

# **CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

- **CSHCN Family Partnership in Shared Decision-Making**
- **Medical Home for CSHCN**
- **Adequate Health Insurance for CSHCN**
- **Early Screening and Intervention for CSHCN**
- **CSHCN Community Based Services**
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# Children with Special Health Care Needs Overview

## Children with Special Health Care Needs

Children with special health care needs (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.

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 this population group.<sup>45</sup> In Hawaii, there are an estimated 35,022 CSHCN, representing 12.3% of all children ages 0-17 years old. Data indicate that the prevalence of CSHCN rises with age and there are more males than females within the population.

## The National Agenda for Children with Special Health Care Needs: Developing Systems of Care

Developed in 1989, this agenda calls for the development of systems of care for CSHCN that are family-centered, community-based, coordinated and culturally competent.

The long-term outcome of systems development is that all families are able to access health and related services along the continuum of care in a manner that is both affordable and meets their needs; that policies and programs are in place to guarantee that children have access to quality health care; that providers are adequately trained; financing issues are equitably addressed; and that families play a pivotal role in how services are provided to their children.

As part of the national agenda for CSHCN, the federal Maternal and Child Health Bureau has established six core outcomes:

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

# CSHCN Family Partnership in Shared Decision-Making

## Goal: Increase the Proportion of CSHCN Whose Families Partner in Decision-Making and Are Satisfied with the Services They Receive

### Issue:

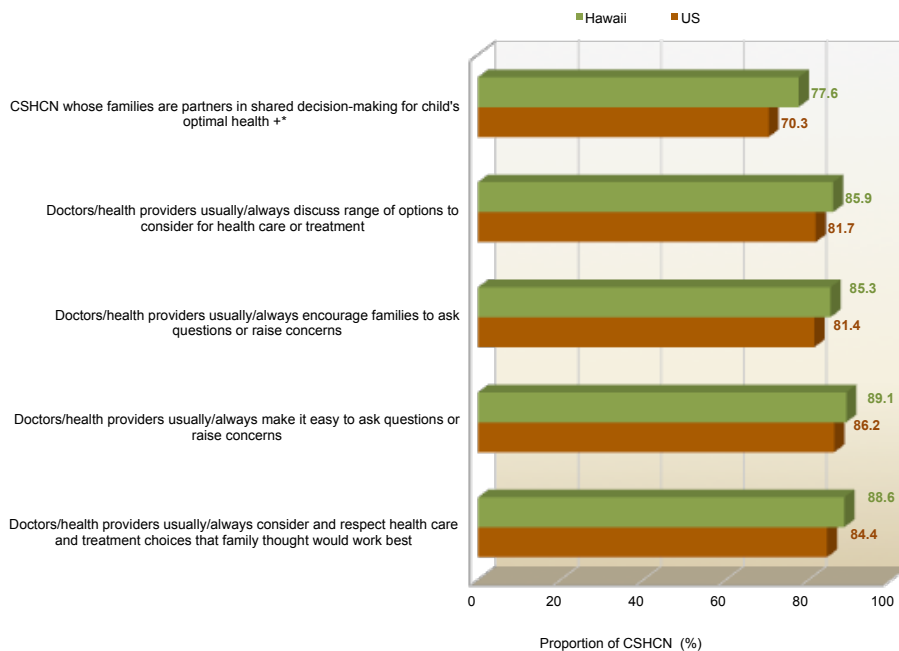
Families have a key role in assuring that services effectively address the needs of children with special health care needs. Families must be involved in decision-making at all levels, from direct care for children to the development of service systems and policy to program planning at local, community and state levels. A challenge for many programs and agencies is involving and partnering with families at program and policy levels and supporting families in their role as partners.<sup>46,47</sup>

### Healthy People 2020 Objective:

Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, coordinated systems to 22.4% for children ages 0-11 years old and 15.1% for children 12-17 years of age.

### Population-Based Data:

**Figure 6.1 Family Partnership in Shared Decision-Making for Child's Optimal Health in Hawaii and U.S.: 2009–2010**



In 2009–2010, Hawaii data from the National Survey of CSHCN showed that the proportion of Hawaii families with CSHCN ages 0-17 years old who reported family partnership in shared decision-making (77.6%) was significantly higher than the national average (70.3%).

The proportions of Hawaii CSHCN whose doctors or other health providers usually or always discuss the range of options, encourage families to ask questions or raise concerns, make it easy to ask questions or raise concerns, and consider and respect health care and treatment choices were similar to national averages.

+ CSHCN outcome, derived from other survey items.

\* Statistical difference between Hawaii and U.S. proportions at 95% confidence interval.

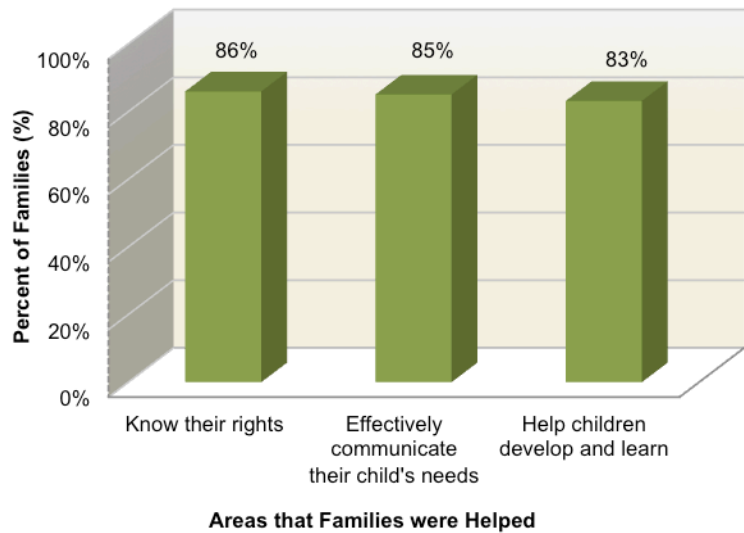
Source: "Hawaii Report from the 2009/10 National Survey of CSHCN." NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12/16/11 from [www.childhealthdata.org](http://www.childhealthdata.org). Additional data analyses by DOH Children with Special Health Needs Branch.

## Program Highlight:

Figure 6.2 Families Who Report That Early Intervention Services Helped the Family: 2012

The **Early Intervention Section** is a federal and state-mandated program that provides services to support the development of infants and toddlers. The section ensures that any child from 0-3 years old with or biologically at risk for a developmental delay receives a timely, multidisciplinary and comprehensive developmental evaluation, and that eligible children receive services as identified on the child's Individual Family Support Plan. The Early Intervention Section also ensures that Hawaii meets the requirements of Part C of the Individuals with Disabilities Education Act.

On December 1, 2012, 1,846 (3.42%) of children age 0-3 years statewide had an Individual Family Support Plan. The cumulative count for Fiscal Year 2012 was 3,943.



Source: Hawaii State Department of Health, Family Health Services Division, Children with Special Health Needs Branch, Early Intervention Section. Data reflects Fiscal year (July 1-June 30) 2012.

Each year, parents complete a family survey to identify the extent to which early intervention services have helped them know their rights, effectively communicate their child's needs, and help their children develop and learn. Figure 6.2 shows that in Fiscal Year 2012, 86% of parents reported that early intervention services helped the family know their rights; 85% reported that services helped the family effectively communicate their children's needs; and 83% reported that services helped the family to help their child learn and grow. Family support is a cornerstone of the Early Intervention Section program. Family engagement strategies include:

- Parents identify their needs, priorities and strengths as part of intake and the Individual Family Support Plan process.
- Parents participate as members of the Individual Family Support Plan team in identifying outcomes, objectives and strategies that are included in the plan.
- Parents participate in the delivery of services, with service providers acting as "consultants" to mentor parents on how to meet their child's developmental needs.
- Parents participate in determining to what extent their children have met their early intervention goals, including improved positive social-emotional skills, acquisition and use of knowledge and skills, and use of appropriate behaviors to meet their needs.
- Family leaders are members of the Hawaii Early Intervention Coordinating Council.

## Other Program Activities:

- The **Children with Special Health Needs Branch** promotes the involvement of families of CSHCN in various ways. Families participate as council, task force and advisory committee members and as co-leaders with professional partners; develop and review parent education materials; participate in presentations and panels; provide testimony on legislative bills; advise on policy issues; and co-write grant applications. Family participants are of diverse ethnic and cultural backgrounds.
- The **Genomics Section** uses community engagement activities (focus groups, surveys, interviews) in its needs assessment, planning and evaluation activities. Family advocates are strong partners on the Genetics Advisory Committee and other advisory committees to help guide section activities.
- The **Hoopaa Project—Autism Spectrum Disorder Implementation Grant** supports the staff addition of a parent of a youth with autism spectrum disorder as Hookele Kokua to the Hilopaa Family to Family Health Information Center. Hookele Kokua means one who supports the steersman of the canoe, i.e., one who supports parents as navigators for their own family.

# Medical Home for CSHCN

## Goal: To Increase the Proportion of Children with Special Health Care Needs Who Have a Medical Home

### Issue:

All children, especially those with special health care needs, should have a medical home. As described by the American Academy of Pediatrics, the medical home is a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective. The medical home provides ongoing primary care; assists in identifying special health care needs; and coordinates with a broad range of other specialty, related services and appropriate community resources for the optimal health of the child. Challenges that medical homes face include the increased time needed to coordinate services, especially for children with complex special needs; having knowledge about community resources; and having appropriate financing to support the medical home model.<sup>47,48</sup>

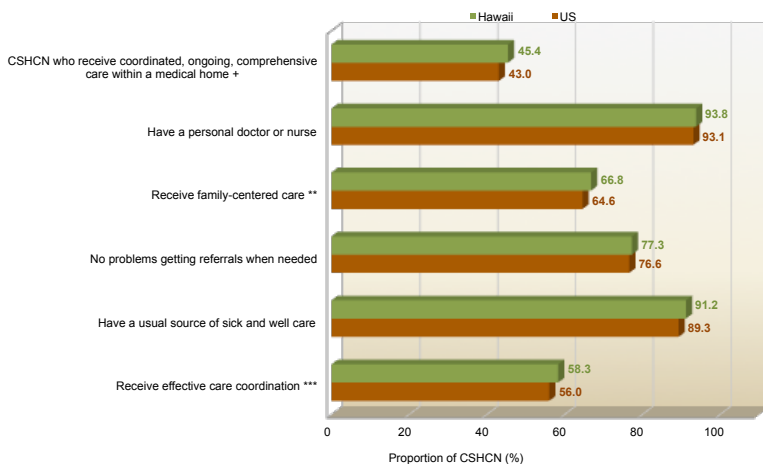
*Though research is still emerging, studies have found that patient-centered medical homes are associated with better preventive care, better disease management, more efficient resource utilization and lower costs.<sup>xix</sup>*

### Healthy People 2020 Objective:

Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, coordinated systems. Increase the proportion of children with special health care needs who have access to a medical home to 54.8%.

### Population-Based Data:

**Figure 6.3 CSHCN Receiving Coordinated, Ongoing, Comprehensive Care Within a Medical Home, Hawaii and U.S.: 2009–2010**



In 2009–2010, Hawaii data from the National Survey of CSHCN showed that the proportion of Hawaii CSHCN ages 0-17 years old who received coordinated, ongoing, comprehensive care within a medical home was similar to the national average (43%).

The proportions of Hawaii CSHCN who have a personal doctor or nurse, receive family-centered care, have no problems obtaining referrals when needed, have a usual source of sick and well care, and receive effective care coordination were also similar to the national averages.

+ CSHCN outcome, derived from other survey items.

\*\* Health providers usually/always spend enough time, listen well, are sensitive to family values and customs, provide needed information, and make family feel like a partner in care.

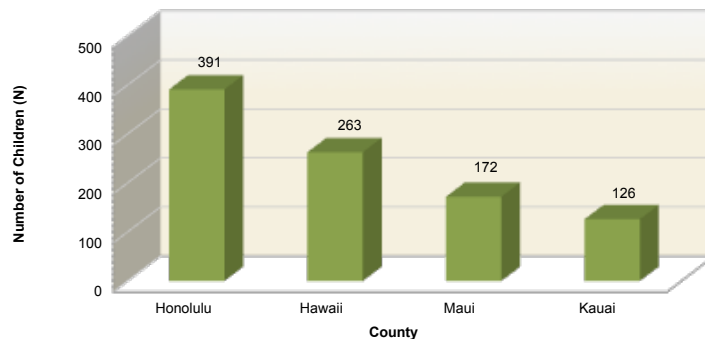
\*\*\*Saw at least 2 medical providers and usually/always got all needed help coordinating care and was very satisfied with the communication between providers and school/daycare and/or between primary provider and other medical providers.

Source: "Hawaii Report from the 2009/10 National Survey of CSHCN." NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12/16/11 from [www.childhealthdata.org](http://www.childhealthdata.org). Additional data analyses by DOH Children with Special Health Needs Branch.

## Program Highlight:

Figure 6.4 Children Served by the Children with Special Health Needs Program by County: 2012

The **Children with Special Health Needs Program** supports the medical home by assisting families of CSHCN ages 0-21 years old who have long-term or chronic medical conditions that require specialized care with access to services. The program provides information and referral, outreach, service coordination, social work and nutrition services. It also provides financial assistance for medical specialty services for eligible children who have no other resources. The program serves clients in all counties, with Honolulu (n=391) and Hawaii (n=263) having the largest number of children served.



Source: Hawaii State Department of Health, Family Health Services Division, Children with Special Health Needs Branch, Children with Special Health Needs Program. Data reflects calendar year (January 1- December 31).

Families on neighbor islands are assisted in accessing pediatric specialty providers on Oahu. Pediatric cardiology, neurology and/or nutrition clinics are provided on the islands of Hawaii, Kauai, Maui and Molokai, where services are not available. The Children with Special Health Needs Program initiated the transition of the program's state-funded cardiac clinic on the island of Hawaii to a clinic located in a Kona community health center that is open to all children in the community.

The program also supports families via the coordination of community-based services, such as at the Kapiolani Medical Center Cleft and Craniofacial Center multidisciplinary clinic, which provides comprehensive services for children with craniofacial disorders and complex medical needs. In addition, the program collaborated with the Hawaii Lions Foundation in the administration of its Uninsured and Underinsured Fund, which assists school-aged students who cannot afford needed vision and hearing testing and services. However, this funding assistance ended in 2013.

## Other Program Activities:

- The **Newborn Metabolic Screening and Newborn Hearing Screening Programs** support the medical home by helping to identify newborns who require follow-up and coordination of referrals and services.
- The **Early Intervention Section** invites the child's medical home providers to Individual Family Support Plan meetings.
- The **Genetics Program** supports the medical home by increasing access to genetic services in the community, offering outreach clinics to the neighbor islands and providing telegenetics activities.
- The **Hoopaa Project—Autism Spectrum Disorder State Implementation Grant** collaborated with the American Academy of Pediatrics-Hawaii Chapter in its conference, "A Physician's Response to Autism." The April 2011 conference was designed to strengthen support for medical home services related to autism spectrum disorder. Session topics included screening tools for primary care providers, personal family stories, community resources, transitions to adulthood, and complementary and alternative therapies. The presentation on screening tools included training on the Modified Checklist for Autism in Toddlers and the Hawaii Quick Medical Home Guide to Screening and Follow Up. About 130 attendees, including health care providers, allied health providers, teachers and family members, attended the conference.
- The FHSD-administered federal **Early Childhood Comprehensive System Grant** has developed a state plan that includes two medical home goals: 1) Family-centered care and family/professional partnerships will be key elements of medical homes, and 2) Developmental surveillance, periodic screening and follow-up for children ages 0-5 years old will be improved. Early childhood providers throughout the state are working in collaboration to implement the plan's objectives.

# Adequate Health Insurance for CSHCN

## Goal: To Increase the Proportion of Children with Special Health Care Needs Who Have Adequate Insurance

### Issue:

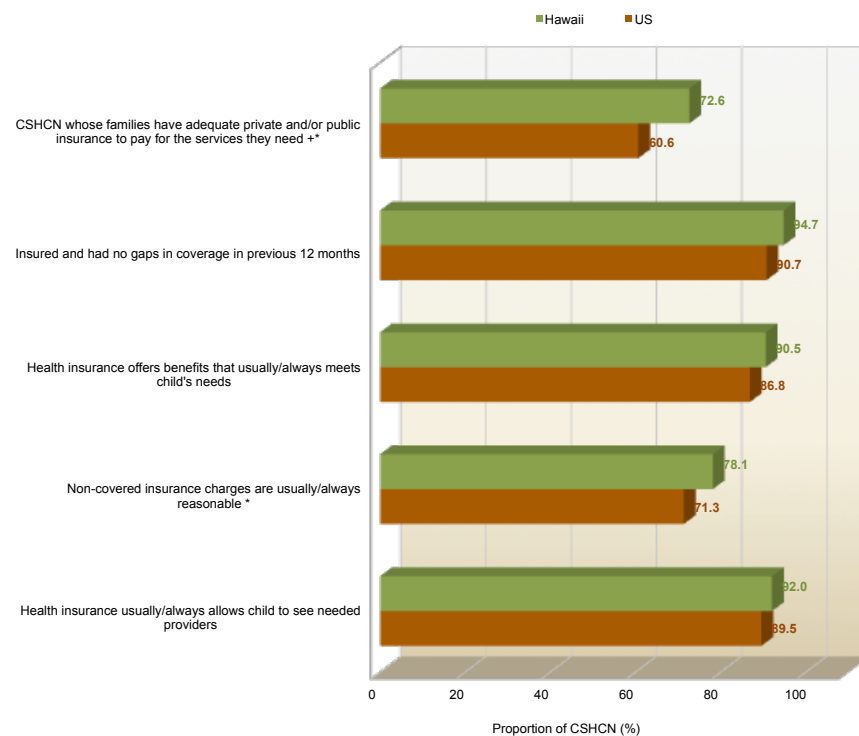
All children, including children with special health care needs, should have access to adequate health care insurance coverage for their needed health care services. Adequate health insurance is critical in ensuring access to family-centered care for CSHCN, including access to medical care, dental care, mental health services, medical equipment, supplies and prescriptions. Adequacy of insurance includes whether health insurance benefits meet the child's needs, whether non-covered charges are reasonable, and whether the plan allows the child to see needed providers.<sup>49</sup>

### Healthy People 2020 Objective:

Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, coordinated systems. Reduce the proportion of individuals who are unable to obtain or experience a delay in obtaining necessary medical care, dental care or prescription medicines.

### Population-Based Data:

Figure 6.5 CSHCN with Adequate Insurance in Hawaii and U.S.: 2009–2010



In 2009–2010, Hawaii data from the National Survey of CSHCN showed that the proportion of Hawaii CSHCN ages 0-17 years old with adequate private and/or public insurance to pay for needed services was significantly higher (72.6%) than the national average (60.6%).

The proportion of Hawaii families of CSHCN who reported that non-covered insurance charges are usually/always reasonable (78.1%) was significantly higher than the national average (71.3%).

The proportions of Hawaii CSHCN who were insured and had no gaps in coverage in the previous 12 months, have health insurance benefits that usually/always meets the child's needs, and have health insurance that usually/always allows the child to see needed providers were similar to the national averages.

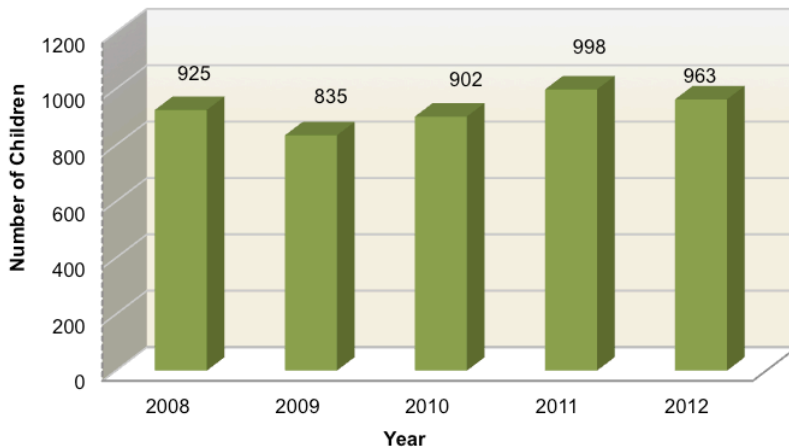
+ CSHCN outcome, derived from other survey items.

\* Statistical difference between Hawaii and U.S. proportions at 95% confidence interval.

Source: "Hawaii Report from the 2009/10 National Survey of CSHCN." NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12/16/11 from [www.childhealthdata.org](http://www.childhealthdata.org). Additional data analyses by DOH Children with Special Health Needs Branch.

## Program Highlight:

Figure 6.6 Children Served by the Children with Special Health Needs Program: 2008-2012



Source: Hawaii State Department of Health, Family Health Services Division, Children with Special Health Needs Branch, Children with Special Health Needs Program. Data reflects calendar year (January 1- December 31).

**Children with Special Health Needs Program** service coordinators assisted CSHCN and their families to obtain and maximize use of health coverage from public and other sources. Acting as a safety net and to increase access to needed services, the program provided financial assistance for medical specialty care, laboratory services, X-rays, hearing aids, and cardiac and neurology clinic access on neighbor islands as well as air/ground transportation for eligible families with no other resources. In Fiscal Year 2012, 963 children were served by the program.

Program staff worked with Maternal Child Health Leadership Education in Neurodevelopmental and Related Disabilities on the issue of insurance coverage of medically necessary orthodontic services for children with cranofacial disorders.

## Other Program Activities:

- **Hoopaa Project – Autism Spectrum Disorder State Implementation Grant** is a collaborative project of Family Voices of Hawaii, Hilopaa Family to Family Health Information Center, the health department's Children with Special Health Needs Branch, American Academy of Pediatrics-Hawaii Chapter and the University of Hawaii School of Medicine Department of Pediatrics. In 2011, in an effort to address adequate insurance coverage for needed services for children with autism spectrum disorder, the project convened a Hawaii Autism Legislative Summit for family members of children and youth with autism spectrum disorder, self-advocates and professional partners. Presentations focused on processes to mandate coverage through the Hawaii Prepaid Health Care Act, lessons learned from a TRICARE Autism Services Demonstration, lessons on licensure, the impact of health care reform on autism spectrum disorder services, and perspectives from the Hawaii health plan.
- The **Genetics and Newborn Metabolic Screening Programs** work with families, third-party payers and policy-makers on improving the process for coverage and reimbursement of medical formulas and foods. The Genetics Program completed a needs assessment in 2010 to determine if the state's mandated coverage for medical formulas/foods helped families of a child with a metabolic disorder. The assessment found that most medical formulas/foods eventually were covered by insurance reimbursement, but many barriers (change in insurance personnel, change in insurance plans, change in formulas) impacted the continued coverage of medical formulas/foods. The assessment also found that most families did not even attempt to get coverage for medical formulas/foods due to the time-consuming process of obtaining reimbursement.
- The **Genetics Program** works with genetics specialists and third-party payers to improve the approval process and reimbursement for genetic services. Reimbursement for genetic services delivered via telehealth has improved during the past five years, and reimbursement rates are equal or close to in-person visit reimbursement rates. However, work still needs to be done to develop more standardized procedures to bill for services provided via telehealth to make the reimbursement process more efficient.
- The **Genomics Section**, as part of the Health Resources and Services Administration-funded Western States Genetic Services Collaborative, developed a web-based, family-friendly resource with information about the Affordable Care Act for families with or at risk for genetic disorders. Using the life-course approach, the website resembles a board game with a circular "path of life" containing 13 boxes. Each box represents a life event, such as a pregnancy or losing a job, and each box is linked to coverage information specific to that life event. In the middle of the path of life is a town square filled with buildings, each linked to additional Affordable Care Act information.



# Early Screening and Intervention for CSHCN

## Goal: To Improve Access to Early Screening, Identification and Intervention Services

### Issue:

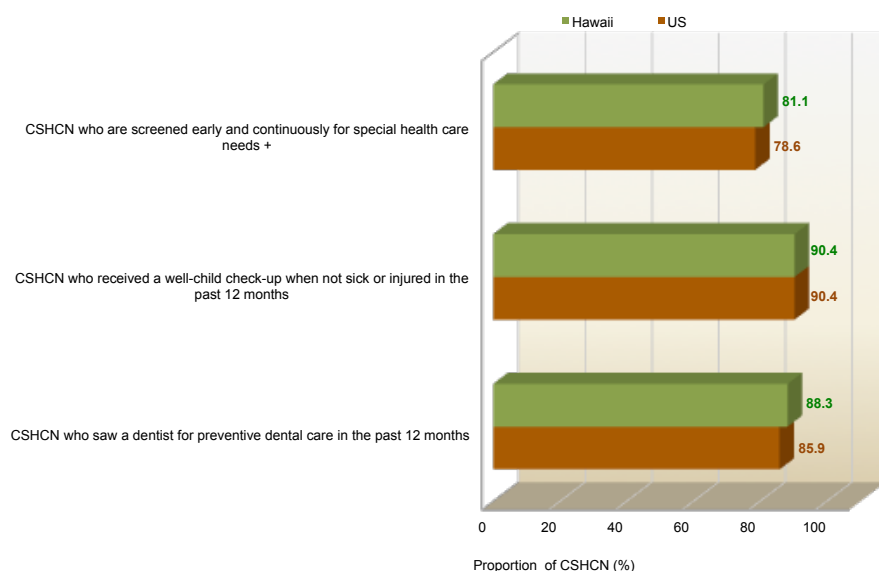
Special health needs must be identified early to assure that infants and children receive care and resources to promote optimal development. When concerns are identified, there must be appropriate follow-up, which may include monitoring, evaluation, diagnosis, and intervention and treatment. Challenges to screening include ensuring that medical homes have adequate office staffing, adequate time for screening and follow-up, and adequate payment by insurance. In addition, community programs must be able to coordinate and link their screening and follow-up services with the medical home.<sup>47,50</sup>

### Healthy People 2020 Objective:

Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, coordinated systems.

### Population-Based Data:

**Figure 6.7 CSHCN Who Are Screened Early and Continuously for Special Health Care Needs in Hawaii and U.S.: 2009–2010**



In 2009–2010, Hawaii data from the National Survey of CSHCN showed that the proportion of Hawaii CSHCN ages 0–17 years old who received early and continuous screening for special health care needs (81.1%) was similar to the national average (78.6%).

The proportions of Hawaii CSHCN who received a well-child check-up or saw a dentist for preventive dental care were similar to the national averages.

+ CSHCN outcome, derived from other survey items.

Source: "Hawaii Report from the 2009/10 National Survey of CSHCN." NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12/16/11 from [www.childhealthdata.org](http://www.childhealthdata.org). Additional data analyses by DOH Children with Special Health Needs Branch.

## Program Highlight:

The **Newborn Metabolic Screening Program** ensures that infants born in Hawaii are satisfactorily tested for metabolic disorders that, if left untreated, could cause intellectual disabilities, developmental disorders, severe health problems and even death. In 2012, 99.4% of all newborns were screened. The program ensures that identified infants are provided with appropriate and timely intervention and treatment. During 2008-2012, 80 infants were identified with metabolic conditions, including phenylketonuria, congenital hypothyroidism, sickle cell disease, biotinidase deficiency, congenital adrenal hyperplasia, organic acid disorders and fatty acid disorders.

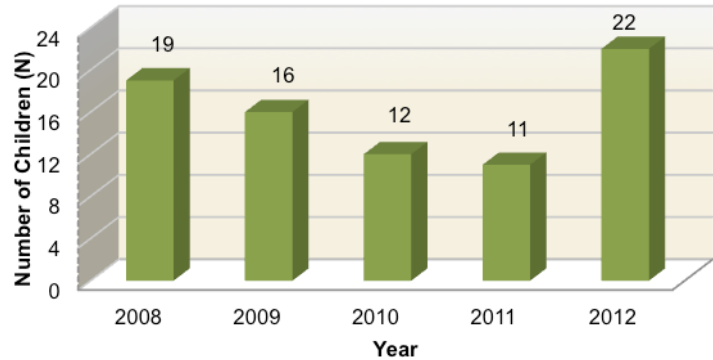
The **Newborn Hearing Screening Program** ensures that infants born in Hawaii are satisfactorily screened for hearing loss. In 2011, 97.8% of all newborns were screened. The program ensures that identified infants are provided with appropriate and timely intervention and treatment, with the goal of screening by 1 month of age, audiologic evaluation by 3 months of age, and enrollment in appropriate intervention services by 6 months of age. Early hearing detection and intervention supports the development of language, social and cognitive skills. During 2009-2012, 224 infants were identified with hearing loss, including permanent sensorineural and conductive hearing loss.

The **Hawaii Birth Defects Program** provides population-based active surveillance for birth defects in Hawaii. Major birth defects affect about one in every 33 babies born in the U.S. each year. They are the leading cause of infant deaths, accounting for more than 20% of all infant deaths. Babies born with birth defects have a greater chance of illness and long-term disability than babies without birth defects.<sup>49</sup> The proportion of birth defects identified in Hawaii has remained consistent, ranging from 3.3% to 4% of all births since 2000. The program continues to build capacity to collect data on birth defects in the State of Hawaii.

## Other Program Activities:

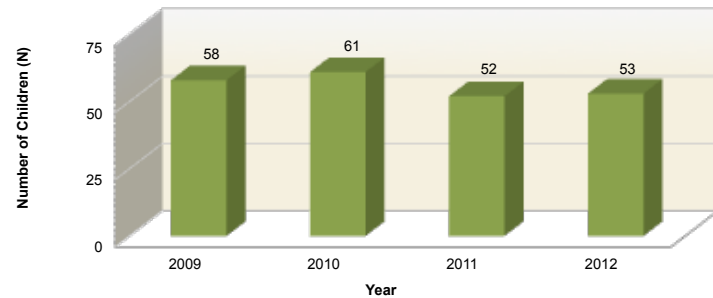
- **Children with Special Health Needs Program** staff provides training and technical assistance to support community organizations in providing hearing and vision screening in preschools and schools.
- **Hiilei Hawaii** is a new collaborative program of the Children with Special Health Needs Branch and the Hilopaa Family to Family Health Information Center. The program provides developmental screening and information for families of young children who may have developmental concerns, but who are not eligible for early intervention services.

**Figure 6.8 Children with Metabolic Disorders Identified Through Newborn Screening: 2008-2012**



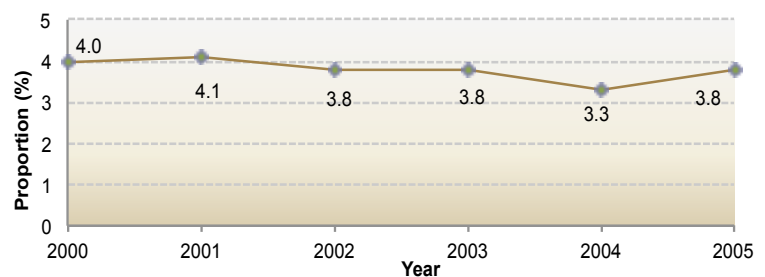
Source: Hawaii State DOH, Family Health Services Division, Children with Special Health Needs Branch, Newborn Metabolic Screening Program.

**Figure 6.9 Children with Hearing Loss Identified Through Newborn Screening: 2009-2012**



Source: Hawaii State DOH, Family Health Services Division, Children with Special Health Needs Branch, Newborn Hearing Screening Program.

**Figure 6.10 Births Identified with Birth Defects in Hawaii: 2000-2005**



Source: State of Hawaii, Department of Health, Family Health Services Division, Children with Special Health Needs Branch, Hawaii Birth Defects Program, Hawaii Birth Defects Surveillance Report 1986-2005 and represents latest data available.

# CSHCN Community-Based Services

## Goal: To Increase the Proportion of Families with CSHCN Who Have Access to Easy-To-Use, Community-Based Service Systems

### Issue:

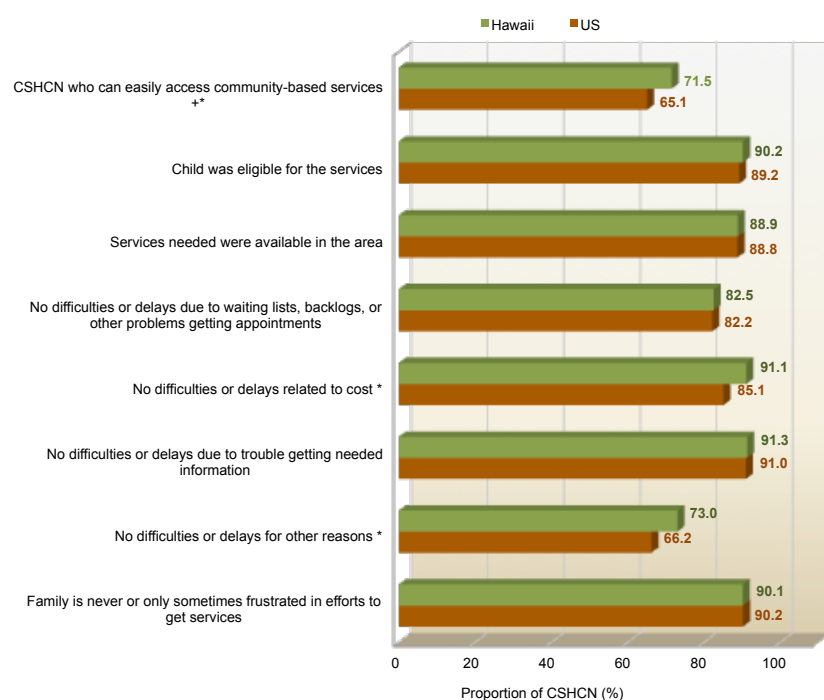
Children with special health care needs should receive their care in family-centered, comprehensive and coordinated systems that are designed to promote the healthy development and well-being of children and their families. These systems of services must be organized so that needed services are available and accessible, with a family-friendly mechanism to pay for them. The medical home is an integral part of the community-based system, offering families a team approach to coordinating access to a broad range of health, social and other services. Today, families face a number of challenges, including differing eligibility criteria for services, duplication and gaps in services, poor coordination among services, inflexible funding streams and inadequate insurance coverage for needed services.<sup>46,47</sup>

### Healthy People 2020 Objective:

Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, coordinated systems.

### Population-Based Data:

**Figure 6.11 CSHCN Who Can Easily Access Community-Based Services in Hawaii and U.S.: 2009–2010**



In 2009–2010, Hawaii data from the National Survey of CSHCN showed that the proportion of Hawaii CSHCN ages 0-17 years old who can easily access community-based services (71.5%) was significantly higher than the national average (65.1%).

The proportion of Hawaii CSHCN whose families had no difficulties or delays related to cost (91.1%) was significantly higher than the national average (85.1%). The proportion of Hawaii CSHCN who had no difficulties or delays for other reasons (73.0%) was also significantly higher than the national average (66.2%).

The proportions of Hawaii CSHCN who had no difficulties due to service eligibility, availability of services in the area, waiting lists or backlogs, or trouble getting needed information were similar to the national averages. The proportion of Hawaii CSHCN whose families are never or only sometimes frustrated in efforts to get services were similar to the U.S. averages.

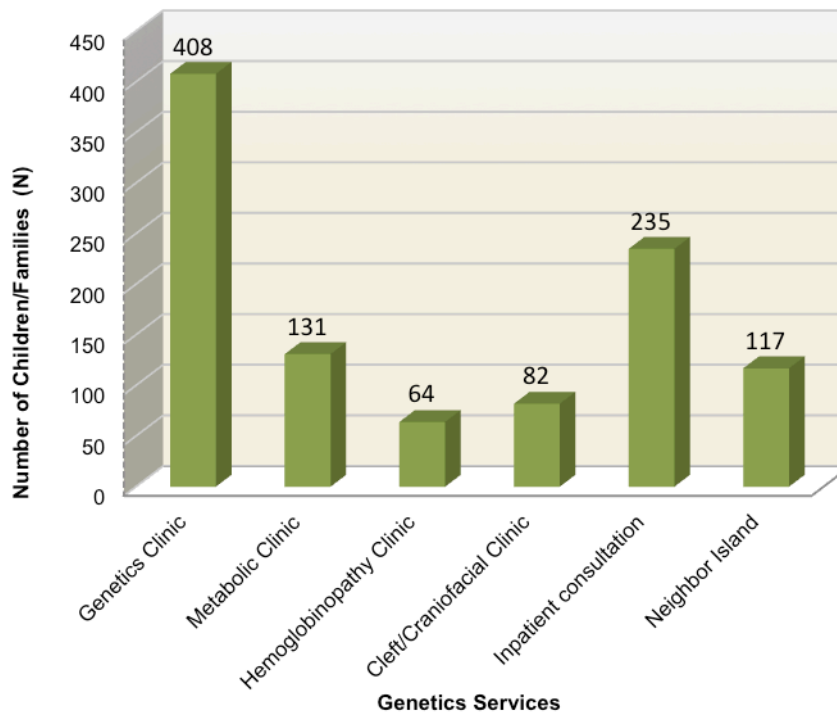
+ CSHCN outcome, derived from other survey items.

\* Statistical difference between Hawaii and U.S. proportions at 95% confidence interval.

Source: "Hawaii Report from the 2009/10 National Survey of CSHCN." NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12/16/11 from [www.childhealthdata.org](http://www.childhealthdata.org). Additional data analyses by DOH Children with Special Health Needs Branch.

## Program Highlight:

Figure 6.12 Children/Families Receiving Genetics Consultation in Hawaii: 2012



\* Includes 9 Fetal Alcohol Spectrum Disorder (FASD) and 13 cancer risk assessments

\*\* Includes 5 telegenetics consults to Neighbor Islands

Source: Hawaii State Department of Health, Family Health Services Division, Children with Special Health Care Needs Branch. Genetics Program.

The **Genetics Program** works collaboratively to develop and maintain Hawaii Community Genetics as a state collaborative clinical genetics unit. The University of Hawaii John A. Burns School of Medicine, Kapiolani Medical Center for Women and Children, and Queen's Medical Center are also partners in this endeavor. The program works to increase access to genetics services among communities, particularly on the neighbor islands. Hawaii Community Genetics geneticists provide genetic evaluation and counseling to families at the Honolulu-based office and at neighbor island in-person clinics on Kauai, Maui, Molokai, and Hawaii (Hilo, Kona and Waimea). Consultations are also provided using telehealth via video conferencing. In 2012, 1,037 families statewide were seen for genetic consultation, with 117 families seen in neighbor island clinics and five families served by telegenetic consults. Family history risk assessment, diagnosis, treatment and management help families to understand their genetic conditions or risk for genetic conditions and help them make choices to improve their family's health.

The Genetics Program provides genetics education to health care providers, public health staff, students and the general public through grand rounds, brown bag sessions, conferences, classroom lectures and public talks. The Genetics Program also works closely with the community to develop policies related to genetics. One example is the development and passage of laws in Hawaii to protect families from genetic discrimination in health insurance coverage and employment.

## Other Program Activities:

- The **Newborn Hearing Screening Program** is responsible for the statewide system of newborn hearing screening in Hawaii as mandated by state law.
- The **Newborn Metabolic Screening Program** is responsible for the statewide system of newborn metabolic screening in Hawaii as mandated by state law.
- The **Early Intervention Section** is responsible for the statewide system of early intervention services for children ages 0-3 years old with or at biological risk for developmental delays as mandated by state law and Part C of the Individuals with Disabilities Education Act. In Fiscal Year 2013, 93% of children and families in early intervention received the majority of services in a natural environment (at home and/or at community settings, such as child care or preschool).
- **Children with Special Health Needs Program** staff provides consultation and in-services to parent groups, community groups and other state agencies regarding hearing and hearing loss.

# Transition for Youth with Special Health Care Needs

## Goal: To Increase the Proportion of Youth with Special Health Care Needs Who Receive Services Needed for Transition to Adult Life

### Issue:

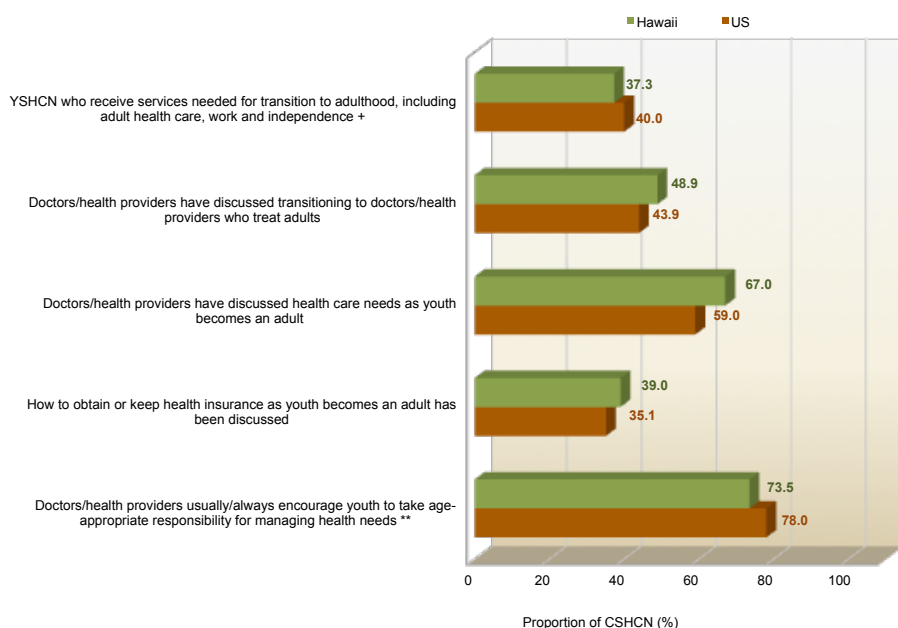
Youth with special health care needs (YSHCN) must be able to expect good quality health care, employment and independence when they reach adulthood. Thus, youth must have access to quality health services, affordable health care and insurance coverage, and be prepared with the necessary skills and knowledge for independence. The community environment, including educational and employment opportunities, should be inclusive and support these youth in their transition to adult life. The medical home must assist with such transitions, especially the transition into adult health care. Challenges to successful transition include the accessibility of information, tools, resources, and strategies to support youth in their successful transition to adult life, the availability of adult health care providers and an inclusive community environment.<sup>46,47</sup>

### Healthy People 2020 Objective:

Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, coordinated systems. Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care to 45.3%.

### Population-Based Data:

**Figure 6.13 Youth with Special Health Care Needs Receiving Services Needed to Transition to Adult Life, Including Adult Health Care, Work and Independence in Hawaii and U.S.: 2009–2010**



In 2009–2010, Hawaii data from the National Survey of CSHCN showed that the proportion of Hawaii YSHCN ages 12-17 years old who received services needed for transition to adult life, including adult health care, work and independence (37.3%), was similar to the national average (40%).

The proportions of Hawaii YSHCN whose doctors/health providers have discussed transition to doctors/health providers who treat adults, health care needs as youth transition to adulthood, obtaining or keeping health insurance as youth transition to adulthood, and youth taking age-appropriate responsibility for managing health needs were similar to the U.S. averages. Hawaii met the Healthy People 2020 goal of doctors discussing transition to adult health care.

\* CSHCN outcome, derived from other survey items.

\*\* Includes taking medication, understanding his/her diagnosis, or following medical advice.

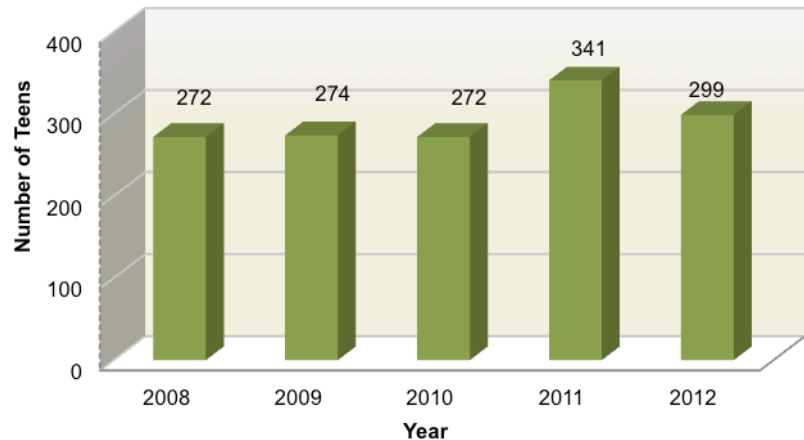
Source: "Hawaii Report from the 2009/10 National Survey of CSHCN." NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12/16/11 from [www.childhealthdata.org](http://www.childhealthdata.org). Additional data analyses by DOH Children with Special Health Needs Branch.

## Program Highlight:

**Figure 6.14 Youth with Special Health Care Needs Ages 12-21 Years Old Served by the Children with Special Health Needs Program: 2008-2012**

The **Children with Special Health Needs Program** works in various ways toward improving transition for YSCHN into adult health care. In Fiscal Year 2012, 299 youth with special health care needs ages 12-21 were served.

The program develops Family Individual Plans with participating families. The purpose of the plan is to identify family needs and services already being provided and to promote family involvement. Guidelines and worksheets for transition planning to young adulthood have been developed and are used in conjunction with the plans. These tools help families focus their transition discussions.



Source: Hawaii State Department of Health, Family Health Services Division, Children with Special Health Needs Branch, Children with Special Health Needs Program. Data reflects calendar year (January 1- December 31).

Transition of YSCHN to adult health care was selected as a state priority for 2010-2015. The Children with Special Health Needs Program convenes a Transition Workgroup to promote and support transition services by networking and partnering with various medical specialists and key state and community agencies to raise awareness about transition planning and share transition resources and tools with YSCHN and their families. The workgroup developed “Footsteps to Transition,” a brief summary of steps in the transition to adult health care, work and independence that families, programs, agencies and Student Disability Services in Higher Education can use to guide their activities. Work continues on a mini-resource pocketbook being developed for youth leaving an alternative educational facility.

## Other Program Activities:

- The **Hoopaa Project – Autism Spectrum Disorder State Implementation Grant** supports the transition to adult life for youth with autism spectrum disorder and other developmental disabilities/special health care needs with the following:
  - Transition workshops and trainings are provided for various state and community groups.
  - The project collaborated in planning the American Academy of Pediatrics-Hawaii Chapter’s conference “A Physician’s Response to Autism” in 2011, which included a session on transition to adulthood.
  - The project sponsored two nationally known speakers to present to Maui and Hawaii islands, the Transition Workgroup and at the Convergence Workshop.
  - “Rainbow Book—A Medical Home Guide to Resources for CSHCN and Their Families” includes programs/services for transition to adult life, including information on education, higher education and disability access, employment and vocational rehabilitation. Trainings are conducted on all islands for health professionals, agency staff, families and others.
- The **Maui County District Health Office** and the Children with Special Health Needs Program participate in the annual Big MAC (Moving Across Community) Transition Fair for students in special education and their families. This event has been the model for transition-planning fairs on other islands. Transition fairs in conjunction with the Department of Education have been held on Kauai, Kona on Hawaii Island, and in Oahu’s Windward and Central districts.