0%
Coordinated services	24.7%
<b>Access–health insur.</b>	
Lack–adequate insurance	33.8%
Insurance payment	28.2%
Uninsured	11.4%
<b>Child development</b>	
Development-behavior	46.9%
Social-emotional	29.0%
<b>Developmental-behavior screening &amp; follow-up</b>	
Dev.-behavior screening	34.2%
Autism screening	15.0%
<b>Family support/education</b>	
Family support services	23.7%
Family to family support	17.9%
<b>Transition to adult life</b>	
Transition–adult health	25.6%
Transition–higher educatn	14.8%
Transition–employment	12.3%
<b>Newborn hearing scr/FU</b>	8.6%
<b>Cultural issues</b>	16.1%
<b>Family-prof. partnership</b>	13.5%

C – 5 Topics

	% Response
<b>Access–health services</b> <i>Includes payment/funding</i>	
Lack–specialists/services	54.8%
Lack–ped. specialists-NI	35.0%
Coordinated services	24.7%
<i>Lack–adequate insurance</i>	33.8%
<i>Insurance payment</i>	28.2%
<i>Uninsured</i>	11.4%
<b>Child development</b> <i>Includes screening&amp;F/U</i>	
Development-behavior	46.9%
Social-emotional	29.0%
Dev.-behavior screening	34.2%
Autism screening	15.0%
<b>Family support/education</b>	
Family support services	23.7%
Family to family support	17.9%
<b>Transition to adult life</b>	
Transition–adult health	25.6%
Transition–higher educatn	14.8%
Transition–employment	12.3%
<b>Newborn hearing scr/FU</b>	8.6%
<i>Applies to all topics:</i>	
<b>Cultural issues</b>	16.1%
<b>Family-prof. partnership</b>	13.5%

D – 4 Topics

	% Response
<b>Access–health services</b> <i>Includes payment/funding</i>	
Lack–specialists/services	54.8%
Lack–ped. specialists-NI	35.0%
Coordinated services	24.7%
<i>Lack–adequate insurance</i>	33.8%
<i>Insurance payment</i>	28.2%
<i>Uninsured</i>	11.4%
<b>Child development</b> <i>Includes screening&amp;FU &amp; family support/education</i>	
Development-behavior	46.9%
Social-emotional	29.0%
Dev.-behavior screening	34.2%
Autism screening	15.0%
<i>Family support services</i>	23.7%
<i>Family to family support</i>	17.9%
<b>Transition to adult life</b>	
Transition–adult health	25.6%
Transition–higher educatn	14.8%
Transition–employment	12.3%
<b>Newborn hearing scr/FU</b>	8.6%
<i>Applies to all topics:</i>	
<b>Cultural issues</b>	16.1%
<b>Family-prof. partnership</b>	13.5%

E – 3 Topics

	% Response
<b>Access–health services</b> <i>Includes payment/funding</i>	
Lack–specialists/services	54.8%
Lack–ped. specialists-NI	35.0%
Coordinated services	24.7%
<i>Lack–adequate insurance</i>	33.8%
<i>Insurance payment</i>	28.2%
<i>Uninsured</i>	11.4%
<b>Child development</b> <i>Includes screening&amp;FU &amp; family support/education</i>	
Development-behavior	46.9%
Social-emotional	29.0%
Dev.-behavior screening	34.2%
Autism screening	15.0%
<i>Family support services</i>	23.7%
<i>Family to family support</i>	17.9%
<i>Newborn hearing scr/FU</i>	8.6%
<b>Transition to adult life</b>	
Transition–adult health	25.6%
Transition–higher educatn	14.8%
Transition–employment	12.3%
<i>Applies to all topics:</i>	
<b>Cultural issues</b>	16.1%
<b>Family-prof. partnership</b>	13.5%

\*CSHCN survey data on % responders who identified topic as one of their biggest concerns.

## Summary of Prioritization Criteria for Title V Needs Assessment<sup>1</sup>

### 1. Extent of the health issue within the target population

Incidence/prevalence

### 2. Urgency/Severity of the health issue within the target population

Death &/or hospitalization over a person's lifetime?

Physical (disability, communicability, other health problems) consequences?

Social-emotional/economic consequences?

Are trends increasing/worsening over time?

Are Hawaii rates higher than national rates?

### 3. Amenable to CHANGE in 5 years

Knowledge of intervention strategies & proven effectiveness

Evidence based strategies preferred

If strategy is not proven, then please indicate

### 4: Feasibility

- **Propriety**: Is the health issue one that falls within the Department of Health's overall mission?
- **Legality**: Does the Department of Health have authority under legislation or policy to implement an intervention/address the health issue?
- **Economics**: Does it make economic sense to address the health issue? Are there economic consequences if the health issue is not addressed?
- **Acceptability**: Is the intervention for the health issue acceptable to the state/legislature/community? Does the state/legislature/community identify the health issues identified as a problem?
- **Resources**: Are resources available or potentially available to address the problem (e.g., staffing, funding, data systems)?

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<sup>1</sup> The criteria are adapted from tools developed by:

- 1) the University of California, San Francisco Family Health Outcomes Project,
- 2) the Washington State MCH program in 2000 using G. Pickett & JJ Hanlon in *Public Health Administration and Practice, 9<sup>th</sup> Edition*, St. Louis,: CV Mosby Company, 1990 and
- 3) Centers for Disease Control, Guide for Establishing Public Health Priorities, modified from the CDC Case Study: Translating Science into Practice.

# Health Issue Workgroup Process

## Steps for Division Needs Assessment

Family Health Services Division

Revised April 12, 2010

1. Complete **Problem Map** for Title V report
  - ✓ *Purpose: to understand the nature of the problem using data and research findings*
  - ✓ *Identify the risk, contributory, causal factors related to the problem.*
  - ✓ *Incorporate data and research to identify evidence for factors. Develop a list of literature, websites, and information sources reviewed for the problem map.*
  - ✓ *If map gets too complex, pare down factors to those that are most important, feasible to change*
  - ✓ *keep list of references, working bibliography to support factors in the map*
  
2. Complete **Fact Sheet** on the health issue (due **April 30**)
  - ✓ *Purpose: to help educate and mobilize stakeholder participation*
  
3. Develop **1-2 page description of Resources** (due **May 15**)
  - ✓ *Purpose: Capture the major resources that can be utilized to identify feasible strategies to address the issue*
  - ✓ *Resources include programs, services, policies, funding, expertise, key stakeholders that can partner on strategies*
  - ✓ *Describe how/whether the state service system capacity has changed due to the economic downturn. Are there more resources available to address this health issue or less?*
  - ✓ *Compile a list of the 10 major programs, services, policy initiatives that affect your health issue. Provide a short description of each resource & describe how the resources have been affected by the economic downturn (loss of key programs, loss of staffing/funding, increased caseloads/needs)*
  - ✓ *Identify whether there are opportunities for new funding or new collaborations*
  - ✓ *May do "environmental scan", surveys, key informant interviews, other research to get updated information*
  
4. Identify at least 1 statewide **Measure** to monitor progress (**May 1st**)
  - ✓ *to be used to report on progress for the annual Title V block grant report*
  - ✓ *Consult Don Hayes if not sure about validity of measure/data*
  
5. Complete 1-2 page summary report that addresses how each of the activities/steps were completed (**May 24**)
  - ✓ *Identify what data was used, key findings from your literature review, environmental scans, surveys, key informant interviews that helped develop the problem map, fact sheet, resource list.*
  - ✓ *Identify how stakeholder input was used throughout the process*
  - ✓ *Evaluate strengths/weaknesses of the NA process (Were there limitations to the data? Was training/technical assistance (TA) helpful? Was it challenging to engage*

## Needs Assessment Steps (*continued*)

*stakeholders? Was stakeholder input used effectively? Did the process lead to staff development of public health expertise/skills building, improve collaboration, strengthen leadership capacity. Identify areas for improvement that may help to further work on your health issue. Identify any technical assistance/training needs)*

### 6. Select **1-3 feasible Actions/Strategies** & Develop Logic Model (due **August 20**)

- ✓ *Brainstorm strategies, seek input from stakeholders*
- ✓ *Work with stakeholders to select 1-3 strategies and plan implementation*
- ✓ *Consider evidence-based or recommended practices*
- ✓ *Determine if any best or promising practices exist in Hawai'i*
- ✓ *Briefly describe what information was used to identify the strategies & how stakeholder input/participation was used to select strategies (no more than 1 page)*
- ✓ *Logic model will help show how and what is needed to implement each strategy*

### 7. Develop **PowerPoint Presentation** on the health issue (for **September 8<sup>th</sup>** Division meeting)

- ✓ *Purpose: to help educate and mobilize stakeholder participation & report on progress to date*

PROBLEM MAP			
Overweight and Obesity in Children ages 0 to 5 years			
	Dietary Factors	Physical Activity Factors	Social, Environmental & Health Factors
<b>Tertiary</b> (Societal, Policy, Programs, Systems)	<ul style="list-style-type: none"> <li>• Poor State Economy (increase in poverty and unemployment) and budget cuts led to elimination of programs.</li> <li>• Need more funding for prevention of childhood obesity programs.</li> <li>• Health insurance does not reimburse for obesity prevention or treatment</li> <li>• Food industry continues to market unhealthy foods to children and does not promote prevention of obesity.</li> <li>• Department of Education Wellness Policy not implemented consistently. No Early Childhood Wellness Policy.</li> <li>• Lack of collaboration on obesity prevention (public health agencies, schools and community organizations)</li> <li>• Need workplace wellness policies to target parents to make healthier choices for themselves and their children.</li> </ul>		
<b>Secondary</b> (Community)	<ul style="list-style-type: none"> <li>• Nutritious food is costly</li> <li>• Lack of access to healthy food</li> <li>• Abundance of fast food restaurants</li> <li>• Fast food can be inexpensive and convenient</li> <li>• Food Insecurity</li> </ul>	<ul style="list-style-type: none"> <li>• Early childhood programs need to promote physical activity for young children.</li> <li>• Need more community programs promoting young children's physical activity.</li> </ul>	<ul style="list-style-type: none"> <li>• Parental under education (&lt; HS)*</li> <li>• Lack of interaction during shared family mealtimes **</li> <li>• Lack of affordable housing*</li> <li>• Limited public transportation</li> <li>• Unsafe parks and neighborhoods*</li> <li>• Proximity of fast food restaurants.</li> </ul>
<b>Primary</b> (Direct: Child, Family, Provider)	<p><u>Child Factors</u></p> <ul style="list-style-type: none"> <li>• Drinking sweetened beverages</li> <li>• Eating Fast food/Junk food</li> <li>• Skipping breakfast</li> <li>• Eating out of boredom or stress</li> <li>• (Over) Eating in front of the TV</li> <li>• Food Insecurity</li> </ul> <p><u>Parental Factors</u></p> <ul style="list-style-type: none"> <li>• Parents have poor food choices</li> <li>• Parents lack nutrition knowledge*</li> <li>• Mothers not breast feeding</li> <li>• No shared family mealtimes.</li> </ul>	<ul style="list-style-type: none"> <li>• Little physical activity by choice or due to disability</li> <li>• Excess (greater than 2 hours a day) of screen time i.e. TV, computer, video games</li> <li>• Lack of physical activity (recommended 60 minutes a day)</li> <li>• Parents lack knowledge about child's need for physical activity.</li> <li>• Parents don't have time for physical activity with children.</li> </ul>	<ul style="list-style-type: none"> <li>• Health Care providers not aware of or don't follow best practices for prevention and treatment of obesity</li> <li>• Cultural perception of healthy weight and physical activity for infants &amp; children</li> <li>• Lack of accepted wellness guidelines for early childhood programs.</li> <li>• Excess calories and portion sizes</li> <li>• Lack of dietary recommendations for fruits and vegetables and whole grains.</li> </ul>
* direct and indirect causes of stress and health disparities			
(Food Insecurity for a family means limited or uncertain availability of nutritionally adequate and safe foods, or uncertain ability to acquire appropriate foods in socially acceptable ways. Food insecurity forces people to buy and consume less-expensive foods, which are often less nutrient dense but more calorically dense and higher in fat than more expensive foods. In contrast, food secure families have access to sufficient food for a healthy lifestyle at all times.)			

### Transition Planning for Youth with Special Health Needs (YSHN) From Pediatric to Adult Healthcare

Problem Map: Key Factors, Behavioral and Social Determinants that Contribute or are Associated with the Issue

Transition planning is the purposeful & deliberate movement from a pediatric to adult health care provider as the individual moves from adolescence to adulthood. Careful transition planning assures developmentally appropriate health care services continue uninterrupted. YSHCN can face significant challenges finding an adult healthcare provider that is able to manage severe medical conditions or disabilities that originate in childhood.

	FAMILY FACTORS	YOUTH FACTORS	HEALTH SERVICE FACTORS
<b>TERTIARY</b> Policy & system contextual influences	<ul style="list-style-type: none"> <li>-Poor State economy leading to increased unemployment &amp; budget cuts to healthcare services</li> <li>-National healthcare reform-impact is unknown at this time</li> <li>-<b>Eligibility &amp; access barriers to enroll into Med-QUEST</b></li> <li>-Medicaid's delay in payment to providers due to budget shortfall</li> </ul>	<ul style="list-style-type: none"> <li>-Fragmentation of adult health care system*</li> <li>-National consensus statement on health care transitions for young adults with special health care needs by the American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine*. Endorsed by the Society of Adolescent medicine*</li> </ul>	
<b>SECONDARY</b> Community, institutional settings, settings where there is interaction	<ul style="list-style-type: none"> <li>-Inadequate transportation services for YSHCN to access healthcare especially on the neighbor islands/rural areas</li> <li>-Lack of education/materials on transition planning for families in English and other languages</li> <li>-Loss of Insurance coverage as the child becomes an adult*</li> <li>-Loss of health insurance due to unemployment or under employment</li> <li>-Difficulty finding &amp; accessing support services for transition planning*</li> </ul>	<ul style="list-style-type: none"> <li>-Youth "age out" of their case management services at age 19-21*</li> <li>-Difficulty finding &amp; accessing support services for transition planning*</li> </ul>	<ul style="list-style-type: none"> <li>-Less community services (SW, Case Managers, etc) to assist with transition planning for young adults*</li> <li>-Inadequate transportation services to access health care services, especially on the neighbor islands/rural areas</li> <li>-Lack of adult primary and specialty providers, (especially on Neighbor Islands)</li> <li>-Fragmentation of primary and specialty care*</li> <li>-No clear model/recommendations for health care transition for YSHCN*</li> <li>-Lack of trainings (materials/resources)for transition planning for health care providers*</li> <li>-Lack of medical reimbursement for transition planning*</li> <li>-Poor reimbursement for chronic illness care*</li> <li>-Limited adult providers w/knowledge and experience of childhood-onset conditions*</li> <li>-Lack of facilitators to coordinate healthcare transition*</li> </ul>
<b>DIRECT</b> Individual behaviors relationships to others	<ul style="list-style-type: none"> <li>-Income below poverty level*</li> <li>-Lack of family support system</li> <li>-Lack of knowledge/education on transition planning*</li> <li>-New immigrants*</li> <li>-Non-English speaking household*</li> <li>-Inadequate transportation</li> <li>-Live on neighbor islands or in rural areas w/limited access to specialized care</li> <li>-Desire to stay w/pediatric providers*</li> <li>-Lack of motivation to plan for transition*</li> <li>-Cultural barriers*</li> <li>-Lack of knowledge about health insurance coverage</li> <li>-Multiple stresses related to many transitions occurring during this time*</li> <li>-Importance of family' role not acknowledged by</li> </ul>	<ul style="list-style-type: none"> <li>-Affects children 14-21 years of age</li> <li>-Males more are less likely to receive planning*</li> <li>-YSHN with severe medical conditions or disabilities*</li> <li>- Uninsured or underinsured*</li> <li>-Limited employment opportunities that offer health insurance</li> <li>-Lack of awareness, motivation to plan for transition*</li> <li>-Lack of self-confidence, self-advocacy skills*</li> <li>-Desire to stay w/pediatric provider*</li> <li>-Lack of knowledge /understanding of their underlying medical condition</li> <li>-No medical home*</li> <li>-May not visit primary care doctor regularly to do transition planning (may see specialists more often)</li> <li>-Maturity level, developmental functioning still emerging</li> <li>-Multiple stresses related to many transitions occurring during</li> </ul>	<ul style="list-style-type: none"> <li>-Difficulty identifying primary care providers willing to take YSHN*</li> <li>-Lack of provider knowledge of transition planning*</li> <li>-Lack of time and reimbursement for planning*</li> <li>-Adult care providers hesitant to take YSHN w/end of life issues in young patients*</li> <li>-Lack of knowledge/connections to community resources*</li> <li>-Resistance from family/youth*</li> <li>-Hesitancy of pediatricians to transition youth to adult health care system*</li> </ul>

**Bullying Problem Map: Key Factors, Behavioral and Social Determinants  
What Makes Them Do What They Do?**

**Bullying**

One's need for power and (negative) dominance; finds satisfaction in causing injury and suffering to others; are often rewarded in some way for their behavior with material or psychological rewards.  
Four components of bullying: duration, frequency, intensity, and power imbalance.

	<b>BULLY</b> A bully has needs for power and (negative) dominance; finds satisfaction in causing injury and suffering to other students; are often rewarded in some way for their behavior with material or psychological rewards.	<b>BULLIED</b> A person is bullied when he or she is exposed, repeatedly and over time, to negative actions on the part of one or more other persons, and he or she has difficulty defending himself or herself.	<b>BYSTANDER</b> The bystander is a peer, sibling or adult who doesn't act to defuse the situation.
<b>Policy and system contextual influences</b>	<ul style="list-style-type: none"> <li>➤ Social Norms</li> <li>➤ Colonial history</li> <li>➤ Technology</li> <li>➤ Economy</li> </ul>	<ul style="list-style-type: none"> <li>➤ International Relations</li> <li>➤ Popular, Historical, Traditional Culture</li> <li>➤ Majority/minority issues</li> <li>➤ Racism</li> </ul>	
<b>Community, institutional settings, settings where there is interaction</b>	<ul style="list-style-type: none"> <li>❖ Policies and procedures</li> <li>❖ Policy environment does not deter harm</li> <li>❖ Institutional norms, rules, structure</li> <li>❖ Unable to get help from adults in setting</li> </ul>	<ul style="list-style-type: none"> <li>❖ Lack of or no security in setting</li> <li>❖ Inadequate supervision</li> <li>❖ Inappropriate adult intervention</li> <li>❖ Institutional prejudice</li> <li>❖ Community or widespread fear</li> </ul>	<ul style="list-style-type: none"> <li>❖ Policies to include technology</li> <li>❖ Safe reporting system</li> <li>❖ Social norms/tolerance</li> <li>❖ Culture that surrounds problem behavior</li> <li>❖ Awareness of problems</li> </ul>
<b>Individual relationships to others</b>	<ul style="list-style-type: none"> <li>• Family attitudes that reinforce power differentials</li> <li>• Family history of violence</li> <li>• Family dysfunction</li> <li>• Poor adult models</li> <li>• Ability to control and influence peers</li> <li>• Activities that promote aggressive behavior as positive</li> <li>• Lack positive connection with neighborhood environment</li> <li>• Exposure to drugs, gangs, criminal activities</li> <li>• Parental availability and supervision</li> <li>• Intolerance of differences, i.e. religious practices, morals, values, beliefs</li> <li>• Poor social behaviors</li> <li>• Individual character traits, i.e. lack of empathy, lack of respect</li> </ul>	<ul style="list-style-type: none"> <li>• Physically weaker</li> <li>• Few friends (socially isolated)</li> <li>• Non-conformist</li> <li>• Lack social skills</li> <li>• Distrust of others</li> <li>• Unable to communicate needs</li> <li>• Shy, sensitive, insecure, low self-esteem, easily intimidated</li> <li>• Feelings of depression, anxiety, helplessness, and hopelessness</li> <li>• Physical disability</li> <li>• Non-traditional lifestyle</li> <li>• Non-membership in dominant group(s)</li> <li>• No confidence in authority figures to provide long-term solutions</li> <li>• Perceived threat to bully</li> </ul>	<ul style="list-style-type: none"> <li>• Social influence</li> <li>• Mislabeled/misperception of aggression</li> <li>• Diffusion of responsibility</li> <li>• Social norms</li> <li>• Fear of retaliation</li> <li>• Lack of empathy for the bullied</li> <li>• Individual versus group responsibility and values (audience inhibition)</li> <li>• Complicit (state of being an accomplice)</li> </ul>

***We need to better identify children at risk for developmental delay to get them into services for their optimal development!***

**PROBLEM MAP**

**Identification of Children for Developmental Delay**

<p><b>Tertiary</b> (Societal, Policy, Programs, Systems)</p>	<ul style="list-style-type: none"> <li>• Poor State economy and budget cuts led to elimination of programs for children and families.</li> <li>• AAP policy needs to be re-enforced to ensure that pediatricians are using a standardized screening tool.</li> <li>• Early childhood practitioners need resources for screening to refer families if there is a concern for developmental delay.</li> <li>• Health care reform needs to advocate for the importance of screening and appropriate follow-up services.</li> <li>• There is no requirement for hearing or vision screening for school enrollment. Passage of laws requiring hearing and vision screening at school entry (similar to HRS §302A-1154, 1159, &amp; 1161).</li> </ul>		
	<p><b>Family Factors</b></p>	<p><b>Child Factors</b></p>	<p><b>Health Service Factors</b></p>
<p><b>Secondary</b> (Community)</p>	<ul style="list-style-type: none"> <li>• Lack of education to inform parents on developmental milestones and the need for periodic developmental screening.</li> <li>• Lack of resources for parents if they have questions about their child’s development.</li> <li>• Lack of resources to support parents to advocate for and express concerns about their child’s development with their primary care providers.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of quality early childhood programs for children to be observed by practitioners able to recognize possible delay.</li> <li>• Lack of a program in the child’s community that provides routine screening.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of community resources for providers to refer parents for concerns about children’s developmental delay.</li> <li>• Lack of assurance measures for completion of screening for EPSDT compliance.</li> <li>• Lack of community safety net services to refer families to.</li> </ul>
<p><b>Primary</b> (Direct: Parent/Family, Child, Provider)</p>	<p><i>Families have an important role in ensuring that their children receive screening and follow-up. Parents may not have an awareness of the need for developmental screening. Parents may not be aware of resources for developmental screening.</i></p> <p>Other factors affecting parents are:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Household income &amp; Employment</li> <li><input type="checkbox"/> Education</li> <li><input type="checkbox"/> Family Structure</li> <li><input type="checkbox"/> Race/ethnicity</li> <li><input type="checkbox"/> Cultural beliefs</li> <li><input type="checkbox"/> Health Literacy &amp; Language</li> <li><input type="checkbox"/> Transportation</li> </ul>	<p><i>Children are dependent on their parents and caregivers to provide them with access to screening, services, and care if they are at risk for developmental delay.</i></p> <p>Some factors include</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Age, Sex</li> <li><input type="checkbox"/> Race/Ethnicity</li> <li><input type="checkbox"/> Health insurance</li> <li><input type="checkbox"/> Environmental Issues</li> <li><input type="checkbox"/> Type of delay (biological, developmental)</li> <li><input type="checkbox"/> Access to primary care or a medical home.</li> </ul>	<p><i>Health care providers can recognize, screen, and assess whether children are at risk for developmental delay.</i></p> <p>Some factors include:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Lack of a standardized developmental screening tool;</li> <li><input type="checkbox"/> Lack of time for providers to spend assessing a child’s development</li> <li><input type="checkbox"/> Barriers to screening by primary care providers: office staffing, time, training, cost of tools, and payment issues.</li> </ul>

## Prevention of Child Abuse and Neglect (Ages 0-5 years)

Problem Map: Key Factors, Behavioral and Social Determinants

**Children Abuse & Neglect: Activities that are targeted to the community at large and impacts families before something happens.**

	Family	Child	Institutional Caregivers & Providers
<b>Policy and system contextual influences</b>	<ul style="list-style-type: none"> <li>➤ Economy, increased rates of unemployment, lack of funding, dependence on outside caregivers because both parents work</li> <li>➤ Family friendly policies – e.g. health insurance, work/employer policies</li> <li>➤ Reporting laws</li> <li>➤ Social stigma</li> <li>➤ Domestic Violence policy re: TRO and CPS referrals</li> <li>➤ Lack of coordinated services</li> </ul>	<ul style="list-style-type: none"> <li>➤ Lack of political will</li> <li>➤ Lack of positive family role models and media images</li> <li>➤ Lack of quality, affordable care for young children</li> <li>➤ Cultural norms – belief that you do not ask/seek assistance</li> <li>➤ Exposure to violence in the home, community, media</li> <li>➤ We often take a problem identification and not a problem solving approach</li> <li>➤ Geographic isolation and challenges of an island State</li> </ul>	
<b>Community, institutional settings, settings where there is interaction</b>	<ul style="list-style-type: none"> <li>❖ Cultural values</li> <li>❖ Religious aspects</li> <li>❖ Unemployment</li> <li>❖ Lack of services for S.A.</li> <li>❖ Lack of education services</li> <li>❖ Availability of parenting support</li> <li>❖ Lack of availability/access to community based services: transportation, substance abuse tx, housing, food services</li> <li>❖ Lack of mental health services</li> </ul>	<ul style="list-style-type: none"> <li>❖ Pediatrician, school, neighbors, community – not reporting CAN, “looking the other way”</li> <li>❖ Lack of awareness, sense of responsibility, accountability</li> <li>❖ Lack of knowledge and awareness of CAN signs and symptoms</li> <li>❖ Exposure to violence</li> </ul>	<ul style="list-style-type: none"> <li>❖ Lack of training (reporting, signs/symptoms)</li> <li>❖ Lack of initiative to learn about services</li> <li>❖ Lack of resources</li> <li>❖ Lack of awareness of scope of resources</li> <li>❖ Lack of access to services</li> </ul>
<b>Individual relationships to others</b>	<ul style="list-style-type: none"> <li>• Social isolation</li> <li>• Lack of knowledge of child development and parenting</li> <li>• Stress: depression (PPD), socio economic disadvantage, unemployment</li> <li>• Substance abuse.</li> <li>• Domestic violence</li> <li>• Mental Illness</li> <li>• Caregiver hx of abuse</li> <li>• Age – young/teen parent</li> <li>• Family &amp; cultural values/practices</li> <li>• Ambivalent feelings about being a parent</li> <li>• Lack of financial resources</li> </ul>	<ul style="list-style-type: none"> <li>• Age</li> <li>• Temperament</li> <li>• Special needs</li> <li>• Gender</li> <li>• Exposure to violence</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of knowledge of child development and parenting</li> <li>• Lack of understanding their role for identifying and preventing CAN</li> <li>• Lack of knowledge of resources</li> <li>• Lack of financial support</li> <li>• Lack of access for parental screening and tools (e.g. Maternal depression)</li> <li>• During times of stress, Lack of recognition and understanding of signs and symptoms of Protective and Risk factors</li> </ul>

<b>PROBLEM MAP</b>			
<b>Unintended Pregnancy</b>			
	<b>FEMALE FACTORS</b>	<b>FAMILY FACTORS</b>	<b>SERVICE PROVIDERS</b>
<b>TERTIARY</b> (Policy, system)	Mass media portrayals of sex without consequences Promotion of sex-enhancing drugs (Viagra, etc) Promotion and normalization of early sex initiation in mass media Promotion and normalization of promiscuous sexual behaviors in mass media		
<b>SECONDARY</b> (Community)	Availability of family planning services Lack of insurance coverage for contraceptives and/or family planning services Cost and availability of contraceptives Lack of community knowledge of consequences of unintended pregnancy Availability and use of alcohol and drugs Cultural or religious beliefs regarding contraception use Community acceptance of adolescent sex Lack of sex education in schools Poor quality of existing sex education programs Dysfunction or abuse within family unit	Availability of family planning services Lack of community knowledge of consequences of unintended pregnancy Cultural or religious beliefs regarding contraception use Lack of insurance coverage for contraceptives and/or family planning services Community acceptance of adolescent sex Lack of sex education in schools Poor quality of existing sex education programs Dysfunction or abuse within family unit	Community acceptance of adolescent sex Lack of sex education in schools Poor quality of existing sex education programs Lack of insurance coverage for contraceptives and/or family planning services Cost and availability of contraceptives Lack of comprehensive family planning training for MDs Lack of community knowledge of consequences of unintended pregnancy
<b>DIRECT</b>	Lack of contraception use Lack of contraception effectiveness High sex frequency Partner behavior Substance use/abuse Lack of health literacy and knowledge Low income Low education Age Intimate partner violence Lack of control over personal decisions Lack of perceived self-efficacy Unmarried marital status Mental illness Coerced or forced sex Early sexual debut Lack of positive role models Older partner Unsupervised activities Peer pressure Low self esteem	Intimate partner violence Lack of insurance Partner behavior Substance use/abuse Low income Early sexual debut Lack of positive role models Unsupervised activities	Lack of insurance Lack of patient counseling and education

**ALCOHOL USE DURING PREGNANCY**  
**Problem Map: Key Factors, Behavioral and Social Determinants**

	<b>MATERNAL FACTORS</b>	<b>SERVICE PROVIDERS</b>
<b>Policy and system contextual influences</b>	<ul style="list-style-type: none"> <li>- Professional guidelines for alcohol use during pregnancy inconsistent (ACOG, Surgeon General, Institute of Medicine)</li> <li>- No universal alcohol screening tool for pregnant women</li> <li>- State does not incorporate the Medicaid reimbursement code for alcohol screen, assessment, referral and treatment</li> </ul>	<ul style="list-style-type: none"> <li>- Lack Screening, Health Education &amp; Referral across systems (e.g. health, judiciary, social services, and schools) for pregnancy and alcohol use</li> <li>- No statewide reporting system for alcohol use during pregnancy</li> </ul>
<b>Community, institutional settings, settings where there is interaction</b>	<ul style="list-style-type: none"> <li>- Social acceptance and availability of alcohol during sporting events, celebrations and holidays</li> <li>- Lack of public awareness on the detrimental effects of alcohol on the developing fetus</li> <li>- Lack of gender specific (women) alcohol/substance abuse treatment specialist and resources</li> <li>- Community resources dwindling due to economic recession</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of Medicaid reimbursement code for alcohol screening, assessment, referral and treatment</li> <li>- Screening, counseling and providing health education for alcohol use in preconception and during pregnancy not included in most medical professionals curriculum (e.g. physician, nursing, psychiatry)</li> <li>+ Universal screening in ACOG standards</li> <li>+ Children's Research Triangle, Upstream Solutions (Chasnoff, et al) establishing 4P's alcohol screening, assessment, referral and treatment resource on the Big Island and one health center on Oahu</li> <li>- Establishments that serve liquor not required to post signage on the detrimental effects of alcohol use during pregnancy</li> </ul>
<b>Individual relationships to others</b>	<ul style="list-style-type: none"> <li>- Partner drinking behavior</li> <li>- Family history for alcohol abuse</li> <li>- Peer pressure or cultural expectation to drink alcohol during sporting events, celebrations and holidays</li> <li>- Lack of health literacy and knowledge re: alcohol and pregnancy</li> <li>- Pregnancy denial and/or unintended pregnancy high-risk for alcohol exposed pregnancy (AEP)</li> <li>- Previous birth of child with FASD</li> <li>- Poor coping skills during stressful times (e.g. domestic violence, financial difficulty, unintended pregnancy)</li> <li>- Pregnant women with live births age &lt; 25 years old</li> <li>- Higher self-report of binge drinking prior to pregnancy by Hawaiian and Samoan ethnicities (PRAMS data 2000-2008)</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of skill sets to properly screen, assess, refer and treat for alcohol use/abuse</li> <li>- Lack Medicaid reimbursement for counseling and intervention services</li> <li>- Limited knowledge of alcohol screening tools</li> <li>- Lack of counseling skills to address behavioral problems</li> <li>- Time limits for medical appointment visits</li> <li>+ PSS Providers received training in 4P's Plus and Brief Intervention and Motivational Interviewing</li> </ul>



# Prevention of Alcohol Use during Pregnancy (draft 9/3/2010)

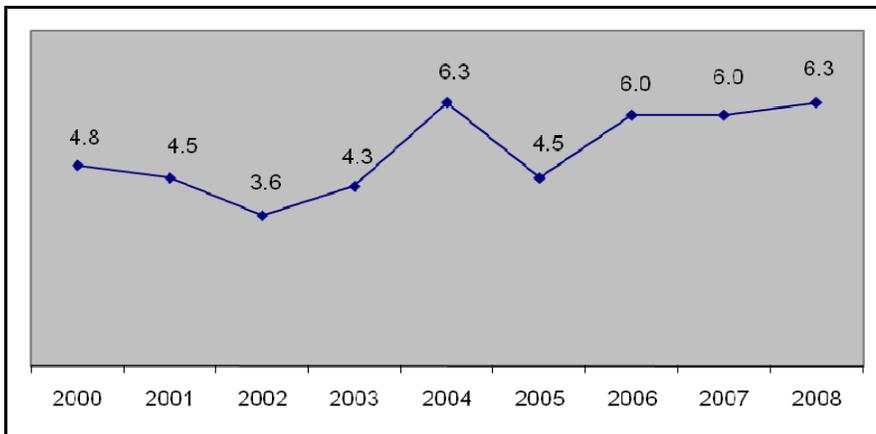
## Issue:

There is no amount of alcohol consumption that is considered safe during pregnancy. A pregnant woman's health and the outcomes of her child are at risk when she drinks alcohol. Drinking alcohol during pregnancy can cause miscarriage, stillbirth, birth defects and a range of lifelong disorders to the child, known as fetal alcohol spectrum disorders (FASD). Alcohol-related birth defects may include growth deficiencies, facial abnormalities, central nervous system impairment, behavior disorders, and impaired intellectual development including mental retardation. Alcohol-related birth defects are completely preventable when women abstain from drinking during pregnancy.

Women should stop drinking alcohol if they are pregnant. Women who are planning to become pregnant or are sexually active and do not use effective birth control should not drink alcohol since women can become pregnant and may not know for several weeks. With over half of the pregnancies in the U.S. unplanned, a woman may unintentionally expose her unborn child to alcohol. Thus, it is important to educate and intervene with all women of childbearing age.

## Data:

### Proportion of Women Who Reported Alcohol Use During Pregnancy, 2000-2008, State of Hawai'i



In Hawai'i, approximately 6.3% of women (1,167) reported using alcohol during their pregnancy in 2008. This is almost a two-fold increase from 2002, when only 3.6% of women reported using alcohol during their pregnancy.

Other data from PRAMS show that from 2005-2008, the rate of alcohol use prior to pregnancy increased from 42.1% in 2004 to 49.2% in 2008,<sup>1</sup> While binge drinking prior to pregnancy remained relatively constant (19.1-19.5%), after an initial increase in 2004 when it was 16.1%.

Data Source: State of Hawaii, Department of Health, Family Health Services Division, Maternal and Child Health Branch, Hawai'i Pregnancy Risk Assessment Monitoring System (PRAMS).

## What is the Problem?

- People are not well informed of alcohol effects on a developing fetus and the importance to abstain from alcohol when pregnant or when they are planning to become pregnant.
- When a woman has an unplanned pregnancy, the risk of consuming alcohol during the early stages of pregnancy is high. Nearly half of all births in the United States are unplanned. Therefore, women of child-bearing age should consult their physician and abstain from drinking alcohol if they are contemplating pregnancy, are sexually active and not using contraceptives or are pregnant.
- Routine screening and counseling of women for alcohol use may not occur during regular health care visits or during pregnancy.
- Alcohol use during pregnancy is attributed to the Fetal Alcohol Spectrum Disorder (FASD) which is a range of adverse birth outcomes of poor neurological, physical and behavioral development including stillbirth, low birth weight, and preterm delivery.

<sup>1</sup> Kazi M, Shor R, Hayes D, Fuddy L. "Preconception Alcohol Use Fact Sheet." Honolulu, HI: Hawai'i Department of Health, Family Health Services Division; August 2010.

## Strategies to Help Prevent Alcohol Use During Pregnancy

- ▶ Promote Awareness at the community level on the adverse effects of alcohol use during pregnancy.
- ▶ Work with the medical profession to ensure that the subject of alcohol effects during pregnancy is included in instructional curriculum and allied health care schools' training.
- ▶ Ensure that local medical professionals and allied healthcare staff implement practices recommended by the U.S. Surgeon General on screening, motivational interviewing and intervention skills for all women of reproductive age.
- ▶ Increase collaboration and improve communication among agencies and programs to provide a cohesive delivery of prevention, intervention, and referral services among the different disciplines from mental health, substance abuse, and women's and children's health.

## Resources Available:

- **“Drinking and Reproductive Health: A Fetal Alcohol Spectrum Disorders Prevention Tool Kit,”** developed by the American College of Obstetrics and Gynecology (ACOG) in collaboration with the Centers for Disease Control (CDC). The tool-kit provides information and guidelines to help health care providers conduct screening and intervention for all women of reproductive age. Available online at <http://www.acog.org/departments/healthIssues/FASDToolkit.pdf>
- **Centers for Disease Control and Prevention (CDC) – Alcohol Use in Pregnancy; Why Alcohol is Dangerous; Surgeon General’s Advisory on Alcohol Use in Pregnancy**, available at <http://www.cdc.gov/ncbddd/fasd/alcohol-use.html> provides user friendly information on the dangers of alcohol use during pregnancy.
- **SAMHSA, Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence:** Available at <http://fasdcenter.samhsa.gov>. The FASD Center for Excellence provides educational materials to prevent FASD.
- **Healthy Mothers Healthy Babies (HMHB) Coalition of Hawaii** – Promotes the national HMHB initiatives to improve health outcomes for babies and mothers. HMHB is taking the lead to promote Text4baby, that uses mobile technology to text health education and information throughout a pregnancy and timed to the expected due date. <http://hmhb-hawaii.org/?p=149>
- **March of Dimes, Hawaii Chapter** - Addresses perinatal issues and focuses on preventing preterm births that contribute to low-birth weight and other compromising neonatal health issues including alcohol use during pregnancy. [www.marchofdimes.com](http://www.marchofdimes.com).
- **Fetal Alcohol Spectrum Disorder Task Force (FASD)** – FASD State Coordinator [naomi.imai@doh.hawaii.gov](mailto:naomi.imai@doh.hawaii.gov) - Promoting abstinence from any alcohol during pregnancy is an objective of the Hawaii FASD Task Force, which also seeks to train and educate local communities and professionals on screening of pregnant women as well as promoting more awareness and screening to identify children with FASD.

**Contact Information:** Prevention of alcohol use during pregnancy is a Title V priority issue for the Department of Health, Family Health Services Division. We encourage your questions and efforts to join us in addressing this important issue.

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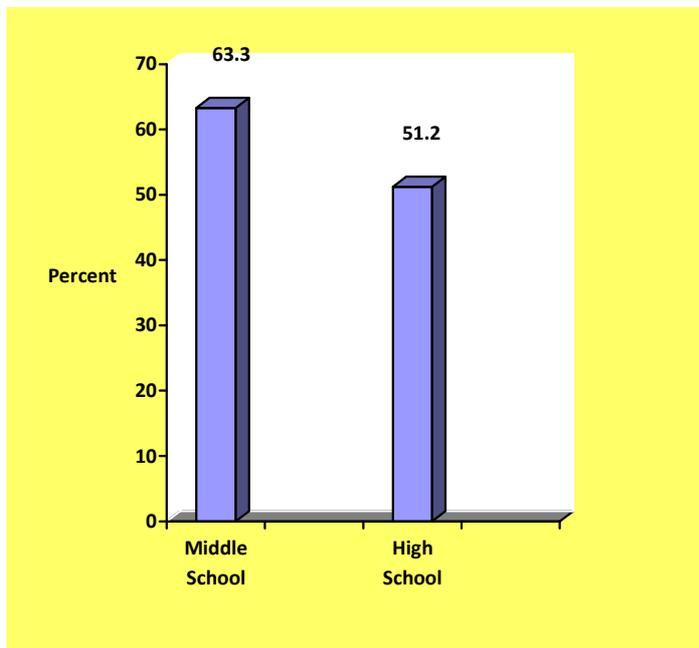
## Preventing Bullying Among Adolescents (Draft 7/13/2010)

### Issue:

- Bullying among adolescents encompasses a variety of negative physical (hitting, kicking, spitting, pushing, taking personal belongings), verbal (taunting, malicious teasing, name calling, making threats) and psychological acts (spreading rumors, manipulating social relationships, or engaging in social exclusion, extortion, or intimidation) carried out repeatedly over time. It involves a real or perceived imbalance of power, with the more powerful child or group attacking those who are less powerful.
- Bullying among school-aged youth is increasingly recognized as a problem that affects the well-being and social functioning of the broader community.
- The consequences of bullying are serious and the costs to communities are high. The Children Safety Network estimates the financial cost of youth violence in the United States at over \$150 billion per year and this includes medical costs, loss of productivity, and mental health costs.

### Data:

#### Hawai'i Students Reporting Bullying & Harassment as a Problem in School 2009



2 in 3 middle school youth in Hawai'i agree bullying is a problem

1 in 2 high school youth in Hawai'i agree bullying is a problem

Source: University of Hawai'i, Curriculum Research and Development Group (DCRG). Hawai'i Youth Behavior Risk Survey (YRBS).

Note: YRBS is administered in odd-numbered years in the public middle schools (n=1,231, n=1,611) and high (n=1,191, n=1,511) schools.

## What is the Problem?

- Bullying behavior has been linked to other forms of antisocial behavior, such as vandalism, shoplifting, skipping and dropping out of school, fighting, and the use of drugs and alcohol.
- Bullying is a pervasive problem that has emerged as a public health issue as a response to prevent youth violence. Youth need to feel safe and need an environment where an individual, family, school, neighborhood, community and society support their safety.

## Strategies to Consider:

- Identify resources and current status of programs/services statewide.
- Identify and convene county stakeholders to identify and work on collaborative strategies.
- Provide community education and awareness to promote training and education on bullying prevention strategies.
- Implement and support education for parents, teachers, and others who are in contact with adolescents to help them recognize and intervene in episodes of bullying.
- Foster coalitions and networks by convening multidisciplinary community-based teams to improve coordination of the assessment of bullying prevention services.
- Mobilize neighborhoods and communities to become active bystanders and to intervene quickly when risk factors are identified.

## Resources Available:

- **Hawaii Anti-Bullying Coalition** supports the Olweus Bullying Prevention Program in five East Hawai'i schools.
- There has been progress on the community level in bullying prevention programs such as:
  - **Asian Pacific Islander Youth Violence Prevention Center's (APIYVPC)** Safe Schools and Communities
  - the **Office of Attorney General's** Prevention Branch
- The **Department of Education's** (DOE) Comprehensive Student Support Services Positive Behavior Support is a sustainable program for schools and their communities to participate. The DOE has also established an online bullying prevention curriculum for teachers on their web site.

**Contact Information:** Bullying Prevention is a Title V priority issue for the Department of Health, Family Health Services Division. We encourage your questions, comments and efforts to join us in addressing this important issue.

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# Child Abuse and Neglect (Draft 7/13/2010)

## Issue:

Child abuse and neglect (CAN) happens to children of every age, race, and family income level. Child abuse can be physical, sexual, emotional, or verbal. Neglect specifically involves the failure to provide for a child’s basic physical or emotional needs. Children, families, communities and society as a whole suffer from the devastating effects of abuse and neglect.

The consequences of CAN include impaired brain development, poor physical health, poor mental and emotional health, cognitive difficulties, social difficulties, juvenile delinquency, adult criminality, alcohol and other drug abuse, and continued abusive behavior.

## Data:

Children under the age of five are the most vulnerable for child abuse and neglect (CAN). For children 0-5 in Hawai‘i in 2008, the rate of CAN was 8.0 (per 1,000 children 0-5 years of age) which is a 36% relative decrease since 2005 when the rate was 12.5. There were no comparable national estimates for this particular age group. In 2007 for all children, the national rate of confirmed CAN reports was 10.1 (per 1,000 children, aged 0-17 years) compared to 7.1 in the State of Hawaii. There was some variation by county with Hawaii County having the highest rate. Although the CAN rates reflect this slight decline since 2005 many experts believe that increased family stress

Hawai‘i rate of Child Abuse and Neglect, Ages 0-5 year (rate per 1,000 children)	
Year	Statewide rate per 1,000
2008	8.0
2007	9.3
2006	8.8
2005	12.5

Data Source: Hawaii State Department of Human Services, Management Services Office, accessed through the University of Hawaii Center on the Family Data Center available at [http://uhfamily.hawaii.edu/Cof\\_Data/cfi/family\\_indicators.asp](http://uhfamily.hawaii.edu/Cof_Data/cfi/family_indicators.asp)

due to the state’s poor economy may result in a rise in cases of family violence including CAN. It should be noted that the definition of a “confirmed” CAN case has changed over time. Also new policies have resulted in reported cases receiving early intervention services to divert families from entering into the child protection system. These two factors may lead to an under reporting of the “true” CAN rate.

Unduplicated Confirmed Reports of Child Abuse & Neglect, Ages 0-17 years (rate per 1,000 children)						
Year	National	State of Hawai‘i	Honolulu	Hawai‘i	Kauai	Maui
2007	10.1	7.1	6.5	10.9	5.7	6.8
2006	11.8	8.3	7.7	13.3	7.8	6.2
2005	12.1	8.9	8.1	15.0	6.2	8.2

Data Source: Hawaii State Department of Human Services, Management Services Office Accessed through the University of Hawaii Center on the Family Data Center available at [http://uhfamily.hawaii.edu/Cof\\_Data/cfi/family\\_indicators.asp](http://uhfamily.hawaii.edu/Cof_Data/cfi/family_indicators.asp)

## What is the Problem?

- For many years, Hawaii’s families have benefited from a broad statewide network of family support and strengthening programs such as parenting education, home visiting, and respite care that can help to reduce incidents of CAN.
- The recent downturn in the economy has resulted in major cutbacks to programs and services.
- Service programs have lost millions of dollars in state funding and witnessed similar reductions in private donations. Some family service programs have closed, laid-off staff, reduced services, or changed service delivery models.
- Many family support programs have experienced delayed payments or release of funds resulting in a reduction and/or elimination of services.

## Strategies to Consider:

In a recent Department of Health survey of family service providers 96% expressed interest in statewide collaboration efforts. Providers can no longer afford to work in relative isolation but must consider how to creatively pool resources to serve families during this difficult time. Creating or enhancing existing mechanisms to share timely information that help promote areas for partnership and collaboration including development of:

- a statewide website
- a statewide Resource Directory of family support services
- a forum for service providers to regularly share updates (on funding opportunities, policy and service program changes, events) and discuss areas for partnerships (for training opportunities, coordinate activities, identify areas for service integration)

## Examples of Resources Available for Strengthening the State's Prevention Service System:

- The **Department of Health (DOH)** helps to assure a continuum of prevention services available to the children and families of the State of Hawaii. Through collaboration with both public and private agencies the DOH ensures that services provided are accessible, culturally appropriate and responsive to the community.
- The **Child Safety Collaborative (CSC)** is a public-private partnership to promote a safe and nurturing environment for children and youth. The CSC conducts public awareness, education, advocacy, and provides leadership for system change; assuring a comprehensive/effective service system; policy development; and provides a forum for communication and collaborative action.
- **Prevent Child Abuse Hawaii (PCAH)** is a private non-profit organization dedicated to the prevention of child abuse and to ensure that all children in the state are able to grow up in a safe and nurturing environment. Programs are designed to promote positive parenting and healthy families through education, public awareness and advocacy. PCAH maintains an informational website of statewide events at [www.preventchildabusehawaii.org](http://www.preventchildabusehawaii.org).
- **Hawaii Children's Trust Fund (HCTF)** was established by statute to support family strengthening programs aimed at preventing CAN and promoting healthy child development. HCTF is a public/private partnership between the DOH and the Hawaii Community Foundation to assure a network of primary prevention services that support and strengthen families to prevent CAN through community-based grants and public awareness.
- **East Hawaii County Coalition to Prevent Child Abuse and Neglect** empowers the community to keep children safe. The Coalition goals are to raise community awareness, support existing prevention programs, strengthen families, conduct educational activities, develops prevention plans. Coalition partners consist of 17 private & public agencies that meet every month to coordinate and plan events and education trainings for providers.
- Maui County **Ho'oikaika Partnership** was established in August 2008 with a mission to create a seamless safety net of CAN prevention of services that is coordinated, effective, culturally responsive, and collaborative for children and their caregivers.
- **Kauai County Children's Justice Center (CJC)** is a program of the Hawaii State Judiciary and part of a national network of Children's Advocacy Centers. CJC brings together multidisciplinary professionals, representing key state/county agencies and community organizations to coordinate activities and investigations of CAN, including forensic interviews and examinations for children who have been sexually assaulted. The CJC is also instrumental in policy development and implementation.
- **Blueprint for Change** through its system of Neighborhood Places and partners in the community, is working for positive change to reduce environmental and social risk factors and increasing protective factors by providing access to resources; building the capacity of at risk families to provide for the safety of their children; and serves as a neutral hub in their communities for service coordination and community building.

**Contact Information:** Child Abuse and Neglect is a Title V priority issue for the Department of Health, Family Health Services Division. We encourage your questions, comments, and efforts to join us in addressing this important issue.

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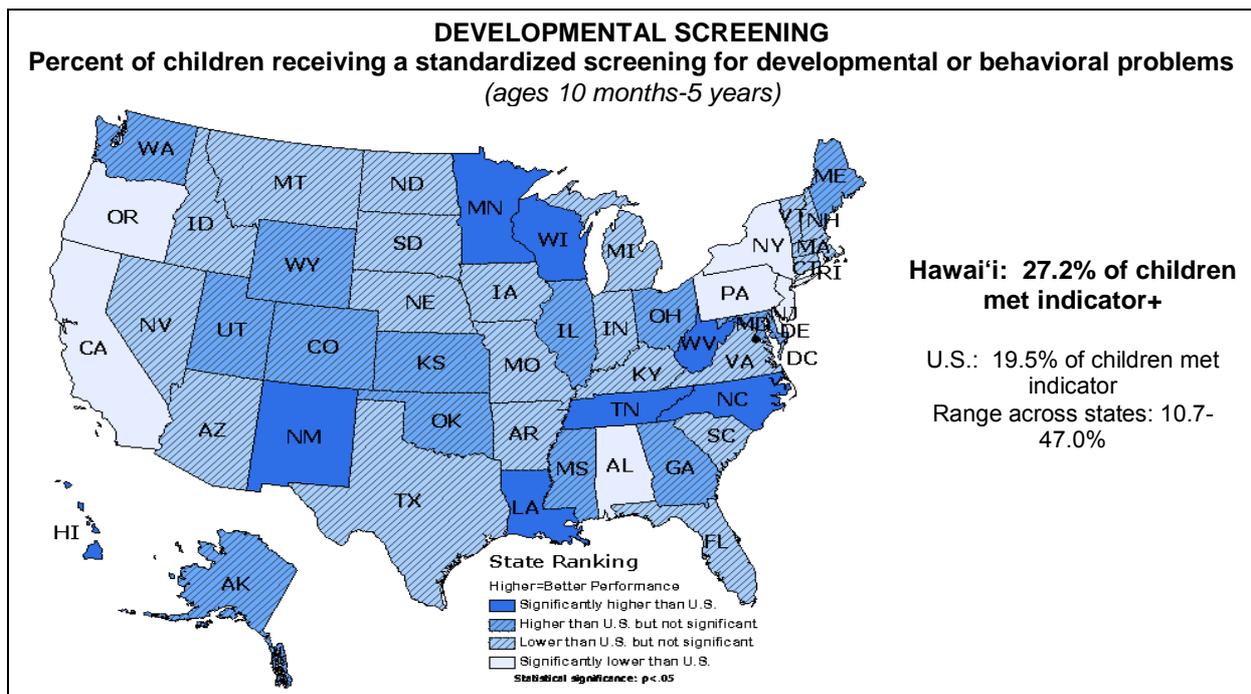
# Identification of Children with Developmental Delay DRAFT 7/13/2010

## Issue:

- Developmental delay must be identified early to assure that young children receive care and resources to promote optimal development. The sooner concerns are identified and needed services are provided, the better chances that the child's development will be optimized.

## Data\*:

- In Hawai'i, 27.6% of all children are at moderate or high risk of developmental, behavioral, or social delays. This is similar to the national rate of 26.4%.
- All children 0-5 should be screened for developmental delay (whether by pediatricians, public health nurses, Healthy Start, early childhood practitioners, etc.). In Hawai'i, only 27.2% of children 0-5 are receiving a standardized screening for developmental or behavioral problems.
- Hawai'i vs. National rates: Hawai'i has a higher rate of standardized developmental/behavioral screening (27.2% vs. 19.5%) but this may decrease in the coming years due to decreased funding to Healthy Start and the discontinuation of Department of Health Preschool Developmental Screening Program.



\*Data source: 2007 National Survey of Children's Health. From: Child and Adolescent Health Measurement Initiative, Data Resource Center on Child and Adolescent Health website. Retrieved 5/21/2009 from <http://www.nschdata.org>.  
+ Statistical difference at the 95% confidence interval between Hawai'i and U.S. rates.

## What is the Problem?

- Developmental screening tests are an important part of preventive health care. They can help ensure that more serious concerns are mitigated when conditions are detected and treated early. The American Academy of Pediatrics (AAP) endorses the ASQ or the PEDS; however, not all physicians are using a standardized screening tool. Primary Care Providers (PCPs) vary in their hearing and vision screening practices and whether they follow EPSDT or American Academy of Pediatrics guidelines. PCPs include pediatricians, pediatric specialists, family physicians, community health centers, general practice, internal medicine, etc.
- Primary care providers need to have adequate insurance payment for their screening services, and may face difficulties obtaining adequate payment.

- Budget cuts led to the elimination of the Preschool Developmental Screening Program (PDSP) which promoted the early identification and intervention for developmental learning, behavioral and social emotional problems for children ages 3 to kindergarten entry. In FY 2008, PDSP screened 916 children and based on screening results, 613 children were referred for additional services.
- While screening is important, appropriate services for those identified children at risk for developmental delay is equally critical. There needs to be formal protocol for the referral system once children are identified at risk.

## Strategies to Consider:

- **Public Awareness:** Develop and disseminate products that promote optimal child development that include screening and services for developmental delay. Families have an important role in ensuring that their children receive screening and follow-up. Education for families and the community may include the importance of screening, follow up, and resources for children and families.
- **Policy Setting:** Advocate for funding for state-wide developmental screening and follow up services to identify children with developmental delay and to do more investigation on mandated coverage for early intervention services.
- **Community-Based Project Focus:** Promote public-private partnerships for the screening system including developing guidelines/screening protocols; collecting/analyzing data; and identifying training and resource needs. An example of this is the Aloha United Way (AUW) Waianae/Nanakuli Developmental Screening Pilot Program through the Learning Disabilities Association of Hawaii's 'Ekolu 'Ehā 'Ike Pono ("To keenly see our Three and Four Year Olds").

## Resources Available

- **American Academy of Pediatrics-Hawaii Chapter** works to enable pediatric providers to perform developmental surveillance at every well-child visit and do developmental screening using a standardized screening tool at 9, 18, and 24 month visits or when a concern is expressed. Recommended standardized screening tools included Parents' Evaluation of Developmental Status (PEDS) and Ages and Stages Questionnaire (ASQ).
- **Hawai'i Department of Education Operation Search** is a multi-media campaign by the Hawai'i State Department of Education to find children who may need special education services but who are not receiving them. Any child who resides in Hawai'i who is between the ages of 3 and 20 and has met the eligibility criteria may receive special education services. Call Operation Search: 1-800-297-2070 statewide.
- **Hawai'i Keiki Information Service System (H-KISS)** is a free information and referral service administered by the Early Intervention Section, which provides families with referrals to appropriate programs for services based on the individual needs of the child. (On Oahu: 594-0066; Neighbor Islands: 1-800-235-5477)
- **Early Intervention Section (EIS)**—is responsible to ensure that any child from birth to three years of age at risk for a developmental delay receives a timely, multidisciplinary, comprehensive developmental evaluation and services as identified on the child's Individual Family Support Plan (IFSP).
- **Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)** is administered by the Department of Human Services Med-QUEST Division which provides health services for individuals under age 21 through Hawaii QUEST, QUEST-Net and Medicaid Fee-For-Services programs. EPSDT provides coverage surveillance for hearing, vision, and development/behavior at all visits.

**Contact Information:** Child Development is a Title V priority issue for the Department of Health, Family Health Services Division. We encourage your questions, comments, and efforts to join us in addressing this important issue.

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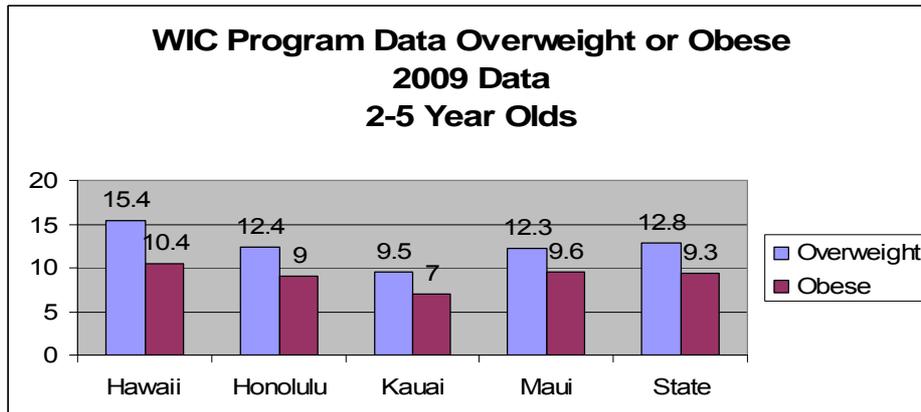


## Prevention of Overweight and Obesity in Children (0-5 years) (DRAFT 7/13/2010)

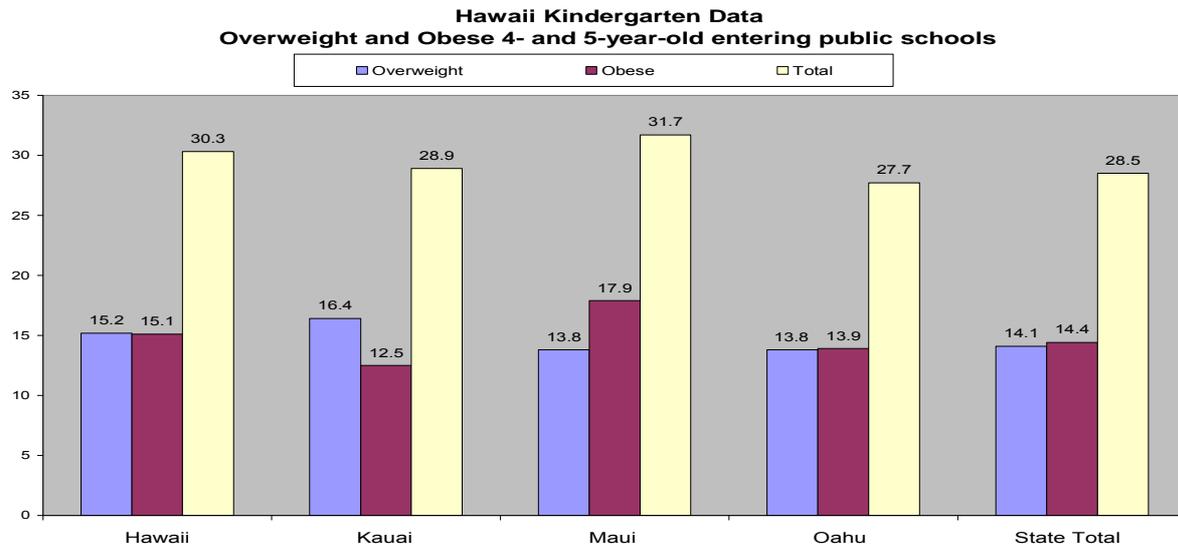
### Issue:

Childhood overweight and obesity is a serious public health problem requiring urgent attention, with prevalence in Hawai'i and the United States growing considerably each year. Young children ages 0-5 are dependent on responsible adults to provide healthy and nutritious meals and to instill regular physical activity and healthy eating behaviors. More emphasis on starting early to develop healthful food and physical activity habits in children will lead to better health outcomes.

### Data:



Source: Centers for Disease Control and Prevention (CDC) Pediatric Nutrition Surveillance System, 2009



Source: Pobutsky AM, Hirokawa R, Zou L, Huang T, Rosen L, Wood B. Overweight and at risk for overweight among Hawai'i public school students entering kindergarten, 2002-2003. *HI Med J* 2006;65:283-7

### What is the Problem?

- A body mass index (BMI) of 85th-94th percentile is considered overweight, a BMI of 95th percentile and above, obese. The complex causes of overweight and obesity include genetic, biological, behavioral and cultural factors and can be related to poor eating habits, overeating, lack of exercise, family history of obesity, medical illnesses (endocrine, neurological problems), medications (steroids, some psychiatric medications), stressful life events or changes (separations, divorce, moves, deaths, abuse), family and peer problems, low self-esteem, depression or other emotional problems.
- Overweight and obesity increases the risk of heart disease, high blood pressure, diabetes, breathing and sleeping problems, depression, discrimination, bullying, poor school grades, low-self-esteem and obesity in adulthood. In addition, there are considerable economic costs with the national health care expenditures for overweight and obese adults alone estimated at over \$129 billion.

## Strategies to Help Prevent Childhood Obesity:

- Early childhood programs can serve nutritious foods and beverages and allow at least 45 minutes of physical activity daily within the curriculum. Such programs can promote and reinforce healthy eating and physical activity family practices at home.
- Health care providers can routinely track BMI and counsel parents of children 2-5 years of age on the following evidence-based prevention strategies: a) limiting consumption of sugar-sweetened beverages, b) encouraging recommended quantities of fruits and vegetables, c) limiting TV and other screen time to no more than 2 hours per day, and removing TV and computers from bedrooms, d) eating breakfast daily, e) limiting eating out, particularly fast food restaurants, f) encouraging family meals in which parents and children eat together and g) limiting portion sizes. Health care providers can learn more about obesity prevention and resources, and use motivational interviewing.
- Parents and caregivers can be role models and practice healthy eating and physical activity. A great start towards obesity prevention and wellness early in a child's life is to breastfeed babies for at least the first six months of life.

## What's Happening Around the State:

- **Women, Infants and Children (WIC):** This federally funded program provides nourishing supplemental foods, nutrition education, breastfeeding promotion and health and social service referrals. WIC participants are either pregnant, breastfeeding, or postpartum women, and infants and children under age five who meet income guidelines and have a medical or nutritional risk. WIC food packages encourage lower fat choices, higher fiber and whole grains, fruits and vegetables; mothers and infants get more foods if breastfeeding. Families receive a Sesame Workshop's "Healthy Habits for Life" kit to promote healthy weight for children. WIC uses motivational interviewing and stages of change to customize discussion with caregivers. <http://hawaii.gov/health/family-child-health/wic/index.html>
- **Maui:** The islands of Kaua'i and Maui are one of 40 recipients of the Communities Putting Prevention to work (CPPW) grant funded by the CDC. The grant's overall goal is to reduce obesity through improved healthy activities and nutrition of all residents, including the hardest to reach and most at risk for diseases preventable by healthier lifestyles. Maui is focusing on improving healthy activities and nutrition primarily by promoting gardening, active volunteering, bike paths and walkable communities. This will include increased community and school gardens and improved networks between farmers, restaurants, grocers and schools. Policy changes to increase the use of local produce in stores and restaurants will be targeted.
- **Kaua'i:** Kaua'i will use the CPPW grant to fund a breastfeeding peer counselor, promote healthy eating and active living (e.g., the Mayor's Walk, Walking Workbus, Walkable Communities) and work with community agencies (e.g., community gardens, nutrition and cooking education classes).
- **West Hawai'i:** Big Island Breastfeeding Promotion Project improves infant nutrition among low-income families through an innovative collaboration that partners WIC Breastfeeding Peer Counselors and existing Early Head Start home visiting programs to provide targeted 1 to 1 infant feeding education and support prenatally through Baby's first birthday. In addition, all West Hawai'i women birthing at Kona Community Hospital are offered breastfeeding education, tools and support as an alternative to promotional gifts of infant formula. Project funding is shared among Family Support Hawai'i, WIC, and the West Hawai'i Local Area Consortia (Big Island Perinatal Health Disparities Project). The Family Support Services of West Hawai'i's Early Head Start program partners with WIC on a Breastfeeding Project that includes peer counselors and staff support to promote exclusivity (breastmilk only) and duration (extended period) of breastfeeding.
- **East Hawai'i:** The East Hawai'i Local Area Consortia (Big Island Perinatal Health Disparities Project) identified breastfeeding as a priority. The Public Awareness committee developed a brochure with information that "normalizes" breastfeeding. This brochure was distributed at a local supermarket during a Hawai'i Alliance Community Health event. The Consortia also sponsored two members to participate in a certification training class on Oahu to be certified lactation consultants.
- **Healthy Hawai'i Initiative (HHI):** HHI's Hawai'i Initiative for Childhood Obesity Research and Education (HICORE), University of Hawai'i, John A. Burns School of Medicine ([www.hicore.org](http://www.hicore.org)) to prevent childhood obesity. HICORE trains pediatricians and their office staff on evidence-based recommendations that help children and families maintain a healthy weight and provides ways to approach the subject during regularly scheduled well child visits. Those who pledge to integrate the approaches into their practice will be provided with handouts and posters that outline the recommendations in a way that is culturally tailored, and easy to read and understand. Patient education materials including translated versions are available online at [www.healthyhawaii.com](http://www.healthyhawaii.com), under the Training section.

**Contact Information:** Childhood Obesity is a Title V priority issue for the Department of Health, Family Health Services Division. We encourage your questions, comments, and efforts to join us in addressing this important issue.

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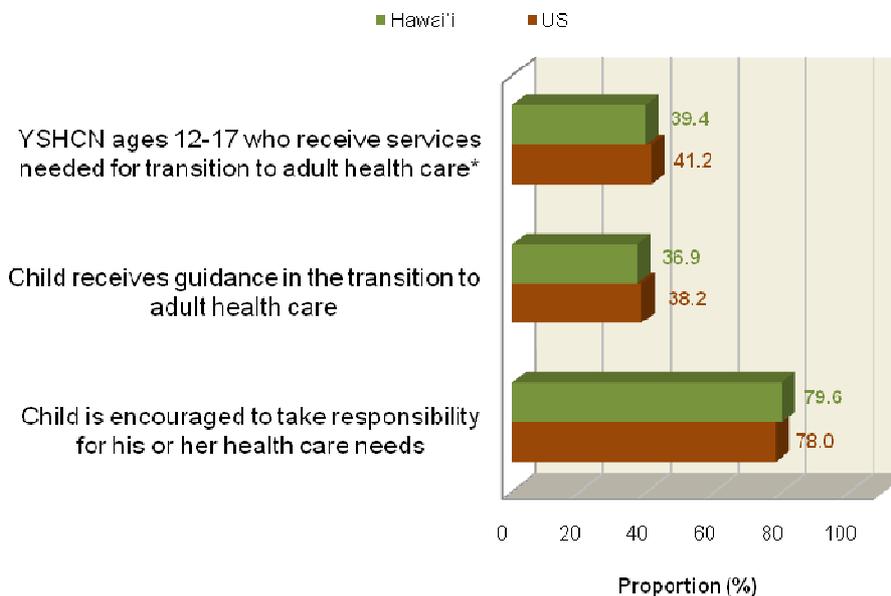


# Transitioning Adolescents with Special Health Care Needs to Adult Health Care

## Issue:

The transition from pediatric to adult health care is a significant issue facing all adolescents, but it is of critical concern to the 17% of adolescents with special health care needs.<sup>1</sup> To make this transition smooth, these young people need assistance over a period of time to assume their new role as informed health care consumers. They also need developmentally appropriate support to understand and manage their condition and to negotiate the changes when they move from pediatric to adult health care systems.

## Health Care Transition Services Data for Youth Ages 12-17 Years with Special Health Care Needs in Hawai'i & the US: 2006



Both national & Hawai'i data reveal major gaps in transition services for Youth with Special Health Care Needs (YSHCN). According to the National Survey of Children with Special Health Care Needs, less than half of parents who have an adolescent with a special health care need report that their child's doctor/health care provider talked about meeting health care needs in adulthood. In fact, as many as three out of five parents with adolescents who have special needs reported not receiving the services necessary to make appropriate transitions to adult health care.

Most parents reported they encourage their adolescent with special needs to take responsibility for their health care.

\*Outcome derived from other survey questions.

Source: U.S. Department of Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics. Summary Tables from the National Survey of Children with Special Health Care Needs, 2005-2006.

## What Is The Problem?

A generation ago, most youth with special health care needs (YSHCN) with severe disabilities died before reaching maturity; now more than 90% survive to adulthood.<sup>2</sup> Most YSHCN are able to find their way to adult systems of care. However, many with severe medical conditions and disabilities (that limit their ability to function) experience difficulty transitioning from child to adult health care for various reasons including:

- There are few adult health care providers who are familiar w/congenital or child onset conditions
- There are limited information, tools, resources, and services for YSHCN, their families, health care providers, and community providers to assist with successful transition to adult health care.

<sup>1</sup> Child and Adolescent Health Management Initiative. 2005/2006 National Survey of Children with Special Health Care Needs. Accessed from [www.cshcndata.org/dataquery/dataqueryprint.aspx](http://www.cshcndata.org/dataquery/dataqueryprint.aspx) on June 1, 2008.

<sup>2</sup> A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs, *Pediatrics*, Vol. 110 No. 6 Dec, 2002 accessed from <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/6/S1/1304>

## What Is The Transition Planning Process?

Ideally, transition planning is a coordinated effort of the YSHCN with support from the family, community agencies and medical professionals. If possible it should include development of the YSHCN to understand his/her strengths/challenges, to develop independent learning attitudes and informed decision-making skills.

Specific steps for ensuring an effective transition include: 1) having a primary care provider with responsibility for transition planning, 2) providing developmentally appropriate health care transition services, 3) maintaining an up-to-date portable medical summary, 4) creating a written health care transition plan by age 14, 5) and ensuring continuous health insurance coverage.

## Strategies To Consider:

- Develop, update, disseminate informational resources and tools on transition planning
- Identify resources and current status of programs/services for transition planning
- Increase collaboration and service integration to improve transition services for YSHCN and their families.

## Resources Available:

- The **Hilopa‘a Family to Family Health Information Center (F2FHIC)**, funded by the MCH Bureau, was established by Family Voices of Hawai‘i in partnership with the Hawai‘i Pediatric Association Research and Education Foundation. F2FHIC provides information and referral, consultation, and training to families of CSHCN and their professional partners statewide. The following useful information can be found at their website: <http://hilopaa.org/default.aspx>.
  - The **Transition Planning Workbook** is a helpful tool to address transition to adult medical care as well as other areas of adult life. It includes tasks, activities, decisions, timeline and resources, and is a planning guide for families, as well as a facilitation guide for providers/programs to talk with families.
  - **Personal Health Record** a four-page form to record critical health information that can be used for transition planning.
  - **Rainbow Book—A Medical Home Guide to Resources for CSHCN and Their Families** includes programs/services for transition to adult life, including education, higher education and disability access, employment, and vocational rehabilitation.
- **“Where Am I Going? How Will I Get There?”** is a handbook for transition planning in aspects of life other than transition to adult medical care. This handbook was developed by the Statewide Independent Living Council of Hawai‘i (ILCH). It is intended to serve as a resource for students and families participating in the development of the transition portion of the student’s Individualized Educational Program. The handbook is available on the ILCH website [www.hisilc.org/Youth/default.asp](http://www.hisilc.org/Youth/default.asp).
- **The Children with Special Health Needs Program (CSHNP)** assists eligible families with coordinating and obtaining services. CSHNP develops Individual Service Plans (ISP) with CSHN families to identify family needs, services being provided, and to promote family involvement. It also assist with information and referral, nutrition consultation, access to medical specialty services, limited financial assistance, and transition planning to adulthood.

**Contact Information:** Transitioning from pediatric to adult health care is a Title V priority issue for the Department of Health, Family Health Services Division. We encourage your questions, comments, and efforts to join us in addressing this important issue.

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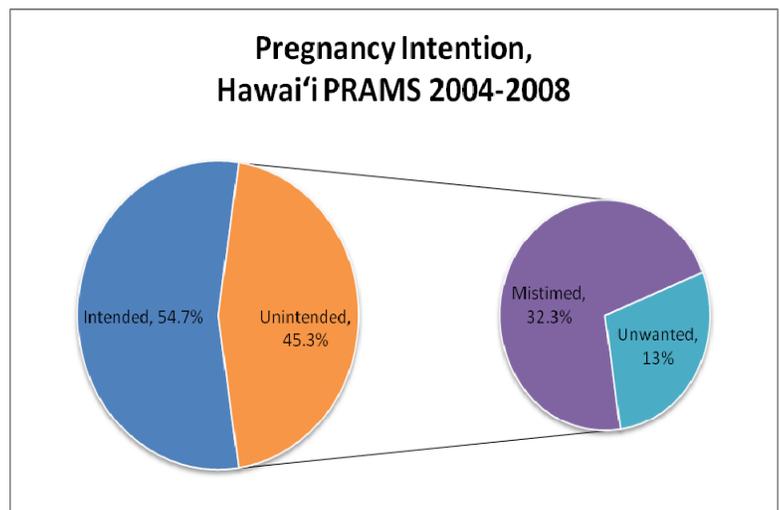


## Issue:

When pregnancies are intended and planned, there is greater opportunity and motivation for women and their partners to adopt or maintain positive health behaviors.<sup>1</sup> Unintended pregnancy is associated with adverse health outcomes for both mother and infant. Pregnancies that are unintended are more likely to result in adverse health behaviors and outcomes before, during and after pregnancy. Unintended pregnancy is associated with late or inadequate prenatal care, low birth weight, neonatal death, domestic violence, child abuse, and exposure of the fetus to harmful substances like tobacco, alcohol, and other drugs. It is also associated with economic hardship, marital dissolution, and failure to achieve education goals.

## Data:

Using data from the Hawai‘i Pregnancy Risk Assessment Monitoring System (PRAMS) for the five most recent years available (2004-2008), it was determined that 45.3% of pregnancies in Hawai‘i are unintended. Among the unintended pregnancies, the majority were classified as mistimed (32.3%), with the remainder being unwanted (13%). Unwanted pregnancies typically have higher rates of poor outcomes than do mistimed and intended pregnancies.<sup>2</sup>



## What is the problem?

Unintended pregnancy is a result of complicated and often interactive factors not just limited to an individual. Some factors that can be related to unintended pregnancy are:

- 1) Lack of knowledge about the ways to prevent pregnancy
  - Effective contraceptives come in many forms.
- 2) Lack of access to highly effective contraceptive methods
  - Are providers trained and comfortable with various methods? Are costs prohibitive?
- 3) Lack of comprehensive sexual health education in schools
  - Comprehensive sexual health education is not routinely provided in Hawai‘i all schools.
- 4) Lack of funding
  - In FY 2010, funding cuts in Hawai‘i have resulted in significant decreases in the number of Department of Health clinical services providers, health educators, and other programs and services designed to reduce unintended pregnancies.
- 5) Partner influence
  - Males also impact family planning decisions, but are less likely than women to be the target of family planning services and programs.

<sup>1</sup> Alexander, G.R. & Krenbrot, C.C.. The role of prenatal care in preventing low birth weight. *The Future of Children*. 1995;5(1):103-120.

<sup>2</sup> Hawai‘i PRAMS is a population-based surveillance system funded by the Centers for Disease Control and Prevention (CDC), Division of Reproductive Health. Estimates of pregnancy intendedness in this report may differ from those in other reports. This is due to the fact that PRAMS samples only women with pregnancies resulting in a live birth, and therefore does not include pregnancies resulting in abortion, miscarriage, or fetal death.

## Strategies to Consider

There is an increasing focus in the field of public health on making sure that health-improvement strategies are evidence-based. A review of the current literature suggests that the most effective prevention strategies include:

- increasing the knowledge and availability of Emergency Contraception (EC) for all populations
- increasing comprehensive sex education for adolescent populations
- increasing condom availability for all populations (*references available upon request*)

## Resources Available

The Department of Health (DOH) **Family Planning Program (FPP)** in the Maternal and Child Health Branch (MCHB) assures access to affordable birth control and reproductive health services to all individuals of reproductive age with a priority on low income and hard-to-reach individuals (uninsured or underinsured persons, immigrants, males, persons with limited English proficiency, homeless persons, substance abusers, persons with disabilities, and adolescents). Services are offered free or at low cost and include education, counseling, cervical and breast exams, provision of appropriate contraceptive methods, testing for pregnancy and sexually transmitted infections. FPP contracts with 20 providers, offering services in 39 clinics and community sites statewide. In FY 2009, a total of 22,137 clients received Title X FP clinical services. For health education and outreach services, 70,753 direct contacts (through individual or group sessions) and 446,714 indirect contacts (health fairs, exhibits, media information) were made for FY 2009.

The FPP, in collaboration with the Hawai‘i DOH **Sexually Transmitted Disease (STD) Branch**, has increased condom availability for the public by purchasing and distributing condoms to contracted Title X agencies across the state. Other condom distribution/availability projects include the condom coupon program being implemented by a Title X agency on the Big Island. With this program, the health educator conducts a FP lesson/presentation, and then distributes condom coupons to participants. This condom coupon allows the participant to go to various outlets in the community that the health educator has established partnerships with, such as a convenience store, to then pick up a pre-packaged bag of condoms and health education materials. This program has been effective in getting condoms to teens that otherwise choose not to or would be able to purchase the condoms or go to a clinic to pick them up.

Population-based services are provided through **Title X statewide FP community health educators**. Activities include presentations, distribution of educational materials, and health fairs. Presentation activities also include comprehensive sex education curricula implementation in schools and other community organizations. Hawai‘i’s health educators use evidence-based curricula such as Making Proud Choices. All Title X agencies throughout the state have been educated on EC and are able to inform patients about it and offer it to them. This service is based on a sliding fee scale, and those that are not able to pay for it or have no insurance get it for free. Title X community health educators also educate their contacts about EC, and the FPP has purchased various EC educational materials to distribute to the community.

The **Male Achievement Network (MAN) Project** through the Waikiki Health Center which provides outreach and educational counseling services to males most likely to engage in risky sexual behaviors including incarcerated, homeless, and runaway youth. In FY 2009 there were 3,040 direct male contacts; of these, 70 received FP clinical services.

## Contact Information:

*Unintended pregnancy is a Title V priority issue for the Hawai‘i Department of Health, Family Health Services Division. We encourage your questions and efforts to join us in addressing this important issue.*

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## **Priority Issue Performance Measures**

The Title V Needs Assessment Steering Committee identified seven state priority issues. These priorities are the programmatic focus areas for FHSD work in partnership with other agencies/programs through 2015. Three priorities are continuing from the 2005 needs assessment: unintended pregnancy, child overweight (with a focus on early childhood), and alcohol use during pregnancy. Each priority is described in relationship to the National and State performance measures used to track them and are listed in no particular order.

### **Priority 1. REDUCE THE RATE OF UNINTENDED PREGNANCY**

The performance measures related to this priority are:

NPM 8 the rate of birth (per 1,000) for teenagers ages 15-17 years

SPM 1 The percent of pregnancies (live births, fetal deaths, abortions) that are unintended.

### **Priority 2. REDUCE THE RATE OF ALCOHOL USE DURING PREGNANCY**

The performance measure related to this priority is:

SPM 2 Percent of women who report use of alcohol during pregnancy.

### **Priority 3. REDUCE THE RATE OF OVERWEIGHT AND OBESITY IN YOUNG CHILDREN AGES 0-5**

The performance measure related to this priority is:

NPM 14 Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile.

### **Priority 4. IMPROVE THE PERCENTAGE OF CHILDREN SCREENED EARLY AND CONTINUOUSLY AGE 0-5 FOR DEVELOPMENTAL DELAY**

The performance measure related to this priority is:

SPM 3 The percentage of parents of children 5 months to 5 years who report completing a standardized developmental and behavioral screener (SDBS) during a health care visit in the past 12 months.

### **Priority 5. IMPROVE THE PERCENTAGE OF YOUTH WITH SPECIAL HEALTH CARE NEEDS AGE 14-21 YEARS WHO RECEIVE SERVICES NECESSARY TO MAKE TRANSITIONS TO ADULT HEALTH CARE**

The performance measure related to this priority is:

NPM 6 The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

### **Priority 6. REDUCE THE RATE OF CHILD ABUSE AND NEGLECT WITH SPECIAL ATTENTION ON AGES 0-5 YEARS**

The performance measure related to this priority is:

SPM 4 The Rate of confirmed child abuse/neglect reports per 1,000 for children aged 0-5 years.

### **Priority 7. PREVENT BULLYING BEHAVIOR AMONG CHILDREN WITH SPECIAL ATTENTION ON ADOLESCENTS AGE 11-18 YEARS**

The performance measure related to this priority is:

SPM 5 Percent of teenagers in grades 6 to 8 attending public schools who report ever being bullied.