

# ***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**

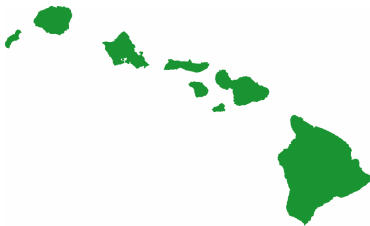
Children with Special Health Needs Branch  
Family Health Services Division  
Hawaii Department of Health

### ***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.

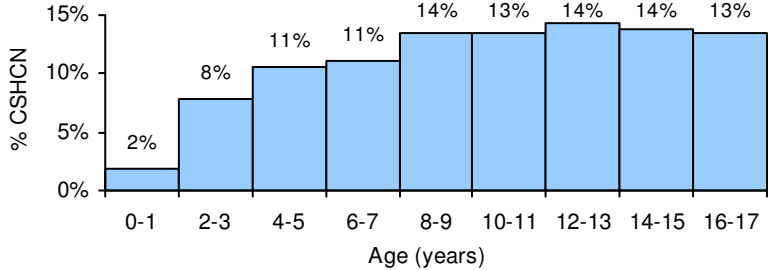
Data show a need to improve outcomes for CSHCN in Hawaii.

## *National Survey of CSHCN*

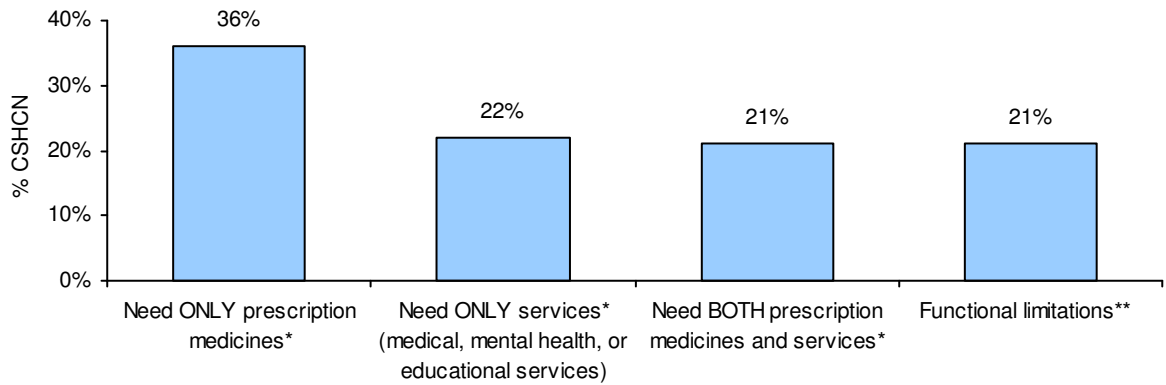
- The National Survey of CSHCN was sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration, and Office of Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.
- The National Center for Health Statistics conducted the survey 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.*
- 
- | Age (years) | % CSHCN |
|-------------|---------|
| 0-1         | 2%      |
| 2-3         | 8%      |
| 4-5         | 11%     |
| 6-7         | 11%     |
| 8-9         | 14%     |
| 10-11       | 13%     |
| 12-13       | 14%     |
| 14-15       | 14%     |
| 16-17       | 13%     |
- 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 subgroups<sup>1</sup>*: For CSHCN who have medical, behavioral, or other health conditions that have lasted or are expected to last 12 months or longer:

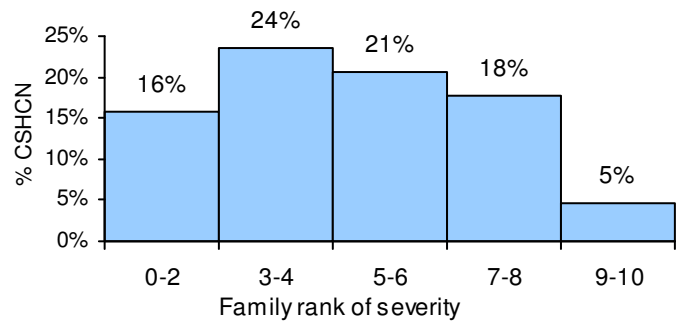


\* No functional limitations.

\*\* 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.<sup>2</sup>**

- 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.

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*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>1</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>2</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?

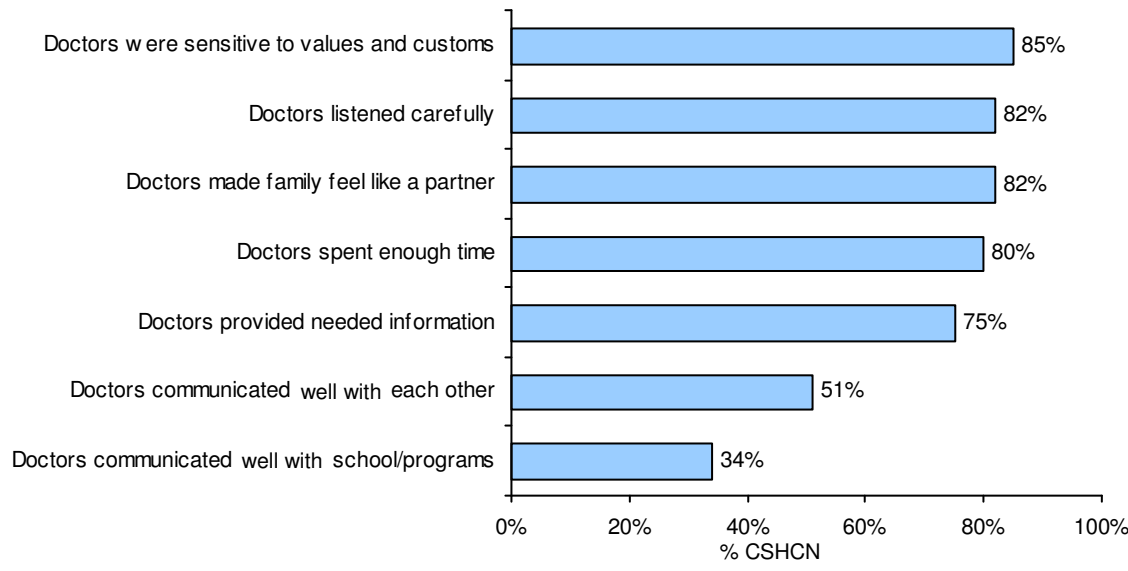
Outcome measure

**48% CSHCN receive coordinated, ongoing, comprehensive care within a medical home.**<sup>3</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%                                |

<sup>3</sup> 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.** <sup>4</sup>

**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>5</sup>     | 70.7%   |
| Public only <sup>6</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.

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<sup>4</sup> The percentage for this outcome measure is derived from 5 indicators (see page 10).  
<sup>5</sup> Private insurance is defined as employer- or union-based or purchased directly. It includes military coverage.  
<sup>6</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>7</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.

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*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>8</sup>

**2010 National Outcome for CSHCN**  
Community-based service systems will be organized so families can use them easily.

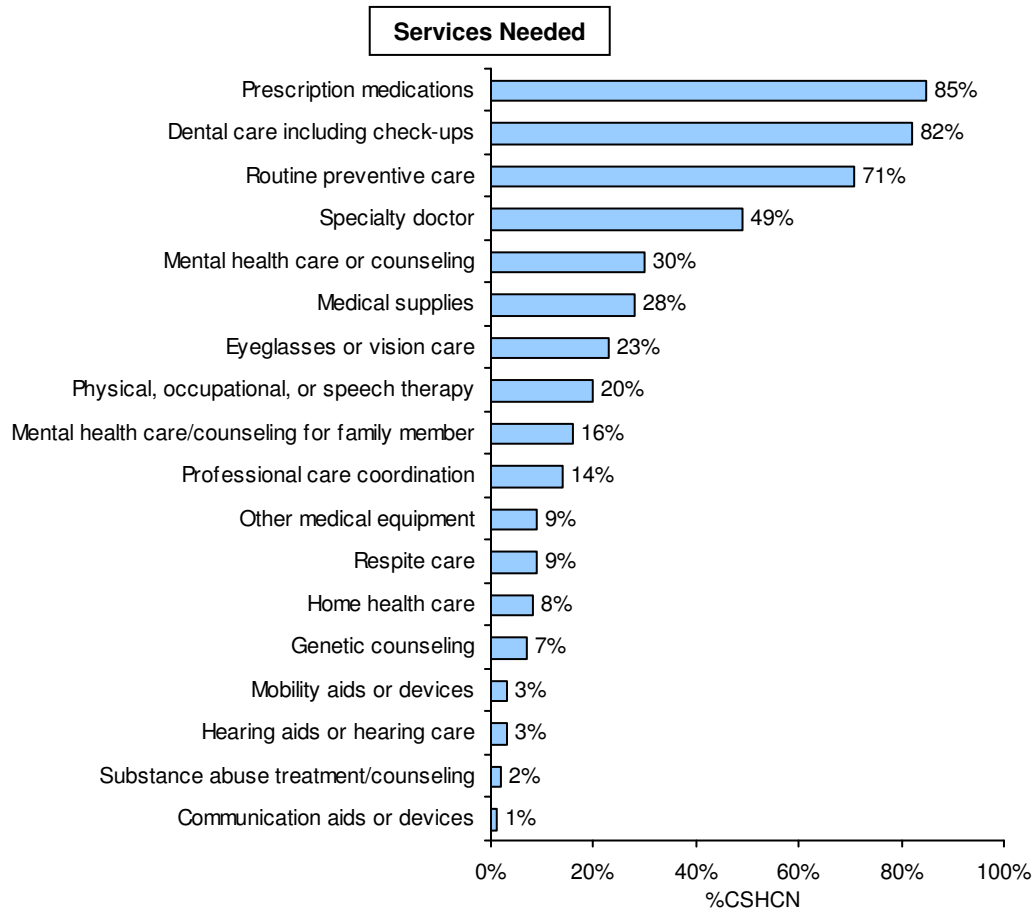
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*The system must be organized so that the needs of children/families can be identified, services are provided, and there is a way to pay for them. Since CSHCN require more medical and related services than other children, services need to be coordinated and easy to use.*

<sup>7</sup> The survey did not have specific indicators for screening.

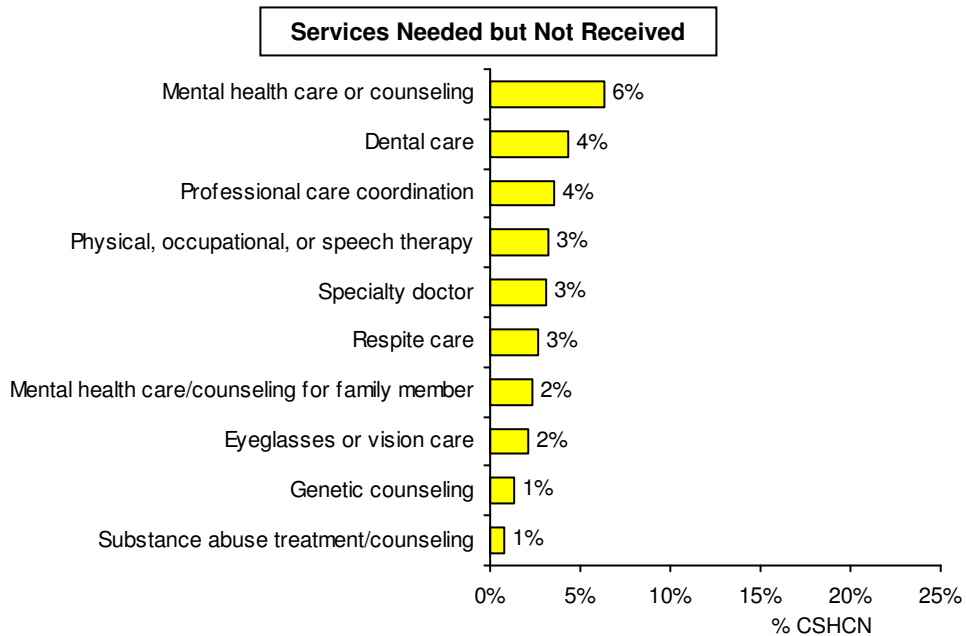
<sup>8</sup> The percentage for this outcome measure is based on 1 indicator (see page 10).

**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***

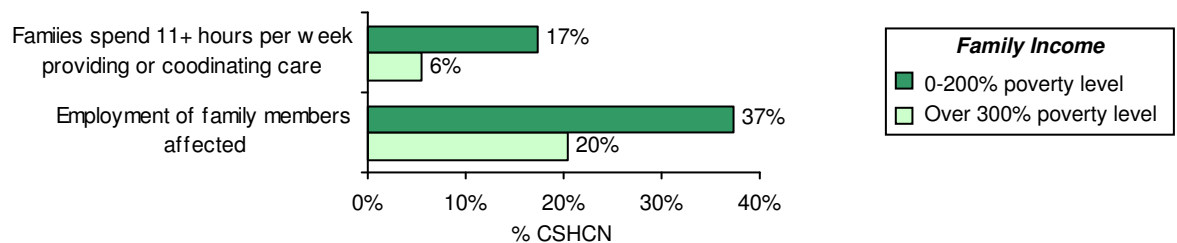
- 43% families of CSHCN paid \$1,000 or more out-of-pocket for medical care / health-related needs in the previous year.
- 13% families of CSHCN had financial problems caused by their child's condition.
- 14% families of CSHCN needed additional income to cover their child's medical expenses.
- 29% CSHCN 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\*:

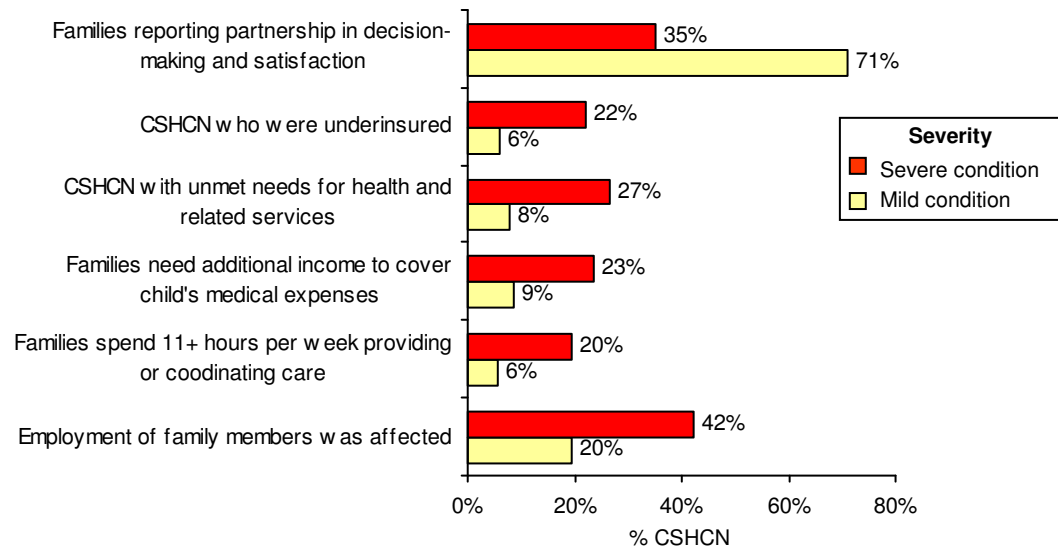


\* Lower income = 0-200% FPL (Federal Poverty Level). Higher income = over 300% FPL. For a family size of 4 family members, 0-200% FPL=\$41,640 or less, and over 300% FPL= over \$62,460 (2002 FPL). Items shown are statistically significant at the 95% confidence interval.



### *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>9</sup>**

- 60% youth with special health care needs have doctors who talked about changing needs as youth becomes an adult.<sup>10</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.*

<sup>9</sup> The percentage for this outcome measure is derived from 2 indicators (see page 10).

<sup>10</sup> 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

| <b>Outcome for CSHCN with indicator(s) used to determine outcome<sup>11</sup></b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | <b>% CSHCN</b>                                                                                                                                                                                                                                                                 |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>% CSHCN age 0-17 years whose families partner in decision-making at all levels and are satisfied with the services they receive</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | <b>52%</b>                                                                                                                                                                                                                                                                     |
| <ul style="list-style-type: none"> <li>• <b>Doctors usually or always made the family feel like a partner</b></li> <li>• <b>Family was very satisfied with services received</b></li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | <ul style="list-style-type: none"> <li><b>81%</b></li> <li><b>56%</b></li> </ul>                                                                                                                                                                                               |
| <b>% CSHCN age 0-17 years who receive coordinated, ongoing, comprehensive care within a medical home</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | <b>48%</b>                                                                                                                                                                                                                                                                     |
| <ul style="list-style-type: none"> <li>• <b>The child had a usual source of care</b> <ul style="list-style-type: none"> <li>○ Child had a usual source for sick care</li> <li>○ Child had a usual source for preventive care</li> </ul> </li> <li>• <b>Child had a personal doctor or nurse</b></li> <li>• <b>Child had no problems obtaining referrals when needed</b></li> <li>• <b>Effective care coordination was received when needed</b> <ul style="list-style-type: none"> <li>○ Child had professional care coordination when needed</li> <li>○ Doctors communicated well with each other</li> <li>○ Doctors communicated well with other programs</li> </ul> </li> <li>• <b>The child received family-centered care</b> <ul style="list-style-type: none"> <li>○ Doctors spent enough time</li> <li>○ Doctors listened carefully</li> <li>○ Doctors were sensitive to values and customs</li> <li>○ Doctors provided needed information</li> <li>○ Doctors made family feel like a partner</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li><b>88%</b></li> <li>98%</li> <li>88%</li> <li><b>88%</b></li> <li><b>76%</b></li> <li><b>28%</b></li> <li>74%</li> <li>51%</li> <li>34%</li> <li><b>63%</b></li> <li>80%</li> <li>82%</li> <li>85%</li> <li>75%</li> <li>82%</li> </ul> |
| <b>% CSHCN age 0-17 years whose families have adequate private and/or public insurance to pay for the services they need</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | <b>70%</b>                                                                                                                                                                                                                                                                     |
| <ul style="list-style-type: none"> <li>• <b>Child had public or private insurance at time of interview</b></li> <li>• <b>Child had no gaps in coverage during year prior to the interview</b></li> <li>• <b>Insurance usually or always met child's needs</b></li> <li>• <b>Costs not covered by insurance were usually or always reasonable</b></li> <li>• <b>Insurance permitted child to see needed providers</b></li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | <ul style="list-style-type: none"> <li><b>98%</b></li> <li><b>94%</b></li> <li><b>89%</b></li> <li><b>78%</b></li> <li><b>90%</b></li> </ul>                                                                                                                                   |
| <b>% Children screened early and continuously for special health care needs<sup>7</sup></b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | <b>–</b>                                                                                                                                                                                                                                                                       |
| <b>% CSHCN age 0-17 years whose families report community-based service systems are organized so they can use them easily</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | <b>69%</b>                                                                                                                                                                                                                                                                     |
| <ul style="list-style-type: none"> <li>• <b>Services were organized for easy use</b></li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | <b>69%</b>                                                                                                                                                                                                                                                                     |
| <b>% Youth with special health care needs who received the services necessary to make transitions to all aspects of adult life</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | <b>5%</b>                                                                                                                                                                                                                                                                      |
| <ul style="list-style-type: none"> <li>• <b>Child has received guidance and support in transition to adulthood</b> <ul style="list-style-type: none"> <li>○ Doctors talked about changing needs as child becomes adult</li> <li>○ Child has plan for addressing changing needs</li> <li>○ Doctors discussed shift to adult provider</li> </ul> </li> <li>• <b>Child has received vocational or career training</b></li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | <ul style="list-style-type: none"> <li><b>15%</b></li> <li>60%</li> <li>54%</li> <li>36%</li> <li><b>29%</b></li> </ul>                                                                                                                                                        |

<sup>11</sup> 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.<sup>12</sup>
- For children with special needs age 0-3 years receiving early intervention (EI) services<sup>13</sup>:
  - 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.<sup>12</sup> 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%.<sup>12</sup>
- 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.<sup>12</sup>
- 39% families of CSHCN said they or family member cut down/stopped working to care for their child.<sup>12</sup>
- 33% families of CSHCN said that extra costs of care for their child resulted in financial problems.<sup>12</sup>

### **Screening**

- 99% newborns are screened for metabolic conditions. 100% infants with metabolic conditions receive appropriate follow-up services.<sup>14</sup>
- 98% newborns are screened for hearing. 92% infants with permanent hearing loss receive appropriate intervention services.<sup>15</sup>
- 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.<sup>16</sup>

### **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.<sup>17</sup>
- 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.<sup>17</sup>
- 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.<sup>12</sup>
- 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.<sup>13</sup>

### **Transition to adult life**

- Anecdotal reports of youths with special needs having difficulty in transitioning from pediatric to adult health care physicians.<sup>18</sup>

<sup>12</sup> Hawaii Department of Health (DOH), Children with Special Health Needs Branch (CSHNB), Survey of Families of CSHCN, 2000.

<sup>13</sup> DOH, CSHNB, Early Intervention Section, and Public Health Nursing Branch. Parent survey, 2002.

<sup>14</sup> DOH, CSHNB, Newborn Metabolic Screening Program, 2002.

<sup>15</sup> DOH, CSHNB, Newborn Hearing Screening Program, 2002 births.

<sup>16</sup> DOH, CSHNB, Healthy Child Care Hawaii, Survey of Physicians, 2001.

<sup>17</sup> DOH, Family Health Services Division, Children's Health Issues 2000.

<sup>18</sup> 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](http://www.medicalhomeinfo.org)

Champions for Progress – *implementing systems of care for CSHCN*: [www.championsforprogress.org](http://www.championsforprogress.org)

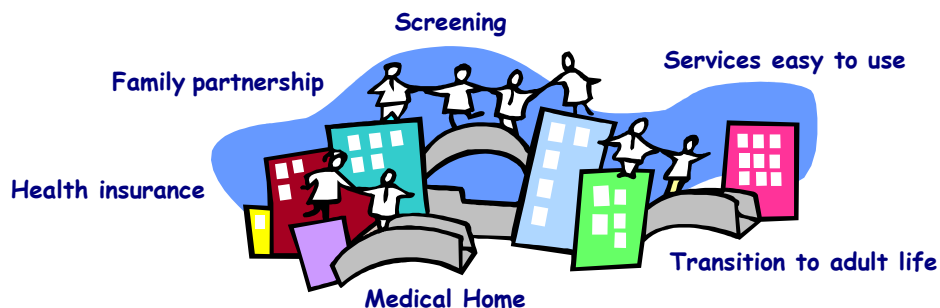
Data Resource Center for Child and Adolescent Health – *National Survey of CSHCN data* – [www.cshcndata.org](http://www.cshcndata.org)

Family Voices – *families speaking on behalf of CSHCN*: [www.familyvoices.org](http://www.familyvoices.org)

Healthy and Ready to Work National Center – *transition to adult life*: [www.hrtw.org](http://www.hrtw.org)

Maternal and Child Health Bureau – *Title V, block grant, CSHCN*, [www.mchb.hrsa.gov/programs](http://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](http://www.cdc.gov/nchs/about/major/slats/cshcn.htm)



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