

State Action Plan Table

Children with Special Health Care Needs

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| | | <p>provide transition materials to other agencies to incorporate into their programs.</p> <hr/> <p>- Provide education/training on transition to adult health care</p> <hr/> <ul style="list-style-type: none"> • Staff development: Promote staff development in transition issues via webinars, trainings, etc. <hr/> <ul style="list-style-type: none"> • Potential opportunities: Investigate the inclusion of transition in other FHSD services/contracts. | | | | |

Children with Special Health Care Needs

Children with Special Health Care Needs - Plan for the Application Year

Preliminary 5-Year Plan

The 5-year needs assessment affirmed the importance of transition to adult health care as a priority issue. Youth with special health care needs, compared to those without special health care needs, are less likely to complete high school, attend college, or be employed. Health and health care are major barriers to making successful transitions.

Transition to adult health care remains an important issue at the national level. In 2011, the American Academy of Pediatrics (AAP), American Academy of Family Physicians, and American College of Physicians jointly published “Clinical Report – Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home”. In 2015, Federal Partners in Transition Workgroup published “The 2020 Federal Youth Transition Plan: A Federal Interagency strategy”, which emphasizes the importance of interagency collaboration and takes an Inclusive

approach to improve adult outcomes. A Healthy People 2020 Objective (DH-5) focuses on increasing the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.

The five-year needs assessment reaffirmed the importance of transition to adult health care as a priority issue in Hawaii:

- Hawaii data from the National Survey of Children with Special Health Care Needs (NSCSHCN) 2009/10 showed that the Hawaii rate for transition (37.3%) was lower than the national rate (40.0%). The Hawaii rate for this measure was 39.4% in 2005/6 and 37.3% in 2009/10, but estimates may not be comparable since the survey method added cell phones in 2009/10.
- Professional and state/community agencies and organizations are interested in transition:
 - AAP-Hawaii Chapter priorities for 2015 and beyond include transition of adolescents to adult care with a focus on youth with special health care needs.
 - Hilopaa Family to Family Health Information Center (F2FHIC) has developed materials and provides education/training on transition to adult health care.
 - Transition fairs have been held throughout the state. On the island of Oahu, planning has involved the FHSD/Children and Youth with Special Health Needs Section, Community Children's Council Office, DOH/Developmental Disabilities Division, Hawaii MCH Leadership Education in Neurodevelopmental and Related Disabilities [MCH LEND] Program, Hawaii State Council on Developmental Disabilities, Hawaii State Department of Education (DOE), Hilopaa F2FHIC, Special Parent Information Network (SPIN), and other agencies/organizations.
 - The Hawaii State Council on Developmental Disabilities 2012-2016 State Plan includes a goal about preparing students at all educational levels for the transition from high school to adult life including employment, self-employment, and/or post-secondary education and training.

Priority: Transition of Youth to Adult Health Care

The state priority is based on the Title V National Performance Measures for transition to adult health care for youth with and without special health care needs. The focus on the transition of children with special health care needs to adult health care is a continuing priority for Hawaii. The focus on the transition of children without special health care needs to adult health care is a new priority for Hawaii.

Objective: By July 2020, increase the percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care to 40%. [Baseline: Hawaii 37.3%, National Survey of CSHCN (NSCSHCN) 2009/10)

The preliminary 5-year plan objectives were developed using the NSCHCN data for Hawaii as a baseline and projected an almost 3 percent improvement over the next five years.

National Performance Measure: Percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care.

5-Year Strategies

- Collaboration:
 - Convene agency and community stakeholders to develop strategies to improve services for adolescents and their families necessary to make transition to adult health care. Include youth in the planning process.
 - Collaborate with stakeholders and reach out to new stakeholders to increase awareness of the importance of health care in transition planning.

- Collaborate with the Hilopaa Family to Family Health Information Center Director (also MCH LEND Co-Director) in working with health care providers.
- Collaborate with the FHSD/MCH Branch/Adolescent Program in working to increase the percent of adolescents age 12-17 years with a preventive medical visit in the past year, and include the transition to adult health care message.
- Develop and implement plan to address key factors (e.g., medical home, health insurance, preventive medical visit, etc.) that support the transition to adult health care.
- Education:
 - Develop educational materials to “chunk” manageable steps for transition for younger ages.
 - Continue to provide transition materials to other agencies to incorporate into their programs.
 - Provide education/training on transition to adult health care.
- Staff development: Promote staff development in transition issues via webinars, trainings, etc.
- Potential opportunities: Investigate the inclusion of transition in other FHSD services/contracts.

Strategy Development

Strategies were developed based on recommendations from national reports as well as discussions at the local level. The 2020 Federal Youth Transition Plan and other reports recommend closer collaboration among providers working with transitioning youth. Many agencies have been working on transitioning their clients to adult life. Most work separately, without consulting others in the youth’s circle of support. The 2020 Plan also recommends quality professional development for staff engaged in providing services to youth. In 2014, the CMS report on Paving the Road to Good Health recommended developing partnerships among key stakeholders and creating adolescent-friendly material.

Plans for Application Year Federal Fiscal Year 2016 (10/1/15-9/30/16)

Much work centers on establishing or continuing partnerships to reach wider audiences, to spread resources and expertise, and to develop youth-friendly material.

- Continue Footsteps to Transition/Big MAC (Moving Across Community)/other transition awareness planning involvement.
- Participate in other large well-established events, such as SPIN Conference, in which participants include youth with special needs and their families.
- Support professional development opportunities to develop competencies in addressing transition issues, via webinars, trainings, conferences, etc.
- Collaborate with FHSD/Adolescent Program to infuse transition planning into their established networks and contracts.
- Assist in supporting Medicaid Buy-in, which was not approved by legislature.
- Research public/private insurance coverage for yearly physical exams for adolescents, and review recommendations from the AAP.
- Collaborate and broaden partnerships to increase awareness of multiple facets of transition to boost successful outcomes. Partnerships may include the Hawaii Immunization Coalition, Project Laulima, Medicaid Buy-in Task Force, Public Health Nursing, and stakeholders in youth/health/service network. Utilize the partnerships to educate participants about the importance of transition to adult health care.
- Develop catchy information materials to use with younger-aged children and their families. Develop a transition brochure with local appeal.

Factors Contributing to Success

Strong encouragement from the Federal level to include transition in agency services has helped to heighten recognition that good transition planning and execution improve adult outcomes. Resources are available (and free)

for health providers, community, and youth/family use. Multiple transition booklets, tips, and recommendations can be found on various nationally-endorsed websites. The national Got Transition website has current transition materials for community providers. The 2020 Federal Youth Transition Plan on enhanced interagency coordination will help to make transition more integrated leading to improved outcomes.

In Hawaii, DOE requires that all high school students have a Personal Transition Plan to transition from high school to college and careers. DOE has also co-sponsored and hosted transition events. QUEST Integration AlohaCare recommends that physicians expand school and sports physicals to meet the criteria of a well-care screening. Their website includes information on adolescent health. MCH LEND and Family Voices continue to promote and educate future/current providers and leaders in the field in the art and science of Transition.

Challenges, Barriers

There are many challenges in addressing transition. However, introducing the idea earlier and in smaller chunks over a longer period of time may mitigate some barriers.

- Families are busy with life, work, their other children, etc. There can be a huge physical and emotional toll of having a family member with a special care need.
- Providers and families are still learning about the importance of transition planning. Preparation for independence, responsibility, and transition is often addressed later, rather than sooner.
- Youth may be connected to multiple systems of care that don't talk to each other, which may make coordination confusing.
- Providers have limited time with clients, have limited staff, and may not feel competent in discussing issues. Until recently, coding for reimbursement was problematic.
- The process needs to be individualized and (if possible) youth needs to have input into the process (self-determination).
- Benefits planning takes skill and expertise. However, low cost/free consultations are limited. Persons with disabilities often need the full coverage of public insurance; they cannot afford to earn "too much" and lose their eligibility.

Completing 5-Year Action Plan Activities

FHSD will continue to work on the current activities discussed above. An update on progress will be provided in next year's Title V report. Any needed changes to the preliminary 5-Year Plan will be made. Based upon guidance provided by AMCHP and the federal MCH Bureau, performance measures will be identified for evidence-based practices.

Children with Special Health Care Needs - Annual Report

NPM 12 - Percent of adolescents with and without special health care needs who received services necessary to make transitions to adult health care

| Annual Objectives | | | | | |
|-------------------|------|------|------|------|------|
| | 2016 | 2017 | 2018 | 2019 | 2020 |
| Annual Objective | 39 | 39 | 39 | 39 | 39 |

For the Children with Special Health Needs (CSHN) population domain Hawaii is reporting on the national and state performance measures which address the following issues:

- NPM 2: CSHN family decision-making & satisfaction

- NPM 3: Medical Home
- NPM 4: CSHN medical insurance coverage
- NPM 5: CSHN community based services
- NPM 6: CSHN transition services
- SPM 9: YSHN transition to adult care

NPM 2: The percent of children with special health care needs age 0 to 18 whose families partner in decision-making at all levels and are satisfied with the services they receive.

Data from the National Survey of CSHCN show that 77.6% of Hawaii CSHCN families partnered in decision making and were satisfied with services compared to 70.3% nationally. Families of children with special health care needs (CSHCN) were involved in decision-making in various ways: as advisory committee members; developing parent education materials; in presentations and panels; interviewing applicants for staff positions; advocacy for legislation; and providing input on program policies and procedures. Parents were compensated or assisted by providing stipends, transportation and child care costs.

The Hawaii Early Intervention Coordination Council (HEICC) advises the DOH regarding early intervention (EI) services. As required by Part C of the Individuals with Disabilities Education Act, the HEICC has parents of CSHCN as members. A Co-Chair of the HEICC is a parent of a youth with special health care needs (YSHCN).

Early Intervention Section (EIS) supports families attending conferences and trainings by paying registration fees, including airfare & ground transportation for Neighbor Island families to come to Oahu, EIS continues to obtain feedback from families through meetings, committees, and an annual family outcome survey.

The Newborn Hearing Screening Program (NHSP) provides parent support to families with children who did not pass newborn hearing screening or who had confirmed hearing loss. Family members participate on the Early Hearing Detection and Intervention (EHDI) Advisory Committee. The Hawaii Chapter of the national parent organization, Hands & Voices (H&V) has been established. NHSP will contract HV to provide parent supports to families. NHSP collaborated with the H&V Hawaii Chapter and the Early Intervention Program to offer parent education and parent support activities.

Family members of children with metabolic conditions participate in Newborn Metabolic Screening (NBMS) Advisory Committee and task forces as new conditions are considered for addition to the newborn screening panel of disorders. Most recently, families had a voice in the decision to start testing all of Hawaii's Newborns for the genetic disorder SCIDS (Severe Combined Immunodeficiency Syndrome). Families of children with genetic conditions participate in State Genetics Advisory Committee and as an integral partner in Western States Genetic Services Collaborative (WSGSC).

The family resource handbook in Children with Special Health Needs Program (CSHNP) includes a Transition section to develop a Family Individual Plan (FIP) for services. The Transition Checklist tool and FIP are developed together with children and their families. Plan components are reviewed annually with the family to address current and emerging concerns. CSHNP also partners with the Arc, Hawaii Department of Education (DOE), Hilopa'a, Developmental Disabilities Branch, Special Parents Information Network (SPIN), Childrens Community Council (CCC) and Best Buddies to host annual transition fairs in the community.

CSHNP coordinates a Hawaii Island Kardiak Kids support group that serves as an active resource for children and parents. The Oahu Kapiolani Kardiak Kids parent support group also provides mentorship and support to the Hawaii Island group. Teen mentorship club members provide positive peer support and speakers for community group events. Teens have their own officers and are encouraged to make an impact in the community. Participants are taught lifestyle management and plan fun group outings.

Children with Special Health Needs Program (CSHNP) works closely with parents of children with orofacial birth defects (cleft lip and palate) to make changes in medical/health insurance coverage. Medicaid and Tricare already provide medical coverage for medically necessary orthodontic treatments for these children as it is part of the reconstruction of the birth defect and would address functional problems such as biting, chewing, speech and respiration. For children covered by commercial/private health plans the high cost of repeated orthodontic treatment

is an out of pocket expense. Parents, medical, dental and community stakeholders collaborated with CSHNP to support legislation to expand insurance coverage for these services. Parents participated in the legislative process by submitting testimony for proposed bills, meeting with the legislators and the creation of a Facebook page, "Lifetime of Smiles", to inform others of this issue. Lifetime of Smiles is also the name of the informal parent support group of parents and their children who have orofacial birth defects. CSHNP has provided leadership, guidance, updates and coordination of these activities but the strength of these activities have come from partnerships with parents who are directly affected by inadequate insurance coverage for medically necessary treatment. Efforts by CSHNP and parents resulted in the successful passage of legislation in 2015 to include orthodontic treatments for these children into all insurance plan benefit packages. The bill was recently signed by the Governor at a public ceremony with the families, legislators, and Title V staff.

Title V participates in the annual Special Parent Information Network (SPIN) conference to provide information on health issues, services, and opportunities to participate in CSHN programs.

NPM 3: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, and comprehensive care within a medical home.

Data from the National Survey of Children with Special Health Care Needs (CSHN) show that 45.4% of Hawaii CSHN had a medical home compared to 43% nationally.

The Children with Special Health Needs Branch (CSHNB) supports medical homes by assisting families with access to specialty services. Pediatric cardiology, neurology and nutrition clinics are provided in neighbor island districts where those services are otherwise unavailable. CSHNB expanded access to cardiology services in West Hawaii. The West Hawaii CSHNB social worker is able to support cardiac clinic services in conjunction with client medical homes. Financial assistance for medical specialty services and neighbor island travel is provided to eligible children. CSHNB provides information and referral, outreach, service coordination, social work, audiology and nutrition services for CSHCN age 0-21. Title V Workgroups on Early Childhood Development/Screening and Transition to Adult Health Care continue efforts to improve access to services for families in collaboration with community partners.

CSHNB is part of the Kapi'olani Medical Center Cleft and Craniofacial Center multi-disciplinary team which sees patients weekly. Parents are given guidance on issues and concerns to discuss with their medical home. The goal is to enable parents to understand the needs of their children so they can communicate and coordinate services with their medical home. In situations where parents require more assistance, direct coordination is done with their medical home and specialists.

The Newborn Metabolic Screening Program (NMSP) provides metabolic screening to all newborns, collaborates with the medical home for follow up and has "Hawaii Practitioner's Manual" posted on their website. The Early Intervention Services (EIS) includes care coordination and involves the medical home in the Individual Family Support Plan conferences with family consent.

The Genomics Program facilitates in person and telemedicine genetics consultations on all islands. The Program is working with neighbor islands to increase referrals for telemedicine genetics consultations. The Western State Genetic Services Collaborative (WSGSC) is working with local and regional medical home advocates to improve primary care provider genetics education and ability to determine the need for referral to a genetics specialist. WSGSC will continue to participate in the national Health Resources and Services Administration (HRSA) efforts to integrate family history and genetics knowledge into medical homes.

In response to a change in Early Intervention program eligibility guidelines in 2013, Hi'ilei Hawaii was created as a safety net developmental follow along program for young children. Hi'ilei Hawaii provides developmental follow-up for young children who are high risk and not eligible for Early Intervention services. Hi'ilei provides screening results to the medical home and involves the medical home when there are referrals to early intervention services or to DOE preschool special education.

The Early Childhood Comprehensive Systems (ECCS) Coordinator is one of the co-leaders for the Executive Office on Early Learning (EOEL) strategic action group addressing the health and development of children prenatal to age 8. The key role of the Medical Home is recognized in the plan activities and outcomes.

On the Neighbor Islands there are challenges securing medical homes for CSHN given shortage of providers. CSHNP staff provide enabling services in coordination with the medical home to secure transportation services for flights to access care on Oahu given limitation of insurance coverage and accessibility issues with the planes for CSHN. CSHN staff also provide case management services at the request of the medical home to assure families keep provider appointments and comply with medication schedules.

The WIC program works to assure all clients have a medical home and insurance coverage through the Health Insurance Exchange. Referrals are also made to federally qualified health centers for care.

NPM 4: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

Data from the National Survey of Children with Special Health Care Needs (CSHCN) show that 72.6% of Hawaii CSHN had adequate insurance coverage to pay for needed services compared to 60.6% nationally. The study also reported 5.3% of CSHCN were without insurance at one or more periods and 94.7% were consistently insured the entire past 12 months.

Children with Special Health Needs Program (CSHNP) service coordinators assisted CSHCN and their families obtain and maximize use of health coverage. CSHNP provided financial assistance for medical specialty, laboratory, x-ray, hearing aids, orthodontic treatment, neighbor island air/ground transportation, lodging, and specialty clinics on Kauai, Maui, and the Big Island. CSHNP administered the Hawaii Lions Foundation Uninsured/Under-Insured Fund for hearing and vision services.

Newborn Metabolic and Hearing Screening Programs provided outpatient screening and diagnostic evaluations for families who could not afford the cost. Hospital screening is generally covered by insurance.

CSHCN with family income up to 300% are eligible for Medicaid services under QUEST managed care or under QUEST Expanded Access (QExA) for individuals who are aged, blind, or disabled (ABD). QExA, began in 2009, provides a comprehensive package of medical, dental, long-term care, and behavioral health care. Expanded Medicaid eligibility under the ACA uses new MAGI rules for income which eliminate the asset test for non-ABD and eliminate disregarded income types by increasing the MAGI FPL to 308%. This increase in coverage helps families whose income fall into the 300-308% range that did not have income which could be disregarded.

CSHNP, Hawaii District FSHD Coordinator, HMSA, medical provider, and West Hawaii Keiki Health Clinic collaborated to expand access of the CSHNP funded cardiac clinic services to the wider pediatric community. The CSHNP Kauai Cardiac Clinic was discontinued and patients transferred to a cardiologist at Kauai Medical Clinic. These actions resulted in greater access for non-CSHNP children and shifted reimbursements from CSHNP to insurance plans.

CSHNP funded neurology, genetic and nutrition clinics on the Big Island, Kauai, and cardiac, genetic and nutrition clinics on Maui. CSHNP coordinated and managed these specialty clinics and collaborated with community providers.

Early Intervention (EI) services for QUEST (Medicaid)-eligible children are in part reimbursed under a Memorandum of Agreement (MOA) between the Department of Human Services (DHS) and DOH. EI services provided a full array of therapies, interventions, and services to address five areas of development; communication, cognitive development, physical, social/emotional, and adaptive skills.

The Ho'opa'a Project, the Hawaii Autism Spectrum Disorders (ASD) State Implementation Grant, helped to develop a framework for integrated service planning and quality monitoring for Medicaid funded program services, with strategies focused on maximizing existing benefits. The Ho'opa'a Project provided workshops to train and educate families on the legislative process and insurance issues related to autism spectrum disorder.

CSHNP, Lifetime of Smiles parent support group, Hawaii Pacific Health and community stakeholders collaborated to address a medical insurance disparity for medically necessary orthodontic treatments for orofacial birth defects such as cleft lip and palate. Tricare and Medicaid were already providing this specific medical benefit whereas private medical plans did not.

During the 2014 legislative session, House Bill (HB) 2522 was introduced through private/public collaboration. This

bill would have required private medical insurance plans cover the high cost out-of-pocket expenses for medically necessary orthodontic treatments for children with orofacial birth defects. The bill did not advance. However, the legislature did pass House Concurrent Resolution, HCR 100. It required the State Auditor's Office to conduct a study of the social and financial effects of requiring private health plans cover medically necessary orthodontic treatment of orofacial birth defects.

In September 2014, the Hawaii State Auditor's Report, No. 14-08, recommended HB 2522 be enacted since coverage would provide a substantial social benefit in exchange for a minimal cost to private insurers due to the small portion of the general population affected. Based on the State Auditor's recommendation advocates organized to support the legislation in 2015.

The Genetics program with the HRSA funded multi-state Western States Genetic Services Collaborative (WSGSC) and national efforts continued to work on issues to improve coverage for medical foods/formulas for children with metabolic conditions. This past year, the WSGSC has started a pilot project to help medical directors of state Medicaid agencies and private third party payers to assess the necessity of genetic services and testing. The medical directors can submit cases to an objective expert panel which reviews the case and provides expert opinion about the requested services to help the medical director make the coverage decision. The Genetics program also continues to work with third party insurers to improve reimbursement for telehealth genetic consultations and newborn screening services.

NPM 5: Percent of children with special health care needs age 0 to 18 whose families report the community-based service system are organized so they can use them easily.

Data from the National Survey of CSHCN indicates that 75.1% of Hawaii CSHN can access community based services compared to 65.1% nationally. Children with Special Health Needs Branch (CSHNB) programs work toward coordinated, family-centered services/systems:

- Early Intervention Section is the lead for Part C of Individuals with Disabilities Education Act (IDEA) for early intervention (EI) services for children age 0-3 years with or at biological risk for developmental delays. The EI system includes central directory, public awareness, child find, evaluation/assessment procedures, Individual Family Support Plan, personnel development, procedural safeguards, complaint resolution, financial policies, and data collection.
- Newborn Hearing Screening Program is responsible for the statewide system of newborn hearing screening, including diagnostic audiological evaluation and link to EI services, technical assistance, quality assurance, data/tracking, and education.
- Newborn Metabolic Screening Program is responsible for the statewide system of newborn metabolic screening, including diagnosis and intervention/follow-up, data/tracking, quality assurance, and education.
- Children with Special Health Needs Program (CSHNP) provides medical specialty, nutrition, social work, neighbor island (NI) clinics, outreach for Supplemental Security Income, and other services as a safety net and to increase access to services.
- Genetics Program and state/community partners work to assure the availability and accessibility of quality genetic services in the state. The Program with the WSGSC developed a Portable Health Record for use by people with genetic/metabolic conditions in times of transition or emergencies to improve access to genetic services.

Hawaii Community Genetics, a partnership of CSHNB Genetics Program, Kapiolani Medical Center, Queen's Medical Center, and UH School of Medicine/Pediatrics, provides clinical genetic/metabolic services, clinics, and telehealth visits. Activities to improve access to genetic services for neighbor island families continue through WSCSC projects and evaluation of approaches utilized.

Neurotrauma Supports, in DOH/Developmental Disabilities Division, addresses needs of brain-injured persons and their families. CSHNB is a member of the State Traumatic Brain Injury Advisory Board.

Family Health Services Division (FHSD) coordinates the Fetal Alcohol Spectrum Disorder (FASD) Task Force for development of a comprehensive statewide system for prevention, identification, surveillance, and treatment of FASD. Training is provided for community providers and programs.

CSHNP participates on the multidisciplinary team for the Kapiolani Medical Center's Cleft and Craniofacial Center by providing service coordination for families to identify needs/resources, providing referrals to community programs, and accessing specialized dental/orthodontic treatment services. Team members include craniofacial surgeon, neonatologist/pediatrician, geneticist, genetic counselor, audiologist, speech therapist, pediatric dentist, oral surgeon, orthodontist, and other specialists.

CSHNP Audiologist is a member of Senator Suzanne Chun Oakland's Deaf and Blind Task Force. A bill was introduced to mandate insurance companies to cover hearing aid purchases but did not pass.

CSHNP leads the Vision Screening Task Force that is setting statewide vision screening protocols. Team members include DOH, DOE, doctors and community organizations. CSHNP partners with community organizations like the Hawaii Lions Foundation to help uninsured/underinsured children get access to hearing/vision services, and with Special Olympics Hawaii and Developmental Disabilities Division to ensure that Summer Games athletes have access to medical care.

CSHNP Social Worker participates in the Hiilei Program. Children age 0-5 who do not qualify for EI services are periodically monitored using the Ages and Stages Questionnaire.

The issues of early childhood development/screening and transition to adult health care were selected as state Title V priorities. Two Title V Workgroups focus on system-building to develop resources, provide information, and incorporate the issues in state planning and policy initiatives.

Ho'opa'a Project—Hawaii Autism Spectrum Disorder (ASD) State Implementation Grant is a collaboration of **Hawaii** Pediatric Association Research and Education Foundation with Hilopa'a, Family Voices of Hawaii, DOH/CSHNB, AAP-Hawaii Chapter, and UH Department of Pediatrics/MCH Leadership Education in Neurodevelopmental and Related Disabilities (LEND) (Sept. 2010-Aug. 2013). Project activities focus on improving/strengthening the system of care for children/youth with ASD and other developmental disabilities in areas of family support, medical home, autism screening, insurance coverage, and information/training on evidence-based practices, community resources, and transition.

With the Hawaii District Office FHSD Coordinator, CSHNP expanded access to pediatric cardiology clinic services in West Hawaii, by transitioning the CSHNP cardiac clinic (limited access) to a community health center with wider community access, supported in part by health insurance. This helped increase access to specialty care and related services.

NPM 6: The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

SPM 9: The percentage of youth with special health care needs, 12-17 years of age who received all needed anticipatory guidance for transition to adult health care.

The foundation for transition begins in early childhood. The DOH CSHNB EIS instills the importance of transition planning and support for children with developmental delays from the initial meeting. Data from the National Survey of CSHCN 2009/2010 show that 37.3% of Hawaii CSHN received transition services compared to 40% nationally. The National Survey also indicated that 34.5% of YSHCN, 12-17 years of age who received anticipatory guidance for transition to adult health care compared to 31.6% nationally. Hawaii selected a measure that best reflects the current focus of program efforts to improve transition services.

CSHNB staff continued to offer outreach services including transition information to medically eligible SSI applicants 16 years old and younger, and other families. CSHNB Chief presented on the needs of YSHCN/families to physicians involved in designing adolescent health strategies for Hawaii Medical Services Association (HMSA).

Title V Transition Workgroup and a Hilopa`a parent participated in the joint Family Voices and National Initiative for Children's Healthcare Quality webinar, "The ABC's of QI". These interactive sessions explained some of the art and science behind QI using PDSA-Plan, Do, Study, Act cycle steps.

Homework included identifying an aim statement and measurements, doing small scale testing, and studying the results. PDSA tools will be used in future planning efforts.

The Title V Transition Workgroup developed an eye-appealing 'Footsteps to Transition' handout. Based on the Hilopa`a Transition Workbook, this one-pager identifies key transition activities for families and/or providers. It is an educational tool shared as part of client services and at public events and presentations. An additional handout, "The Student Disability Services in Higher Education" was developed by the workgroup listing of university, community college, and adult education program contact information. The handout is updated regularly. These tools may be used with the general adolescent population, with some modification.

Following Maui's Big MAC Transition Fair's footsteps, the islands of Kauai, Oahu, and Hawaii hosted similar events for youth and their families. Presentations were conducted by local and national experts, youth panel speakers and agency/program exhibits to help youth and families access transition services. All families received a Hilopa`a Transition Workbook and Personal Health Record (PHR).

The events are conducted in partnership with the DOE, Title V, Hilopa`a F2FIC, the Arc, Special Parent Information Network (SPIN), the Children's Community Councils, DOH Developmental Disabilities Division (DDD), Department of Health and Human Services Vocational Rehabilitation program, Disability and Communication Access Board (DCAB) and other agencies. The DOE have become strong supporters of the events providing the venue, security, and staffing as well as promoting the fairs to DOE staff and YSHCN.

Building on the success of the school health fairs, Kauai CSHNP received a \$2500 Hawaii State Rural Health Association grant for a series of Transition to Adulthood education sessions targeting 16-17 year old special need youth, their parents/caregiver, and service providers. The sessions were held in the evenings to accommodate parents/caregivers. Dinner was provided. Over the six sessions participants were provided information on:

- medical health care needs such as establishing a medical home, other specialist providers and obtaining medical insurance to enable YSHN to be more empowered about their own health care, and
- post high school preparation (alternatives such as college, trade school or vocation training, employment, programs that supportive services, living independent) to promote greater independence.

Thirteen families and 18 YSHCN participated. Evaluations indicate the sessions were very helpful for the families and youth as well as the 12 agencies represented. Plans are being developed to offer future sessions.

CSHNP participates in the annual SPIN Conference, sharing information about transition planning and services.

Roughly, 500 families attend this major event. This interactive display includes a "Wheel of Fortune", spin the wheel game comprised of transition topics/questions that family/youth "contestants" have to answer. Small prizes given.

CSHNP staff worked with the Kona Kardiak Kids support group on the island of Hawaii to educate them about transition planning. The group arranged for older peers experienced with transition challenges to work with younger group members for mentoring and support. Neighbor island CSHNP staff in Hilo also integrated transition information and resources for families as part of their "Malama Da Mind" fair. Malama means to protect/care for in Hawaiian.

