

STATE OF HAWAI'I
MATERNAL &
CHILD HEALTH
NEEDS
ASSESSMENT

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SUMMARY

Hawaii Maternal Child Health Priorities

Nine priority issues were identified through the Title V maternal and child health (MCH) needs assessment process. These priorities are 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 (2005-2010). The 9 priorities for the state MCH population are:

1. Reduce the rate of unintended pregnancy (*continuing priority*)
2. Ensure that all infants and children receive appropriate and timely hearing evaluation and early intervention services (*continuing priority*)
3. Prevent overweight and obesity in children (*continuing priority*)
4. Improve the oral health of children (*continuing priority*)
5. Prevent underage drinking among adolescents
6. Reduce the rate of adolescent Chlamydia
7. Increase abstinence from alcohol use during pregnancy
8. Increase abstinence from smoking during pregnancy
9. Improve transition to adult life for youth with special health care needs

Changes in Priorities Since the Last Needs Assessment

Five priority needs were dropped from the list of 10:

1. Ensure that all children 0-3 years who are developmentally delayed, or biologically or environmentally at-risk receive needed early intervention services;
2. Reduce family violence and child maltreatment;
3. Improve access to health care;
4. Assure that parenting support and information is made available to all families with children; and
5. Improve assessment and surveillance of MCH populations, including children with special health care needs.

The justification to drop these priorities varies. For the early intervention (EI) services priority, sufficient progress has been made as indicated by the performance measure for this priority; however, EI services will continue as a CSHNB priority to assure that progress is sustained and that necessary improvements are made to the EI system. There are several major initiatives underway to address violence prevention including plans to improve child abuse prevention and child welfare services, establishment of a statewide violence prevention coalition and a state special fund (financed by marriage license certificate fees) to assure continued support for domestic violence programs.

The priorities for access to care and parenting support were too global in scope to adequately address effectively. And, while building core public health capacity remains an important need, it is not unique to the maternal and child health agency, but a commitment for the entire Department of Health and public health profession. To make a measurable impact on the MCH priorities, core public health capacity must be developed and strengthened.

The 2000 priority to reduce adult and adolescent substance abuse continues to be an important concern for the state. The Lt. Governor issued a State Drug Control Plan in 2005 and substantial state and federal funds have been appropriated to combat substance use through prevention, treatment and law enforcement. To effectively address substance use in the MCH population, the priority need has been redescribed to target three specific problems:

- Prevent underage drinking among adolescents
- Increase abstinence from alcohol use during pregnancy
- Increase abstinence from smoking during pregnancy

The two new priorities in 2005 are:

- Reduce the rate of adolescent chlamydia
- Improve transition to adult life for youth with special health care needs (YSHCN)

These two priorities were selected because of quantitative and qualitative data that indicate these are critical needs. Hawaii maintains one of the highest adolescent Chlamydia rates in the U.S., however, there is little awareness in general about this health threat to Hawaii's youth.

Like much of the nation, state data shows transition services for YSHCN is an area for improvement for this population. Community meetings, focus groups with YSHCN families and providers confirm this finding.

Four priorities will continue from the previous 2000 needs assessment as noted on the previous page.

Summary of Needs Assessment Process

Organizationally, the NA process was managed by a Steering Committee comprised of FHSD senior management to provide guidance, assure progress, and coordinate efforts between work groups. A work group was established for each of the three target populations: 1) Women and Infants (WI), 2) Child and Adolescent (CA), and 3) Children with Special Health Care Needs (CSHCN).

The needs assessment process involved several steps:

- Evaluation of previous needs assessment process and priorities
- Problem definition: identify preliminary list of health issues
- Prioritization: identify final list of priorities utilizing specific criteria scoring
- Problem Analysis: identify key goals, targeted behaviors, determinants/influencing factors, existing services & interventions using a logic model format
- Activities/Plan

Input from stakeholders was collected for all steps in the process using videoconferencing, email, telephone conference calls, community meetings, focus groups, coalition meetings and interviews. The process has helped to identify new stakeholders and improve working relationships with existing agency partners.

The CSHN work group was able to complete enough of the assessment to develop a plan and secure grant funding for the two CSHN priorities: hearing and transition services. The WI and CA work groups will continue to refine the problem analysis/logic models in conjunction with stakeholders and utilize the findings for future planning.

The Title V Steering Committee will continue to provide guidance to the ongoing needs assessment process to assure progress over the next five years because of limited numbers of staff available to work on the new priority issues.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Introduction

Children with special health care needs (CSHCN) represent a significant population in Hawaii. Due to the complexity of their health needs, and the need to assure access to comprehensive, coordinated, community-based services, increasing attention has been focused on CSHCN. CSHCN are defined as children who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition(s) and who require health and related services of a type or amount beyond that required by children generally (definition from federal Maternal and Child Health Bureau [MCH] Bureau).

As part of the national agenda for CSHCN, the MCH Bureau has established six core outcomes for 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.

Hawaii's Title V needs assessment includes a focus on the six core outcomes for CSHCN.

Priority Needs

As part of the assessment process, input was solicited from private and public stakeholders on the strengths, needs, opportunities, and challenges related to the core outcomes for CSHCN. Hawaii data from the National Survey of CSHCN related to the core outcomes were provided to stakeholders. Additional Hawaii data were gathered from various sources.

In selecting priority areas for CSHCN, consideration was given to the issue's or problem's extent, urgency/severity, whether it was amenable to change, propriety, economics, acceptability, resources, and legal basis. The following areas were selected as Title V State priority areas for CSHCN:

- Ensure that all infants and children receive appropriate and timely hearing evaluation and early intervention services. *(related to outcome #4)*
- Improve transition to adult life for youth with special health care needs. *(related to outcome #6)*

These priorities are only a few of the many areas that need to be addressed. Because the six core outcomes are inter-related, to achieve family-centered, comprehensive, coordinated, and community-based systems of services, all six core outcomes for CSHCN and their families must be addressed and services must be integrated into a larger "braided" service system. The following is a summary of other significant needs:

1. Transitions
 - Lack of centralized information regarding resources.
 - With no less than 17 potential points of entry into the system of services for CSHCN, information on resources must be distributed, utilized, and appropriately and consistently shared with

- families. At any point of entry, the first point of contact should provide the necessary assistance in guiding families to the appropriate service.
- There needs to be a focus on the “little” transitions along the way, strengthening the knowledge base of families, community partners and the medical home, as well as targeting specific areas of improvement, in order to have a positive effect on the “big” transition to adulthood.
2. Navigating the system training
 - Families said that there are two critical transition points, where understanding the system is needed for making informed decisions. (a) Families whose children age 24-42 months who are exiting 0-3 and/or transitioning into the Department of Education special education would benefit in learning about the system, service array, and family advocacy. (b) Families whose children were ages of 11-14 year would benefit in learning about preparatory activities, resources, and the “process” for transitioning youth with special health care needs (YSHCN) to adulthood.
 3. Family resources for family support, leadership development, and training
 - While there are several agencies, programs, and community groups in one way or another providing support, training, and mentoring, these resources are not universally known by families.
 - There may also be a gap between what families need and what is offered, and resources may need to enhance their activities to better meet family needs.
 4. Family participation in decision-making
 - Finding “experienced” youth/families for advisory councils, or helping youth/families develop the skills and knowledge to be “advisors” can sometimes be difficult. Some agencies/programs are not aware of the potential advantages and opportunities with having family or youth advisors participate as decision makers on a policy level.
 - Families need more opportunities for leadership development and/or to be linked with programs. While some families have had training, such as through the Partners in Policymaking, they are not linked to programs in advisory capacities.
 - Opportunities are needed for YSHCN to build leadership and self-advocacy skills.
 5. Medical Home residency education program focused on integrated services
 - The University of Hawaii/Department of Pediatrics currently offers pediatric resident training that integrates a medical home approach. The training now needs to be expanded to the Family Practice Residents. The curriculum needs to be enhanced to cover transition to adulthood and role of the Medical Home in an integrated service system for CSHCN.
 6. Transition to adult health care.
 - Youths with developmental disabilities/mental retardation need additional support in transferring from pediatric to adult health care providers.
 - Pediatricians are concerned that the transition of youth with special health care needs to adult health care is time-consuming, and physicians do not receive any reimbursement for the time needed to contact adult health care providers and support the transition.
 - The Medical Home Project was able to set up the infrastructure to utilize the “Specialized Services” under the Waiver to reimburse physicians for the counseling and training required to transition these youth. However, this project has not yet been implemented, and physicians have not yet been informed about or engaged in transitioning youth in their practices.
 7. Developmental screening, referral and follow-up.
 - Few pediatricians conduct standardized developmental screening, and few physicians understand the system well enough to make the appropriate referral for additional services. Physicians may have difficulty getting children to test, lack of staff trained to screen, inadequate reimbursement, and sometimes no screening tool in the office.
 - Necessary linkages and connections have not been made to serve as an integrated service system from referral to assessment to intervention. While the system is better developed for children age 0-3 (under Part C of IDEA), it is less developed for children age 3-5 years.

Data Sources

The Children with Special Health Needs Branch (CSHNB) in the Family Health Services Division (FHSD) of the Hawaii State Department of Health (DOH) was instrumental in gathering data for the needs assessment.

Data sources included:

- CSHCN Needs Assessment community meetings around the state, with over 200 parents and state/community partners, on the islands of Oahu, Kauai, Maui, and Hawaii. Each group was asked to identify the strengths and needs within their communities, and opportunities and challenges for system change, as related to the 6 outcomes. In partnership with CSHNB, these meetings were conducted and data were analyzed by the Family Voices of Hawaii State Coordinator.
- Hawaii data from the National Survey of CSHCN, 2001. This population-based telephone survey was sponsored by the MCH Bureau and conducted by the National Center for Health Statistics. Children were screened in all 50 states to identify CSHCN under age 18 years. Sample numbers were weighted and adjusted for total population of Hawaii. Hawaii data were analyzed by CSHNB and reported in “A Family View of Children with Special Health Care Needs – Hawaii 2001” (Appendix 5-A). Hawaii data were also obtained from the Data Resource Center for Child and Adolescent Health, www.nschdata.org.
- Hawaii data from the National Survey of Children’s Health, 2003. This population-based telephone survey was sponsored by the MCH Bureau and conducted by the National Center for Health Statistics. Families who were surveyed were also screened to identify CSHCN under age 18 years. Sample numbers were weighted and adjusted for total population of Hawaii. Hawaii data were analyzed by the CSHNB and reported in “A Family View of Children’s Health in Hawaii: Children With and Without Special Health Care Needs, 2003” (Appendix 5-B). Hawaii data were also obtained from the National Survey of Children’s Health Data Resource Center, www.nschdata.org.
- Data and information from federal, state, and community agencies, including: DOH – Office of Health Status Monitoring (births, deaths), HIV/AIDS Surveillance Program (AIDS prevalence), Asthma Control Program (asthma prevalence); Hawaii Medical Services Association – “Health Trends In Hawaii 2003” (physician numbers); Department of Education (students under Part B or IDEA); Department of Human Services (EPSDT data); Social Security Administration (SSI data); Hawaii Maternal and Child Health Leadership in Education in Neurodevelopmental and Related Disabilities (MCH LEND); and others.
- Data and information from CSHNB programs and projects include:
 - Newborn Metabolic Screening Program (NBMSPP) – statewide screening and follow-up data.
 - Newborn Hearing Screening Program (NHSP) – statewide screening and follow-up data.
 - Genetics Program – genetics services in Hawaii.
 - Hawaii Birth Defects Program (HBDP) – statewide birth defects surveillance data.
 - Children with Special Health Needs Program (CSHNP) – study of need for vision and hearing screening in elementary and middle schools in two school districts on Oahu, 2000; “safety net” services.
 - Early Intervention Section (EIS), lead agency for Part C of the Individuals with Disabilities Education Act (IDEA) within the Hawaii State Department of Health – information on children served under Part C. EIS also conducted family support survey to gather information from families who are or were utilizing early intervention services, regarding their opinions of services and supports received; and held focus groups statewide to study the different types of support families would find useful, from initial identification throughout their enrollment in early intervention and transition to the next setting.
 - Preschool Developmental Screening Program (PDSP) – program data on referrals received for children with developmental/behavioral concerns.
 - Healthy Child Care Hawaii (HCCH) – survey of primary care pediatricians for young children, 2001. The survey included developmental, hearing, and vision screening practices and barriers. HCCH is a collaborative project of CSHNB, University of Hawaii/School of Medicine/Department of Pediatrics, and American Academy of Pediatrics-Hawaii Chapter.

POPULATION DATA AND HEALTH STATUS

Prevalence

The prevalence of CSHCN in Hawaii is 11.0-15.0%, based on Hawaii data from the National Survey of CSHCN and the National Survey of Children's Health (Table 4-1).

	National Survey of CSHCN (2001)	National Survey of Children's Health (2003)
% of CSHCN among children age 0-17 years	11.0%	15.0%
% of households with children that have CSHCN age 0-17 years	16.4%	-
Number of CSHCN age 0-17 years	32,500	44,310

Source: Hawaii data from the National Survey of CSHCN, 2001, and National Survey of Children's Health, 2003. Analysis by the Hawaii State Department of Health, Children with Special Health Needs Branch, 2004 and 2005.

The prevalence of CSHCN by demographic variables is shown in Table 4-2. Data indicate that the prevalence of CSHCN rises with age, more males than females have special health care needs, CSHCN cross all income levels, and Asians have a lower prevalence rate compared to other race/ethnic groups.

	% Children Age 0-17 Years
Prevalence By Age	
Children 0-5 years	6.6
Children 6-11 years	12.8
Children 12-17 years	13.4
Prevalence By Sex	
Male	12.4
Female	9.4
Prevalence By Poverty Level	
0%-99% FPL	10.8
100%-199% FPL	10.3
200%-399% FPL	11.8
400% FPL or greater	12.6
Prevalence By Race/Ethnicity	
Hispanic	12.2
White (non-Hispanic)	12.3
Black (non-Hispanic)	12.4
Multi-racial (non-Hispanic)	11.4
Asian (non-Hispanic)	6.7
Native American/Alaskan Native (non-Hispanic)	*
Native Hawaiian/Pacific Islander (non-Hispanic)	11.2

* Due to the small size of this group, data were suppressed to protect respondents' confidentiality.
Source: Hawaii data from the National Survey of CSHCN, 2001. Analysis by the Data Resource Center for Child and Adolescent Health, www.nschdata.org.

Health Status

Hawaii data from the National Survey of CSHCN show the overall CSHCN health status (Table 4-3).

	% CSHCN
CSHCN whose health conditions affect their activities usually, always, or a great deal	22.0
CSHCN with 11 or more days of school absences due to illness	12.2

Source: Hawaii data from the National Survey of CSHCN, 2001. Analysis by the Data Resource Center for Child and Adolescent Health, www.nschdata.org.

Hawaii data from the National Survey of Children's Health show that compared with children without special health care needs, CSHCN have significantly poorer health; more moderate/severe health problems; miss more school due to illness/injury; have more concerns regarding learning, development, or behavior; and have more difficulties with emotions, concentration, behavior, and getting along with others (Table 4-4).

	% CSHCN	% Children Without Special Health Care Needs	
Children whose overall health is excellent or very good	72.1	89.2	*
Children with health problems rated as moderate or severe by parents	37.3	0	*
School age children who missed 11 or more days of school in past year due to illness or injury	11.3	2.9	*
Children age 0-5 whose parents have one or more concerns about child's learning, development, or behavior	61.4	39.8	*
Children age 3-17 with moderate or severe difficulties in the area of emotions, concentration, behavior, or getting along with others	31.3	3.2	*

* Statistically significant difference between CSHCN and Not CSHCN rates at the 95% confidence interval.
 Source: Hawaii data from the National Survey of Children's Health, 2003. Analysis by the Data Resource Center for Child and Adolescent Health, www.nschdata.org. Statistical analysis by Hawaii State Department of Health, Children with Special Health Needs Branch, 2005.

Health Conditions

The Hawaii data from the National Survey of CSHCN and the National Survey of Children's Health show similar data for the general health care needs of CSHCN (Table 4-5).

	National Survey of CSHCN (2001)	National Survey of Children's Health (2003)
% CSHCN, who have a medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer, and:		
Need or use medicine prescribed by a doctor	69.3 %	69.6%
Need or use more medical, mental health, or educational services than is usual for most children of the same age	45.5%	38.9%
Are limited or prevented in his/her ability to do things most children of the same age can do	28.8%	28.3%
Need or get special therapy, such as physical, occupational or speech therapy	21.0%	21.3%
Have an emotional, developmental or behavioral problem that lasted or is expected to last 12 months or longer	14.1%	14.6%

Source: Hawaii data from the National Survey of CSHCN, 2001, and National Survey of Children's Health, 2003. Analysis by Hawaii State Department of Health, Children with Special Health Needs Branch, 2004 and 2005.

Hawaii data from the National Survey of Children’s Health provides some information on the health conditions of CSHCN, although the list is incomplete (Table 4-6). Families said that 44% of the health conditions or limitations were “moderate” or “severe”.

	% CSHCN
Parent has been told by a doctor or health professional that their child has this condition:	
Asthma	46.4
Attention Deficit Disorder (ADD) or Attention Deficit Hyperactive Disorder (ADHD) (<i>children >24 months</i>)	25.6
Behavioral or conduct problems (<i>children ≥24 months</i>)	20.3
Depression or anxiety problems (<i>children ≥24 months</i>)	14.8
Any developmental delay or physical impairment	13.6
Bone, joint, or muscle problems	9.1
Frequent or severe headaches, including migraines, in past year (<i>children ≥36 months</i>)	8.5
Stuttering, stammering, or other speech problems, in past year (<i>children ≥36 months</i>)	8.4
Hearing problems or vision problems that cannot be corrected with glasses or contact lenses (<i>children ≥24 months</i>)	6.4
Autism	1.7
Diabetes	0.5
Child’s health condition(s) or limitation(s) is:	
Minor	54.4
Moderate	37.4
Severe	6.8
Source: Hawaii data from the National Survey of Children’s Health, 2003. Analysis by Hawaii State Department of Health, Children with Special Health Needs Branch, 2005.	

Birth Defects

Birth defects surveillance data for 1986-2002 (Table 4-7) show that 4.5% of all infants/fetuses delivered in Hawaii had birth defects, and that 5.2% of all infants/fetuses delivered in Hawaii had adverse reproductive outcomes (birth defects, plus other health conditions such as neoplasms, congenital infections, and maternal substance use during pregnancy). The most common birth defects are cardiac & circulatory, limb & musculoskeletal, and genital & urinary conditions. The most common adverse reproductive outcome is maternal substance abuse.

	Rate		Rate
Birth Defect		Adverse Reproductive Outcome	
Hawaii birth defects rate	4.5%	Hawaii birth defects rate	5.2%
Major categories (per 10,000 births):		Major categories (per 10,000 births):	
Cardiac & circulatory	189.8	Maternal substance abuse	77.9
Limb & musculoskeletal	127.0	Neoplasms	10.0
Genital & urinary	106.3	Congenital infection	7.7
Orofacial & gastrointestinal	57.5		
Skin & integument	56.6		
Chromosome & syndrome	53.9		
Eye, ear, face, & neck	43.2		
Brain & nervous system	39.8		
Respiratory	23.8		

Source: Hawaii Birth Defects Program, December 2003. "1986-2002 Statewide Data, Surveillance Report Number 11 on Birth Defects in Hawaii".

Children Age 0-3 Served Under Part C of IDEA

Children age 0-3 years with or at risk for developmental delays are served through the Department of Health's Early Intervention Section (lead agency for Part C of Individuals with Disabilities Education Act [IDEA]), Healthy Start, and Public Health Nursing Branch. Data for 2004 show that 7.3% of the 0-3 population are receiving early intervention services, of which 4.4% have a developmental delay or are at biological risk, and 2.8% are at environmental risk (Table 4-8).

	# Children Age 0-3	% Population Age 0-3
All children with or at risk for developmental delays (<i>total</i>)	3,936	7.3%
Developmental delay or at biological risk	2,389	4.4%
At environmental risk	1,547	2.8%

* Child count on December 1, 2004.
Source: Hawaii State Department of Health, Early Intervention Section, Annual Performance Report, 2005. The population estimate for 2003 is from Annual Report Tables for 2003 (U.S. Office of Special Education Programs), www.ideadata.org.

Children and Youth Age 3-21 Served Under Part B of IDEA

Children and youth age 3-21 years with disabilities are served under Part B of IDEA by the Hawaii State Department of Education. In 2003, data show that 4.96% of children age 3-5 years, 10.27% of children age 6-17 years, and 1.03% of youth age 18-21 years are receiving special education services (Table 4-9).

Age Group	# Children/Youth in Part B	Est. Population	% Population Served Under IDEA
Age 3-5 years	2,284	46,027	4.96%
Age 6-17 years	20,220	196,859	10.27%
Age 18-21 years	762	74,324	1.03%

Source: U.S. Office of Special Education Programs, Part B Annual Report Tables for 2003, www.ideadata.org.

The disability categories are shown in Table 4-10. For children age 3-5, the most common category is developmental delay. For children/youth age 6-17 years, the most common categories are specific learning disability, emotional disturbance, other health impairment, and mental retardation. For youth age 18-21 years, the most common categories are specific learning disability, mental retardation, and emotional disturbance.

Disability	% Population Age 3-5 Years (N=2,284)	% Population Age 6-17 Years (N=20,220)	% Population Age 18-21 Years (N=762)
All disabilities	4.96%	10.27%	1.03%
Autism	0.33%	0.30%	0.03%
Deaf blindness	0%	0%	0%
Developmental delay	3.46%	0.55%	-
Emotional disturbance	0.10%	1.38%	0.18%
Hearing impairment	0.13%	0.18%	0.03%
Mental retardation	0.05%	0.92%	0.23%
Multiple disabilities	0.12%	0.15%	0.04%
Orthopedic impairment	0.04%	0.05%	0.01%
Other health impairment	0.21%	1.06%	0.06%
Specific learning disability	0.02%	4.99%	0.43%
Speech or language impairment	0.48%	0.61%	0%
Traumatic brain injury	0.01%	0.03%	0.01%
Visual impairment	0.02%	0.03%	0%

* Based on 2003 population estimates
Source: U.S. Office of Special Education Programs, Part B Annual Report Tables for 2003, www.ideadata.org.

Asthma

Based on data from the Behavioral Risk Factor Surveillance System (BRFSS), Hawaii has approximately 9.7% (28,600) children age 0-17 years who currently have asthma. Prevalence was highest for Hawaii County (12.2%), followed by City & County of Honolulu (9.5%), Maui County (8.6%), and Kauai County (8.5%). The BRFSS also showed that about 14.1% (41,600) children reported having asthma at some point in their lifetime. (Source: Hawaii State Department of Health/Asthma Control Program, "State of Asthma - Hawaii 2004".)

Acquired Immunodeficiency Syndrome (AIDS)

As of September 15, 2003, of 1,248 persons living with AIDS, 0.3% were age 13 years or younger, and 0.2% were age 13-24 years. (Source: Hawaii State Department of Health/HIV/AIDS Surveillance Program, "Integrated Epidemiologic Profile of HIV/AIDS in Hawaii", May 2005.)

Children & Youth with Disabilities Receiving SSI Payments

Data for children/youth 0-17 years with disabilities receiving SSI payments are shown in Table 4-11. Eligible children/youth must have limited income and resources, and have a chronic physical and/or mental condition that results in "marked and severe functional limitations". Data show that of children/youth receiving SSI payments, a greater proportion are in the older age groups, there are more males than females, and about 18% are not in their parent's household.

	# CSHCN	% CSHCN		# CSHCN	% CSHCN
Age (years)			Sex		
0-1	77	5.4%	Male	912	63.4%
2-3	139	9.7%	Female	526	36.6%
4-5	143	9.9%	Living arrangements		
6-7	131	9.1%	Own household	159	11.1%
8-9	184	12.8%	Another's household	77	5.4%
10-11	185	12.9%	Parent's household	1,176	81.8%
12-13	199	13.8%	Medicaid institution	26	1.8%
14-15	192	13.4%			
16-17	188	13.1%	<i>Total</i>	1,438	100%

Source: Social Security Administration. Advance data provided to the Healthy and Ready to Work National Center, February 2005.

U.S. data on conditions for children and youth age 0-17 years receiving SSI payments include: mental retardation (23.8%), other mental disorders (40.1%), nervous system and sense organs (9.7%), congenital anomalies (4.9%), respiratory system (2.7%), blood and blood-forming organs (1.3%), neoplasms (1.0%), musculoskeletal system and connective tissue (0.8%), endocrine/nutritional/metabolic disease (0.7%), and other conditions (15.0%). (Source: Social Security Administration. Children Receiving SSI, December 2003.)

Causes of Deaths

Causes of deaths for children/youth age 0-17 years include congenital anomalies and perinatal conditions (Table 4-12).

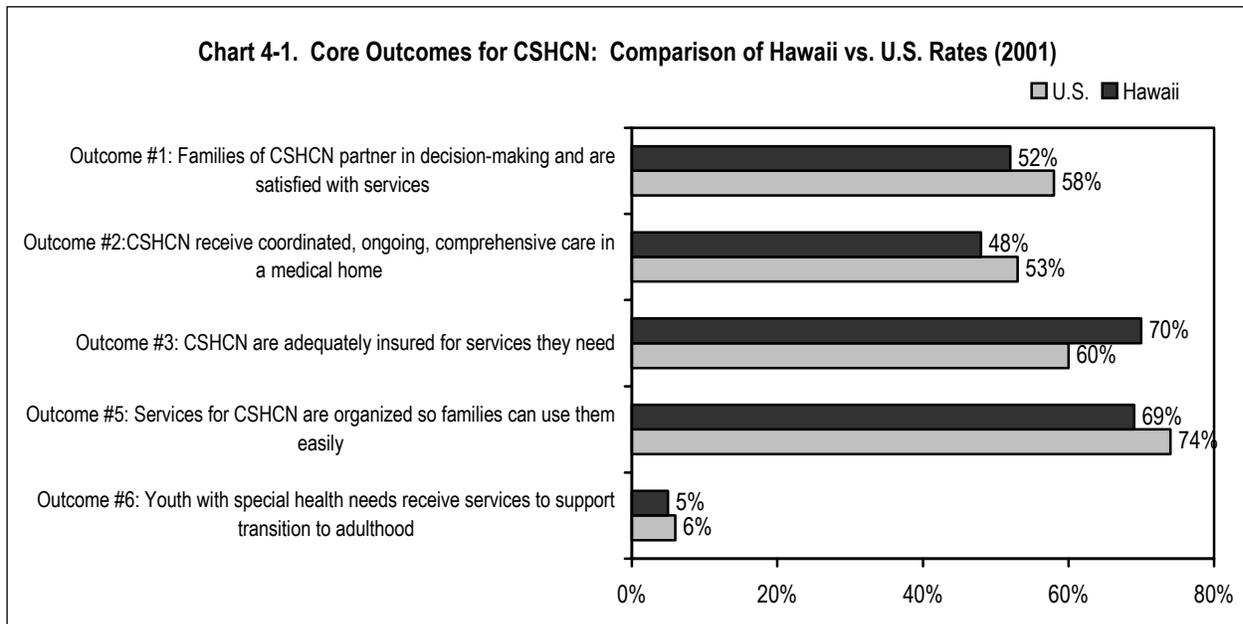
Table 4-12. Causes of Deaths for Children Age 0-17 years, Hawaii, 2003

	# Deaths	% Deaths
Leading causes of infant deaths (N=131)		
Short gestation	24	18%
Diseases of the circulatory system	9	7%
Maternal complications of pregnancy	7	5%
Hypoxia/asphyxia	5	4%
Other congenital anomaly	16	12%
Other respiratory condition	7	5%
Other hemorrhagic and hematologic disorder	6	5%
Other perinatal condition	6	5%
All other causes	51	39%
Leading causes of death for children age 0-17 years (N=190)		
Perinatal conditions	68	36%
Congenital anomalies	22	12%
Symptoms, signs, and ill-defined conditions, including sudden infant death syndrome (SIDS)	18	9%
All other causes	82	43%

Source: DOH/Office of Health Status Monitoring, Vital Statistics Report – 2003 (hawaii.gov/health/statistics/vital-statistics/vr_03/index.html).

CSHCN Core Outcomes: Comparison of Hawaii vs. U.S. Rates

The National Survey of CSHCN provided data on five of the six core outcomes for CSHCN. A comparison of rates for Hawaii and U.S. (Chart 4-1) shows that Hawaii’s low rate of 5% for outcome #6 on transition is comparable to the U.S. rate. While Hawaii’s rate is higher than the U.S. rate for insurance, and lower for the other outcomes, these differences are not statistically significant.



Source: Hawaii data from the National Survey of CSHCN, 2001. Analysis by Hawaii State Department of Health, Children with Special Health Needs Branch, 2004

CSHCN Core Outcome #1: Family Partnership in Decision-Making and Satisfaction

Hawaii data on family partnership from the National Survey of CSHCN showed:

- 52% CYSHCN/families partner in decision-making at all levels and are satisfied with the services they receive. (*CSHCN core outcome measure*)
- 81% CYSHCN/families say their doctors usually/always made family feel like a partner.
- 55% CYSHCN/families were very satisfied with the services received.

Hawaii data on family partnership from the National Survey of Children's Health showed:

- 2.6% CSHCN did not receive all needed medical care, during the past 12 months. For CSHCN not receiving needed medical care, 48.2% families said that dissatisfaction with the doctor was a reason for not getting all the care needed.
- 4.6% CSHCN did not receive all needed routine preventive dental care, during the past 12 months. For CSHCN not receiving needed dental care, 8.2% families said that dissatisfaction with the dentist was a reason for not getting all the care needed.

State/community/family participants provided the following information on family partnership at CSHCN Needs Assessment community meetings throughout the state, 2004:

- Strengths:
 - There is evidence of long-term family participation and opportunities for family involvement because of mandated participation, covering CYSHCN from birth (Hawaii Early Intervention Coordinating Council) through adulthood (State Council on Developmental Disabilities).
 - CSHNB programs include families on their advisory committees. Family participation is encouraged and supported through invitation, engagement and compensation.
 - The Special Parent Information Network, the state Parent Training Institute, and Learning Disabilities Association of Hawaii provide opportunities for families to expand their knowledge through training and conferences about the Individuals with Disabilities Education Act (IDEA) and Section 504.
 - In some communities, the Community Children's Councils have been excellent vehicles for family professional partnerships to nurture into responsible self-directed teams making decisions and policy recommendations for their school community.
- Needs:
 - Families want increased access to information regarding services/resources for CYSHCN, in order to make appropriate decisions regarding their child's care and services.
 - Families want training in navigating the system so they are fully aware of the coordination, collaboration, and resources to support CYSHCN.
 - Families want training in their child's condition at the time of diagnosis and throughout the child's development.
 - Families want opportunities to participate and "share their story" with other families, providers, and policy makers, to help shape the service system for CYSHCN.
- Opportunities:
 - Focus on families transitioning out of Early Intervention; provide them with training to understand the system so they will be able to become better advocates for their children and to participate as partners at a system level.
 - Provide networking opportunities for families to interact with professionals and other partners in their own communities, to establish relationships outside of a medical encounter.
 - Encourage all programs to have families participate on Advisory Committees.
 - Capitalize on the strength of the Community Children's Councils which have demonstrated successful family professional partnerships as a community stakeholder.

- **Challenges:**
 - Opportunities for leadership development for families are restricted to the priority areas of “funders”. For example, Learning Disabilities Association of Hawaii focuses only on the skills families need to navigate services under IDEA. It does not include navigating the health care system, or how to build partnerships within the Medical Home.
 - Service planning processes and protocols within the Department of Education, DOH/Developmental Disabilities Division, and Medicaid Waiver are based upon a process that require the families to identify needs first, and then families are informed of corresponding services. Families would prefer to know what the services are first, and then be able to explain their relevant needs. These processes lead to frustration and mistrust.

The Early Intervention Section conducted a family support survey to gather information from families who are or were utilizing early intervention services, regarding their opinions of services and supports received. This was relevant to the Early Intervention State Goal that family supports, services, and resources increase the family’s capacity to enhance outcomes for infants and toddlers and their families. Survey findings (Table 4-13) show that a high proportion of families are receiving needed services and supports.

	% Families Who Agree or Strongly Agree (N=81)
Families know who to talk to when they need help or have questions about services.	99%
Families got enough information or help when they needed it.	100%
Families got enough information to help them make informed decisions and choices about services for their child.	98%
Families' beliefs, traditions, and lifestyle were respected.	100%
Families were taught activities that helped their child grow and learn.	99%
Families were given activities that fit into their daily life.	98%
Child's services supported families' concerns, priorities, and resources	100%
Families have learned about other community resources and services.	93%

Source: Hawaii State Department of Health, Early Intervention Section, Annual Performance Report, 2005.

The Early Intervention Section studied the different types of support families that would find useful, from initial identification throughout enrollment in early intervention and transition to the next setting. A “veteran” parent conducted focus groups statewide to gather information from families as to how Hawaii’s Part C System could better support families. Focus group findings showed the following:

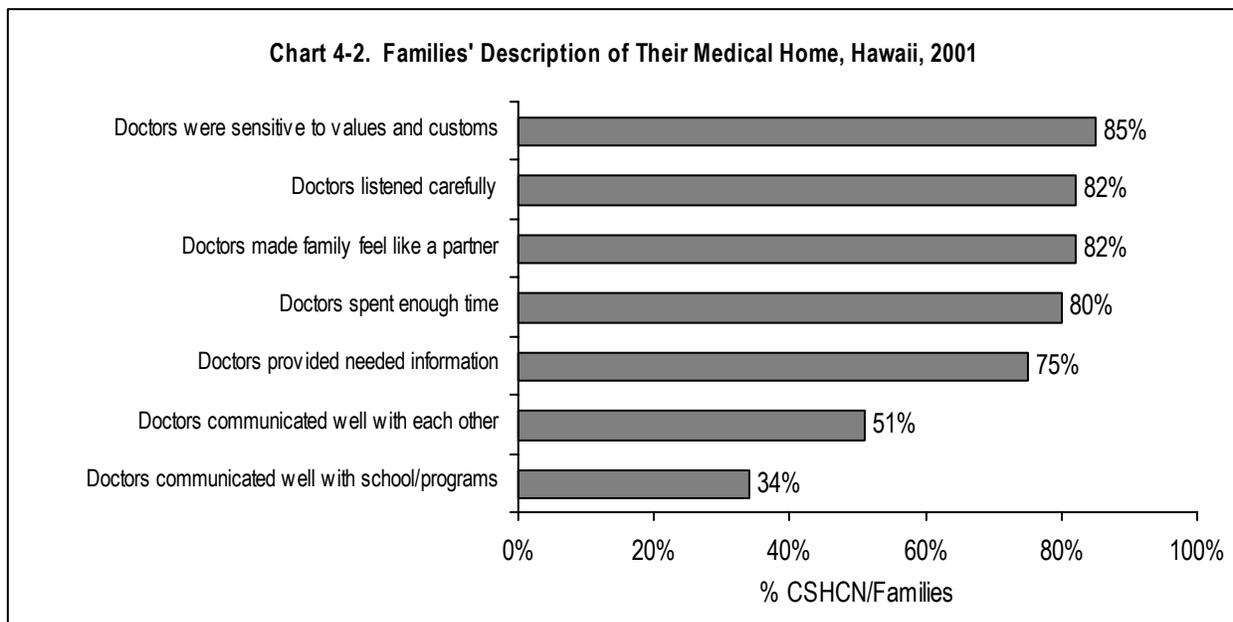
- **Preliminary findings**
 - Families want to speak with or meet other families who have “gone through the system.”
 - Families prefer a more informal setting, preferably as part of a group activity including parents and children.
 - Families were somewhat interested in a facilitated family group, but only if led by a parent mentor.
 - Families were least interested in an electronic network.
 - Parents would like to speak to other parents, but do not feel comfortable either calling a parent directly or calling a warm line; they would prefer to go through someone else and to be called by them.

- Some parents felt isolated, and their only link was the provider who came to their home.
- For some parents, the EI provider was like a “mental health therapist” who provided support for anxiety, depression, etc. As these families would have not gone for psychological counseling, having someone to talk to was a great benefit to both their child and themselves.
- Preliminary recommendations
 - Provide an array of family support options ranging from regularly scheduled “family and child get-togethers” to parent to parent phone support.
 - Provide periodic opportunities for family “in-services” or training.
 - Ensure any group facilitation is led by a parent mentor.
 - Provide meetings “outside” of IFSP meetings to bring together the team (including the family) to discuss the child’s condition and development, and to answer questions or concerns of the family.
 - Nurture the relationships built from the families that participated in these focus groups and continue the momentum, so they can see that their voice counts.

CSHCN Core Outcome #2: Medical Home

Hawaii data on medical home from the National Survey of CSHCN showed:

- 48% CYSHCN receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN core outcome measure)
- 98% CYSHCN had a usual place to go for sick care. 88% CSHCN had a usual place for preventive care. 88% CYSHCN had a personal doctor or nurse.
- 76% CYSHCN had no problems obtaining referrals when needed.
- 28% CYSHCN received effective care coordination when needed. This was based on children having professional care coordination when needed (74%), doctors communicating well with each other (51%) and with other programs (34%).
- Families’ description of their medical home is shown in Chart 4-2. In general, doctors are sensitive to values and customs, listen carefully, made families feel like a partner, and spent enough time. However, improvements were needed in the doctors’ communication with each other, schools, and other programs.



Hawaii data on medical home from the National Survey of Children's Health showed:

- 88.7% CSHCN have a personal doctor or nurse (health professional who knows child well and is familiar with child's health history).
- 79.1% CSHCN's personal doctor or nurse usually/always spent enough time with child. 93.4% CSHCN's personal doctor or nurse usually/always explained things in a way that family/child can understand.
- 98.2% families/CSHCN usually/always got the help or advice needed, when family called child's personal doctor or nurse over the phone. 90.6% CSHCN usually/always got care from his/her personal doctor or nurse as soon as wanted, when care was needed right away for an illness or injury.
- 14.2% CSHCN/families had a moderate/big problem getting care from specialist doctor(s) when needed. 83.1% CSHCN's personal doctor, nurse, or office staff helped family to get care from specialist doctor(s). 63.5% CSHCN's personal doctor or nurse usually/always talked with family about what happens during visits to specialist doctor(s).
- 100% CSHCN/families were able to usually/always get someone other than a family member to help speak with the doctors or nurses, when an interpreter was needed.
- Of CSHCN who did not receive all needed medical care during the past 12 months, 48.2% families said that a reason was that they couldn't find a doctor who accepted the child's insurance, and 13.6% said a reason was that their doctor did not know how to treat or provide care.
- Of CSHCN who did not receive all needed routine preventive dental care during the past 12 months, 30.1% families said that a reason was not convenient times or they could not get appointment, and 9.0% said that a reason was that they couldn't find a dentist who accepted child's insurance.
- Of CSHCN who did not receive all needed prescription medication during the past 12 months, 80.4% families said that a reason was that the doctor did not know how to treat or provide care.

State/community/family participants provided the following information on medical home at CSHCN

Needs Assessment community meetings throughout the state, 2004:

- Strengths:
 - AAP-Hawaii Chapter has been a champion of several initiatives relative to CYSHCN (Genetics, Metabolic Screening, School Health, etc).
 - Community pediatricians committed to serving CYSHCN are willing to find ways to strengthen the medical home (which may include continued education, participation in service planning meetings, home visitation, etc.).
- Needs:
 - Increased coordination/collaboration between primary care and other providers, community agencies, and programs (emergency services, subspecialists, DOE, etc.).
 - Increased access to Medical Homes.
 - Expand the Medical Home concept to Family and General Practitioners.
 - Increased access to pediatric subspecialists on the neighbor islands.
- Opportunities:
 - Expand residency programs to require training on the Medical Home.
 - Provide "learning opportunities" for primary care providers to understand the roles of the other members of a health care team.
 - Distribute a resource guide for physicians/staff – by island for whole state.
- Challenges:
 - Many established community pediatricians have not made time or expressed an interest in

- o participating in Medical Home building opportunities.
- o Geographic pockets of our state do not have access to pediatricians.
- o There are no vehicles to obtain reimbursement for physicians to participate in service planning activities (Individual Family Support Plan, Individual Education Plan, etc.).

CSHCN Core Outcome #3: Adequate Health Insurance

Hawaii data on health insurance from the National Survey of CSHCN showed:

- o 70% CSHCN have adequate private and/or public insurance to pay for needed services. (CSHCN core outcome measure)
- o 97.7% CSHCN have health insurance coverage.
- o 94% CYSHCN had no gaps in coverage during previous year.
- o 11% CYSHCN had insurance that never or only sometimes met their needs.
- o 22% CYSHCN had costs (not covered by insurance) that were not reasonable.
- o 10% CYSHCN had insurance that never or only sometimes permitted child to see needed providers.

Hawaii data on health insurance from the National Survey of Children's Health showed:

- o 93.2% CSHCN had health coverage, including health insurance, prepaid plans such as HMO's, or government programs such as Medicaid. This rate was not significantly different from the 95.1% children without special health care needs who had insurance coverage.
- o 12.0% CSHCN were covered by health insurance for only a portion of the past 12 months.
- o 87.8% CSHCN had insurance that helped to pay for routine dental care including cleanings, x-rays and examinations.
- o Of CSHCN who did not receive all needed medical care during the past 12 months, reasons included: 71.6% - cost too much; 67.4% - no insurance; 48.2% - health plan problem; 48.2% - can't find doctor who accepts child's insurance.
- o Of CSHCN who did not receive all needed routine preventive dental care during the past 12 months, reasons included: 44.3% - cost too much; 27.9% - no insurance; 9.0% - can't find dentist who accepts child's insurance; 8.1% - health plan problem.
- o Of CSHCN who did not receive all needed prescription medication during the past 12 months, reasons included: 19.6% - cost too much; 19.6% - no insurance.

State/community/family participants provided the following information on health insurance at CSHCN

Needs Assessment community meetings throughout the state, 2004:

- Strengths:
 - o State Medicaid program provides the most comprehensive coverage for CYSHCN. Hawaii's State Children's Health Insurance Program (SCHIP) is a Medicaid expansion providing comprehensive benefits for children up to 200% Federal Poverty Level.
 - o State has had mandated employer-provided health insurance for employees who work more than 19 hours a week for 3 consecutive weeks since 1975 under the Prepaid Health Care Act.
- Needs:
 - o There needs to be a baseline of care established for CYSHCN prior to the conversion of our state Medicaid program from fee for service to managed care.
 - o State programs and services funded through Medicaid, Medicaid Home and Community Based Waiver Programs, and EPSDT need better coordination and collaboration.

- Families need training opportunities to learn about insurance benefits or Medicaid system.
- Commercial insurance needs to provide coverage for transportation for parents as well as CYSHCN to access services on Oahu, that are not provided in their home communities on the neighbor islands.
- Opportunities:
 - Families have an opportunity to participate in the re-design of Medicaid in Hawaii, through the State Medicaid Managed Care Advisory Council.
 - Establish a virtual One Stop Center to help families find services and resources.
 - Provide “learning opportunities for families” to learn about their insurance and how to navigate the system.
- Challenges:
 - Commercial insurance companies and health plans in our state have no systematic way to identify CYSHCN, let alone their service and claims history as a group.
 - The state Medicaid program is converting to an entirely managed care model. There are concerns about an adverse impact on health care access for CYSHCN.
 - Some employers restrict the hours of employment for their employees so they do not have to comply with the Prepaid Health Care Act. Some parents have multiple part-time jobs so they can receive “full time” salary, but still lack the health care benefit.

CSHCN Core Outcome #4: Early and Continuous Screening

State/community/family participants provided the following information on screening at CSHCN Needs Assessment community meetings throughout the state, 2004:

- Strengths:
 - Programs and agencies serving CYSHCN are using similar standardized screening tools to validate development, identify delays, and customize curriculum to meet the needs of their children.
 - Specific best practices are emerging where there is cross-training on screening tools.
 - Families are resilient and resourceful and may initiate screening with the medical home, to address a perceived delay or developmental concerns.
- Needs:
 - School screening for vision, hearing, scoliosis, and height/weight is no longer done.
 - The referral system is extremely weak, once a child has been screened and is in need of further evaluation; primary care providers are not consistently making referrals.
 - Need more screening tools in native languages.
- Opportunities:
 - Because of the heightened awareness currently around screening, provide opportunities for interagency collaboration with the Medical Home to refine the screening and referral processes.
 - Provide opportunities to families to learn about periodic screening and its importance.
 - Provide mentors in the community to assist primary care providers.
- Challenges:
 - Because of various reasons for conducting screening within the community, the adoption of a “statewide” tool may be restrictive to certain provider types.
 - Some physicians view screening as time intensive and laborious and that insurance companies bundle screening into the “well baby visit”, therefore they are unable to get reimbursed for the “extra time” spent on the screening.
 - Because basic vision, hearing, height/weight, dental and scoliosis screens are no longer provided in schools, there are concerns about the “gap group” of children who do not have primary care and once in the school system may not have access to regular screening.

Newborn Metabolic Screening

In July 1997, the number of disorders screened increased from two disorders (phenylketonuria, congenital hypothyroidism) to seven disorders (with the addition of biotinidase deficiency, congenital adrenal hyperplasia, galactosemia, hemoglobinopathies, and maple syrup urine disease). Table 4-14 shows the incidence of these disorders in Hawaii (with U.S. comparison).

Table 4-14. Incidence of Disorders Identified Through Newborn Metabolic Screening, Hawaii, July 1997 - May 2005			
Disorder	Hawaii		U.S. Incidence
	# Cases	Incidence	
Biotinidase deficiency	2 profound 2 partial	1/34,783	1/70,000
Congenital adrenal hyperplasia	3 salt-wasters 3 virilized	1/23,189	1/15,000
Congenital hypothyroidism	53 primary 2 hypopituitary 1 compensated 1 undetermined 17 transient	1/2,625	1/4,000
Galactosemia	0 classic 9 Duarte variants 1 Los Angeles Duarte	0/139,131	1/60,000
Hemoglobinopathies	2 sickle cell (SS) disease 3 sickle C (SC) disease 1 C disease (CC) 1 F only 8 probable Hemoglobin E disease 131 possible Hemoglobin H disease 1 Hemoglobin Lepore 1 New York variant 605 S trait 401 E trait 149 C trait 26 D or G trait 3,050 alpha thalassemia (Bart's) trait	1/27,826	1/15,000 general population
Maple syrup urine disease	4 classic 1 intermediate	1/27,826	1/250,000
Phenylketonuria (PKU)	2 classic 1 hyperphenylalaninemia	1/46,377	1/18,000

Source: Hawaii State Department of Health, Newborn Metabolic Screening Program, 2005.

In September 2003, the newborn screening panel expanded from 7 to 31 disorders, with the addition of 24 disorders (amino acid, urea cycle, organic acid, and fatty acid disorders) screened using tandem mass spectrometry. Up to May 2005, one case each of medium-chain acyl-CoA dehydrogenase deficiency (MCADD), holocarboxylase synthetase deficiency, and carnitine palmitoyl transferase I deficiency (CPT I) were diagnosed.

In 2004, 99.7% of eligible newborns received metabolic screening. Of infants confirmed with metabolic disorders, 100% (12/12) infants received appropriate follow-up. All confirmed cases are under medical supervision and none have been lost to follow-up. Quality assurance data regarding timing of specimen collection and transit shows generally acceptable rates for specimen collection >7 days (0.57%); specimen over 5 days in transit (2.26%, partially due to severe weather and holidays); turnaround time (average 3.58

days, maximum 6.53 days); specimens <6 days (98.83%); and inadequate specimens <24 hours (0.99%).

The following are needs regarding newborn metabolic screening:

- A medical community decision is needed on whether newborn screening should include cystic fibrosis. A 2005 report “Newborn Screening: Toward a Uniform Screening Panel and System” recommended a national core panel of disorders for screening (American College of Medical Genetics report, commissioned by the MCH Bureau, www.mchb.hrsa.gov/screening/summary.htm). Cystic fibrosis is the only disorder in the core panel that is not currently in Hawaii’s newborn screening panel.
- Children with metabolic disorders must have access to appropriate genetic/metabolic services. Issues include sufficient funding for genetic/metabolic services, adequate insurance reimbursement, need for additional nutritionists with metabolic experience, and health care organization referrals.
- Expansion of the Hemoglobinopathy Clinic is needed for sickle cell disease and trait follow-up/genetic counseling.
- The Genetics Program with the Newborn Metabolic Screening Program has used focus groups to develop a brochure and a large poster on newborn metabolic screening. A study is needed to determine whether the poster or brochure is more effective in the obstetricians’ office waiting room or exam room.

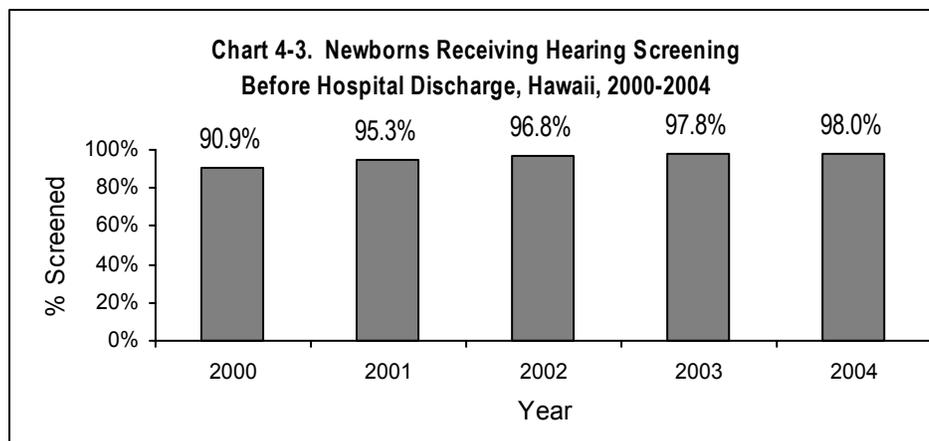
Source: Hawaii State Department of Health, Newborn Metabolic Screening Program, 2005.

Newborn Hearing Screening

The Newborn Hearing Screening Program (NHSP) began in 1990 through a law that mandated that the Department of Health develop methodology to establish a statewide program for screening of infants and children age 0-3 with hearing loss. Amendment of the law in 2001 mandated screening of all newborns for hearing loss and reporting screening results to the DOH.

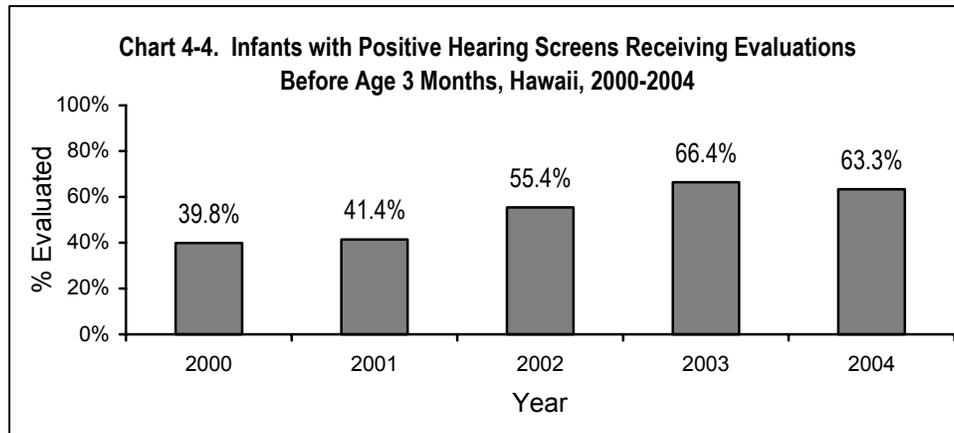
Screening began in 2 hospitals in 1992, was provided in all birthing facilities by 1999 and is now part of standard newborn care in Hawaii. Each birthing facility has a newborn hearing screening program.

Data on Hawaii newborns receiving hearing screening before hospital discharge, 2000-2004 (Chart 4-3) show a 2004 rate of 98.0%. This is close to meeting the national standard that all newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.



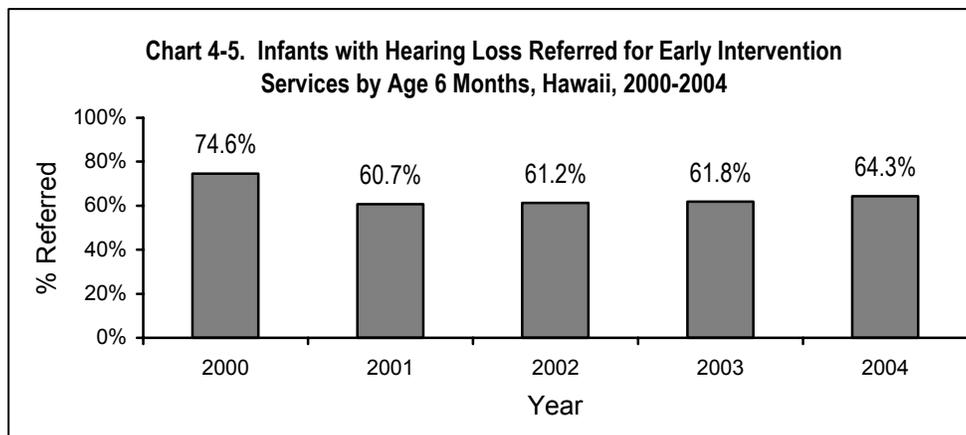
Source: Hawaii State Department of Health, Newborn Hearing Screening Program, 6/20/05. Denominator is the number of births, excluding deaths <24 hours.

Data on Hawaii infants with positive screens receiving evaluation before age 3 months, 2000-2004 (Chart 4-4) show a 2004 rate of 63.3%. This indicates a need for improvement to meet the national standard that all infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age.



Source: Hawaii State Department of Health, Newborn Hearing Screening Program, 6/20/05. Denominator is the number of infants referred for diagnostic audiologic evaluation who did not pass the newborn screen.

Data on Hawaii infants with permanent hearing loss after positive screens who were referred for early intervention (EI) services before age 6 months, 2000-2004 (Chart 4-5) show a 2004 rate of 64.3%. This indicates a need for improvement to meet the national standard that all infants [with positive screens] identified with a hearing loss will begin receiving appropriate early intervention services before age 6 months.



Source: Hawaii State Department of Health, Newborn Hearing Screening Program, 6/20/05. Denominator is the number of infants with permanent hearing loss who did not pass the newborn screen.

Of 18,141 births in 2003, there were 54 (0.3%) children who were identified with a permanent childhood hearing loss through newborn hearing screening. Table 4-15 shows the types and severity of hearing loss.

Type of Hearing Loss	Children with Permanent Congenital Hearing Loss					
	Total		Mild	Moderate	Severe	Profound
	#	%	#	#	#	#
Unilateral	23	43%				
Sensorineural	9	17%	5	2	1	1
Conductive	12	22%	-	12	-	-
Mixed	2	4%	-	2	-	0
Bilateral	31	57%				
Sensorineural	23	43%	9	4	8	2
Conductive	2	4%	-	2	-	-
Mixed	6	11%	-	2	4	-
Total	54	100%	14	24	13	3

Source: Hawaii State Department of Health, Newborn Hearing Screening Program, "Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DPSHWA) Data Reporting Form – Reporting Year 2003".

The following are needs regarding newborn hearing screening:

- Screening by age 1 month:
 - Hospitals: ABR screening equipment is needed for rural hospitals with a small number of births to permit two-technology screening. Two-technology screening will help hospitals reduce the number of babies falsely identified on inpatient screens because it will give hospitals two different ways to find out if babies can hear. When false positive results are decreased, fewer babies require outpatient rescreening. When fewer babies require outpatient rescreening, fewer babies are at risk of not completing outpatient follow-up. Handheld screening ABR equipment that can store results for a few children at a time would be appropriate in hospitals that have less than 600 or so births per year. Hospitals with higher annual birth rates would likely need PC based screening ABR equipment that has more data capacity. In addition, screening ABR equipment will function as backup equipment in hospitals that do not have backup equipment, in order to reduce the number of infants who miss screening due to breakdown of OAE screening equipment.
 - Homebirths: Outreach to educate midwives on newborn hearing screening is needed to increase screening rates for homebirths.
 - Education: Comprehensive outreach to provide information on the importance of screening and follow-up to primary care providers, public health nurses, midwives, and other community providers statewide, would increase compliance with EHDl timelines and protocols. This may help health care providers encourage and clearly communicate to families about the importance of obtaining the re-screen or diagnostic audiologic evaluation.
 - Data and tracking system: The State NHSP needs to obtain individual child record data from all hospitals in order to maintain a complete database for quality assurance and monitoring that all infants are screened for hearing.
 - Infrastructure: Completion of the process to establish administrative rules is needed to permit the Department of Health to refine statewide standards and guidelines for conducting and reporting child specific results of newborn hearing screening, evaluation and intervention for all infants. The State NHSP and Early Intervention Section do not have an audiologist on staff to provide audiologic consultation/support for NHSP and early intervention care coordinators; review audiologic reports to confirm hearing loss and recommend referral for early intervention services; quality assurance; review policies and procedures; and review informational materials. NHSP therefore needs to contract with an audiologist for this consultation.

- Diagnostic audiologic evaluation by age 3 months:
 - Education: The newborn hearing screening and intervention manual for primary care providers needs to be completed. Protocols for services from newborn hearing screening to early intervention should be reviewed for consistency with the manual.
 - Audiology services: Families in rural areas need improved access to diagnostic audiological evaluations. Difficulties include lack of or limited availability of diagnostic equipment and audiological services on several Neighbor Islands. Infant audiological assessment guidelines need to be reviewed for consistency with the Provider manual and current best practice.
 - Data and tracking system: The data collection process needs to be improved so that the state NHSP consistently receives information about audiologic evaluations and diagnosis of permanent hearing loss after infants are referred for evaluation. Part of the difficulty relates to Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) issues related to early intervention services sharing data with State NHSP. Need to streamline the data analysis process for identifying infants who passed the newborn hearing screen but were later referred for evaluation. Currently this is possible only by looking at individual records.

- Infants with hearing loss receiving appropriate intervention services by age 6 months:
 - Education: Materials, brochures and resource guides are needed in several languages for use with families, physicians and service providers across the state. Additional inservice training opportunities are needed on each island to increase skills and knowledge of physicians, service providers, families, and early intervention care coordinators.
 - Family support: Additional family-to-family support opportunities are needed on all islands. Additional materials are needed to increase inter-island access to lending library materials.
 - Data and tracking system: The data collection process needs to be improved so that the state NHSP consistently receives information about EI enrollment after infants with hearing loss are referred for EI services. Part of the difficulty relates to Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) issues related to early intervention services sharing data with State NHSP. The data analysis process needs to be streamlined in order to identify infants who passed the newborn hearing screen but were later identified with hearing loss. Currently this is possible only by looking at individual records.

Source: Hawaii State Department of Health, Newborn Hearing Screening Program, 2005.

Developmental Screening for Young Children

Hawaii data on developmental/behavioral screening from the National Survey of Children's Health showed:

- Of children age 0-5 years who have seen doctors during the past 12 months, 58.8% CSHCN's doctors or other health care professionals asked if family had concerns about child's learning, development, or behavior.
- Of children age 0-5 years with concerns who have seen doctors during the past 12 months, 51.7% CSHCN's doctors or other health care professionals gave family specific information to address family's concerns about child's learning, development, or behavior.

A survey of physicians was conducted by Healthy Child Care Hawaii (HCCH) in 2001, in part to obtain information on developmental, hearing, and vision screening of young children. The survey was mailed to 648 physicians who were Vaccines for Children providers, American Academy of Pediatrics- Hawaii Chapter members, or Hawaii Medical Association members who had a combined Internal Medicine/Pediatrics specialty. Regarding developmental screening, of 144 providers of primary care for children age 3-4 years:

- 77% screened most (75-100%) of their children age 3-4 years for development.
- 8% screened only a small proportion (0-25%) of their children age 3-4 years for development.

- 71% screened children using standardized or objective tests.
- Barriers to development screening included: difficulty getting child to test (32%), lack of staff time (27%), reimbursement (20%), lack of staff trained to screen (16%), and no screening tool in office (9%).
- 38% are interested in training in developmental screening for their staff.

Source: Healthy Child Care Hawaii, "A Survey of Physicians on Child Care Health Consultation and Screening of Young Children - May 2001".

- Data from the Preschool Developmental Screening Program (PDSP) indicate the importance of screening and follow-up for preschool-aged children with developmental/behavioral concerns, and PDSP's essential role in the system of follow-up for children with such concerns. During FY2005, PDSP received 876 referrals from physicians, families, H-KISS (early intervention central information and referral line), community agencies, and other sources. As a result of screening/evaluation, 189 (22%) children required speech evaluations, 32 (4%) needed psychological evaluations, and 168 (19%) were referred to the Department of Education special education preschool. (Source: Hawaii State Department of Health, Preschool Developmental Screening Program, 2005)

Vision Screening for Young Children

The HCCH survey described above showed that for vision screening, of 144 providers of primary care for children age 3-4 years:

- 67% screened most (75-100%) of their children age 3-4 years for vision.
- 8% screened only a small proportion (0-25%) of their children age 3-4 years for vision.
- 73% screened children using standardized or objective tests.
- Barriers to vision screening included: difficulty getting child to test (61%), lack of staff time (18%), reimbursement (21%), lack of staff trained to screen (11%), and no screening tool or equipment in office (10%).
- 32% are interested in training in vision screening for their staff.

Source: Healthy Child Care Hawaii, "A Survey of Physicians on Child Care Health Consultation and Screening of Young Children - May 2001".

Hearing Screening for Children

The HCCH survey described above showed that for hearing screening, of 144 providers of primary care for children age 3-4 years:

- 66% screened most (75-100%) of their children age 3-4 years for hearing.
- 9% screened only a small proportion (0-25%) of their children age 3-4 years for hearing.
- 67% screened children using standardized or objective tests.
- Barriers to hearing screening included: difficulty getting child to test (60%), lack of staff time (21%), reimbursement (21%), lack of staff trained to screen (11%), and no screening tool or equipment in office (11%).
- 33% are interested in training in hearing screening for their staff.

Source: Healthy Child Care Hawaii, "A Survey of Physicians on Child Care Health Consultation and Screening of Young Children - May 2001".

To determine the extent to which hearing loss was identified in school-age children, the Department of Health/Children with Special Health Needs Program conducted a hearing and vision screening needs assessment study in elementary and middle schools (grades preschool, K, 1, 2, 5, 7) in two school districts on Oahu from January to June 2000. The study was a follow-up to the elimination of the Department of Health/Hearing and Vision Program in 1995 as a result of budget restrictions and the view that this screening was the responsibility of primary care providers. The study showed that of 951 children screened for hearing, 52 (5.5%) children failed screening and were referred for further evaluation, and that of 1,250 children screened for vision, 45 (3.6%) children failed screening and were referred for further evaluation.

Source: Hawaii State Department of Health, Children with Special Health Needs Program, 2000.

CSHCN Core Outcome #5: Community-Based Service Systems are Easy to Use

Hawaii data on systems from the National Survey of CSHCN showed:

- 69% CSHCN/ families report that community-based service systems are organized so they can use them easily. (CSHCN core outcome measure)

Hawaii data from the National Survey of Children’s Health on access to health care are shown in Table 4-16.

Table 4-16. Access to Health Care Services, Hawaii, 2003	
	% CSHCN
Medical Care	
CSHCN age 0-17 years who did not receive all needed medical care, during past 12 months	2.6
For CSHCN not receiving needed medical care, reason included:	
Can’t find doctor who accepts child’s insurance	48.2
Not available in area/transport problems	48.2
Did not know where to go for treatment	48.2
Doctor did not know how to treat or provide care	13.6
Dental Care	
CSHCN age 0-17 years who did not receive all needed routine preventive dental care, during past 12 months	4.6
For CSHCN not receiving needed dental care, reasons included:	
Not convenient times/ could not get appointment	30.1
Can’t find dentist who accepts child’s insurance	9.0
Not available in area/transport problems	8.1
Prescription Medications	
CSHCN age 0-17 years who did not receive all needed prescription medication, during past 12 months	0.6
For CSHCN not receiving needed prescription medication, reasons included:	
Doctor did not know how to treat or provide care	80.4
Source: Hawaii data from the National Survey of Children’s Health, 2003. Analysis by Hawaii State Department of Health, Children with Special Health Needs Branch, 2005.	

State/community/family participants provided the following information on systems at CSHCN Needs Assessment community meetings throughout the state, 2004:

- Strengths:
 - There is strong collaboration and coordination between the primary service agencies within Early Intervention (Early Intervention Section, Public Health Nursing, Healthy Start and numerous contracted providers).
 - There are very strong community based STEPS teams that focus on supporting transitioning children from Early Intervention (Part C services) to Special Education (Part B services).
- Needs:
 - There is an ongoing need for awareness and education amongst professionals and parents as to the resources and services in the communities and how to access them.
 - Families have difficulty finding an “entry point” once they are in the system, and need a mechanism to access services regardless of the entry point.
 - There is inconsistency in the knowledge of community services and resources amongst providers and agency personnel, limiting access as families may not know these services exist.
 - Access to pediatric subspecialty care continues to be a problem on the neighbor islands.
- Opportunities:
 - Strengthen and structure the referral processes between agencies and programs to facilitate coordinated services and minimize fragmented services.
 - Provide learning opportunities for families, providers, agencies, and others working with CYSHCN on the resources and services available to children.
 - Look at the concept of a virtual One Stop Center and expand the information database with the state Real Choices® System and 211.
 - Utilize telemedicine to support the needs of CYSCHN on the neighbor islands.
- Challenges:
 - With significant progress in identifying CYSHCN, provider capacity has increased to meet the needs of the children. However, many new providers and agencies servicing our community are unaware of community resources. Many of these providers have come from other service delivery models that are not based upon Family Centered Care, and lack fundamental competencies to provide coordination and family support.
 - Medical Case Management is provided to specific groups of CYSHCN who meet specific eligibility criteria. While we have ensured that our most vulnerable CYSHCN are provided these services, families who do not meet income, diagnosis, or level of care requirements are tasked to provide their own case management. Families currently do not have tools, protocols, standards, or training to do this kind of case management.

To study factors contributing to difficulty using community-based services by families of CSHCN in Hawaii, data from the 2001 National Survey of CSHCN were analyzed. Logistic regression analysis showed that the odds of reporting difficulties in using community-based services were almost 5 times higher for families who did not partner in decision-making, 2.9 times higher for families who did not receive family-centered coordinated care, and 2.7 times higher for families who did not have adequate health insurance than for families who were satisfied with the care received. It was concluded that families who reported difficulties in using community-based services have children who need extensive and varied services. Lack of involvement in decision-making, lack of coordinated care in a medical home, and insufficient health insurance were the main obstacles to their ability to use community-based services easily. The article “Factors Associated with Ease of Using Community-Based Systems of Care for CSHCN in Hawaii”, by G. Baruffi, C. Prince, L. Miyashiro, and P. Heu, has been accepted for publication in the Maternal and Child Health Journal.

CSHCN Core Outcome #6: Transition to Adult Life

Hawaii data on health insurance from the National Survey of CSHCN showed:

- 5% youth with special health care needs (YSHCN) have received the services necessary to make transitions to all aspects of adult life. *(CSHCN core outcome measure)*
- 60% YSHCN have doctors who talked about changing needs as youth becomes an adult.
- 54% YSHCN have a plan for addressing changing needs.
- 36% YSHCN have doctors who discussed the shift to an adult health care provider.
- 29% YSHCN have received vocational or career training.

Hawaii data for children 6-17 years from the National Survey of Children's Health, related to transition to adult life, including work and independence, are shown in Table 4-17. Data show that CSHCN have significantly higher proportions of school-related problems, compared to children without special health care needs. Having school problems could impact the eventual transition to adult employment.

Children Age 6-17 Years	% CSHCN	% Children Without Special Health Care Needs	
School			
During the past 12 months, child/youth missed 11 or more days of school due to illness or injury, during the past 12 months	8.2	1.8	*
For children enrolled in school, child/youth's school contacted family two or more times about problems child was having with school, during the past 12 months	36.0	12.3	*
Starting with kindergarten, child/youth has repeated grades	14.3	5.9	*
School/Community Activities			
Child/youth was on a sports team or took sports lessons after school or on weekends, during the past 12 months	54.2	64.3	
Child/youth participated in clubs or organizations (such as Scouts, religious group, Boys/Girls club) after school or on weekends, during the past 12 months	53.9	48.0	
Child/youth participated in other organized events or activities, during the past 12 months	7.4	6.2	
Youth Service Or Work			
Youth age 12 years and older has been involved in community service or volunteer work at school, church, or in the community, during the past 12 months	64.5	67.8	
Youth age 12 years and older has worked for pay	15.7	14.8	
* Statistically significant difference between CSHCN and Not CSHCN rates at the 95% confidence interval. Source: Hawaii data from the National Survey of Children's Health, 2003. Analysis by Hawaii State Department of Health, Children with Special Health Needs Branch, 2005.			

State/community/family participants provided the following information on transition at CSHCN Needs Assessment community meetings throughout the state, 2004:

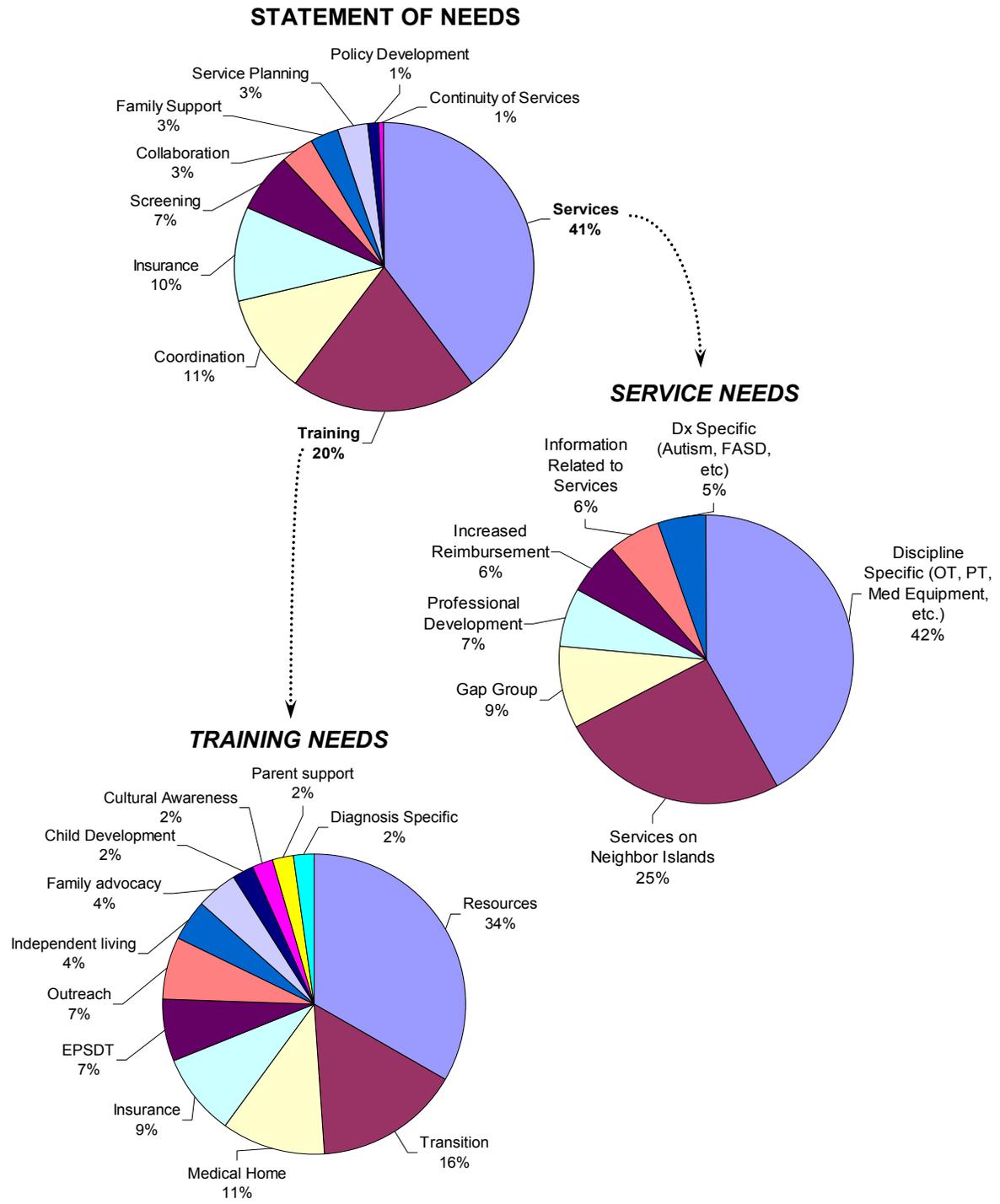
- **Strengths:**
 - There is a lot of momentum focusing on the area of transition for youth with developmental

- disabilities within the state, primarily focused on consumer directed services.
- Hawaii received a grant from the Administration on Developmental Disabilities Family Support 360 One Stop Center, which will focus on “virtual” one stops for transitioning youth and families.
- DOH/Children with Special Needs Program supports children/youth from birth through 21.
- Needs:
 - Better coordination is needed between Department of Education, Vocational Rehabilitation, and the Developmental Disabilities Division. Statewide policies outlining referral and coordinated services planning need to be implemented.
 - Many pediatricians follow YSHCN through adulthood because they cannot find an appropriate adult medicine physician.
- Opportunities:
 - Develop a cadre of physicians to mentor adult medicine physicians to take YSHCN into their practices at adulthood.
 - Develop statewide best practices/tools to facilitate transition of primary care for YSHCN.
 - Support the Family Support 360 One Stop Center.
- Challenges:
 - The state of Hawaii is aging, creating a large demand on adult medicine providers. There is no financial incentive for adult primary care physicians to take YSHCN into their practices, as their practices are already filled to capacity.
 - Programs for young adults are based upon funder priorities and may be restrictive. This creates silos which are difficult to transcend, let alone understand. It also created a system whereby YSHCN have to pursue opportunities in a sequential nature to receive the appropriate “denial”, in order to then move to the next program.
 - Only 4 agencies within the state provide supportive employment through the Vocational Rehabilitation Division. The most experienced agency, Winners at Work, provides services on Oahu. There are very few opportunities on the neighbor islands.

Summary of Needs Identified at the CSHCN Needs Assessment Community Meetings

The CSHCN Needs Assessment community meetings in 2004 involved over 200 parents and state/community partners, on the islands of Oahu, Kauai, Maui, and Hawaii. Responses were recorded and thematically labeled and aggregated (Chart 4-6). By stated needs, services are the largest need (41%), followed by training (20%), coordination (11%), and insurance (10%). Further analysis of service needs showed that discipline specific (OT, PT, medical equipment, etc.) were the most needed (42%), followed by services on the Neighbor Islands (25%), and gap group (9%). Further analysis of training needs showed that training on resources was the greatest need (34%), followed by transition (18%), medical home (11%), and insurance (9%).

Chart 4-6. Summary of Needs Identified at the CSHCN Needs Assessment Community Meetings, Hawaii, 2004



DIRECT HEALTH CARE AND ENABLING SERVICES

Financial Access to Health Care and Health-Related Services

Health Insurance

- In 1974, the Prepaid Health Act mandated that all employers provide health insurance to employees working more than 19 hours a week. This has had a major impact on assuring that a large segment of Hawaii residents had health insurance coverage. However, being uninsured and underinsured are still concerns.

- Uninsured Rates

- Estimated uninsured rates range from 2.3 to 9.9%.

- The Hawaii uninsured rate from the Current Population Survey was 9.9%, based on a 3-year average from 2001 to 2003. (Source: U.S. Census Bureau, Current Population Survey, 2002 to 2004, Annual Social and Economic Supplements).

- The 2003 Hawaii Health Survey showed that 63,693 individuals (5.2% of the population) in Hawaii were uninsured. Uninsured rates were highest for Hawaiian/Part Hawaiian (7.0%), followed by Caucasian (6.4%), Filipino (3.9%), Chinese (3.5%), and Japanese (2.0%); the rate for the other/unknown group was 7.7%. Hawaii County had the highest percentage of uninsured residents (9.2%), followed by Maui County (8.1%), Kauai County (7.0%), and City & County of Honolulu (Oahu) (3.9%). Of the 8,388 children between age 0-17 years who were uninsured, 6,267 (2.6%) were children age 0-14 years, and 2,121 (4.3%) were youths age 15-17 years.

- Hawaii data from the National Survey of CSHCN showed an uninsured rate of 2.7% for CSHCN age 0-17 years.

- Hawaii data from the National Survey of Children's Health showed an uninsured rate of 5.5% for children age 0-17 years, with a rate of 7.1% for CSHCN and 5.2% for children without special health care needs.

Insurance Problems

Hawaii data from the National Survey of CSHCN show that families have problems with insurance:

- 11% CSHCN had insurance that never or only sometimes met their needs.
- 22% CSHCN had costs (not covered by insurance) that were not reasonable.
- 10% CSHCN had insurance that never or only sometimes permitted child to see needed providers.
- 13% CSHCN/families believe their child's health plan is not good for CSHCN.
- 12% CSHCN/families called/wrote to any of the child's health plans with a complaint or problem.
- 25% CSHCN/families, if they had a chance, would switch to a different health care plan.
- Hawaii data from the National Survey of CSHCN also indicate that an estimated 12% CSHCN are underinsured (based on health insurance not paying for a needed service, or inability of a family with health to afford out-of-pocket costs for services):
 - 3% CSHCN with insurance did not get or delayed needed care because of cost for services such as preventive care, specialty care, dental care, prescription medication, physical therapy, occupational therapy, speech therapy, mental health, substance abuse treatment/counseling, respite, genetic counseling.

- 9% families of CSHCN with insurance paid over \$500 in out-of-pocket costs for medical/health-related expenses in the past year, and had financial problems caused by their child's health conditions or needed additional income to cover their child's medical expenses.

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- Financial Difficulties for Families

- Hawaii data from the National Survey of CSHCN show some of the financial difficulties that families face in getting needed services:

- 43% families of CSHCN paid \$1,000 or more out-of-pocket for medical care / health-related needs in the previous year.
- 13% families of CSHCN had financial problems caused by their child's condition.
- 14% families of CSHCN needed additional income to cover their child's medical expenses.
- 29% CSHCN had family members whose employment was affected by the child's condition (for example, reduced work hours or stopped working).

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- Medicaid Changes

- The Medicaid QUEST managed care program currently covers adults with incomes at or below 100% of the federal poverty level (FPL) and uninsured children with family incomes at or below 200% FPL. In addition, a QUEST-Net program provides full Medicaid benefit for children with family incomes 200-300% FPL and a limited benefit package for adults with incomes at or below 300% FPL; to be eligible, individuals must be enrolled in QUEST or Medicaid fee-for-service when their income or assets rise above the QUEST or Medicaid FFS eligibility limits.

Hawaii is proposing changes to QUEST managed care program to include:

- The Aged, Blind, and Disabled (ABD) population (with some exclusions) will be enrolled into managed care plans. This includes children who are in the Medically Fragile Community Care Program, and children/adults in Nursing Home Without Walls, and children/adults in the HIV Community Care Program (July 2007). For children/adults in the DD/MR waiver, primary and acute health care will be provided by managed care plans in July 2007, with long-term home and community-based and nursing facility services to begin January 2009.
- The upper income limit (to be determined) for SCHIP will be raised.
- A requirement for prior Medicaid enrollment to be eligible for QUEST-Net will be eliminated, so that children above the SCHIP eligibility level but at or below 300% FPL will be eligible for QUEST-Net.
- All Medicaid-eligible children in the Child Welfare system will be eligible for coverage under a QUEST plan with enhanced benefits (multi-disciplinary assessment) that are now only provided for children in foster care.
- A limited dental benefit for TANF and TANF-related adults will be added.

Early intervention services will continue to be provided through a carved-out, non-risk, capitated plan offered by DOH.

DHS is providing updates to state/community agencies and providers at QUEST Expanded Roundtables. DHS has established an Advisory Council regarding implementation; members include representatives of Family Voices, American Academy of Pediatrics, and the State Council on Developmental Disabilities.

Cultural Acceptability of Health Care and Health-Related Services

The State of Hawaii is unique in its ethnic diversity. With over 1.2 million residents, there is no one ethnic group that comprises a majority. The population comprises White 24.3%, Black or African American 1.8%, American Indian/Alaska Native 0.3%, Asian 41.6% (including Japanese 16.7%, Filipino 14.1%, Chinese 4.7%, Korean 1.9%), Native Hawaiian/Other Pacific Islander 9.4%, other 3.9%; persons reporting 2 or more races 21.4%; and Hispanic/Latino origin 7.2%. (Source: US Census, 2000)

Foreign-born persons comprise 17.5% of the state's population. Language is sometimes a barrier. 26.6% of residents over 5 years of age reported speaking a language other than English at home, with 12.7% reported speaking English less than "very well". Languages spoken at home include Other Pacific Islands 7.9%, Tagalog 5.4%, Japanese 5.0%, Chinese 2.6%, Spanish and Spanish Creole 1.7%, Korean 1.6%. (Source: US Census, 2000)

- Approaches to cultural competency within the Department of Health and other state/community programs include: hiring ethnically/culturally-diverse staff with experience in working with people in various cultures; use of translators in communicating with non-English speaking persons; translation of written materials into other languages; providing information on how to obtain translators; having members of diverse ethnic backgrounds on advisory boards and committees; having individuals of various ethnic and cultural groups review and provide input to the appropriateness of programs, messages, and interventions; and education/training to develop cultural competence and awareness.

Availability of Prevention and Primary Care

Hawaii data from the National Survey of CSHCN show:

- 98% CSHCN had a usual place to go for sick care. 88% CSHCN had a usual place for preventive care.
- 88% CSHCN had a personal doctor or nurse.
- Hawaii data from the National Survey of Children's Health (2003) indicate that a significantly higher proportion of CSHCN age 0-17 years receive preventive/medical care services, compared to that for children without special health care needs (Table 4-18).

	% CSHCN	% Not CSHCN	
Child has a personal doctor or nurse (health professional who knows child well and is familiar with child's health history, who can be a general doctor, pediatrician, specialist doctor, nurse practitioner, or physician assistant)	88.7	83.9	
Child visited his/her personal doctor or nurse for preventive care during the past 12 months	84.2	75.9	★
Child saw a doctor, nurse, or other health care professional for medical care during the past 12 months	92.5	83.6	★

★ Statistically significant difference between CSHCN and Not CSHCN rates at the 95% confidence interval.
Source: Hawaii data from the National Survey of Children's Health, 2003. Analysis by Hawaii State Department of Health, Children with Special Health Needs Branch, 2005.

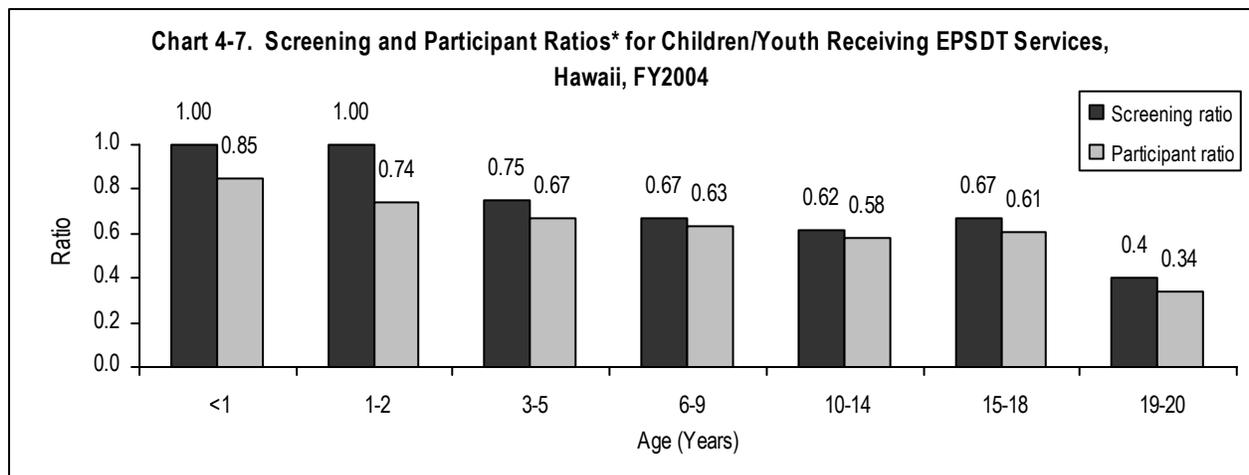
Primary care providers, including private physicians and community health centers, are available on all islands.

Community health centers (CHCs) in underserved areas are located on the islands of Oahu (5 centers), Kauai (2), Maui (2), Molokai (1), and Hawaii (5). Special populations served include those with limited financial resources, uninsured, Native Hawaiians, Pacific Islanders, and immigrants. Services are provided on a sliding fee basis.

Pediatric residents of the University of Hawaii/School of Medicine/Department of Pediatrics provide primary care at the Pediatric Outpatient Clinic at by Kapiolani Medical Center for Women and Children

In 2002, there were 3,201 licensed physicians in Hawaii, of whom 96% were in active practice and providing patient care. Of the 3,091 active physicians, 53.4% were primary car physicians (including general practitioners, pediatricians, obstetrician/gynecologists, family physicians, and internists). Data on the proportion of health care providers (licensed physicians, licensed dentists, licensed practical nurses, and advanced practice registered nurses) by county population show that Oahu had a disproportionate share of the health care workforce. The ratio of physicians per 1,000 population is the highest for the City & County of Honolulu (2.81), with lower ratios for Kauai (2.02), Maui (1.94), and Hawaii (1.94). (Source: Hawaii Department of Commerce and Consumer Affairs, Professional and Vocational Licensing Branch, Records, 1990-2003; reported in HMSA Foundation, "Health Trends in Hawaii – A Profile of the Health Care System, sixth edition, 2003", www.healthtrends.org.)

Early Periodic Screening, Diagnosis, and Treatment (EPSDT) data from the Hawaii State Department of Human Services provides information on periodic screening services for Medicaid eligible children under age 21 years. Screening services include health/developmental history, physical examination, immunizations, laboratory tests, health education, vision, hearing, developmental, and dental services. Screening and participant ratios (Chart 4-7) for Hawaii for Fiscal Year 2004 show a decrease in screening services with increasing age.



* Screening ratio = (total screens received)/(expected number of screenings), showing the extent to which EPSDT eligibles receive the number of initial and periodic screening services required by Hawaii's periodicity schedule, adjusted by the proportion of the year for which they are Medicaid eligible. Source: Data from Hawaii State Department of Human Services, Med-QUEST Division, Form CMS-416 - Annual EPSDT Participation Report, Hawaii FY2003 and 2004. Information on screening ratios is from Centers for Medicare & Medicaid Services, www.cms.hhs.gov/medicaid/epsdt/default.asp.

Participant ratio = (total eligibles receiving at least one initial or periodic screen)/(total eligibles who should receive at least one initial or periodic screen), showing the extent to which EPSDT eligibles are receiving any initial and periodic screening services during the year.

Source: Data from Hawaii State Department of Human Services, Med-QUEST Division, Form CMS-416 - Annual EPSDT Participation Report, Hawaii FY2004. Information on participant ratios is from Centers for Medicare & Medicaid Services, www.cms.hhs.gov/medicaid/epsdt/default.asp.

Developmental, vision, and hearing screening by primary care providers is an area for improvement – see “CSHCN Core Outcome #4 – Early and Continuous Screening” in the section on “Population and Health Status”.

Availability of Specialty Care

- The state of Hawaii is composed of seven populated islands located almost in the center of the Pacific Ocean. The majority of specialty care services are located on Oahu, with the greatest concentration in the capital city of Honolulu.

Access to community-based pediatric subspecialty care on Neighbor Islands and in Rural Oahu is a problem identified at CSHCN Needs Assessment meetings (2004) and Hawaii State Legislature (2005). 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 largely uncompensated on-call coverage; and insufficient opportunities for appropriate continuing education and professional collaboration/interaction.
 - Neighbor Island residents who need to travel to Oahu for specialty services may have financial difficulties, since health insurance plans may not include airfare, ground transportation, lodging, and meals as covered benefits. The airfare cost between a Neighbor Island and Oahu now ranges from \$180-300 per round-trip, a rise from \$100 per round-trip five years ago. The number of flights has decreased, and airline tickets now have more restrictions. Residents may incur lost wages due to the time it takes to travel inter-island. They may also incur the unreimbursed travel cost for the accompanying caregiver, companion, or parent.
 - Some Neighbor Island families have difficulty traveling to health services on their own island, due to factors such as long distances, winding roads, length of travel time, cost for gasoline, and lack of public transportation system.
 - There is a national shortage of physicians in some specialty fields, adding to the difficulty in recruiting physician specialists to Hawaii.
 - The limited number of practitioners who are willing to participate in Medicaid or QUEST or to serve the uninsured population may add to the difficulty of accessing specialist services.
 - Hawaii's designation as a federal health professional shortage area does not address access to specialty care.
- CSHNB provides or supports pediatric cardiology, neurology, endocrinology, genetics, and hematology/thalassaemia clinics on Oahu and on three 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.

- Administered

through CSHNP, the Hawaii Lions Foundation Uninsured-Underinsured Fund for Hearing and Vision Services assists eligible DOE students in receiving needed vision and hearing testing and services. Services may include ophthalmology or otolaryngology evaluation, eyeglasses, and hearing aids.

- Honolulu Shriners Hospital for Children provides surgical and rehabilitative orthopedic care to children from Hawaii and the Pacific Basin under age 18 years with bone, muscle and joint disorders and disabilities, at no cost to families.
- Tertiary health care facilities are located on Oahu, with none on the Neighbor Islands. Kapiolani Medical Center for Women and Children, the only facility in the state specializing in pediatrics, has a 24-hour pediatric emergency room, pediatric intensive care, neonatal intensive care. Access of other tertiary care facilities on Oahu is limited to health maintenance organization members or to the military.

Linkages that Promote Provision of Services and Referrals between Primary Care, Specialized Secondary Care, and Highly Specialized Tertiary Care

Hawaii data from the National Survey of CSHCN on care coordination show:

- o 14% CSHCN/families needed professional care coordination. Of these, only 74% received care coordination.
- o Of CSHCN/families receiving care coordination, 85% were somewhat or very satisfied with the help they received in coordinating care.
- o Comparing with CSHCN who need prescription medicines and/or services, CSHCN with functional limitations have the greater need for care coordination:

	<i>% needing care coordination</i>
CSHCN who need ONLY prescription medicines	4%
CSHCN who need ONLY services	16%
CSHCN who need BOTH prescription medicines and services	16%
CSHCN with functional limitations	30%

- o 76% CSHCN had no problems obtaining referrals when needed.

Hawaii data from the National Survey of Children’s Health on assistance for children needed specialist care or special services are shown in Table 4-19.

	% CSHCN
Children Needing Specialist Care	
Family had a moderate/big problem getting care from specialist doctor(s) when needed.	14.2
Child’s personal doctor, nurse, or office staff helped family to get care from specialist doctor(s)	83.1
Children Needing Special Services (such as physical therapy, wheelchairs, special education services, counseling)	
Family had a moderate/big problem getting special services, equipment, or other care when needed	16.0
Child’s personal doctor or nurse helped family to get the special care or equipment that child needed	73.6
Source: Hawaii data from the National Survey of Children’s Health, 2003. Analysis by Hawaii State Department of Health, Children with Special Health Needs Branch, 2004.	

Care coordinators who assist with referrals and linkages include CSHNP nurses and social workers, Early

Intervention social workers, public health nurses, developmental disabilities case managers, EPSDT care coordinators, medically fragile waiver care coordinators, hospital case managers, health plan care coordinators, and others. A general effort is made toward a family having only a single care coordinator. 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.

- 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 for specialized care not available in Hawaii. The team includes neonatologists/pediatricians, nurses, and respiratory therapists.

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Relationship of Title V with Others in the State Who Address Inadequate, or Poorly Distributed, Health Care Resources

- FHSD contracts for the provision of pediatric primary care services at community health centers; and supports the development of community health centers in underserved areas of Hawaii. FHSD works closely with the Primary Care Association.

- CSHNB contracts with private providers for the provision of pediatric cardiology, neurology, and endocrinology specialty on Neighbor Islands, and provides funding support for genetics and hematology/thalassemia clinics on Oahu. Genetics clinics on Neighbor Islands are planned. These services are otherwise not available.

- EIS contracts for early intervention services on Neighbor Islands with community agencies. Oahu early intervention staff (such as nutritionist, psychologists, vision specialist, hearing specialist, etc.) provide services on Neighbor Islands where these services are not otherwise available.

- Services on Neighbor Islands are also provided by other Oahu-based medical specialists, pediatric audiologists, and Honolulu Shriners Hospital for Children.

- A legislative resolution (SCR 195) recognized the need for a collaborative solution to inadequate and poorly distributed specialty services. The State Health Planning and Development Agency (SHPDA) was designated to identify and evaluate the barriers to community-based access to specialty care and to make recommendations to improve access to specialty care on the neighbor islands and in rural Oahu. SHPDA was requested to consult with the Department of Health, Department of Human Services, State Council on Developmental Disabilities, Insurance Commissioner; Hawaii Health Systems Corporation, representatives of health plans, University of Hawaii, John A. Burns School of Medicine, Office of Rural Health, Hawaii Primary Care Association, Healthcare Association of Hawaii, Hawaii Psychological Association, Hawaii Psychiatric Medical Association, Hawaii Disability Rights Center, other associations and stakeholder groups, and rural and neighbor island communities and health care providers.

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POPULATION-BASED SERVICES

- **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 Hawaii are screening for 31 mandated disorders. These disorders are phenylketonuria, congenital hypothyroidism, congenital adrenal hyperplasia, galactosemia, sickle cell and other hemoglobinopathies, biotinidase deficiency, maple syrup urine disease, and 24 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.
- Monthly newborn metabolic screening practice profiles are sent to birthing facilities and submitters, in an effort to decrease errors in transit time, timing of specimen collection, specimen quality, and reporting of demographic information; birthing facilities use these screening practice profiles as a quality assurance tool. The screening practice profiles and updated information on newborn metabolic screening are also provided on the DOH website. 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 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/distribution: Screening is available statewide at all birthing facilities. Screening is also available at outpatient laboratories through midwives.
- Funding mechanism: 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 have 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.

- Legislative mandate: The State law is H.R.S. §321-291, Newborn Metabolic Screening. State administrative rules are H.A.R. Chapter 11-143, Testing of Newborn Infants for Metabolic and Other Disorders.

- Needs: See “Newborn Metabolic Screening” under “CSHCN Core Outcome #4: Early and Continuous Screening”, in the section “Population and Health Status”.

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- **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 Hawaii are screened for hearing.

- Screening began in two Honolulu hospitals in 1992, and all birthing facilities in Hawaii 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, and tracks follow-up for infants monitored for late onset hearing loss. 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 were provided to birthing hospitals to support efficient data reporting of newborn hearing screening results to NHSP. Alternate methods of data submission are being explored for 2 of 14 hospitals.

- NHSP monitors hospital inpatient and outpatient newborn hearing screening rates and provides technical assistance to address barriers to screening, such as outdated screening equipment or lack of backup equipment. By the end of 2004, 8 of 14 hospitals had backup equipment and 2 had replaced outdated equipment. NHSP and the Newborn Metabolic Screening Program began coordinating quality assurance efforts to more efficiently identify infants who need additional follow-up due to missed screens.

- 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. A practitioner’s manual is under development.

State coordination with other agencies and organizations: The Early Hearing Detection and Intervention Advisory Committee advises the Newborn Hearing Screening Program, the Baby Hearing Evaluation and Access to Resources and Services (HEARS) Project, and the Tracking, Integration and Research for Early Screening, Assessment, and Intervention (EASI) Project (funded by the Centers for Disease Control and Prevention). The committee includes: parents, AAP-Hawaii Chapter, Center for Disabilities Studies, early intervention programs, Hawaii Academy of Audiology, Hawaii Speech Language and Hearing Association, Hawaii Center for the Deaf and Blind, UH/Department of Pediatrics, hospital newborn hearing screening program, Gallaudet University regional center, Hawaii Kids Count, and pediatric audiologists.

- Relevant in-service 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 Hawaii. NHSP works closely with Hawaii's American Academy of Pediatrics-Hawaii Chapter EHDI Champion to increase awareness regarding early hearing detection and intervention.
- Geographic availability/distribution: Screening is available statewide at all birthing facilities and at various outpatient locations.
- Funding mechanism: 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 Hawaii. 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.
- Legislative mandate: The State law is H.R.S. §321-361 to 363, Statewide Newborn Hearing Screening. State administrative rules are now being drafted.
- Needs: See "Newborn Hearing Screening" under "CSHCN Core Outcome #4: Early and Continuous Screening", in the section "Population and Health Status".
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- **Early Intervention Services**
- State role: The Early Intervention Section of the Children with Special Health Needs Branch of the Family Health Services Division, DOH, is the lead agency responsible for the statewide system of early intervention (EI) services for infants/toddlers 0-3 years who are developmentally delayed or biologically/environmentally at risk.
- EI services include: assistive technology, audiology, family training, counseling, home visiting, health services, medical services (diagnostic/evaluation), nursing, occupational therapy, physical therapy, psychological, social work, special instruction, speech pathology, transportation, vision services. EI services are typically provided in natural environments by EIS, Healthy Start, and Public Health Nursing Branch (PHNB), and through state and contracted programs, fee-for-service providers, and other programs such as Early Head Start.

EIS is responsible for developing, maintaining, and improving components of the statewide EI system, including: a central directory of service providers, public awareness, child find, evaluation/assessment, Individual Family Support Plan (IFSP), personnel standards, procedural safeguards, complaint resolution, interagency agreements, data collection, and quality assurance. Public awareness activities include participation in health fairs and other community activities, brochures, newsletters, and information to pediatricians/family practitioners. Information is included in hospitals' birth packets.

State coordination with other agencies and organizations: The Hawaii 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, legislators, pediatrician, and representatives from the DOE, DHS, University of Hawaii (UH), and health insurance. Membership of the HEICC will be expanded to meet the new requirements in IDEA 2004.

- EIS works collaboratively on various initiatives, projects and services with the Hawaii State Department of Human Services (DHS) (Keiki Care project, Inclusion Project, EI services through QUEST managed care), Hawaii State Department of Education (DOE) (State Improvement Grant II, transition, early intervention services as an Extended Year Services option), and the DOH/Child and Adolescent Mental Health Division (CAMHD) (internal reviews Project COACH). EIS also participates in an Interagency Quality Assurance Taskforce that includes DOE, CAMHD, DHS, and Hawaii Families as Allies and focuses on how to streamline the internal review process so it is more effective.

- Geographic availability/distribution: Early intervention services are available statewide, on all islands.
- Funding mechanism: Funding includes federal funds under Part C of IDEA, state funds, EI Special Fund from QUEST reimbursement for EI services provided to Medicaid-eligible children, state funds from other programs when available when EIS is in deficit, and as necessary, emergency state funds through the State Legislature.

- Mandates: Part C of Individuals with Disabilities Education Act (IDEA), State law is H.R.S. §321-351 TO 357. The EI system was under the Felix Consent Decree until May 2005.

- Needs: Addressing temporary service gaps due to staff vacancies, recruiting difficulties, increased travel time to serve children in natural environments, insufficient number of providers; changing its State Plan and State Statues due to the reauthorization of IDEA 2004; developing a 6-year Office of Special Education Programs (OSEP)-required State Performance Plan; change some aspects of the EI system based on the new requirements of IDEA 2004, including identifying serving children who are confirmed child abuse and neglect and homeless children; work toward 100% compliance with IDEA Part C requirements, especially in the area of comprehensive developmental evaluations (CDE) for all children, meeting federal timelines, having complete Individual Family Support Plans (IFSPs), providing all services on IFSPs, developing appropriate transition plans, ensuring timely transition to DOE preschool special education or community programs; expanding monitoring of all EI public and private programs to identify and correct areas of noncompliance; expand EI state and contracted programs as needed to serve the increased number of children with developmental delays; monitoring and tracking the number of children served and the cost of serving all children at EI programs; obtaining adequate resources to meet needs.

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INFRASTRUCTURE-BUILDING SERVICES

State's Capacity to Promote Comprehensive Systems of Services

- To assess the capacity to promote comprehensive systems of services, a framework is the "Ten Essential Public Health Services to Promote MCH" applied to CSHCN (from: "Public MCH Program Functions Framework: Essential Public Health Services to Promote MCH in America, prepared by H.A. Grason and B. Guyer of the Johns Hopkins University Child and Adolescent Health Policy Center (1995):

1. Assess and monitor health status to identify and address problems. Efforts have included: data linkage between newborn hearing and metabolic screening with birth records; analysis of Hawaii data from the National Survey of CSHCN (2001); special analysis of Hawaii data on ease of use of community-based services from the National Survey of CSHCN (2001); analysis of Hawaii data from the National Survey of Children's Health (2003); analysis of birth defects data regarding incidence, trends, and clusters; analysis of newborn hearing screening data to determine extent and timing of screening, follow-up, and referral to early intervention services; analysis of newborn metabolic screening to determine extent of screening.

2. Diagnose and investigate health problems and health hazards affecting women. Birth defects surveillance is provided by the CSHNB/Hawaii Birth Defects Program. HBDP finds and abstract all Centers for Disease Control and Prevention (CDC) designated birth defects diagnoses (about 1,000 in Hawaii per year) within twelve months of the close of the calendar year. These are examples of how HBDP contributes to the identification of genetic, environmental hazards, and other causes or risk factors. (a) Birth defects data were used by the State Attorney General's office for cluster investigations in the Village Park and Royal Kunia neighborhoods where concerned residents perceived an increased number of birth defects due to environmental hazards, and considered initiating class action lawsuits against the State of Hawaii for damages. HBDP data showed there were no differences when comparing the prevalence of birth defects in the Village Park/Royal Kunia neighborhoods, compared with that for the entire state. (b) The Department of the Navy's "Gulf War Syndrome Project" used Hawaii as its pilot test site and HBDP data to investigate birth defects among infants of Persian Gulf War veterans born in Hawaii and among infants of military and non-military personnel in Hawaii. HBDP data showed that birth defects overall were not more prevalent in Gulf War veterans.

3. Inform and educate the public about CSHCN issues.

- Newborn Metabolic Screening Program conducts educational sessions for practitioners, nurses, laboratories, and birthing facilities. NBMSD distributes its newborn metabolic screening brochure to birthing facilities and providers, and updates it as needed.

The Genetics Program's project on the financial, ethical, legal, and social issues (FELSI) surrounding tandem mass spectrometry in newborn screening utilized multi-state collaboration to identify strategies and develop educational materials for a culturally and ethnically diverse population. Information obtained from the fourteen focus groups in four Western states (Hawaii, Alaska, California, and Oregon) were used to develop model educational materials. Hawaii's model newborn metabolic screening brochure is now being used to educate parents about newborn metabolic screening at the Baby Expo, health fairs, etc.

Newborn Hearing Screening Program develops and disseminates 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. Newborn hearing screening, audiological assessment, and early intervention brochures are available in 9 languages. Educational sessions/training are provided for hospital newborn hearing screening staff, audiologists, physicians, early intervention, and other providers to improve the quality of newborn hearing screening and audiological follow-up. NHSP works closely with Hawaii's American Academy of Pediatrics-Hawaii Chapter Early

Hearing Detection and Intervention Champion to increase awareness regarding early hearing detection and intervention.

Since 1989, Hawaii Birth Defects Program has disseminated over 1,700 pieces of information to parents, communities, and health care providers, and has given over 125 presentations, including to physicians at grand rounds and to teen/pregnant mothers in high schools. HBDP has published over 100 articles/educational pieces, including 12 in peer-reviewed professional journals.

The Early Intervention Section provides and/or supports education/training for early interventionists, public health nurses, Healthy Start providers, Early Head Start staff, fee-for-service providers, community preschool staff, other community providers, and family members. Areas of training include: Part C and Hawaii's requirements, care coordination, transition, Individual Family Support Plan (IFSP), supporting children with challenging behaviors, support for families of children with hearing loss, and other areas.

Information about CSHCN, including Hawaii data from the National Survey of CSHCN and from the National Survey of Children's Health, is provided at various conferences, meetings, councils, or advisory groups.

4. Mobilize community partnerships between policymakers, health care providers, families, general public, and others to identify and solve CSHCN problems. See "Coordination Efforts" (below).

5. Provide leadership for priority-setting, planning, and policy development to support community efforts to assure the health of CSHCN. See Hilopa`a Project in "State Program Collaboration with Other State Agencies and Private Organizations" in the section on "Four Constructs of a Service System" below.

6. Promote and enforce legal requirements that protect the health and safety of CSHCN, and ensure public accountability for their well-being. During the past 10 years, CSHNB has initiated legislative bills that became law:

- 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.

- 7. Link CSHCN to health and other community and family services, and assure access to comprehensive, quality systems of care. See “Availability of Specialty Care”, “Linkages That Promote Provision of Services and Referrals Between Primary Care, Specialized Secondary Care, and Highly Specialized Tertiary Care” Relationship of Title V with Others in the State Who Address Inadequate, or Poorly Distributed, Health Care Resources” in the section on “Direct Health Care And Enable Services”.
- 8. Assure the capacity and competency of the public health and personal health workforce to effectively address CSHCN needs. See “3. Inform and educate the public about CSHCN issues” above. In addition, health professionals and state/community program staff have opportunities to participate in various trainings, conferences, web-casts, in-services, and other relevant trainings in Hawaii provided by state agencies, University of Hawaii/School of Medicine/Department of Pediatrics (continuing medical education), professional organizations such as the American Academy of Pediatrics-Hawaii Chapter or the Hawaii Public Health Association, community agencies, State Council of Developmental Disabilities, University of Hawaii Center on Disability Studies, etc. There are also opportunities to attend trainings in the continental U.S. locations, such as those on early childhood comprehensive systems planning, early hearing detection and intervention, epidemiology conferences, or Part C of IDEA, which may be funded through HRSA, CDC, or Office of Special Education. Technical assistance may also be obtained.
 - The Hawaii Maternal and Child Health Leadership in Education in Neurodevelopmental and Related Disabilities (MCH LEND) Program prepares health professionals for leadership roles to improve supports and services for CSHCN. The Hawaii MCH LEND, funded by the MCH Bureau, is a program of the University of Hawaii/Center of Disability Studies. During the upcoming year, the MCH LEND will focus on the following:
 - Applied Research: In conjunction with the Hilopa`a Project and the State QUEST Expanded Advisory Council, MCH LEND trainees will be conducting focus groups of families of CSHCN and potentially some youth to explore their understanding of Managed Care. The findings of the focus groups will be used to design outreach materials and training curriculum which will be incorporated into the Request for Proposal the state will release to procure outreach services to facilitate the transition. The information from the focus groups will also be provided to prospective health plans to better understand their future client base.
 - Public Policy & Advocacy: MCH LEND trainees will be studying the revisions and enhancements found in the Reauthorization of IDEA. Upon completion of their review, trainees will provide public comment and testimony to the state Lead Education Agency, during their public comment hearings. Trainees will be asked to prepare their testimony based upon the perceived impact on their disciplinary role as a provider as well as the impact on the families that they serve.
 - Support Systems: Each year, the State Council on Developmental Disabilities sponsors a “Day at the Capitol” to encourage family members and self advocates to come and meet with their legislators during the legislative session. This year, the MCH LEND trainees will assist with the planning and implementation of the event. They will also work to recruit families of children and youth ages 0-21 to augment the large adult consumer population that attends on a regular basis. The trainees will also work with families to develop materials for table top displays.
- 9. Evaluate the effectiveness, accessibility, and quality of personal and population-based health services. See “Standards, Guidelines, Monitoring, Evaluation, Quality Improvement” below.
- 10. Support research and demonstrations to gain new insights and innovative solutions to CSHCN health-related problems. Formal research projects within CSHNB are: “An Investigation of the Epidemiology of

Hearing Loss in Infants and Young Children”, which includes genetic causes of hearing loss; and “Efficacy of Early Identification of and Intervention for Congenital Hearing Loss” (CSHNB, Early Hearing Detection and Intervention/Early Screening, Assessment, and Intervention” [EASI] Project, funded by the CDC). Hawaii data from the 2001 National Survey of CSHCN were used to study factors contributing to difficulty using community-based services by families of CSHCN, in a collaborative study of the Department of Public Health at the University of Hawaii/School of Medicine, FHSD/MCH Epidemiologist, and DOH/CSHNB; the article has been accepted for publication in the Maternal and Child Health Journal. Since 1989, HBDP conducted special birth defect cluster studies and other research studies, and has published over 100 articles/educational pieces, including 12 in peer-reviewed professional journals.

Coordination Efforts

The Title V CSHCN program participates in a network of coalitions, advisory groups and coordination efforts throughout the state.

Within the **Department of Health**, 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, State Health Planning and Development Agency, Maternal and Child Health Branch, and WIC Services 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.

CSHNB/Early Intervention Section (EIS) is the lead agency for Part C of IDEA. EIS works the **Department of Education** (DOE) in several areas:

- The State Improvement Grant II is a collaborative effort of the DOE, University of Hawaii Center on Disability Studies, DOH/EIS, and DOE/Parent Training Information Center to improve systems providing early identification, educational, early intervention, and transitional services to children with disabilities. Through a Memorandum of Agreement with DOE, EIS will be funded to identify and address barriers to early identification of infants/toddlers with disabilities, improve the process of transitioning eligible children and their families from the Early Intervention Program to DOE preschool special programs or other options, and assist in the process and outcome evaluation plan.
- EIS and DOE collaborate on the transition of children receiving early intervention services to the DOE special education program. EIS and DOE developed transition materials and regularly provide joint training to early interventionists, DOE staff, families, and other community members.
- To support the transition of young children with autism, the DOE is utilizing space at an early intervention program for a DOE classroom and regularly includes children under age 3 with autism in classroom activities.
- EIS and DOE are continuing a pilot project to support the continuation of early intervention services as an Extended Year Services option for eligible children who turn age 3 during the summer months and are eligible for DOE preschool special education services.
- EIS collaborates with the DOE and DOH/Child and Adolescent Mental Health Division (CAMHD) by implementing internal reviews for children from birth to age 3. This is a methodology to “test” whether children are learning and developing appropriately, and whether the system performs in such a way as to support the growth, development, and education of children. This coming year’s

focus is on children in the transition process between early intervention and preschool special education, to identify both the strengths and needs in the transition process. EIS also participates in an Interagency Quality Assurance Taskforce that includes DOE, CAMHD, DHS, and Hawaii Families as Allies and focuses on how to streamline the internal review process so it is more effective.

Department of Human Services/Med-QUEST Division provides funding to FHSD through a Memorandum of Agreement for early intervention services provided by the Early Intervention Section, Healthy Start, and Public Health Nursing Branch, through a carved-out, non-risk, capitated plan offered by DOH for QUEST-eligible infants and toddlers who are developmentally delayed or biologically/environmentally at risk.

DHS/Benefits, Employment, and Support Services Division (BESSD) provides funding for EIS through Memoranda of Agreement for the Inclusion Project which provides tuition support for infants/toddlers with developmental delays to participate in child care or community-based programs; and for the Keiki Care Project which provides technical assistance and training to community preschool staff serving children ages 3-5 with behavioral challenges and their families.

DHS/BESSD also provides funding to CSHNB for a Healthy Child Care Hawaii project (see below).

DHS/Disability Determination Branch 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 medical, education, and social needs. These are “rehabilitation” services required by Title V for individuals under age 16 years receiving benefits under Title XVI of the Social Security Act.

CSHNB/Children with Special Health Needs Program (CSHNP) Audiologist worked with DHS Med-QUEST Division (MQD) on the Medicaid coverage for hearing aids for Medicaid-eligible individuals less than 21 years of age. Following the CSHNP model, MQD was able to arrange discounted rates with a hearing aid manufacturer. MQD also obtained input from community audiologists prior to finalizing changes. Medicaid fee-for-service changes included coverage for digital hearing aids, manufacturer’s hearing aid loss/damage extended warranty, manufacturer’s hearing aid accessories without charge with the initial purchase of hearing aids, and clearer process for prior authorization. Medicaid also arranged with the CSHNP Audiologist to make available the manufacturer’s hearing aids for “trials”.

The **Hawaii 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, legislators, pediatrician, and representatives from the DOE, DHS, University of Hawaii/Center on Disabilities Studies, and health insurance. Membership of the HEICC will be expanded to meet the new requirements in IDEA 2004.

The **Creating Opportunities for All Children (COACH) Project** is an EIS project funded by the DOH/Child and Adolescent Mental Health Division through a Memorandum of Agreement. This project provides technical assistance and consultation to community preschool staff serving children ages 3-5 who were in early intervention services, are not DOE eligible, but continue to have social/emotional/behavioral challenges.

Tracking, Integration and Research for Early Screening, Assessment, and Intervention (EASI) project is a collaborative effort of CSHNB with the UH Center for Disabilities for data integration and research studies related to early hearing detection and intervention. EIS provides space and use of equipment to UH Center for Disabilities Studies staff. Project is funded through a CDC cooperative agreement.

The **Special Education Advisory Council (SEAC)** is an advisory committee to the Superintendent of Education for policies on any issues in the education of students with disabilities. Appointed members include representative of consumer advocate groups, parents, individuals with disabilities, regular and special education personnel, DOH, DHS, and UH. The Council has been actively working with the DOE and voicing its concerns about enhancing the work environment and improving the recruitment and retention of qualified special education teachers and other support staff. The Council is working with the DOE in its implementation plan for a Comprehensive Student Support System (CSSS) and school-based mental health services, training initiatives, and assuring that educational needs of special education students within the Justice System are being addressed. EIS is represented on SEAC.

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 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.

The **Hawaii Birth Defects Program (HBDP) Advisory Committee** is composed of representatives from the community, medical, university, and public and private sectors. Members offer scientific guidance and input into the program and have expertise in the areas of children with special health needs, service delivery, epidemiology, research, family health, fetal diagnosis, genetics, health information management, maternal and child health, neonatology, nursing, pediatrics, perinatology, public health, and fetal/pediatric ultrasonography.

The **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.

The **Healthy Child Care Hawaii (HCCH) Advisory Team** includes the American Academy of Pediatrics (AAP)-Hawaii Chapter, UH/Department of Pediatrics, DOH, DHS, DOE, parents of young children, pediatrician health consultants, early childhood centers, Head Start, Hawaii Association for the Education of Young Children, Hawaii Medical Home Implementation Project, Hawaii Covering Kids, Good Beginnings Alliance, and People Attentive to Children. HCCH promotes the health and safety of young children in child care. Project activities include: recruit, train, and link health consultants to child care programs; train pediatric residents in promoting quality child care and providing health information to families and staff in child care settings; and promote the Caring for Our Children National Health and Safety Performance Standards for child care programs. This is a collaborative project of DOH/CSHNB, University of Hawaii/School of Medicine/Department of Pediatrics,

American Academy of Pediatrics-Hawaii Chapter, and DHS. Funding, originally from the MCH Bureau, is now provided by DHS.

The **Early Hearing Detection and Intervention Advisory Committee** advises the Newborn Hearing Screening Program, the Baby Hearing Evaluation and Access to Resources and Services (HEARS) Project, and the Tracking, Integration and Research for Early Screening, Assessment, and Intervention (EASI) Project. The committee includes: parents, AAP-Hawaii Chapter, Center for Disabilities Studies, early intervention programs, Hawaii Academy of Audiology, Hawaii Speech Language and Hearing Association, Hawaii Center for the Deaf and Blind, UH/Department of Pediatrics, hospital newborn hearing screening program, Gallaudet University regional center, Hawaii Kids Count, and pediatric audiologists.

Hawaii Community Genetics is a partnership of DOH/CSHNB Genetics Program, Kapiolani Medical Center for Women and Children, Queen's Medical Center, and University of Hawaii John A. Burns School of Medicine to develop clinical genetics and metabolic services in Hawaii. HCG has successfully recruited a full-time geneticist for clinical services. Clinical genetics services are expanding with the addition of a hemoglobinopathy clinic, neighbor island clinics, and telemedicine visits.

The **core team of CSHNB, Family Voices, UH/School of Medicine/Department of Pediatrics, and American Academy of Pediatrics-Hawaii Chapter**, with other key state/community partners, continues to work closely together in various projects toward achieving the six core outcomes for CSHCN. Current collaborative projects are **Medical Home Implementation Project**, **Hilopa`a Project**–Integrated Services for Children & Youth with Special Health Care Needs, and a **transition & family leadership project** funded by the Champions for Progress Center (MCHB cooperative agreement with Utah State University that provides leadership support for state Title V/CSHCN programs in systems building). The same team had also been members of various CSHNB/CSHCN planning efforts, the earlier Tri-Regional State Team, and the State Team that attending the first Champions for Progress Multi-State Meeting in June 2004.

CSHNB is a member of the **State Council on Developmental Disabilities**. Act 175 of the 2001 Legislature required that the Council's membership include a representative of Title V of the Social Security Act. The Council's responsibilities include: development of the state plan which guides the development and delivery of all services for individuals with developmental disabilities, coordination of departments and private agencies, evaluation, and advocacy. Council members also include representatives from DOE special education, vocational rehabilitation, DHS Medicaid, DOH/Developmental Disabilities, community agencies, individuals with disabilities, and others.

CSHNB is participating on the **Advisory Board for Successful Transitions in Diverse Environments (STRIDE)** Mentoring Project to design, develop, implement, and evaluate an effective vocational rehabilitation model for mentoring culturally-diverse youth and young adults with disabilities as they transition into meaningful community environments, post-secondary education or employment. The target population is youth and young adults age 16-26 in transition who are referred by the Hawaii DHS/Division of Vocational Rehabilitation.

CSHNB is participating on the **Advisory Council for the Hawaii 360 Youth and Family Project**, which is implementing a pilot project to design and implement a Navigational One-Stop System in Hawaii for transitioning youth with developmental disabilities and their families. Project activities includes defining and

developing a One-Stop system certification process for agencies, utilizing www.RealChoices.org as a virtual one-stop center, and developing a system to track and provide coordinated services and supports for youth/families. This is a collaborative project of the Department of Labor and Industrial Relations/Office of Community Services, State Council of Developmental Disabilities, University of Hawaii/Center on Disability Studies, Hawaii Disabilities Rights Center, and DOH/Developmental Disabilities Division.

The Hawaii Birth Defects Program Coordinator is a member of the **Hawaii Perinatal Consortium (HPC)**, a statewide leaders' forum to share information and data, define the unique needs of Hawaii, and promote strategies to improve perinatal health. HPC includes government, corporate, and community decision makers.

The CSHNB Newborn Metabolic Screening Coordinator is a member of the **Healthy Mothers, Healthy Babies (HMHB)** Coalition of Hawaii, a network of organizations and individuals committed to improving maternal, child and family health through collaborative efforts in public education, advocacy, and collaboration. HMHB distributes cross-cultural educational materials for pregnant women and provides leadership for advocacy efforts by convening quarterly meetings of perinatal providers, disseminating information, and advocating for the adoption of statutes and policies affecting perinatal health.

CSHNB, with the FHSD MCH Epidemiologist, collaborated with the **Department of Public Health at the University of Hawaii/School of Medicine** to study factors contributing to difficulty using community-based services by families of CSHCN in Hawaii. Data from the 2001 National Survey of CSHCN were analyzed community-based services easily. The article has been accepted for publication in the Maternal and Child Health Journal.

Four Constructs of a Service System

State Program Collaboration with Other State Agencies and Private Organizations

See "Coordination Efforts" above for program collaboration with other agencies and organizations. The following collaborative efforts address the development of community-based systems of services for CSHCN:

- The core team of CSHNB, Family Voices, UH/School of Medicine/Department of Pediatrics, and American Academy of Pediatrics-Hawaii Chapter, with other key state/community partners, are collaborating on the Hilopa`a Project-Integrated Services for Children & Youth with Special Health Care Needs, and a transition & family leadership project funded by the Champions for Progress. The project aims to improve the access for CSHCN and their families to quality, comprehensive, coordinated, and community-based systems of services. Its eight goals are: transitions, navigating the system training, family resources, family participation, medical home residency education program, monitoring managed care for CSHCN, transitioning to adult health care, and developmental screening and follow-up. Project activities include: develop and implement a "One Stop/Transition Certification" Program for programs, agencies, providers and families based upon the best practices, protocols, and standards for referral/transition for programs in DOH and DHS or their contracted providers; develop and provide training on navigating the system for families of CSHCN age 0-3 and families for middle school youth with special health care needs prior to age 14; enhance current opportunities for family support and training to better meet the needs of families in their communities; develop a resource pool of parents and self-advocates to be strategically linked to programs serving CSHCN to participate as trainers,

family representatives and partners; and convene a paid Youth Advisory Committee of 6-9 youths/self-advocates to develop personal leadership, self determination and community advocacy skills. Project activities are now at the beginning stage of development and implementation.

The Hawaii Early Intervention Coordinating Council (HEICC) advises on issues related to the planning, implementation, evaluation, and monitoring of the statewide system of early intervention services, and assists DOH in achieving the full participation, coordination, and cooperation of all appropriate public agencies in the state. HEICC members include parents of children with special needs, early intervention providers, legislators, pediatrician, and representatives from the DOE, DHS, University of Hawaii/Center on Disabilities Studies, and health insurance.

CSHNB is participating on the Advisory Council for the Hawaii 360 Youth and Family Project, which is implementing a pilot project to design and implement a Navigational One-Stop System in Hawaii for transitioning youth with developmental disabilities and their families. Project activities include defining and developing a One-Stop system certification process for agencies, utilizing www.RealChoices.org as a virtual one-stop center, and developing a system to track and provide coordinated services and supports for youth/families. This is a collaborative project of the Department of Labor and Industrial Relations/Office of Community Services, State Council of Developmental Disabilities, University of Hawaii/Center on Disability Studies, Hawaii Disabilities Rights Center, and DOH/Developmental Disabilities Division.

The State Council on Developmental Disabilities is responsible for the development of a state plan which guides the development and delivery of services for individuals with developmental disabilities, coordination of departments and private agencies, evaluation, and advocacy. Council members include representatives from DOH/CSHNB, DOE special education, vocational rehabilitation, DHS Medicaid, DOH/Developmental Disabilities Division, community agencies, individuals with disabilities, and others. The Council has four committees – Community Supports; Employment & Education; Health & Early Childhood; and Public Awareness, Self-Determination & Training Committee. Committee goals that support the core outcomes for CSHCN include: persons with developmental disabilities are employed consistent with their interests and abilities; school transitions are meaningful and individualized consistent with the principles of self-determination; people with developmental disabilities have access to needed medical and dental care; children with developmental disabilities and their families have access to services needed for optimal health care and support; appropriate family-centered, community-based, culturally-appropriate services and supports are available to all young children with special needs; individuals with developmental disabilities and their circles of support have increased self-advocacy skills; individuals/families have the information and supports to make informed choices, and receive services based on individual choice and self-determination.

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 various communities throughout the state, in order to provide community-based services for families. CSHNP arranges neurology, cardiology, endocrinology, and nutrition

clinics at community-based Neighbor Islands. EIS provides early intervention programs on all islands that are either 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

Coordination of health and other services at the community level is coordinated in part by physicians/medical homes. Other care coordinators at the community level include CSHNP nurses and social workers, Early Intervention social workers, public health nurses, developmental disabilities case managers, EPSDT care coordinators, medically fragile waiver care coordinators, hospital case managers, health plan care coordinators, and others. A general effort is made toward a family having only a single care coordinator. 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.

Because of the complexity of navigating the service systems, the Hilopa`a Project includes developing and implementing a “One Stop/Transition Certification” Program for programs, agencies, providers and families whose framework is based upon the best practices, protocols, and standards for referral and transition for programs in DOH and DHS or their contracted providers; and developing and providing training on navigating the system for families of CSHCN age 0-3 and families for middle school youth with special health care needs prior to age 14.

Standards, Guidelines, Monitoring, Evaluation, Quality Improvement

Early Intervention Services

The Early Intervention (EI) State Plan articulates components for the statewide system for early intervention services for children age 0-3 years, including: Hawaii Early Intervention Coordinating Council composition and functions, state definition of developmental delay, central directory, comprehensive child find system, evaluation and assessment, individualized family support plans, statewide system of early intervention services, natural environments, timetables for serving all eligible children and toddlers, public awareness program, personnel standards, comprehensive system of personnel development, procedural safeguards, supervision and monitoring of programs, lead agency procedures for resolving complaints, policies and procedures related to financial matters, interagency agreements and resolutions of disputes, policy for contracting services, and data collection.

EI quality assurance (QA) assures that a) all children under the age of 3 with developmental delays and their families are provided, through a family-centered, community-based, coordinated process, the necessary early intervention services to meet their needs; and b) all services are provided in conformance with federal

IDEA Part C and state requirements. The 4-year cycle includes:

- 1) On-site monitoring of EI programs.
- 2) Focused monitoring of all Part C programs (Early Intervention Section [EIS], Healthy Start, Public Health Nursing Branch) using the same monitoring instrument which was developed by EIS with input from all Part C agencies and family members, the same criteria to identify charts to review, and same training for monitors to ensure consistency in the monitoring. A statewide parent survey was also developed and distributed to a sample of parents to gather feedback on their opinions/satisfaction of the early intervention services and support received.
- 3) Program self-assessment.
- 4) Child/family outcomes. Internal reviews provide an objective observation of a child's and family's progress and to what extent the system supports the child and family. Outcomes for system performance include functioning service team, unity of effort across agencies, coordination of services, and problem-solving. Feedback is provided to the agencies on findings.

EIS is participating in nationwide efforts to identify appropriate child and family outcomes. Hawaii's Part C Coordinator is participating in a workgroup organized by the Early Childhood Outcomes Center to identify appropriate child and family outcomes that will be presented to OSEP as possible nationwide child and family outcomes. In addition, the Stanford Research Institute in collaboration with EIS received funding for a grant proposal to identify and pilot outcome indicators with all Hawaii's Part C programs.

Five EI QA specialists support compliance and assure that corrections will be completed/met. The EIS QA Supervisor will participate in a state procurement workgroup to identify how past performance can be incorporated/addressed in the next statewide Request for Proposal.

Newborn Metabolic Screening

- The Newborn Metabolic Screening Program (NBMS) standards are established in the Hawaii Administrative Rules and in the Hawaii 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. The centralized laboratory Oregon State Public Health Laboratory provides monthly data for the state and each birthing facility on the percent of specimens submitted without error, specimen transit errors, specimen collection timing errors, inadequate specimen errors, and demographic data errors. NBMS provides this data to each birthing facility both monthly and in a 6 month summary, and assists birthing facilities as needed to improve their newborn screening practices.

- **Newborn Hearing Screening**

The Newborn Hearing Screening Program (NHSP) is developing a practitioner's manual. Written guidelines are in place on audiological follow-up for infants who failed newborn hearing screening.

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. Contacting hospitals monthly to reconcile state data against hospital delivery logs is planned. As needed,

NHSP provides technical assistance to address barriers to screening, such as outdated screening equipment or lack of backup equipment. NHSP and the Newborn Metabolic Screening Program are coordinating quality assurance efforts to more efficiently identify infants who need additional follow-up due to missed screens. NHSP continues to work with hospitals and primary care providers to assure that follow-up is provided.

- **Children with Special Health Care Needs**

The Hawaii 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 uses these national and other local data sources as available. As needed, surveys on selected topics for a specific population group are also conducted.

Contracts

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

Early Hearing Detection and Intervention Logic Model

INTERVENTIONS	DETERMINANTS	BEHAVIOR	GOAL
<p>Tertiary</p> <ul style="list-style-type: none"> • MCH Bureau support for newborn hearing screening (funding, Title V national performance measure). CDC support for early hearing detection and intervention (EHDI) integration (funding, guidelines). CDC and MCH Bureau collaborate/coordinate in these efforts, & working with stakeholders at national level. • Technical assistance is available through National Center for Hearing Assessment and Management (NCHAM) • “Year 2000 Position Statement: Principles and Guidelines for EHDI Programs” (Joint Committee on Infant Hearing). • American Academy of Pediatrics (AAP) educational materials on hearing screening and follow-up • Screening guidelines – AAP, EPSDT • State law mandating newborn hearing screening and reporting of results to DOH. Establishment of administrative rules. • Child find component of Part C of IDEA. • State goal of “All children will be safe, healthy, and ready to succeed” 	<p><u>Tertiary</u></p> <ul style="list-style-type: none"> + Statutes and regulations mandating newborn hearing screening and follow-up + Information and education provided at national level + Coordination with stakeholders at national level + Financial support for newborn hearing screening and follow-up provided at national levels + Guidelines and protocols for screening and follow-up are provided at national level + Technical assistance provided at national level + Statewide policy supporting success in early childhood 		
<p><u>Secondary Level/Community</u></p> <ul style="list-style-type: none"> • HI*TRACK data management system is in place, with data from hospitals submitted to the State Newborn Hearing Program. • State Newborn Hearing Screening Program provides technical assistance and support to hospital newborn screening programs. • Each birthing facility has its own newborn hearing screening coordinator/program. • Birthing facilities provide hearing screening information to families. • Purchase of hospital newborn hearing screening program equipment through MCH Bureau and CDC grant funds if hospital lacks funds. • Education sessions and materials for physicians, midwives, and other providers on screening and appropriate follow-up. • State has a mechanism to ensure that infants not born in birthing hospitals will receive hearing screening, and to assure follow-up for infants who fail screening. 	<p><u>Secondary Level/Community</u></p> <p>State Newborn Hearing Screening Program:</p> <ul style="list-style-type: none"> + Data management system for tracking screening/follow-up and quality assurance. <p>Hospital newborn hearing screening program:</p> <ul style="list-style-type: none"> + Every birthing facility has a newborn hearing screening program. - Lack of adequate hearing screening equipment especially in rural areas, and insufficient funding for equipment. <p>Primary care physicians, midwives, and other providers:</p> <ul style="list-style-type: none"> - Insufficient knowledge about screening and appropriate follow-up. - Incomplete tracking system to ensure every infant under their care receives appropriate screening and follow-up. 	<p>Infant receives hearing screening by age 1 month</p>	<p>Early identification and intervention for infants with hearing loss</p>
<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> • Physicians, midwives, and others provide information/education to families on screening/follow-up. • Health insurance pays for newborn screening as part of fee for hospital infant care. Newborn Hearing Screening Program pays for screening for families who lack health insurance or whose health insurance does not fully cover outpatient hearing screening. • Written educational materials are available in different languages. 	<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> - Family lacks information about hearing screening. - Family lacks financial resources for hearing screening. - Homebirths are less likely to have screening. - Infant's medical condition may delay screening. 		

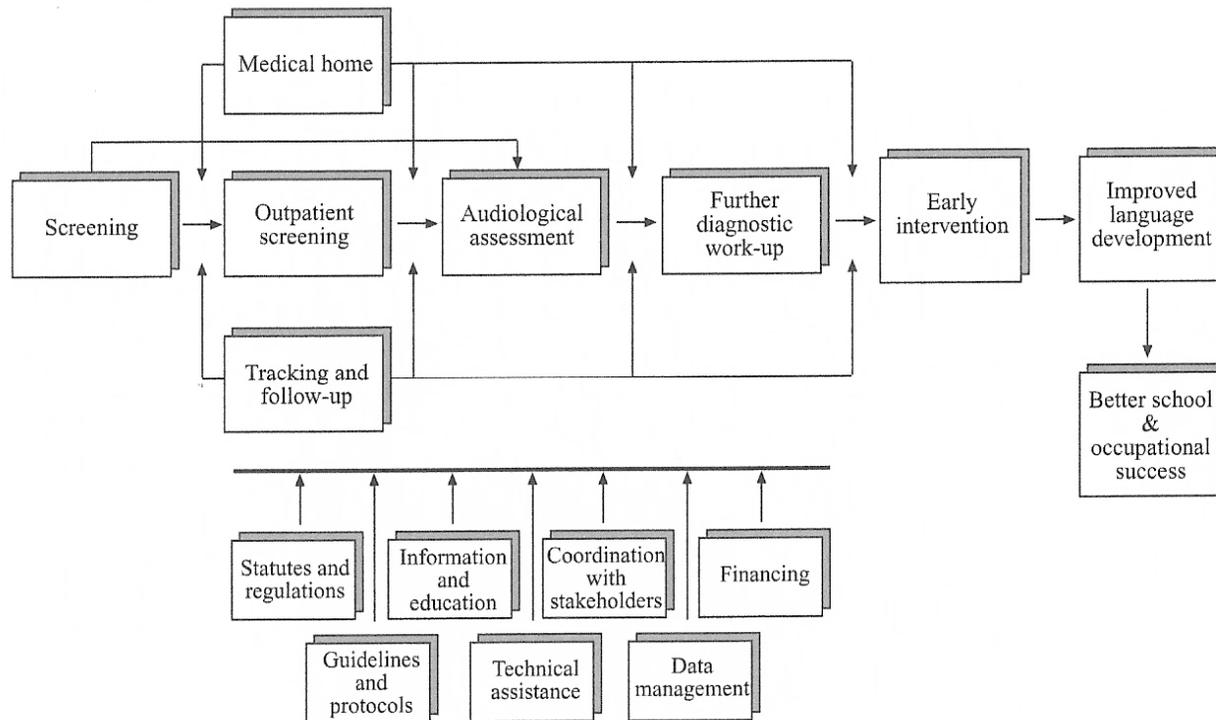
INTERVENTIONS	DETERMINANTS	BEHAVIOR	GOAL
<p><u>Tertiary</u> See previous section.</p>	<p><u>Tertiary</u> See previous section.</p>		
<p><u>Secondary Level/Community</u></p> <ul style="list-style-type: none"> • HI*TRACK data management system is in place. • System is in place to reduce financial and geographic barriers to diagnostic audiologic evaluations. • Establishment of guidelines for pediatric diagnostic audiologic evaluations. • Education for primary care providers, care coordinators, audiologists, etc., on appropriate diagnostic follow-up for infants who fail hearing screening. 	<p><u>Secondary Level/Community</u></p> <p>State Newborn Hearing Screening Program:</p> <ul style="list-style-type: none"> - Lack of data management system to track all diagnostic audiologic evaluations and follow-up for infants who fail hearing screening. <p>Audiologists</p> <ul style="list-style-type: none"> - Insufficient number of audiologists on Neighbor Islands. + Guidelines for pediatric diagnostic audiologic evaluations <p>Primary care physicians</p> <ul style="list-style-type: none"> - Insufficient knowledge about diagnostic audiologic evaluation and follow-up. 	<p>Infant who fails hearing screen receives diagnostic audiologic evaluation by age 3 months</p>	<p>Early identification and intervention for infants with hearing loss</p>
<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> • Provision of education to families about the importance of early diagnosis for hearing loss, provided by the child/families physicians, care coordinators, etc. • Newborn Hearing Screening Program pays for diagnostic audiologic evaluation for families who lack health insurance or whose health insurance does not fully cover confirmatory diagnostic audiological evaluations. • Newborn Hearing Screening Program pays for and arranges transportation for Neighbor Island families to Oahu for diagnostic audiologic evaluation services when they are not available on a Neighbor Island, for families who lack other resources to pay for transportation to confirmatory diagnostic audiological evaluations. 	<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> - Family lacks or has insufficient information about importance of early diagnosis for hearing loss. - Family lacks health insurance coverage for diagnostic audiologic evaluation. - Family lacks transportation (e.g. Neighbor Island to Oahu) for diagnostic audiologic evaluation. - Family may not be interested in further evaluation when infant fails hearing screen. - Infant's medical condition may delay evaluation. 		

INTERVENTIONS	DETERMINANTS	BEHAVIOR	GOAL
<p><u>Tertiary</u> <i>See also previous section.</i></p> <ul style="list-style-type: none"> • Advocacy for appropriate insurance payment for hearing aids & related services • Part C of IDEA 	<p><u>Tertiary</u> <i>See also previous section.</i></p> <p>Financing:</p> <ul style="list-style-type: none"> - Health plans may not cover hearing aids, or may have inadequate payment for hearing aids & related services. 		
<p><u>Secondary Level/Community</u></p> <ul style="list-style-type: none"> • EIS has a deaf educator to provide consultation on communication, amplification options and appropriate intervention services for children with hearing loss. • Language enrichment playgroups. • Lending library of educational materials for families and EI staff. • Family to family support is provided through gatherings of families of children with hearing loss or parent mentors and advisors (“Ohana Time”). • Deaf Mentors provide/ individualized family support. • Education/training for primary care providers, care coordinators, etc., on appropriate follow-up (e.g., referral for EI services, ENT evaluation, etc.) for infants with diagnosed hearing loss. 	<p><u>Secondary Level/Community</u></p> <p>Newborn Hearing Screening Program</p> <ul style="list-style-type: none"> - Incomplete data on enrollment of children with hearing loss in EI services. Family Educational Rights and Privacy Act (FERPA) prevents sharing enrollment information with the Newborn Hearing Screening Program without a FERPA consent. <p>Early intervention services:</p> <ul style="list-style-type: none"> + Appropriate early intervention services for children with hearing loss. + Family-to-family support for families/children with hearing loss. <p>Primary care physicians:</p> <ul style="list-style-type: none"> - Lack of knowledge about appropriate follow-up when hearing loss is diagnosed. 	<p>Infant who is diagnosed with hearing loss receives early intervention services by age 6 months</p>	<p>Early identification and intervention for infants with hearing loss</p>
<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> • Families are provided early intervention services that meet the needs of families/children with hearing loss. • Primary care providers provide information/education to families of children with hearing loss about early intervention services, communication options, etc. • Children with Special Health Needs Program pays for hearing aids for eligible children whose families are above income for Medicaid and QUEST and below 300% of the federal poverty level, if the family does not have other resources. • Early Intervention Section provides financial assistance for hearing aids for eligible children whose families are above income for the Children with Special Health Needs Program, if the family cannot afford to pay the full cost. 	<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> - Family of child with hearing loss lacks awareness and knowledge about importance of early intervention services and appropriate amplification for the development of language and communication skills. - Family lacks health insurance coverage for hearing aids. - Family of infant with hearing loss may not be interested in early intervention services (“denial”). - Family of infant with hearing loss may not be interested in obtaining hearing aids for their baby (“denial”). - Infant’s medical condition may delay intervention. 		

+ Protective factor - Risk factor

CDC Logic Model of the Early Hearing Detection and Intervention System

From: Centers for Disease Control and Prevention, *Early Hearing Detection and Intervention Program Guidance Manual*, February 2003, page 10.



Transition of Youth with Special Health Care Needs (YSHCN) to Adult Life Logic Model

INTERVENTIONS	DETERMINANTS	BEHAVIOR	GOAL
<p><u>Tertiary</u></p> <ul style="list-style-type: none"> • Individuals with Disabilities Education Act (IDEA) mandates transition services beginning at age 16. • MCH Bureau supports system-building regarding transition (funding, state grants, Title V national performance measure, etc.) • Collaboration/coordination of stakeholders at national level (MCHB, Family Voices, AAP, etc.) • Technical assistance is available through the Healthy and Ready to Work National Center (guidelines, educational materials, etc.) • “A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs” (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine): • American Academy of Pediatrics (AAP) medical home educational materials on “Medical Home & Transitions: A Life-Span Process”. 	<p><u>Tertiary</u></p> <ul style="list-style-type: none"> + Statutes and regulations mandating transition services. + Information and education provided at national level. + Coordination with stakeholders at national level. + Financial support at federal level for state planning regarding transition to adult life. + Technical assistance provided at national level. + Guidelines and protocols for transition at national level. - Programs for adults with special health care needs vary in eligibility criteria which fragments the continuum of services 	<p>YSHCN receive services necessary to transition to adult health care</p>	<p>YSHCN make the transitions to adult life, including adult health care, work, and independence</p>
<p><u>Secondary Level/Community</u></p> <ul style="list-style-type: none"> • Establish interagency workgroups with physicians, other health care providers, educators (child care ->college), workforce development, business, health care financing, transportation, personal support. • Include transition issues in program documentation, quality assurance, outcome measurement, and personnel description/evaluation. • Provide education/information to physicians and residents on the medical aspects of pediatric-onset conditions, community resources, developmentally appropriate transition services, etc. • Develop network of pediatric and adult medical care providers who offer information/support in caring for YSHCN. • Develop and distribute “primers on health insurance” for youths/families in a variety of community settings including schools, parent resource groups, etc. • Develop strategies for adult health care, e.g., select adult health care provider, encourage youth/family to visit and interview physician/office staff, have pediatrician remain involved as a “consultant” while the adult health care provider assumes responsibilities, facilitate communication among medical home and specialty providers. • Establish best practices/tools to facilitate transition of health care for YSCHN to adult health care providers. 	<p><u>Secondary Level/Community</u></p> <p>Primary care providers, care coordinators, etc.:</p> <ul style="list-style-type: none"> - Lack knowledge and skills to transition YSHCN toward adult health care, work, and independence. <p>Pediatric health care providers:</p> <ul style="list-style-type: none"> - Insufficient time/reimbursement needed to transition YSCHN to adult health care providers. - Do not discuss shift to adult health care provider with YSCHN/family - May not have adequate professional relationships to transition YSCHN to colleagues who are Adult health care providers <p>Adult health care providers:</p> <ul style="list-style-type: none"> - Insufficient number of adult health care providers who are willing to assume care for YSHCN. - Transition is not defined as a priority by adult health care provider professional organizations which have the influence to set standards and best practices. <p>Agencies and programs for YSHCN:</p> <ul style="list-style-type: none"> - Agencies who service Adults with special health care needs have a focused service array which address social needs, therefore they lack awareness of health issues and the need to transition to adult health care. - Agencies who serve YSHCN are entitlement and eligibility based, there is no single agency that has the enrollment capacity or advising and supporting all YSHCN through transition 		

<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> • Develop a written health transition plan that includes: proactive wellness (diet, safety, risk reduction), increasing responsibility for self-care and health, transition to adult health care, health care funding options, future plans that may be influenced by health (work, school, recreation, community involvement), preventive care, secondary disabilities. Update plan annually. • Provide information to youth on medical aspects of pediatric-onset conditions, and implications of health condition for adult life. • Advise families of strategies and alternatives to guardianship to facilitate the participation of the family in the youth's the health care • Insure that families have information regarding access to adequate and appropriate health coverage for the YSHCN. • Encourage YSHCN to develop health care skills, e.g., make a list of questions/concerns to ask health care provider, make their own appointments, call in their refill prescriptions, develop a portable medical summary, self-care, involvement in medical therapies. Use health care skill checklist. • Develop strategies for transitioning to adult health care providers, e.g., selection of adult health care provider, encourage youth/family to visit and interview physician/office staff, have pediatrician remain involved as a "consultant" while the adult health care provider assumes responsibilities, facilitate communication among medical home and specialty providers. • Assist YSHCN/families in navigating the system to obtain adult health care services. Provide information on adult health care, e.g., resource packets, at community meetings, at support groups, parent mentoring. 	<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> - YSHCN lack knowledge, skill, and experience needed to manage their own condition and lives, be self-advocates, determine their own lives. - YSHCN/families are not aware of changing needs as youth become adult. - YSCHN/families have difficulty in navigating the system to obtain adult health care services. - YSCHN/families are not prepared for differences in health care, insurance coverage, etc., as youth become adult. 		
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INTERVENTIONS	DETERMINANTS	BEHAVIOR	GOAL
<p><u>Tertiary</u> See previous section.</p>	<p><u>Tertiary</u> See previous section.</p>		
<p><u>Secondary Level/Community</u></p> <ul style="list-style-type: none"> • Work with community professionals & families to understand and use “the system.” Promote service focus that includes primary, secondary, tertiary prevention of disabilities; transportation; housing; access to quality health care; affordable insurance; personal care assistants & job supports; assistive technology. • Provide opportunities to assist families to build natural support systems • Coordinate multiple funding streams available for transition services (health, education, business, private organizations). • Develop referral and communication systems that connect youth and families to State and federal government programs for work preparation and employment experiences for youth with disabilities. • Collaborate with the Early Intervention system to help families start early in planning for the future. • Encourage employers to hire youth. • Develop “virtual” one stop centers for transitioning youth (Family Support 360 Project). 	<p><u>Secondary Level/Community</u> Agencies serving YSHCN:</p> <ul style="list-style-type: none"> - May not provide adequate assistance when referring to other agencies. - May not have adequate knowledge of other services of other agencies. - Services between agencies may not be coordinated. <p>Higher education institutions may not provide adequate supports for youth with disabilities.</p> <p>Employers:</p> <ul style="list-style-type: none"> - May not be interested in employing youths with disabilities. - May not provide adequate supports for youth with disabilities. - May not receive adequate supports to accommodate youth with disabilities (ADA compliance, job carving, job coaches, etc.) 		
<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> • Support skill-building for families, caregivers, and youth, to build competencies and self-confidence in working with issues and agencies for their children and youth with special needs. • Ensure youth/family are aware of IDEA transition requirements that by age 16, IEP must include: appropriate postsecondary goals related to training, education, employment & independent living skills; transition services to assist in reaching those goals, including courses of study. • Connect youth to other youth and adult mentors. • Refer YSHCN to programs that provide work preparation and employment experiences. • Provide benefit counseling services to youth to comprehend the interrelationship between SSI, SSDI, SSP, wages and Medicaid. • Encourage youth to work, volunteer, learn work habits early. • Encourage peer socialization and inclusion in opportunities. • Encourage YSHCN to be aware of their needs, seek help when needed, and advocate to ensure their health needs are met in school. • Help families negotiate the education system (IDEA/IEP/special education, 504, and regular education and accommodation plan). • Mentor children/youth & families in learning lifelong transition skills of proactive planning, problem solving, self-advocacy, negotiation. • Provide information on employment & education, e.g., resource packets, at community meetings. 	<p><u>Primary/Individual Level</u> YSHCN:</p> <ul style="list-style-type: none"> - May not have developed skills needed for transition to higher education or employment. - May not have received vocational services or career/higher education counseling. - May not be aware of available resources for to support youth in education or employment. <p>Families:</p> <ul style="list-style-type: none"> - Lack understanding of changing needs as youth becomes adult. - Lack knowledge or skills to assist youth in developing skills needed for high education and employment. - Lack knowledge of available resources for YSCHN as they became adults. <p>Programs:</p> <ul style="list-style-type: none"> - Lack of appropriate or timely referrals and or coordination between agencies (VR and Medicaid Waiver) allow for YSHCN to be lost in the system. - Department of Education. - Lack of consistent, systematic training for families at the age of transition fosters misinformation and knowledge disparity. 	<p>YSHCN receive services necessary to transition to employment</p>	<p>YSHCN make the transitions to adult life, including adult health care, work, and independence</p>

INTERVENTIONS	DETERMINANTS	BEHAVIOR	GOAL
<p><u>Tertiary</u> See previous section.</p>	<p><u>Tertiary</u> See previous section.</p>		
<p><u>Secondary Level/Community</u></p> <ul style="list-style-type: none"> Collaborate with and refer to state and federally funded agencies providing independent living training, transportation, and assistive technology services. Families serve on Advisory and Planning Committees to focus on global and local issues in transition. Collaborate with family and youth leadership organizations: Encourage and provide connections that will build competencies and self-confidence in working with issues and agencies for their children and their special needs. Mentor youth leaders as they serve on policy councils. Establish youth advisory committees, to give YSHCN the opportunity to build leadership skills, so that they can become spokespeople for youth with health, work, education, and social service professionals. 	<p><u>Secondary Level/Community</u> State/community agencies:</p> <ul style="list-style-type: none"> May not be assisting YSHCN to develop the skills needed for independence. May not be assisting YSHCN to work toward independence. May not be assisting YSHCN to dream of their future life, and take the necessary steps to achieve their dream. 		
<p><u>Primary/Individual Level</u></p> <ul style="list-style-type: none"> Encourage youth to be involved in independence building and work experiences. Connect youth with Scouts, Winners at Work, Special Olympics, local parks and recreation programs and other independence and social skill building organizations. Be aware and access appropriate resources and services such as: school to work, ticket to work, school or job training opportunities, centers for independent living, housing, transportation, recreation and social activities, mental health supports, personal care attendants, scholarships, Vocational Rehabilitation, Supplemental Security Income (SSI), home and community-based waivers, vocational rehabilitation. Encourage role/responsibilities in family's home (chores, pet care, etc). Increase YSHCN involvement in decision making Ask child/youth what he or she wants to do when grown up (dreams, jobs, relationships, etc). Support his or her aspirations. Discuss legal transition at 18 years from minor to adult rights without support/with support. Review guardianship options (full, partial, total independence, surrogate decision maker, and or durable power of attorney). Encourage parent-child interactions that encourage independence, beginning in early childhood. Provide opportunities for family support to assist families in adjusting and celebrating their child's independence. Provide information on independent living; e.g., resource packets, at community meetings. 	<p><u>Primary/Individual Level</u> YSHCN:</p> <ul style="list-style-type: none"> May not have skills of proactive planning, problem solving, self-advocacy, and negotiation needed for transition to independence. May not be aware of resources and services to assist them in working toward independence. <p>Families:</p> <ul style="list-style-type: none"> May not know how to assist youth in developing skills needed for independence. May not be aware of resources and services to assist their youth in working toward independence. 	<p>YSHCN receive services necessary to transition to independence</p>	<p>YSHCN make the transitions to adult life, including adult health care, work, and independence</p>

+ Protective factor - Risk factor

A Family View Of Children with Special Health Care Needs Hawaii 2001

Hawaii Data from the National Survey of Children with Special Health Care Needs

Children with Special Health Needs Branch
Family Health Services Division
Hawaii Department of Health

How Are Children with Special Health Care Needs Faring in Hawaii?

- 52% families of CSHCN partner in decision-making at all levels, and are satisfied with the services they receive.
- 48% CSHCN receive coordinated, ongoing, comprehensive care within a medical home.
- 70% CSHCN have adequate private and/or public insurance to pay for the services they need.
- 69% CSHCN/families report that community-based service systems are organized so families can use them easily.
- 5% youth with special health care needs receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

Children with special health care needs are children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions, and require health and related services of a type or amount beyond that generally required by children.

Definition from Maternal and Child Health Bureau,
U.S. Dept. Health and Human Services,
and American Academy of Pediatrics



Hawaii data from the National Survey for Children with Special Health Care Needs (CSHCN) provide information on five of the six national outcomes for CSHCN. These outcomes were established as part of the national action plan to achieve community-based service systems for CSHCN and their families (*Measuring Success for Healthy People 2010: A working document, 1999*).

The survey assesses the prevalence and impact of special health care needs among children, and provides a family view of health issues and challenges for CSHCN and their families.

Data show a need to improve outcomes for CSHCN in Hawaii.

National Survey of CSHCN

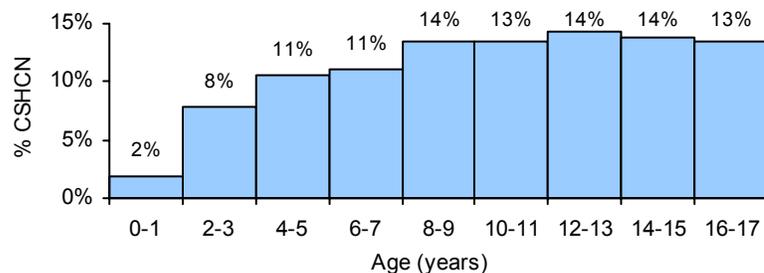
- The National Survey of CSHCN was sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration, and Office of Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.
- The National Center for Health Statistics conducted the survey from October 2000-April 2002.
- The survey was population-based, using random-digit-dial sampling. Telephone and/or written interviews were conducted in English, Spanish, Cantonese, Japanese, Korean, Mandarin, Tagalog, Vietnamese, and other languages.
- In each state, approximately 750 CSHCN under age 18 years were identified using criteria that crossed diverse health care needs. CSHCN were children who had a medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer, and met one or more of the following:
 - increased use of medical care, mental health, or educational services
 - need for prescription medicines
 - limited ability to do things
 - need for special therapy
 - need for treatment/counseling for an emotional, developmental, or behavioral problem
- State data were weighted for the entire CSHCN population.
- Hawaii data were analyzed by the Children with Special Health Needs Branch, Hawaii Department of Health. Outcomes were determined according to the method established by the Maternal and Child Health Bureau, which counted only children who met all applicable indicators as achieving the outcome.

Hawaii Data from the National Survey of CSHCN

Who are children with special health care needs?

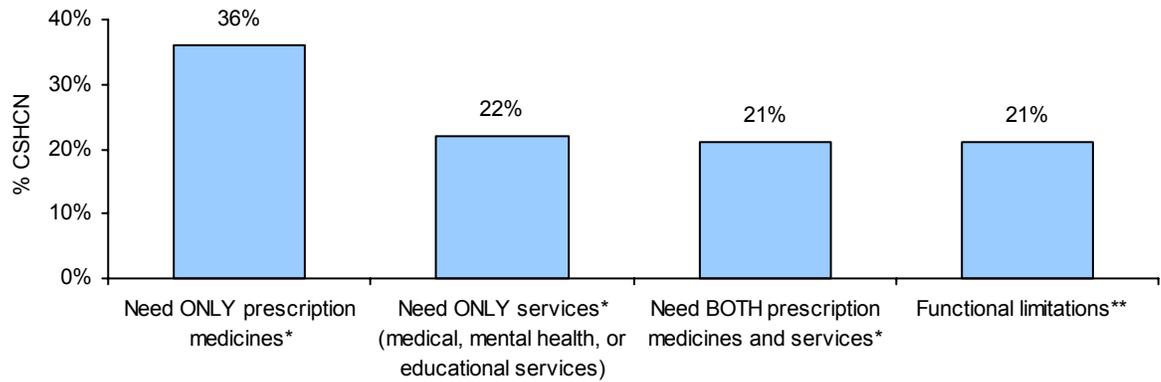
- Hawaii has approximately 32,500 CSHCN age 0-17 years. They comprise 11% of all Hawaii children.
- Approximately 25,300 households have at least one child with special health care needs. They comprise 16% of households with children.

- A greater proportion of CSHCN are in the older ages. *This may reflect increasing identification and/or development of special health needs with age.*



- There are more males (59%) with special health care needs, compared to females (41%).
- Over half of the CSHCN are in families with income under 300% federal poverty level (FPL). By income:
 - 20% families had income less than 200% FPL.
 - 38% families had income 201-300% FPL.
 - 42% families had income over 300% FPL.

- *Special health care needs by subgroups²*: For CSHCN who have medical, behavioral, or other health conditions that have lasted or are expected to last 12 months or longer:

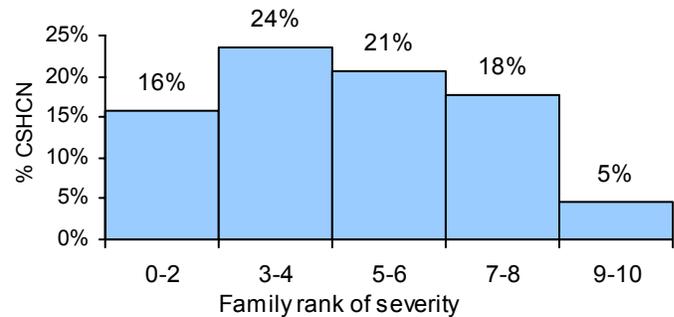


* No functional limitations.

** Limited in ability to do things most children of the same age can do. This subgroup includes children with functional limitations who also need prescription medicines and/or more services.

- *Severity*: Families ranked their children’s conditions or problems on a scale from 0-10, with 10 as the most severe.

- 45% CSHCN had moderate conditions or problems (rank 3-6).
- 23% CSHCN had severe conditions or problems (rank 7-10).



What do families say about being effective partners?

Outcome measure

52% CSHCN/families partner in decision-making at all levels and are satisfied with the services they receive.³

- 81% CSHCN/families say that their doctors usually or always made the family feel like a partner.
- 55% CSHCN/families were very satisfied with the services received. 32% were somewhat satisfied.

2010 National Outcome for CSHCN

Families of CSHCN will partner in decision-making at all levels, and will be satisfied with the services they receive.

~~~~~  
*Families are the constants in the child’s life, and are pivotal in making any system work. Families must have a leading role in the development of systems at all levels of policy, programs, and practice. Their participation in decision-making helps to ensure that services are family-centered and meet the needs of families.*

<sup>2</sup> Subgroups are based on health consequences experienced by CSHCN. These are categories developed by Child and Adolescent Health Measurement Initiative, [www.cshcndata.org](http://www.cshcndata.org).

<sup>3</sup> The percentage for this outcome measure is derived from 2 indicators (see page 10).

## What do families say about their child's medical home?

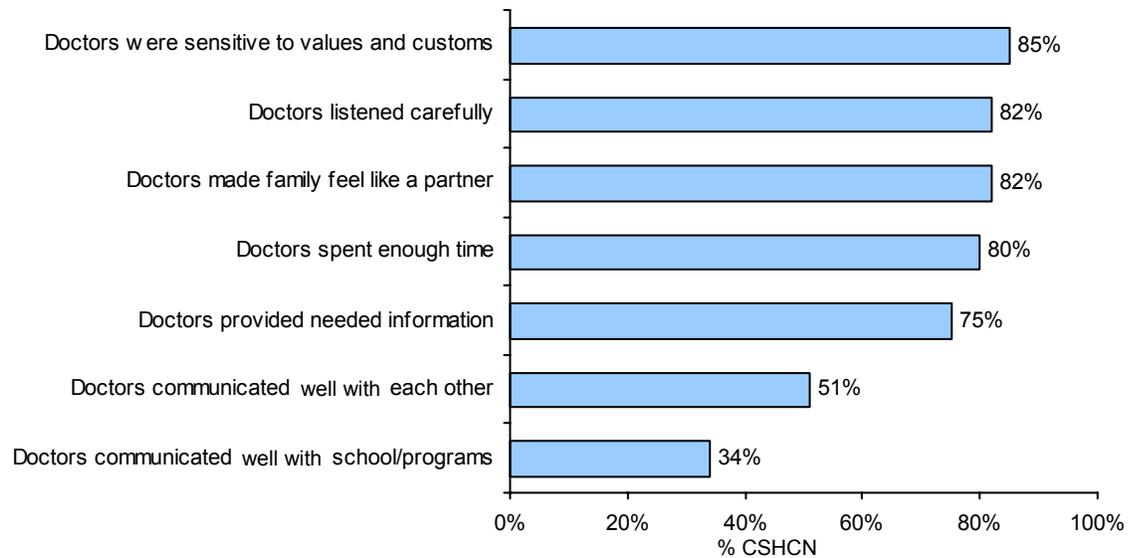
### Outcome measure

**48% CSHCN receive coordinated, ongoing, comprehensive care within a medical home.**<sup>4</sup>

### **Health care provider**

- 98% CSHCN had a usual place to go for sick care. 88% CSHCN had a usual place for preventive care.
- 88% CSHCN had a personal doctor or nurse.
- Family views of medical homes for CSHCN:

**2010 National Outcome for CSHCN**  
 CSHCN will receive coordinated, ongoing, comprehensive care within a medical home.  
 ~~~~~  
Children with special health care needs require a medical home – a source of ongoing routine health care in their community. The medical home assists in the early identification of special health care needs, provides ongoing primary and preventive care, and coordinates with other health and related services. Care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-effective.



Referrals

- 76% CSHCN had no problems obtaining referrals when needed.

Care coordination

- 14% CSHCN/families needed professional care coordination. Of these, only 74% received care coordination.
- Of CSHCN/families receiving care coordination, 85% were somewhat or very satisfied with the help they received in coordinating care.
- Comparing subgroups, CSHCN with functional limitations have the greatest need for care coordination:

	<u>% needing care coordination</u>
CSHCN who need ONLY prescription medicines	4%
CSHCN who need ONLY services	16%
CSHCN who need BOTH prescription medicines and services	16%
CSHCN with functional limitations	30%

⁴ The percentage for this outcome measure is derived from 5 indicators (see page 10).

What do families say about health insurance for CSHCN?

Outcome measure

70% CSHCN have adequate private and/or public insurance to pay for needed services.⁵

2010 National Outcome for CSHCN
 Families of CSHCN will have adequate private and/or public insurance to pay for services they need.
 ~~~~~  
 Families must have a way to pay for services. Having private and/or public insurance is essential. CSHCN need access to a full range of needed health care and related services.

### **Insurance coverage**

- 97.7% CSHCN have health insurance coverage.
- Types of health insurance coverage:

|                               | % CSHCN |
|-------------------------------|---------|
| Private only <sup>6</sup>     | 70.7%   |
| Public only <sup>7</sup>      | 15.0%   |
| Private and public            | 9.9%    |
| Other comprehensive insurance | 2.1%    |
| None                          | 2.3%    |

- 94% CSHCN had no gaps in coverage during previous year.
- 90% CSHCN/families have enough information about how their child's health plan works.

### **Insurance problems**

- 11% CSHCN had insurance that never or only sometimes met their needs.
- 22% CSHCN had costs (not covered by insurance) that were not reasonable.
- 10% CSHCN had insurance that never or only sometimes permitted child to see needed providers.
- 13% CSHCN/families believe their child's health plan is not good for CSHCN.
- 12% CSHCN/families called/wrote to any of the child's health plans with a complaint or problem.
- 25% CSHCN/families, if they had a chance, would switch to a different health care plan.

<sup>5</sup> The percentage for this outcome measure is derived from 5 indicators (see page 10).

<sup>6</sup> Private insurance is defined as employer- or union-based or purchased directly. It includes military coverage.

<sup>7</sup> Public insurance includes Medicaid/QUEST.

***Underinsured CSHCN***

- An estimated 12% CSHCN are underinsured (based on health insurance not paying for a needed service, or inability of a family with health to afford out-of-pocket costs for services).
  - 3% CSHCN with insurance did not get or delayed needed care because of cost for services such as preventive care, specialty care, dental care, prescription medication, physical therapy, occupational therapy, speech therapy, mental health, substance abuse treatment/counseling, respite, genetic counseling.
  - 9% families of CSHCN with insurance paid over \$500 in out-of-pocket costs for medical/health-related expenses in the past year, and had financial problems caused by their child's health conditions or needed additional income to cover their child's medical expenses.

***What do families say about screening for special health care needs?***<sup>8</sup>

*Preventive care includes screening for newborn hearing and metabolic conditions, development, vision, hearing, oral health, behavior, mental health, and other areas.*

- 88% CSHCN had a usual place to go for preventive care.
- 88% CSHCN had a personal doctor or nurse.
- 99% CSHCN received needed routine preventive care, such as a physical examination or well-child check-up in the previous 12 months.

**2010 National Outcome for CSHCN**  
 Children will be screened early and continuously for special health care needs.  
 ~ ~ ~ ~ ~  
*Screening may identify health conditions early, which helps infants and children to get timely services and intervention. Ongoing screening for children with special health care needs helps to identify new concerns and prevent secondary conditions.*

***Are services organized, coordinated, and easy to use?***

Outcome measure  
**69% CSHCN/families report community-based service systems are organized so they can use them easily.**<sup>9</sup>

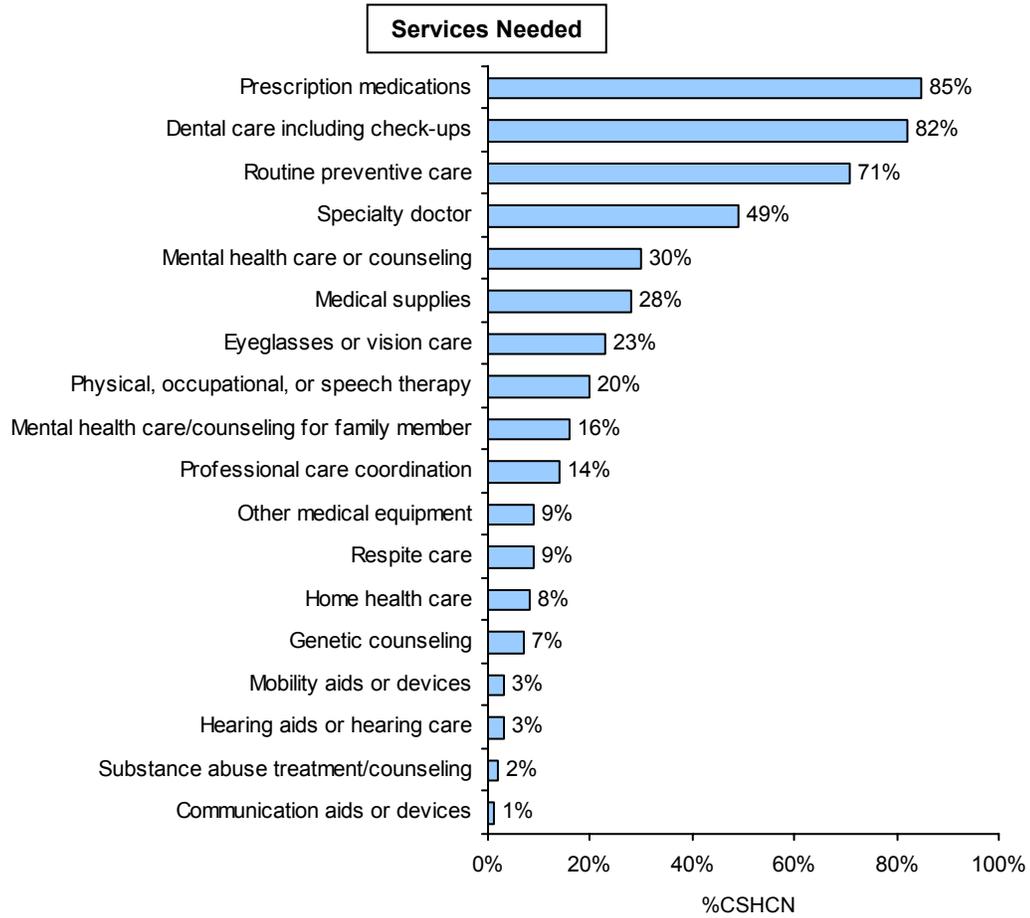
**2010 National Outcome for CSHCN**  
 Community-based service systems will be organized so families can use them easily.  
 ~ ~ ~ ~ ~  
*The system must be organized so that the needs of children/families can be identified, services are provided, and there is a way to pay for them. Since CSHCN require more medical and related services than other children, services need to be coordinated and easy to use.*

<sup>8</sup> The survey did not have specific indicators for screening.

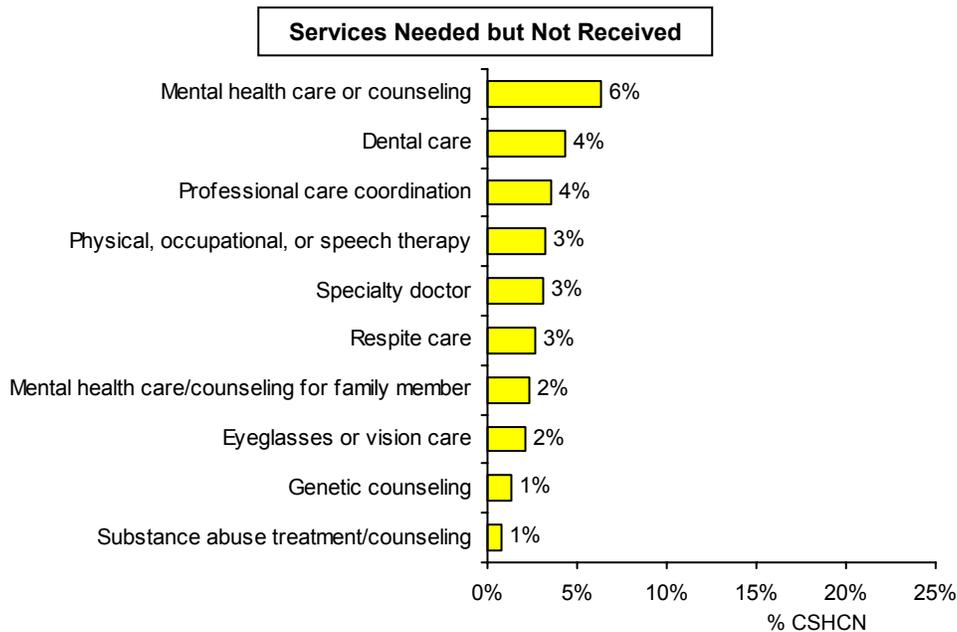
<sup>9</sup> The percentage for this outcome measure is based on 1 indicator (see page 10).

**Services needed**

- Health and related services needed by CSHCN include the following:



- Approximately 16% CSHCN are not receiving one or more needed health or related services. The greatest unmet needs are mental health care/counseling and dental care.



- Reasons for not receiving services included the following:

|                                                                                                                                                                                                                                             | <u>% CSHCN<br/>not receiving service</u> |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------|
| Service not available in area / transportation problem                                                                                                                                                                                      | 23%                                      |
| Provider did not know how to treat or provide care                                                                                                                                                                                          | 18%                                      |
| Cost too much                                                                                                                                                                                                                               | 16%                                      |
| Health plan problem                                                                                                                                                                                                                         | 16%                                      |
| Not convenient times                                                                                                                                                                                                                        | 7%                                       |
| Other reasons                                                                                                                                                                                                                               | 18%                                      |
| <i>No insurance, could not get referral,<br/>difficulty getting appointment, couldn't find someone,<br/>dissatisfaction with provider, lack of resource in school,<br/>did not know service was available,<br/>did not know where to go</i> |                                          |

***Financial difficulties in getting needed services***

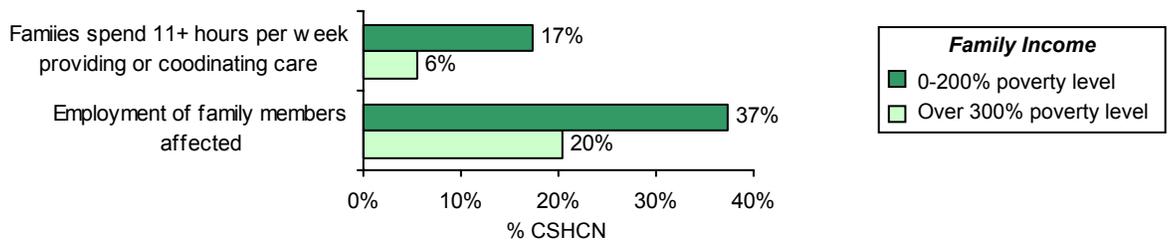
- 43% families of CSHCN paid \$1,000 or more out-of-pocket for medical care / health-related needs in the previous year.
- 13% families of CSHCN had financial problems caused by their child's condition.
- 14% families of CSHCN needed additional income to cover their child's medical expenses.
- 29% CSHCN had family members whose employment was affected by the child's condition (for example, reduced work hours or stopped working).

***Increased time in providing care***

- 11% families of CSHCN spend 11 or more hours per week providing or coordinating care.
- 5% CSHCN have health care needs that change all the time.
- 13% CSHCN had 11 or more days of school absences due to illness in the previous year.
- 10% CSHCN had 11 or more visits to doctor or other health care provider in previous year.

***Increased difficulty for families with lower income***

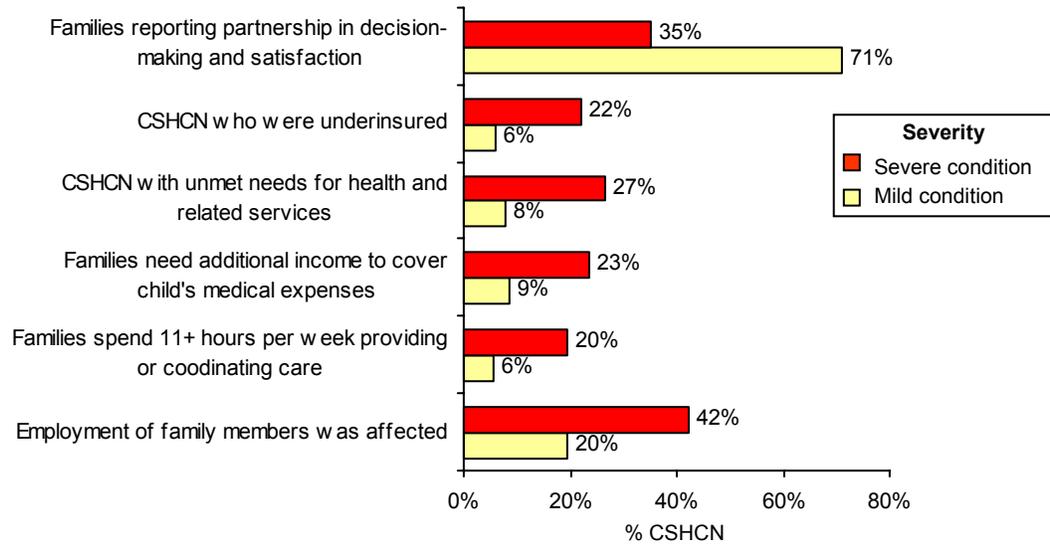
- Families of CSHCN with lower income are impacted more than families with higher income, in the following areas\*:



\* Lower income = 0-200% FPL (Federal Poverty Level). Higher income = over 300% FPL. For a family size of 4 family members, 0-200% FPL=\$41,640 or less, and over 300% FPL= over \$62,460 (2002 FPL). Items shown are statistically significant at the 95% confidence interval.

***Increased difficulty for families of CSHCN with severe conditions***

- Families of CSHCN with severe conditions are impacted more than those with mild conditions, in the following areas\*:



\* Severity grouping was based on family ranking of children’s conditions or problems on a scale from 0-10, with “mild”=0-2, “moderate”= 3-6, “severe”=7-10. Items shown are statistically significant at the 95% confidence interval.

***What do families say about the transition of youths with special health care needs to adult health care, work, and independence?***

Outcome measure

**5% youth with special health care needs have received the services necessary to make transitions to all aspects of adult life.**<sup>10</sup>

- 60% youth with special health care needs have doctors who talked about changing needs as youth becomes an adult.<sup>11</sup>
- 54% youth with special health care needs have a plan for addressing changing needs.<sup>10</sup>
- 36% youth with special health care needs have doctors who discussed the shift to adult health care provider.<sup>10</sup>
- 29% youth with special health care needs have received vocational or career training.<sup>10</sup>

**2010 National Outcome for CSHCN**  
 Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.  
 ~~~~~  
 Youth with special health care needs need to be prepared to take charge of their own health care and to lead a productive life as they choose. Appropriate adult health care services must be available to them.
 Transition services can give youths the opportunities to achieve their goals for adult life.

¹⁰ The percentage for this outcome measure is derived from 2 indicators (see page 10).

¹¹ Due to small numbers, these percentages may not be accurate and the actual percentages may be up to 10-15% higher or lower than the stated number.

Summary of Outcomes for Hawaii CSHCN

Outcome for CSHCN with indicator(s) used to determine outcome¹²	% CSHCN
% CSHCN age 0-17 years whose families partner in decision-making at all levels and are satisfied with the services they receive	52%
<ul style="list-style-type: none"> • Doctors usually or always made the family feel like a partner • Family was very satisfied with services received 	81% 56%
% CSHCN age 0-17 years who receive coordinated, ongoing, comprehensive care within a medical home	48%
<ul style="list-style-type: none"> • The child had a usual source of care <ul style="list-style-type: none"> ○ Child had a usual source for sick care ○ Child had a usual source for preventive care • Child had a personal doctor or nurse • Child had no problems obtaining referrals when needed • Effective care coordination was received when needed <ul style="list-style-type: none"> ○ Child had professional care coordination when needed ○ Doctors communicated well with each other ○ Doctors communicated well with other programs • The child received family-centered care <ul style="list-style-type: none"> ○ Doctors spent enough time ○ Doctors listened carefully ○ Doctors were sensitive to values and customs ○ Doctors provided needed information ○ Doctors made family feel like a partner 	88% 98% 88% 88% 76% 28% 74% 51% 34% 63% 80% 82% 85% 75% 82%
% CSHCN age 0-17 years whose families have adequate private and/or public insurance to pay for the services they need	70%
<ul style="list-style-type: none"> • Child had public or private insurance at time of interview • Child had no gaps in coverage during year prior to the interview • Insurance usually or always met child's needs • Costs not covered by insurance were usually or always reasonable • Insurance permitted child to see needed providers 	98% 94% 89% 78% 90%
% Children screened early and continuously for special health care needs⁷	—
% CSHCN age 0-17 years whose families report community-based service systems are organized so they can use them easily	69%
<ul style="list-style-type: none"> • Services were organized for easy use 	69%
% Youth with special health care needs who received the services necessary to make transitions to all aspects of adult life	5%
<ul style="list-style-type: none"> • Child has received guidance and support in transition to adulthood <ul style="list-style-type: none"> ○ Doctors talked about changing needs as child becomes adult ○ Child has plan for addressing changing needs ○ Doctors discussed shift to adult provider • Child has received vocational or career training 	15% 60% 54% 36% 29%

¹² Only children who met all applicable indicators were counted as achieving the outcome. Similarly, only children who met all applicable sub-indicators were counted as achieving the indicator. The outcome indicators and method of analysis were established by the federal Maternal and Child Health Bureau.

Additional Hawaii Data Related to the Outcomes for CSHCN

Families partnership

- 89% families of CSHCN are included in making decisions about child's health care.¹³
- For children with special needs age 0-3 years receiving early intervention (EI) services¹⁴:
 - 93% families are satisfied with family supports provided to meet child's needs.
 - 91% families are satisfied with progress their child made while receiving EI services/supports.

Medical home

- 92% families of CSHCN have a doctor who knows about child's health.¹² Families say:
 - 90% – child's doctor listens carefully to them.
 - 89% – families are included in making decisions about child's health care.
 - 88% – families get information about child's condition and care.
 - 86% – doctor talks about child's growth, behavior, preventing injuries, immunizations.
 - 82% – when child is sick, doctor or other doctors are available at all hours of the day or night.
 - 74% – families get reassurance and support about the care families provide.
 - 71% – doctor arranges/coordinates services provided by different doctors, therapists, other persons.
 - 70% – families' cultural background is recognized and respected.
 - 57% – families get information about educational and other support services in the community.

Health insurance

- CSHCN with insurance coverage: health – 97%; dental – 87%; drug – 91%; vision – 74%.¹²
- 62% families of CSHCN had out-of-pocket costs for their child's health care in the last 12 months, with 18% families having costs of over \$1,000.¹²
- 39% families of CSHCN said they or family member cut down/stopped working to care for their child.¹²
- 33% families of CSHCN said that extra costs of care for their child resulted in financial problems.¹²

Screening

- 99% newborns are screened for metabolic conditions. 100% infants with metabolic conditions receive appropriate follow-up services.¹⁵
- 98% newborns are screened for hearing. 92% infants with permanent hearing loss receive appropriate intervention services.¹⁶
- Primary care physicians screening most of their children age 3-4 years for development – 77%, hearing – 66%, and vision – 67%. Barriers to screening included: difficult getting child to test, lack of staff time, reimbursement, lack of staff trained to screen, no screening tool or equipment in office.¹⁷

Organized system of services

- 6% CSHCN age 5-11 years had difficulty getting health care, due to: insurance was not accepted, could not afford cost, hard to get appointment, other reason.¹⁸
- 11% CSHCN age 5-11 years difficulty getting dental care, due to: could not afford cost, transportation problem, hard to get appointment, could not find the kind of dentist needed, other reason.¹⁷
- 32% families of CSHCN reported that their child needed but did not get service(s), due to: not available in area, not covered by health plan, cost too much, not convenient times, transportation problem, plane fare and/or overnight lodging not covered by health plan, not able to find person with skills or training.¹²
- For children age 0-3 years receiving EI services, 89% families say that all providers and agencies listed in the Individual Family Support Plan (IFSP) work together in providing services to child and family.¹³

Transition to adult life

- Anecdotal reports of youths with special needs having difficulty in transitioning from pediatric to adult health care physicians.¹⁹

¹³ Hawaii Department of Health (DOH), Children with Special Health Needs Branch (CSHNB), Survey of Families of CSHCN, 2000.

¹⁴ DOH, CSHNB, Early Intervention Section, and Public Health Nursing Branch. Parent survey, 2002.

¹⁵ DOH, CSHNB, Newborn Metabolic Screening Program, 2002.

¹⁶ DOH, CSHNB, Newborn Hearing Screening Program, 2002 births.

¹⁷ DOH, CSHNB, Healthy Child Care Hawaii, Survey of Physicians, 2001.

¹⁸ DOH, Family Health Services Division, Children's Health Issues 2000.

¹⁹ DOH, CSHNB.

Role of Children with Special Health Needs Branch In Developing the System of Services for CSHCN

The Family Health Services Division (FHSD), Hawaii Department of Health, is the lead state agency for Title V (Maternal and Child Health Block Grant) of the Social Security Act. Within FHSD, the Children with Special Health Needs Branch (CSHNB) has the Title V CSHCN responsibility:

To provide and promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based, systems of service for such children and their families.

Within CSHNB, mandates for system development also include:

- Children with special health needs – Hawaii Revised Statutes (HRS) §321-51 to 54.
- Early intervention services for children age 0-3 years with special needs – HRS §321- 351 to 357 and Part C of the Individuals with Disabilities Education Act (IDEA).
- Newborn hearing screening – HRS §321-361 to 363.
- Newborn metabolic screening – HRS §321-291.
- Birth defects program – HRS §321-421 to 426.

CSHNB works in collaboration with state, county, and community public/private partners and families to accomplish these goals. Resources are directed toward a combination of direct health care services, enabling services, population-based services, and infrastructure or resource-building activities.

Websites for More Information

American Academy of Pediatrics – *medical home, screening*: www.medicalhomeinfo.org

Champions for Progress – *implementing systems of care for CSHCN*: www.championsforprogress.org

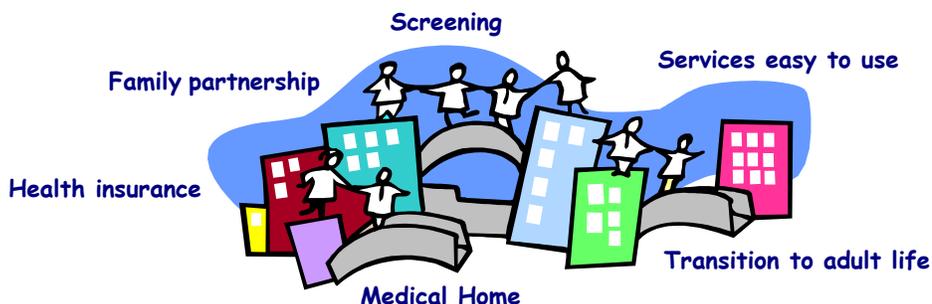
Data Resource Center for Child and Adolescent Health – *National Survey of CSHCN data* – www.cshcndata.org

Family Voices – *families speaking on behalf of CSHCN*: www.familyvoices.org

Healthy and Ready to Work National Center – *transition to adult life*: www.hrtw.org

Maternal and Child Health Bureau – *Title V, block grant, CSHCN*, www.mchb.hrsa.gov/programs; *Title V Information System for state programs, services, activities, and performance measures*
<https://performance.hrsa.gov/mchb/mchreports>

National Center for Health Statistics – *National Survey of Children with Special Health Care Needs*:
www.cdc.gov/nchs/about/major/slats/cshcn.htm



For more information, contact:
Children with Special Health Needs Branch
Hawaii Department of Health
741 Sunset Avenue
Honolulu, Hawaii 96816
Phone (808)733-9070 • Fax (808)733-9068

APPENDIX 4-B: Hawaii Data from the National Survey of Children's Health (2003)

A Family View of Children's Health in Hawai'i: Children With and Without Special Health Care Needs, 2003

Hawai'i Data from the National Survey of Children's Health

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National Survey of Children's Health – 2003

The National Survey of Children's Health was sponsored by the Maternal and Child Health Bureau, in partnership with the Centers for Disease Control and Prevention/National Center for Health Statistics. It was conducted as a component of the State and Local Area Integrated Telephone Survey (SLAITS).

Random-digit-dial samples were used. The survey was conducted in English and Spanish, using computer-assisted telephone interviews. About 2000 children age 0-17 years per state were surveyed January 2003 - July 2004.

Children with special health care needs (CSHCN) are defined as "those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions, and require health and related services of a type or amount beyond that generally required by children" (Maternal and Child Health Bureau, 1995). For this survey, CSHCN were identified by their having a medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer, and meets one or more of the following:

- Increased use of medical care, mental health, or educational services
- Need for prescription medicines
- Limited ability to do things
- Need for special therapy
- Need for treatment/counseling for an emotional, developmental, or behavioral problem

In Hawaii, 2,021 children were surveyed, of which 320 met the CSHCN criteria. Sample numbers were weighted and adjusted for total population of Hawaii. County and island information were not available.

The data for Hawaii State Profile was provided by the National Survey of Children's Health Data Resource Center (www.nschdata.org), a project of the Child and Adolescent Health Measurement Initiative. Hawaii data were further analyzed by the Children with Special Health Needs Branch in the Family Health Services Division, Hawaii Department of Health.

Table Notes

Sig. Diff. Significant Difference

★ Statistically significant difference between CSHCN and Not CSHCN rates at 95% confidence interval.

Hawaii State Profile

Children Age 0-17 Years		U.S.	Hawaii	Hawaii CSHCN	Hawaii Not CSHCN	Sig. Diff.
Child's Health Status						
Overall Child Health Status	% children whose overall health is excellent or very good	84.1	86.7	72.1	89.2	★
Moderate or Severe Health Problems	% children with health problems rated as moderate or severe by parents	7.9	5.6	37.3	0	★
Impact of Asthma on Family	% children with asthma whose families are greatly or moderately affected in some way by child's health condition	16.3	7.4	7.4	7.4	
Impact of Asthma	% children affected by asthma during past year	8.0	10.3	39.0	5.4	★
Injury	% children age 0-5 with injuries requiring medical attention during past year	9.4	7.9	9.6	7.7	
Missed School Days	% school age children who missed 11 or more days of school in past year due to illness or injury	5.2	4.3	11.3	2.9	★
Parents' Concerns	% children age 0-5 whose parents have one or more concerns about child's learning, development, or behavior	36.6	42.3	61.4	39.8	★
Socio-Emotional Difficulties	% children age 3-17 with moderate or severe difficulties in the area of emotions, concentration, behavior, or getting along with others	9.2	7.6	31.3	3.2	★
Breastfeeding	% children age 0-5 who were breastfed for any length of time	72.3	82.2	69.5	83.9	★
Child's Health Care						
Current Health Insurance	% children currently insured	91.2	94.8	93.2	95.1	
Consistent Insurance Coverage	% children currently uninsured or not insured for some period during past year	14.9	9.2	12.0	8.8	
Preventive Health Care	% children with a preventive medical care visit in past year	77.8	79.0	85.3	77.8	
Preventive Health and Dental Care	% children with both a preventive medical care visit and a preventive dental care visit in the past year	58.8	63.7	72.2	62.2	
Mental Health Care	% children with current emotional, developmental, or behavioral problems who received some type of mental health care during the past year	58.7	66.1	70.8	48.8	
Medical Home	% children who have a personal doctor or nurse from whom they receive family-centered, accessible, comprehensive, culturally sensitive and coordinated health care	46.1	45.3	39.8	46.3	
Child's School and Activities						
Early Childhood School	% children age 3-5 who regularly attended preschool, kindergarten, Head Start or Early Start during past month	60.7	64.4	79.1	62.4	
Activities Outside of School	% children age 6-17 who participate in one or more organized activities outside of school	81.0	82.5	80.9	82.9	
Repetition of Grade	% children age 6-17 who repeated at least 1 grade in school	11.3	7.3	14.3	5.9	★
Staying Home Alone	% children age 6-11 who stayed home alone during past week	15.9	21.9	25.4	21.3	
Child's Family						
Reading to Young Children	% children age 0-5 read aloud to by family members every day during the past week	47.8	54.9	57.5	54.6	
Household Smoking	% children who live in households where someone smokes	29.5	28.5	31.3	28.0	
Religious Services	% children who attend religious services at least once a week	55.7	51.5	51.9	51.5	
Mother's Health	% children with mothers whose overall physical and mental health is excellent or very good	58.9	61.7	54.2	63.0	
Child and Family's Neighborhood						
Supportive Neighborhood	% children living in neighborhoods parents describe as supportive	81.4	83.8	85.3	83.5	
Safety of Child in Neighborhood	% children living in neighborhoods or communities parents feel are usually or always safe	83.8	81.9	80.4	82.2	
Child Care Issues	% children age 0-5 whose parents had to make different child care arrangements in the past month or a job change for child care reasons in the past year, or both	33.2	34.4	41.5	33.5	

Hawaii Data Demographics

Children Age 0-17 Years	All Children (N=296,099) %	CSHCN (N=44,310) %	Not CSHCN (N=251,789) %	Sig. Diff.
Age:				
0-5 years	34.4	26.5	35.8	
6-11 years	31.7	32.6	31.6	
12-17 years	33.9	40.9	32.7	
Gender:				
Male	51.4	59.5	50.0	
Female	48.6	40.5	50.0	
Highest level of education attained by anyone in the household is high school, college, or graduate school:				
<12 years	2.4	4.2	2.1	
12 years	24.1	25.3	23.9	
>12 years	73.2	69.5	73.8	
Primary language spoken in the home:				
English	94.1	97.4	93.6	★
Other language	5.9	2.6	6.5	★
Child is of Hispanic or Latino origin	11.9	12.6	11.8	
Race:				
White only	17.5	21.0	16.9	
Black only	3.7	5.2	3.4	
Multiple race	32.7	35.9	32.2	
Asian only	30.2	22.4	31.6	★
Native Hawaiian/Pacific Islander	15.2	15.5	15.1	
Other	0.7	0.0	0.7	
Born in the United States:				
Mother	75.3	88.7	72.9	★
Father	81.7	86.6	80.9	
Child	94.0	97.0	93.5	
A household member was employed at least 50 of the past 52 weeks	91.4	90.8	91.5	
Total combined family income by poverty level (P.L.):				
Less than 100% P.L.	17.6	17.2	17.7	
100 to below 150% P.L.	12.9	12.9	12.9	
150 to below 200% P.L.	12.9	15.5	12.4	
200 to below 300% P.L.	19.6	17.4	20.0	
300 to below 400% P.L.	16.5	16.2	16.5	
At or above 400% P.L.	20.6	20.8	20.5	
Someone in household received cash assistance from a state welfare program, at any time during the past 12 months	16.6	16.8	16.6	
Child in household received Food Stamps, during past 12 months	21.6	22.4	21.5	
Children over age 3 years:				
Child in the household received free or reduced-cost breakfasts or lunches at school	(N=148,167) 41.9	(N=22,351) 47.3	(N=125,916) 41.0	
Someone in the household currently receives benefits from the Women, Infants, and Children (WIC) Program	19.2	21.5	18.8	

Health Status

Children Age 0-17 Years	All Children (N=296,099) %	CSHCN (N=44,310) %	Not CSHCN (N=251,789) %	Sig. Diff.
Child's health is described as "Excellent" or "Very Good"	86.6	72.1	89.1	*
Nutritional status (based on Body Mass Index [BMI]):				
Underweight	9.3	10.0	9.2	
Normal weight	54.9	54.6	55.0	
At risk for overweight	13.5	12.0	13.8	
Overweight	22.2	23.3	22.0	
Any need:				
Need or use medicine prescribed by a doctor	17.5	75.4	7.3	*
Need or use more medical, mental health, or educational services than is usual for most children of the same age	9.5	43.8	3.5	*
Limited or prevented in his/her ability to do things most children of the same age can do	5.1	25.0	1.6	*
Need or get special therapy, such as physical, occupational or speech therapy	4.7	19.2	2.2	*
Has emotional, developmental or behavioral problem that lasted or is expected to last 12 months or longer	5.7	6.4	1.2	*
Parents have been told (by a doctor, health professional, teacher, or school official) that child has a learning disability	8.7	25.9	5.5	*
Health Conditions				
Parent has been told by a doctor or health professional that their child has this condition:				
Asthma	17.1	46.4	11.9	*
Bone, joint, or muscle problems	2.7	9.1	1.6	*
Diabetes	0.1	0.5	0	
Autism	0.3	1.7	0	
Any developmental delay or physical impairment	3.6	13.6	1.9	*
Fever or any respiratory allergy, in past year	9.4	27.4	6.3	*
Food or digestive allergy, in past year	2.2	6.1	1.5	*
Eczema or skin allergy, in past year	8.7	16.0	7.5	*
<i>Children ≥24 months:</i>	<i>(N=257,804)</i>	<i>(N=40,579)</i>	<i>(N=217,225)</i>	
Hearing problems or vision problems that cannot be corrected with glasses or contact lenses	2.0	6.4	1.2	*
Attention Deficit Disorder (ADD) or Attention Deficit Hyperactive Disorder (ADHD)	5.6	25.6	1.8	*
Depression or anxiety problems	3.4	14.8	1.2	*
Behavioral or conduct problems	4.1	20.3	1.1	*
<i>Children ≥36 months:</i>	<i>(N=246,029)</i>	<i>(N=38,680)</i>	<i>(N=207,349)</i>	
Frequent or severe headaches, including migraines, in past year	3.2	8.5	2.2	*
Stuttering, stammering, or other speech problems, in past year	2.4	8.4	1.3	*
Three or more ear infections, in past year	3.1	6.6	2.4	
Child's health condition(s) or limitation(s) is:				
Minor	71.2	54.4	80.1	*
Moderate	24.4	37.4	17.6	*
Severe	3.5	6.8	1.9	

Asthma

Children Age 0-17 Years Who Currently Have Asthma	All Children (N=34,979) %	CSHCN (N=18,040) %	Not CSHCN (N=16,938) %	Sig. Diff.
Health difficulties caused by asthma are:				
Minor difficulties	77.2	71.5	83.4	
Moderate difficulties	18.7	21.6	15.6	
Severe difficulties	4.0	6.8	1.0	
Burden placed by asthma on the family:				
Great or moderate	7.4	7.4	7.4	
Little or none	92.5	92.5	92.6	
Length of time since child last took asthma medication:				
Less than 7 days ago	31.9	50.6	11.6	*
1 week to less than 3 months ago	29.7	28.5	31.0	
3 months to less than 1 year ago	21.7	12.0	32.3	*
One year or more ago	16.7	8.9	25.2	*
During the past 12 months, child had an episode of asthma or an asthma attack	46.5	56.1	36.4	
During the past 12 months, child stayed overnight in a hospital because of asthma	3.0	4.5	1.4	

Oral Health

Children Age 1-17 Years	All Children (N=273,648) %	CSHCN (N=42,457) %	Not CSHCN (N=231,191) %	Sig. Diff.
Condition of child's teeth:				
Excellent	45.6	50.7	44.6	
Very good	25.2	21.3	25.9	
Good	22.7	19.7	23.3	
Fair	5.1	7.4	4.7	
Poor	1.5	0.9	1.6	
For children with "fair" or "poor" teeth, problems with teeth:	(N=17,992)	(N=3,525)	(N=14,468)	
Pain	1.8	0	2.3	
Cavities	59.0	47.0	61.9	
Broken front tooth, or teeth that need repair	11.1	8.7	11.6	
Crooked teeth, or teeth that need braces	32.6	51.5	28.0	
Other	0.8	0	1.1	
Hygiene	2.2	0.6	2.6	
Discoloration	1.8	4.7	1.1	
Enamel problems	0	0	0	
Gum problems	2.4	9.3	0.8	
Teeth problems	4.1	3.5	4.2	
Nerves	2.8	0	3.5	
Length of time since child last saw a dentist (including orthodontist, oral surgeon, or other dental specialist):				
Never	10.3	6.3	11.0	*
6 months or less	69.1	74.1	68.2	
Over 6 months to 1 year ago	13.7	12.5	13.9	
Over 1 year ago	4.6	4.1	4.6	

Difficulties with Emotions, Concentration, or Getting Along with Others

Children Age 3-17 Years	All Children (N=246,029) %	CSHCN (N=38,680) %	Not CSHCN (N=207,349) %	Sig. Diff.
Children with difficulties with emotions, concentration, or getting along with other people	16.9	46.9	11.4	*
These difficulties are:				
Minor	9.3	15.7	8.1	*
Moderate	6.8	26.8	3.0	*
Severe	0.8	4.3	0.2	*
Burden put on family by child's mental and emotional health:				
A great deal	1.0	5.6	0.1	*
A medium amount	2.6	9.7	1.3	*
A little	5.0	17.1	2.7	*
Children with ADD/ADHD who are currently taking medication for ADD/ADHD	2.5	15.6	0.1	*

Health Insurance

Children Age 0-17 Years	All Children (N=296,099) %	CSHCN (N=44,310) %	Not CSHCN (N=251,789) %	Sig. Diff.
Child has health coverage, including health insurance, prepaid plans such as HMO's, or government programs such as Medicaid	94.5	92.9	94.8	
Child's health coverage is Medicaid/QUEST	22.5	24.7	22.1	
Child was covered by health insurance for only a portion of the past 12 months	7.9	11.2	7.3	
Child has insurance that helps pay for routine dental care including cleanings, x-rays and examinations	88.5	87.8	88.6	

Health Care Access**Medical Care**

Children Age 0-17 Years	All Children (N=296,099) %	CSHCN (N=44,310) %	Not CSHCN (N=251,789) %	Sig. Diff.
Child saw a doctor, nurse, or other health care professional for medical care, including sick-care, well-child check-ups, physical examinations, and hospitalizations, during the past 12 months	85.0	92.5	83.6	*
Child needed medical care, but did not see a doctor, nurse, or other health care professional, during the past 12 months	0.1	0.1	0.1	
Child saw a doctor, nurse, or other health professional for preventive care at least 1 time during the past 12 months	77.7	84.8	76.5	*
Child went to a hospital emergency room at least 1 time during the past 12 months	14.2	21.9	12.9	*
<i>Children who saw a health professional for sick-child care</i>	(N=251,556)	(N=40,975)	(N=210,580)	
Child saw a doctor, nurse, or other health professional for sick-child care during the past 12 months (excluding emergency room visits, hospitalizations, well-child care):				
0 times	32.5	17.1	35.5	*
1-5 times	62.1	63.0	61.9	
6-10 times	3.8	14.7	1.7	*
11-15 times	0.9	2.6	0.5	
Over 15 times	0.8	2.6	0.4	
Child did not receive all needed medical care, during the past 12 months	0.6	2.6	0.2	
<i>Children not receiving needed medical care</i>	(N=1,915)	(N=1,217)	(N=699)	
Reasons for not getting all the medical care needed:				
Cost too much	48.5	71.6	8.2	*
No insurance	45.8	67.4	8.2	
Treatment is ongoing	37.5	55.1	6.8	
Dissatisfaction with doctor	36.3	48.2	15.6	
Health plan problem	30.6	48.2	0	
Can't find doctor who accepts child's insurance	30.6	48.2	0	
Not available in area/transport problems	30.6	48.2	0	
Did not know where to go for treatment	30.6	48.2	0	
Doctor did not know how to treat or provide care	14.4	13.6	15.6	
Child refused to go	2.6	4.1	0	
Vaccine shortage	0	0	0	
Not convenient times/ could not get appointment	0	0	0	
No referral	0	0	0	
Lack of resources at school	0	0	0	
Other	27.7	3.7	69.4	*

Mental Health Care

Children Over Age 1 Year	All Children (N=273,648) %	CSHCN (N=42,457) %	Not CSHCN (N=231,191) %	Sig. Diff.
Child received mental health care or counseling, during the past 12 months	6.2	26.5	2.5	*

Dental Care

Children Over Age 1 Year	All Children (N=275,186) %	CSHCN (N=42,785) %	Not CSHCN (N=232,401) %	Sig. Diff.
Child saw a dentist (including orthodontist, oral surgeon, or other dental specialist) for routine preventive dental care (including check-ups, screenings, and sealants), during the past 12 months	77.7	82.7	76.7	
Child did not receive all needed routine preventive dental care, during the past 12 months	2.7	4.6	2.4	
<i>Children not receiving needed dental care</i> Reasons for not getting needed dental care:	(N=7,466)	(N=1,972)	(N=5,494)	
Not convenient times/ could not get appointment	28.7	30.1	28.1	★
No insurance	17.7	27.9	14.0	
Cost too much	17.1	44.3	7.3	
Can't find dentist who accepts child's insurance	9.3	9.0	9.4	
Lack of resources at school	7.1	2.4	8.8	
Health plan problem	6.9	8.1	6.5	
Dentist did not know how to treat or provide care	6.7	0	9.1	
Child refused to go	6.0	3.2	7.1	
Treatment is ongoing	5.2	9.5	3.6	
Not available in area/transport problems	4.3	8.1	2.9	
Dissatisfaction with dentist	2.2	8.2	0	
Did not know where to go for treatment	0.6	0	0.8	
No referral	0	0	0	
Other	0	0	0	

Prescription Medication

Children Age 0-17 Years	All Children (N=296,099) %	CSHCN (N=44,310) %	Not CSHCN (N=251,789) %	Sig. Diff.
Child used prescription medication, during past 12 months	53.8	93.8	46.7	★
Child did not receive all needed prescription medication, during the past 12 months	(N=159,255) 0.6	(N=41,559) 0.6	(N=117,697) 0.6	
<i>Children not receiving needed prescription medication</i> Reasons for not getting the needed prescription medication:	(N=937)	(N=232)	(N=705)	
Cost too much	4.8	19.6	0	
No insurance	33.8	19.6	38.5	
Doctor did not know how to treat or provide care	19.9	80.4	0	
Treatment is ongoing	18.9	0	25.1	
Health plan problem	13.3	0	17.7	
Can't find doctor who accepts child's insurance	0	0	0	
Not available in area/transport problems	0	0	0	
Not convenient times/ could not get appointment	0	0	0	
Dissatisfaction with doctor	0	0	0	
Did not know where to go for treatment	0	0	0	
Child refused to go	0	0	0	
No referral	0	0	0	
Lack of resources at school	0	0	0	
Other	2.2	9.0	0	

Medical Home

Children Age 0-17 Years	All Children %	CSHCN %	Not CSHCN %	Sig. Diff.
<i>All children</i> Child has a personal doctor or nurse (health professional who knows child well and is familiar with child's health history, who can be a general doctor, pediatrician, specialist doctor, nurse practitioner, or physician assistant)	(N=296,099) 84.6	(N=44,310) 88.7	(N=251,789) 83.9	
<i>Children who have a personal doctor or nurse</i> Child's personal doctor or nurse usually/always spent enough time with child	(N=250,459) 74.6	(N=39,287) 79.1	(N=211,172) 73.8	
Child's personal doctor or nurse usually/always explained things in a way that family/child can understand	92.0	93.4	91.7	
Child visited his/her personal doctor or nurse for preventive care (such as well-child check-up, routine physical exam, immunization, health screening), during past 12 months	77.2	84.2	75.9	*
Immediate Help Or Care				
<i>Families needing help or advice</i> Family usually/always got the help or advice needed, when family called child's personal doctor or nurse over the phone	(N=87,130) 92.7	(N=20,772) 98.2	(N=66,358) 91.0	
<i>Children needing immediate care from personal doctor/nurse</i> Child usually/always got care from his/her personal doctor or nurse as soon as wanted, when care was needed right away for an illness or injury	(N=58,741) 92.0	(N=13,970) 90.6	(N=44,771) 92.5	
Specialist Care				
<i>Children who have a personal doctor or nurse</i> Child's personal doctor or nurse thought child needed to see a specialist doctor(s)	(N=250,459) 19.4	(N=250,459) 52.8	(N=211,172) 13.2	*
<i>Children needing specialist care</i> Family had a moderate/big problem getting care from specialist doctor(s) when needed.	(N=48,543) 14.1	(N=20,730) 14.2	(N=27,813) 14.0	
Child's personal doctor, nurse, or office staff helped family to get care from specialist doctor(s)	77.3	83.1	73.0	
Child's personal doctor or nurse usually/always talked with family about visits to specialist doctor(s)	61.8	63.5	60.5	
Special Services				
<i>Children who have a personal doctor or nurse</i> Child needed special services, equipment, or other health care (such as physical therapy, wheelchairs, special education services, counseling), during the past 12 months	(N=250,459) 8.3	(N=39,287) 34.5	(N=211,172) 3.4	*
<i>Children needing special services</i> Family had a moderate/big problem getting special services, equipment, or other care when needed	(N=20,729) 12.2	(N=13,569) 16.0	(N=7,160) 5.0	
Child's personal doctor or nurse helped family to get the special care or equipment that child needed	71.6	73.6	68.0	
Child's personal doctor or nurse usually/always talked with family about the child's special care or equipment	57.2	56.6	58.3	
Interpreter Services				
<i>Children whose primary language is not English</i> Child/family needed an interpreter to help speak with his/her doctors or nurses	(N=17,395) 5.7	(N=1,143) 31.7	(N=16,252) 3.8	*
<i>Families needing an interpreter</i> Child/family were able to usually/always get someone other than a family member to help speak with doctors or nurses	(N=989) 71.0	(N=362) 100.0	(N=627) 54.2	

Young Children Age 0-5 Years

Children Age 0-5 Years	All Children (N=101,853) %	CSHCN (N=11,722) %	Not CSHCN (N=90,132) %	Sig. Diff.
Learning, Development, or Behavioral Concerns				
Family has concerns about child's learning, development, or behavior	7.0	20.6	5.2	
<i>Children age 4-9 months</i>	(N=11,349)	(N=1,194)	(N=10,155)	
Family has a lot of concerns about how child:				
Makes speech sounds	8.2	0	9.2	
Understands what family says	9.8	0	11.0	
Uses his/her hands and fingers to do things	17.5	57.6	12.8	
Uses his/her arms and legs	17.5	57.6	12.8	
<i>Children age 10-17 months</i>	(N=13,159)	(N=1,159)	(N=12,000)	
Family has a lot of concerns about how child:				
Talks and makes speech sounds	5.8	39.1	2.6	
Understands what family says	9.4	58.3	4.7	*
Uses his/her hands and fingers to do things	10.0	39.0	7.2	*
Uses his/her arms and legs	9.1	35.7	6.5	
Behaves	7.9	32.2	5.6	
Gets along with others	6.7	28.3	4.7	
Is learning to do things for him/herself	7.8	28.3	5.8	
<i>Children age 18-71 months</i>	(N=70,856)	(N=9,038)	(N=61,818)	
Family has a lot of concerns about how child:				
Talks and makes speech sounds	6.7	6.1	6.7	
Understands what family says	8.2	4.8	8.7	
Uses his/her hands and fingers to do things	8.0	4.2	8.6	
Uses his/her arms and legs	7.5	10.0	7.2	
Behaves	8.8	16.8	7.7	
Gets along with others	8.0	8.9	8.0	
Is learning to do things for him/herself	8.0	4.8	8.5	
Is learning preschool or school skills	9.2	13.5	8.6	
Medical Home				
<i>Children age 0-5 who saw doctors during past 12 months</i>	(N=92,925)	(N=11,234)	(N=91,691)	
Child's doctors or other health care professionals asked if family had concerns about child's learning, development, or behavior	43.4	58.8	41.2	
<i>Children age 0-5 with concerns who saw doctors during past 12 months</i>	(N=16,612)	(N=4,724)	(N=11,889)	
Child's doctors or other health care professionals gave family specific information to address family's concerns about child's learning, development, or behavior	46.1	51.7	43.8	
Early Care and Education				
During the past month, child regularly attended:				
Child care center	28.6	45.2	26.5	
Family-based child care outside of home	26.9	37.1	25.6	
Child care in family's home provided by a nanny or relative other than a parent or guardian	24.5	16.0	25.6	
Head Start or Early Start program	10.1	12.2	9.8	
<i>Children age 36 months and older</i>	(N=51,784)	(N=6,092)	(N=45,692)	
Nursery school, preschool, or kindergarten	63.1	79.0	61.0	

Children Age 0-5 Years	All Children (N=101,853) %	CSHCN (N=11,722) %	Not CSHCN (N=90,132) %	Sig. Diff.
Early Care and Education (continued)				
During the past month, family has had to make different arrangements for childcare at the last minute because family's usual plans changed due to circumstances beyond the family's control	99.7	100.0	99.7	
During the past month, someone in the family had to quit a job, not take a job, or greatly changed his/her job because of problems with childcare	89.6	85.4	90.1	
Injury				
Child was injured and required medical attention (includes emergency room visits, doctor's attention, care administered by parent), during the past 12 months	7.9	9.6	7.7	
<i>Children who were injured</i>	(N=8,081)	(N=1,127)	(N=6,954)	
Where child was injured:				
At home	61.9	69.4	60.6	
At child care	11.1	0	12.9	
In some other place	29.9	30.6	29.7	
Poisoning				
Child was poisoned by accident and required medical attention (includes emergency room visits, doctor's attention, care administered by parent), during past 12 months	0.3	0.3	0.2	
<i>Children who were poisoned</i>	(N=263)	(N=40)	(N=223)	
Child was poisoned at home	100	100	100	
Breast-Feeding				
Child has breastfed or been fed breast milk	81.0	69.2	82.5	
Reading to Child				
Number of days that family members read stories to child, during the past week				
0-1 days	7.9	8.5	7.8	
2-3 days	21.4	16.1	22.1	
4-5 days	13.2	17.9	12.6	
6-7 days	57.4	57.5	57.4	

Children & Youth Age 6-17 Years

Children Age 6-17 Years	All Children (N=194,246) %	CSHCN (N=32,588) %	Not CSHCN (N=161,657) %	Sig. Diff.
School				
During the 12 months, child was:				
Enrolled in public school	78.6	76.7	78.9	
Enrolled in private school	18.8	19.8	18.6	
Home-schooled	2.5	3.3	2.3	
Not enrolled in school	0.1	0.2	0.1	
Child/youth missed 11 or more days of school due to illness or injury, during past 12 months	4.3	11.3	2.9	★
<i>Children enrolled in school</i>	(N=189,324)	(N=31,450)	(N=157,874)	
Child/youth's school contacted family two or more times about child's problems with school, during past 12 months	16.2	36.0	12.3	★
Starting with kindergarten, child/youth has repeated grades	7.3	14.3	5.9	★
School/Community Activities				
Child/youth was on a sports team or took sports lessons after school or on weekends, during past 12 months	62.6	54.2	64.3	
Child/youth participated in clubs or organizations (such as Scouts, religious group, Boys/Girls club) after school or on weekends, during past 12 months	49.0	53.9	48.0	
Child/youth participated in other organized events or activities, during past 12 months	6.4	7.4	6.2	
Family Participation In Child/Youth's Activities				
<i>Children participating in events or activities</i>	(N=159,985)	(N=26,339)	(N=133,646)	
Family attended events or activities that child and his/her friends participated in, during the past 12 months:				
Always / usually	73.4	72.1	73.6	
Sometimes / never	26.5	27.8	26.3	
Family Meeting Child/Youth's Friends				
Family has met:				
All or most of child/youth's friends	75.1	76.7	74.9	
Some or none of child/youth's friends	24.4	22.7	24.8	
Supervision of Children				
<i>Children under age 12 years</i>	(N=93,881)	(N=14,447)	(N=79,434)	
Child spent time caring for him/herself either at home or elsewhere, without an older person responsible for them	21.9	25.4	21.2	
Youth Service Or Work				
<i>Children age 12 years and older</i>	(N=100,365)	(N=18,141)	(N=82,224)	
Youth was involved in community service or volunteer work at school, church, or in the community, during past 12 months	67.2	64.5	67.8	
Youth has worked for pay	15.8	15.7	14.8	
Sleep				
Number of nights that child/youth got enough sleep for his/her age, during the past week:				
0-1 nights	2.1	3.1	1.9	
2-3 nights	4.6	4.8	4.5	
4-5 nights	14.8	11.9	15.4	
6-7 nights	77.5	79.4	77.2	

Children Age 6-17 Years	All Children (N=194,246) %	CSHCN (N=32,588) %	Not CSHCN (N=161,657) %	Sig. Diff.
Physical activity				
Number of days that child/youth exercised or participated in physical activity for at least 20 minutes that made him/her sweat and breathe hard, during the past week:				
0-1 days	13.2	18.9	12.1	
2-3 days	25.1	22.0	25.8	
4-5 days	28.5	22.3	29.7	
6-7 days	33.1	36.7	32.4	
Child/youth has ridden a bike, scooter, skateboard, roller skates, or rollerblades, during the past 12 months	73.5	73.5	73.5	
<i>Child/youth riding a bike, scooter, skateboard, roller skates, or rollerblades</i>	(N=142,528)	(N=23,772)	(N=118,756)	
Child/youth usually/always wears a helmet	54.1	58.8	53.2	
Reading				
<i>Children enrolled in school</i>	(N=159,382)	(N=24,756)	(N=134,626)	
Child/youth spends time reading (or is read to by someone else) for pleasure	96.2	94.9	96.5	
Computer, TV, Video Games				
Child/youth uses a computer for purposes other than schoolwork, on an average school day	63.5	64.7	63.3	
Child/youth usually watches TV, watch videos, or play video games, on an average school day	79.6	78.3	79.9	
Family has rules about what television programs the child/youth is allowed to watch	80.4	82.8	80.0	
Family Thoughts About Child/Youth				
Family currently has a lot of concerns about child/youth:				
Child/youth's achievement	47.3	51.8	46.4	
Having enough time with child/youth	42.6	43.4	42.4	
Family's relationship with child/youth	42.2	42.5	42.2	
Child/youth's self-esteem	39.5	41.0	39.2	
Child/youth's coping with stressful things	37.8	44.8	36.4	
Learning difficulties	27.6	38.2	25.5	*
Depression or anxiety	22.5	34.1	20.1	*
Substance abuse	23.9	24.8	23.7	
Violence in home, school, or neighborhood	22.0	17.3	22.4	
Being "bullied" by classmates	20.1	22.9	19.5	
Eating disorders	15.9	18.8	15.3	
Family says child/youth during past month usually/always:				
Argues too much	15.0	26.3	12.8	*
Bullies, or is cruel or mean to others	1.9	4.5	1.4	
Shows respect for teachers and neighbors	89.6	83.9	90.7	
Gets along well with other children	91.0	82.3	92.8	*
Is disobedient	3.8	6.6	3.3	
Is stubborn, sullen, or irritable	7.4	16.8	5.5	*
Tries to understand other people's feelings	70.7	65.7	71.7	
Tries to resolve conflict with classmates, family, friends	64.0	58.3	65.1	
Feels worthless or inferior	2.1	2.8	2.0	
Is unhappy, sad, or depressed	1.6	2.6	1.4	
Is withdrawn, and does not get involved with others	1.8	2.5	1.6	

Family

Children Age 0-17 Years	All Children (N=295,273) %	CSHCN (N=44,310) %	Not CSHCN (N=250,963) %	Sig. Diff.
<i>Children age 0-5 years</i>	(N=101,853)	(N=11,722)	(N=90,132)	
Number of times in the past week that family took child/youth on an outing, such as to the park, library, zoo, shopping:				
None	3.1	0	3.2	
1-5 times	66.6	71.5	65.9	
6-10 times	27.8	26.4	28.0	
11 or more times	2.5	2.0	2.6	
Number of days in the past week that all family members in the household ate a meal together:				
0-1 days	8.3	10.4	7.9	
2-3 days	13.3	12.3	13.4	
4-5 days	18.5	16.5	18.8	
6-7 days	59.9	60.7	59.7	
Child/youth attends religious service at least once per week	51.4	51.9	51.4	
<i>Children age 6 years and older</i>	(N=194,047)	(N=32,588)	(N=161,458)	
Family's relationship with child is very close	83.9	77.0	85.2	
Family and child share ideas or talk very well about things that really matter	74.1	67.3	75.4	
Family is coping very well with day-to-day demands of parenthood/raising a child	58.6	42.2	61.4	★
Family usually/always felt, during past month:				
Child is harder to care for than most children that age	6.3	10.7	5.5	
Child does things that really bothers the family a lot	4.1	9.5	3.2	
They were giving up more of their life to meet child's needs than expected	12.3	17.1	11.5	
Angry with child	2.7	6.1	2.1	
Family has someone that they can turn to for day-to-day emotional help with parenthood/raising children	89.8	90.0	89.7	
When there is a serious disagreement with other household members, a family member's response is to usually/always:				
Keep opinions to oneself	41.6	46.1	40.8	
Discuss disagreements calmly	65.9	69.7	65.3	
Argue heatedly or shout	38.2	44.3	37.2	
Hit or throw things	4.1	4.0	4.2	
Parents:	(N=294,424)	(N=44,310)	(N=250,114)	
Two parents (biological/adopted)	66.6	59.3	67.9	
Two parent stepfamily	6.4	7.6	6.2	
Single mother, no father present	21.8	27.8	20.8	
Other	5.1	6.3	5.1	
Child's mother ¹ in the household:	(N=276,572)	(N=41,604)	(N=234,968)	
General health is good/excellent	93.2	86.1	94.5	★
Mental & emotional health is good/excellent	95.3	87.7	96.6	★
Child's father ² in the household:	(N=223,764)	(N=30,906)	(N=192,858)	
General health is good/excellent	94.9	90.3	95.6	
Mental & emotional health is good/excellent	96.6	94.6	96.9	

¹ Mother = biological, step-, foster, or adoptive mother² Father = biological, step-, foster, or adoptive father

Neighborhood

Children Age 0-17 Years	All Children (N=293,955) %	CSHCN (N=44,264) %	Not CSHCN (N=249,691) %	Sig. Diff.
Families definitely/somewhat agree that:				
"People in this neighborhood help each other out."	85.6	86.9	85.4	
"We watch for each other's children in this neighborhood."	86.1	85.5	86.2	
"There are people I can count on in this neighborhood."	87.5	90.2	87.0	
"There are people in this neighborhood who might be a bad influence on my child/children."	51.4	58.1	50.2	
"If my child were outside playing and got hurt or scared, there are adults nearby who I trust to help my child."	90.7	93.6	90.2	
Family usually/always feels that their child is safe in their community or neighborhood.	81.4	80.1	81.7	
<i>Children age 6 years and older, in school</i>	<i>(N=187,485)</i>	<i>(N=31,404)</i>	<i>(N=156,081)</i>	
Family usually/always feels that their child is safe at school	87.3	88.8	87.0	
Family usually/always feels that their child is safe at home	97.2	96.5	97.3	

Hawaii CSHCN Prevalence from Two Surveys

	National Survey of of CSHCN (2001)	National Survey of Children's Health (2003)
Hawaii		
CSHCN prevalence	11.0% <i>32,500 CSHCN</i>	15.0% <i>44,310 CSHCN</i>
CSHCN, who have a medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer:		
Need or use medicine prescribed by a doctor	69.3 %	69.6%
Need or use more medical, mental health, or educational services than is usual for most children of the same age	45.5%	38.9%
Limited or prevented in his/her ability to do things most children of the same age can do	28.8%	28.3%
Need or get special therapy, such as physical, occupational or speech therapy	21.0%	21.3%
Has emotional, developmental or behavioral problem that lasted or is expected to last 12 months or longer	14.1%	14.6%
U.S. Comparison		
CSHCN prevalence	12.8%	17.6 %

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