STATE OF HAWAIʻI
DEPARTMENT OF HEALTH

Children with Special Health Needs Branch

2025-2030 Strategic Plan

PĀ'ANA KA LĀ NO NĀ KEIKI
SUNSHINE FOR CHILDREN

07/15/25

EXECUTIVE SUMMARY

The Hawai‘i State Department of Health (DOH) Children with Special Health Needs Branch (CSHNB) 2025-2030 Strategic Plan outlines a comprehensive, coordinated approach to improving services and support for Children and Youth with Special Health Care Needs (CYSHCN) across the state. This plan aligns with national frameworks, including the Blueprint for Change, and focuses on ensuring equitable access, high-quality care, and a sustainable support system for families and service providers. However, this plan relies heavily on the coordination and support of a vast array of partners working across the state more efficiently to utilize the resources within the state effectively. This strategic plan outlines how the CSHNB will work toward achieving its goals over the next five years.

Vision and Mission

The vision of the DOH is to ensure that all Hawai‘i residents have a fair and just opportunity to achieve optimal health and well-being. The CSHNB builds upon this vision by emphasizing family-centered, culturally competent, and community-based care for CYSHCN, ensuring that they thrive from childhood through adulthood.

Strategic Priorities

The strategic plan is organized around five key priorities, all centered on enhancing services and support for CYSHCN and their families utilizing a systems-based approach:

- **Engagement** – Engage at three levels to improve the experience of CYSHCN and their families, while ensuring they receive necessary care and making full use of available resources.
- **Workforce** – Build and sustain a workforce that is adequately staffed and equipped to meet the unique needs of CYSHCN and their families. This includes recognizing the importance of workforce retention and supporting professional development, quality of care and services, as well as employee well-being and safety.
- **Data Systems** – Collect, protect, and analyze data in a thoughtful and ethical manner, engaging multidisciplinary teams to ensure inclusive dialogue. Use these insights to guide decisions that impact the services, resources, and functions supporting CYSHCN, their families, and those who work in the system.
- **Financing** – Explore and optimize existing and potential funding sources to ensure the system has the financial capacity to deliver high-quality care, services, and resources that enable CYSHCN and their families to thrive within their home communities.
- **Policy** – Inform and shape policies, structures, and mechanisms that support CYSHCN across the state. Engage all relevant stakeholders and apply the best available evidence to create an environment in which CYSHCN and their families can thrive.

Approach and Implementation

The Strategic Plan is designed to support and promote a coordinated, family-centered, and sustainable system of care for CYSHCN. This approach is informed by national best practices, including the Blueprint for Change Framework, and incorporates key public health principles, data-driven decision-making, and community engagement.

The Blueprint for Change, developed by the Health Resources and Services Administration (HRSA) and the American Academy of Pediatrics (AAP), serves as the foundational model for this strategic plan. This framework envisions a system in which CYSHCN thrive across their lifespan and have access to comprehensive, high-quality, and equitable services. The strategic plan aligns with the four core interdependent domains of the Blueprint – Family and Child Well-being & Quality of Life; Access to Services; Financing of Services; and Health Equity.

The plan aims to support all children with special health needs, but a particular focus on underserved and high-risk populations, including blind; deaf/hard of hearing; children with medical complexity or disability; Native Hawaiian children; immigrant/migrant families; and those who self-identify as gender non-conforming or non-heterosexual.

The CSHNB will optimize existing programs, including Newborn Screening, Early Intervention, and Children and Youth with Special Health Needs services, while also implementing new strategies to address emerging needs. This includes expanding those services among populations not aware by enhancing community outreach, strengthening

relationships in the communities, and being more present. We have heard from our families that this is the most significant value in the service we provide, which is the human connection to the families we serve.

To ensure the success of this strategic plan, the CSHNB will integrate a multilevel approach that incorporates data-driven insights, workforce capacity-building, policy advocacy, and partner engagement. Strategic objectives under each of the five strategic priorities help to provide further clarity on a number of themes the CSHNB will undertake, which include:

- **Community and Family Engagement** – Actively incorporating families and individuals with lived experience into program planning, evaluation, and policy discussions.
- **Multidisciplinary Collaboration** – Strengthening partnerships among healthcare providers, state agencies, community organizations, and advocacy groups to enhance service integration.
- **Workforce Development** – Investing in training, recruitment, and retention strategies to ensure that Hawai‘i has a well-equipped workforce capable of addressing the unique needs of CYSHCN.
- **Data-Driven Decision-Making** – Enhancing data collection and analysis to track service utilization, identify gaps, and ensure continuous quality improvement (CQI) in programming, services, and needs of CYSHCN.
- **Legislative and Policy Support** – Collaborating with policymakers and advocates to support resources or guidance for funding, service expansion, and regulatory changes that benefit CYSHCN and their families.

By prioritizing equitable, high-quality, and coordinated care, support and services, this strategic plan works to ensure that all CYSHCN in Hawai‘i receive the comprehensive support needed to thrive. Its success depends on ongoing collaboration among families, healthcare providers, policymakers, and community organizations, fostering a shared commitment to the well-being of the most vulnerable children in Hawai‘i and their families. Through the implementation of these strategies and alignment with the Blueprint for Change, the CSHNB aims to create a more resilient, equitable, and effective system that empowers all CYSHCN and their families to achieve optimal health and well-being from childhood to adulthood.

Table of Contents

Abbreviations

Acronym	Definition
AAP	American Academy of Pediatrics
ABA	Applied behavior analysis
AIMHI	Association for Infant Mental Health Hawai‘i
APRN	Advanced Practice Registered Nurse
ASQ	Ages and stages questionnaire
BDSP	Birth Defects Surveillance Program
BFC	Blueprint for Change Framework
CAMHD	Children and Adolescent Mental Health Division
CBO	Community-based organization
CDC	Centers for Disease Control and Prevention
CDS	Center on Disability Studies
CJC	Hawai‘i Children’s Justice Centers
CSHNB	Children with Special Health Needs Branch
CQI	Continuous quality improvement
CTE	Career and Technical Education
CYP	Child & Youth Professional
CYSHCN	Children and youth with special health care needs
CYSHN	Children and youth with special health needs
CYSHNS	Children and youth with special health needs section
DCAB	Disability and Communication Access Board
DDC	Developmental Disability Council
DDD	Developmental Disabilities Division
DEI	Diversity, Equity and Inclusion
DHH	Deaf and hard of hearing
DHO	District Health Office
DHRD	Department of Human Resources Development
DHS	Department of Human Services
DOE	Department of education
DOH	Department of health
DVR	Division of Vocational Rehabilitation
DSCSHN	Division of services for children with special health needs
EI	Early intervention
EIS	Early intervention services
EPSDT	Early and Periodic Screening, Diagnostic, and Treatment
FHSD	Family Health Services Division
FNP	Family Nurse Practitioner
FQHC	Federally qualified health center
HAAP	Hawai‘i Chapter – American Academy of Pediatrics
HAFP	Hawai‘i Academy of Family Physicians
HCAN	Hawai‘i Children’s Action Network
HCIR	Hawai‘i Coalition for Immigrant Rights
HCG	Hawai‘i Community Genetics Clinic
HCRC	Hawai‘i Civil Rights Commission
HEICC	Hawai‘i Early Intervention Coordinating Council
HEIDS	Hawai‘i Early Intervention Data System
HMSA	Hawai‘i Medical Services Association
HPH	Hawai‘i Pacific Health
HPHA	Hawai‘i Public Housing Authority
HRO	Human Resources Office
HRSA	Human Resource Services Administration
HUD	Housing and urban development
IDD	Intellectual and developmental disability
IDEA	Individuals with Disabilities Education Act
IFSP	Individualized family service plan
IT	Information technology
JABSOM	John A Burns School of Medicine

KMC CMC	Kapiʻolani Medical Center Children with Medical Complexity Clinic
LAUNCH	Linking Actions for Unmet Needs in Children's Health
LDAH	Leadership in Disabilities & Achievement Hawaiʻi
NHSP	Newborn Hearing Screening Program
NMSP	Newborn metabolic screening program
NSCH	National Survey for Child Health
OLA	Office of Language Access
OWR	Office of Wellness and Resilience
PA	Physician Assistant
PCP	Primary care provider(s)
PDSA	"Plan-do-study-act"
PMHCA	Pediatric Mental Health Care Access grant
PMHNP	Pediatric mental health nurse practitioner
PNP	Pediatric Nurse Practitioner
Pre-K	Pre-Kindergarten
PREL	Pacific Resources for Education and Learning
RLI	Residential lead inspection
SDH	Social determinants of health
SSI	Social Security Insurance
TANF	Temporary assistance for needy families
TCS	Tata Consulting Services
UH	University of Hawaiʻi
WIC	Women, infant and children – special supplemental nutrition program
WHO	World Health Organization
YMCA	Youth Men's Christian Association

Purpose

The Hawai‘i State Department of Health’s (DOH) Children with Special Health Needs Branch (CSHNB) has two major goals:

(1) Ensuring all children and youth with special health care needs (CYSHCN), including young children with developmental delays, receive appropriate services to optimize health, growth, and development.
(2) Improving access to quality health care by developing a comprehensive, coordinated community-based system of care that is patient- and family-centered and culturally competent.

In collaboration with partners and families, the CSHNB developed a strategic plan to guide existing programs in better supporting the needs of CYSHCN across the state. The plan outlines five strategic priorities that the CSHNB, together with partners and families, will pursue to improve care, resources, and support for CYSHCN, their families, and caregivers.

Audience

This strategic plan is meant to help guide staff, providers, and contracted staff and agencies under the CSHNB to work in a more coordinated, cohesive, and comprehensive fashion to meet the needs of the community.

This plan is also important for partners who work to serve the CYSHCN population in the state as well, including healthcare providers, health systems, insurers, community programs, and advocacy groups. This aims to better coordinate the current resources for families to access, as well as provide information on additional resources needed to meet the need of the CYSHCN community.

Lastly, this plan is also meant to be a tool to support transparency with the broad CYSHCN community across the state to be aware of what the CSHNB intends to do during the next five-year period to support children and families. Continuous engagement will include public updates on progress, new developments, and any adjustments made in response to shifting public needs. It will also prioritize feedback from families and individuals with lived experience to ensure their voices guide the work of the CSHNB.

DOH Vision and Mission with consideration to CYSHCN

The Hawai‘i State DOH has defined its vision, mission, and values, which help further guide the work of the CSHNB as a part of the department.

Vision

The vision of the DOH is that all Hawai‘i residents have a fair and just opportunity to achieve optimal health and well-being. For the CSHNB, this vision is focused specifically on CYSHCN, who are children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally and their families.

Nationally, the Human Resource Services Administration (HRSA), under Title V Maternal and Child Health Block Grant, has helped to bring further clarity to the vision of supporting CYSHCN. The ‘Blueprint for Change’ is a framework meant to provide some guidance on the system of services for CYSHCN. This framework will be further explored, but its vision sets forth to “[build] a system in which CYSHCN enjoy a full life, from childhood to adulthood, and thrive in systems that support their families and their social, health, and emotional needs and ensure dignity, autonomy, independence, and active participation in their community.” These visions provide CSHNB with a clear direction in which to set our goals and aspirations for the present and future.

Mission

The mission for the DOH is to protect and promote the physical, psychological, and environment health of the people of Hawai’i through assessment, policy development, and assurance. For the CSHNB, this mission is central to the

services and resources children need in order to optimize their health conditions and general well-being so that they may thrive in their respective lives. This mission also clearly outlines three key tasks that guide CSHNB to: (1) assess the needs of the community statewide and determine how to address those needs; (2) work with experts, partners, communities, and legislature—when and where appropriate—to define or inform on guidance, policy, or law to help protect and respond to the public health need and well-being for CYSHCN; and (3) ensure not only by monitoring for conditions and health needs, but also by supporting families in navigating the services and resources they need while providing continuous engagement with families to ensure those needs are being met.

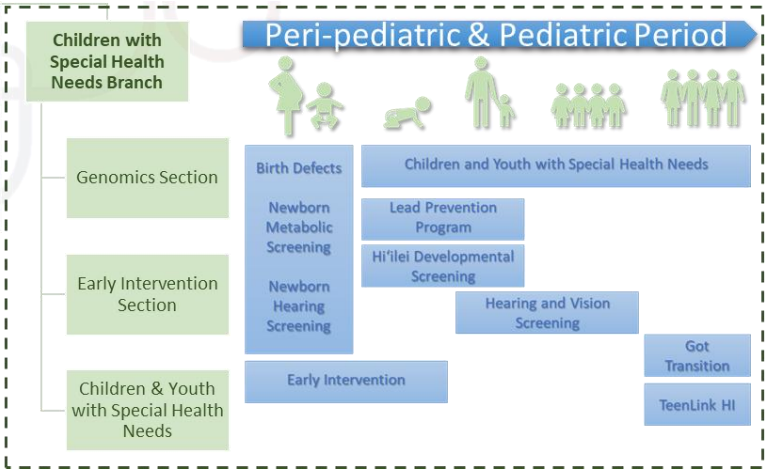
Values

The DOH grounds itself with the following values:

- ✓ Integrity: Do the right thing, even when no one else will know
- ✓ Stewardship: Responsibility for current and future resources
- ✓ Science: Pursue evidence-based practice and policy
- ✓ Curiosity: Seek to understand why, how, and what
- ✓ Innovation: If you're not failing, you're not trying hard enough
- ✓ Communication: Share information, disagree without being disagreeable

To uphold these values, DOH prioritizes caring for its workforce; being a trusted source of information; improving efficiency and effectiveness; pursuing fair and just opportunities for all to achieve optimal health and well-being; improving client/family experiences; and generating interest in public health careers. These values are also reflected in the work and operation of the CSHNB, striving to not only meet the needs of the CYSHCN population in today's world, but also preparing to build systems to be more robust for the future challenges yet to be encountered.

Introduction



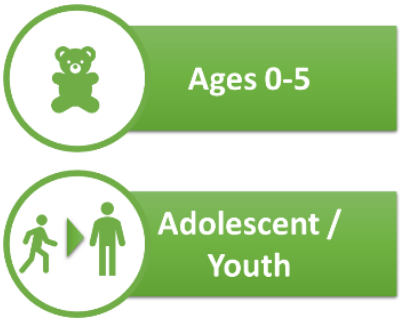
To achieve the goals mentioned at the start, CSHNB has three sections that aim to provide support to children and families along the continuum of the peri-pediatric life span from fetal development to young adulthood. The three sections that comprise the branch include the Genomics Section (which includes the Hawai'i Birth Defects Program, the Newborn Hearing Screening Program, and the Newborn Metabolic Screening Program); Early Intervention Section (EIS) (which includes all Individuals with Disabilities Education Act [IDEA] Part C required services, including the initial evaluation and assessments for services, as well as transition support to IDEA Part B under the Department of Education [DOE]); and Children and Youth with Special Health Needs Section (CYSHNS) (which includes the Hawai'i Childhood Lead Poisoning Prevention Program, the Hi`ilei Developmental Screening program, neighbor island clinics [i.e., cardiac and nutrition], the Hearing and Vision Screening Program, the Early Childhood Program [including infant and early childhood mental health and the Project LAUNCH grant], CYSHCN Specialty Support Program, and transition to adult health care).

Special Populations

CSHNB services provide crucial support to CYSHCN. However, there is a gap between the number of potential children who meet the definition for CYSHCN (about 20% of children under 18 years old[1]) versus those receiving direct services from CSHNB programs.

[1] National Survey of Children's Health (NSCH). Accessed on 12/10/24 from

Although some of CSHNB programs do intend to reach all children (such as the newborn screening programs), others are specific for CYSHCN, which include support for children with medical complexity who require special attention given their unique needs. For this reason, the CSHNB has identified subgroups within the Hawai'i CYSHCN population that will require additional effort to support health equity. These populations are those who are: (1) deaf or hard of hearing; (2) blind; (3) have medical complexity[2] or disability[3]; (4) Native Hawaiian; (5) those for whom spoken English is not their primary language; (6) immigrants, migrants, or non-citizens; and (7) those who are gender non-conforming or non-heteronormative identifying. These seven subgroups are uniquely challenged by the social determinants of health (SDH) and structural impact to their quality of life, health, and well-being, posing health equity challenges in terms of available resources and access to services. Socioeconomic status, poverty, housing insecure, and limited education are other factors that all reflect challenges with respect to the SDH as well. There will need to be proactive efforts from the CSHNB and partners to not only assess health disparities among these groups, but also identify the unique challenges they may face in navigating the existing resources and services in the state, as well as those that should be sought to address ongoing needs among these groups.



Further, there are two age-bands that also merit special attention. First, **the birth to 5-years age-band**, which forms the core of the CSHNB services, is important to ensure that all due screenings, services, and resources are being provided. These years are critical for building and securing an optimal foundation for the growth and development of the child and will therefore have some of the most dramatic implications on that child's life path. Early recognition and support are the best ways of helping that child thrive and manage their needs, as well as those of the family and caretakers. The second group consists of **adolescents and youth transitioning from pediatric to adult care**. This is an important transition for all youth under the care of a pediatrician or pediatric specialist, as they establish care with an adult primary care provider and specialist, respectively. This transition is important in maintaining the care of the individual as they age and ensuring they continue to thrive into adulthood. The CSHNB aims to focus attention on CYSHCN who have unique challenges and needs during this vulnerable transition, but the Branch will also continue to support public information efforts so that all youth in the state are ready for this transition and are informed and prepared health care system utilizers.

The CSHNB will work with the available resources, partners, and mechanisms to align services with those that need them. Some programs and services do have criteria that limit access based on factors such as income level. However, it is important for the public to know that the **services provided by the CSHNB are largely not income-**

[2] "…children with medical complexity (CMC), [are] a subset of children and youth with special health care needs (CYSHCN), have multiple significant chronic health problems, functional limitations, high health care and resource need and/or utilization. They may need medical technological devices to improve or sustain life and daily function." (AAP Children with Medical Complexity Overview, accessed from https://www.aap.org/en/patient-care/children-with-medical-complexity/ on 12/10/24)

[3] "The term "child with a disability" means an individual who— (A) has a significant physical or mental impairment, as defined pursuant to State policy to the extent that such policy is established without regard to type of disability; or (B) is an infant or a young child from birth through age 8 and has a substantial developmental delay or specific congenital or acquired condition that presents a high probability of resulting in a disability if services are not provided to the infant or child." 42 U.S.C. § 15092(a)(1) (Developmental Disabilities Assistance and Bill of Rights Act 42 U.S.C. § 15001 et seq.)

dependent nor require proof of citizenship. Where appropriate, we will make referrals and connections with partners who have capacity and means to support children and families that meet their respective eligibility criteria and focus, while also attempting to assist those who may not have other options available.

The Approach to the Strategic Plan

The following sections will describe the three core elements of this strategy, which inform its development, conceptual understanding, and implementation for the CSHNB, as well as highlight our work with other partners and families supporting the needs of CYSHCN across the state.

Blueprint for Change

The Blueprint for Change is "a national framework for a system of services for CYSHCN where they enjoy a full life and thrive in their community from childhood through adulthood."[4] This framework is led in partnership between the Health Resource Services Administration, Division of Services for Children with Special Health Needs (DSCSHN) and the American Academy of Pediatrics. Journal articles detailing the Blueprint were published in a supplemental publication of the Journal of Pediatrics, June 2022. DSCSHN worked with a broad range of partners (including families, consumers, health care professionals, public health leaders, researchers, and academic institutions) over a two-year period to realize this framework.

The four domains of the framework include quality of life and well-being, access to services, financing of services, and health equity. These are interdependent domains, which means that the influence of any one domain will invariably impact the other domains. That said, it is important to clearly define each domain.

Family and Child Well-Being and Quality of Life

The sentiment of this domain is that the "service system prioritizes quality of life, well-being, and supports flourishing for CYSHCN and their families." This is supported by families having access to high-quality, affordable, community-based services that support medical, behavioral, social, and emotional well-being of the child, youth, and family. The health system should also place value on measurement, using child and family well-being and quality of life outcomes and health outcomes to assess and ensure improvement.

Access to Services

Access to services refers to the availability of services in a timely manner that are "integrated, high-quality health care and supports" to meet the needs of CYSHCN and their families. This broadly includes all services (including promotion, prevention, care/treatment, rehabilitation, and palliation) and support, which should be easy for families and providers to navigate when, where, and how they need them. Achieving this will require a trained and capable workforce, that is also culturally competent, to meet the needs of children, families, and communities. Systems

[4] AAP. About the Blueprint for Change and the National Center: What is the Blueprint for Change? Accessed on 12/10/24.

improvements must also be made to increase access by addressing administrative hurdles that hinder access to services, support, or resources.

Financing of Services

Financing for services can be a significant obstacle, particularly for low-income, or even middle-income, families whose funds are stretched further due to competing expenses. This domain aims to account for "health care and other related services [being] accessible, affordable, comprehensive, and continuous," prioritizing the well-being of CYSHCN and their families. This requires health care and related services to be financed and paid for in ways that support and maximize an individual's values and choice to address health needs. Making health and social service investment to address the SDH can be beneficial to impact well-being of the child and the family. Additional systemic improvements may include adopting value-based payment strategies[5] to support families, advance equity, and incorporate continuous quality improvement (CQI) by enhancing team-based integrated care. Much of this work will require close collaboration with health insurers, as well as the health systems that provide that care, and groups with financial and personal interest.

Health Equity

"All CYSHCN have a fair and just opportunity to be as healthy as possible and thrive throughout their lives (e.g., from school to the workforce), without discrimination, and regardless of the circumstances in which they were born or live." By addressing the structural and systemic causal barriers to health equity—such as discrimination, poverty and other social risk factors—children, youth, and families can be better supported in optimizing their respective quality of life and well-being, providing them with the best opportunity to thrive. This will require systems and programs to monitor, fund, and deliver services and support to reduce the health disparities and improve health outcomes for all, while tailoring approaches for those most disadvantaged by the current system.

Continuous Quality Improvement

There was a World Health Organization (WHO) publication that looked at various definitions for continuous quality improvement (CQI), which can be summarized as "continuous study and improvement of the processes of providing health care services to always better meet the needs of patients and other persons."[6] This will require a means to measure and identify patterns in the system; analyze those patterns to identify opportunities for improvement; and action to improve the quality of services and care provided for children and families. A practical tool that can aid in programs actualizing CQI is the "plan-do-study-act" model. Specifically, the development of an operational plan should be informed by the current status and needs known by the programs. The programs should then make necessary adjustments to respond to those needs. Programs should monitor and study the progress following modification or improvement. Lastly, there should be further action or refinement based on data, feedback, and outcomes to further make improvement to programs and the system at large. This shall be a continuous and ongoing process to meet or exceed expectations of current times and support accountability to families utilizing services.

Multidisciplinary approaches to team participation are important because the systems our programs work within are complex and often rely on collaboration among multiple partners to successfully meet the needs of children and their families. For this reason, it is essential that programs and teams maintain active partnerships with other departments, agencies, programs, and organizations—as well as that with families and people with lived experience—to a degree that all vested parties feel ownership and recognize their contribution towards the improvement to the system. Although multidisciplinary teams are encouraged, when and how different partners are brought in should be

[5] Note: Value-based design refers to the V-BID approach which structures health insurance in a way that incentivizes and drives patients and providers toward the most valuable services—those showing the most benefit relative to costs. Source: https://www.cdc.gov/nccdphp/dch/pdfs/value_based_ins_design.pdf

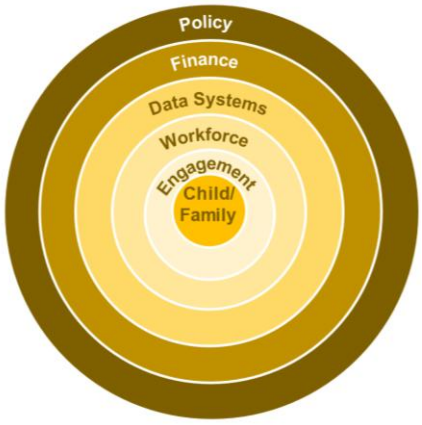
[6] WHO. (2018). Improving the quality of health services" tools and resources. Accessed on 12/2/2024.

thoughtfully considered to minimize service disruption, maintain productivity, and respect the time and effort of each vested party.

The "Plan-do-study-act (PDSA) Tool" from The National Implementation Research Network's Active Implementation Hub, University of North Carolina at Chapel Hill's FPG Child Development Institute (2017)[7] is available for team incorporation.

Strategic Priorities

The analysis of the input from staff, partners and families yielded the development of five strategic priories that organize the strategic objectives outlined in this five-year plan. These priorities are not only a way to organize the strategies outlined here, but also provide a conceptual model to understand the interdependent nature of this systemic approach to strengthening the CSHNB work for CYSHCN and their families. The five priorities broadly include the following areas: policy, finance, data systems, workforce and, engagement—all with the child and family at the center. It is important to start with the child and the family/caregiver. This nucleus is the center and represented as one because of the dependency of the child with the parents or caretakers. The survival and development of the child is inextricably tied to this unit—so it is important for CSHNB programs and partners to remember and consider what needs the family may have that will impact the health and well-being of the child. Focusing solely on the child may ignore and perpetually expose the child to additional external harm that may be due to indirect circumstances experienced through the family. A clear example is poverty or housing insecurity, which may limit the opportunities of addressing the child's basic needs. Recognizing these factors may present opportunities to more fully appreciate and identify the benefits and resources that can address the social and environmental determinants of health that impact child health and well-being.



1. Engagement: Engage at three levels to improve the experience of CYSHCN and their families, while ensuring they receive necessary care and making full use of available resources.

Engagement here should be seen with a broad understanding to include those with and among health and social service providers (including both governmental and nongovernmental), private industry, religious groups, community organizations, as well as families and people with lived experience. This broad engagement is essential to optimizing service delivery and ensuring responsiveness. With adequate communication and bidirectional partnership, trust can strengthen between the system and the people that interact with that system. This will require broad inclusion of the workforce in this venture as well as those who depend on that workforce. The first layer at the core is the peer-to-peer connection between children, families, people with lived experience, and advocates who share that experience as a community. The second layer includes the encounter of the service or care provided to children and their family from both clinical care providers, such as the primary care provider, specialist, or therapist, as much as with case managers, care coordinators, and specialists for social support services. This is also where families or people with lived experience can contribute to provider understanding and support opportunities for feedback on the care and services provided for future improvement. Engagement should also include families and people with lived experience, placing them in a position to understand the data on how the system is performing and enabling their voice to contribute to addressing challenges—including at the policy and finance levels. The third layer of engagement focuses on how well the various service and care providers engage with each other—how referrals are transmitted and feedback shared for follow-up or peer knowledge growth and professional development. This can also inform providers about resources available that may facilitate recognized services from one agency to another, ensuring

[7] https://cdn.who.int/media/docs/default-source/reproductive-health/contraception-family-planning/plan-do-study-act-tool.pdf

families receive all necessary services. All three types of engagement require purposeful and mindful communication, knowledge, and respect.

Engagement

3) Provider/Servicer - Provider/Servicer
2) Family – Provider/Servicer
(care/service provision; contribution/feedback)
1) Family/Peer – Family/Peer

2. Workforce: Build and sustain a workforce that is adequately staffed and equipped to meet the unique needs of CYSHCN and their families. This includes recognizing the importance of workforce retention and supporting professional development, quality of care and services, as well as employee well-being and safety.

The workforce includes a wide range of professionals—from primary care providers and specialists to social workers, therapists, and public health staff—who are appropriately trained to meet the unique needs of CYSHCN. A strong workforce is diverse, knowledgeable about local resources, and able to deliver respectful, timely care and support to CYSHCN and their families. This will require confronting the barriers to ensuring an adequate number of personnel available across the state where and when appropriate, as well as maximizing the effectiveness of trained staff to competently provide care and services to CYSHCN and their families. This begins with recruitment and recognition of our academic partners training the future workforce here locally—as well as efforts to attract talent more broadly. Information and data should be available to help providers focus on the needs of this population, monitor its progress, and provide transparency to the public on systemic progress. Equally, there needs to be specific concerted efforts to support this workforce not only in their professional capacity of keeping them up to date with the growing and evolving evidence base in their respective fields, but also fostering their well-being to ensure retention and maintain a valued workforce dedicated to serving CYSHCN and their families.

Workforce

Recruitment/
Hiring and Onboarding
Capacity Building and Support
Quality Improvement / Assurance
Retention and Well-Being

3. Data Systems: Collect, protect, and analyze data in a thoughtful and ethical manner, engaging multidisciplinary teams to ensure inclusive dialogue. Use these insights to guide decisions that impact the services, resources, and functions supporting CYSCHN, their families, and those who work in the system.

This will include the continuum of the data system, starting from the point at which data is being collected, how it is collected, and how it is protected, while balancing the documentation burden on staff. This process must appreciate the value that data has to inform decision-making and assessing progress. The analysis of the data is also important, as this can be used to better understand the needs in the community, evaluate the impact of interventions on the population, and help shape future priorities and improvements. Lastly, the subsequent use of that data to inform programs that support CYSHCN, as well as insurers, health systems and providers, policymakers, and families is important to ensuring accountability and transparency of the system. By informing the public, officials, and programs about how the system is performing and what the apparent needs are in the community, there can be more inclusive contribution, particularly from families and people with lived experience. Collectively, we can respond in a more

informed manner. This will require investments in systems for the CSHNB, as well as continued work to integrate data systems between different agencies and organizations, to have a more holistic understanding of the impact on health and well-being for CYSHCN. Looking at data through a systems lens may also yield identification of potential opportunities to optimize the utilization of services. This data can also help guide efforts to ensure health equity and may inform decisions on how and where funds should be allocated to achieve a population-level impact for families across the state. By better allocating resources, this will also inform health financing strategies and priorities, as well as policy.

4. Financing: Explore and optimize existing and potential funding sources to ensure the system has the financial capacity to deliver high-quality care, services, and resources that enable CYSHCN and their families to thrive within their home communities.

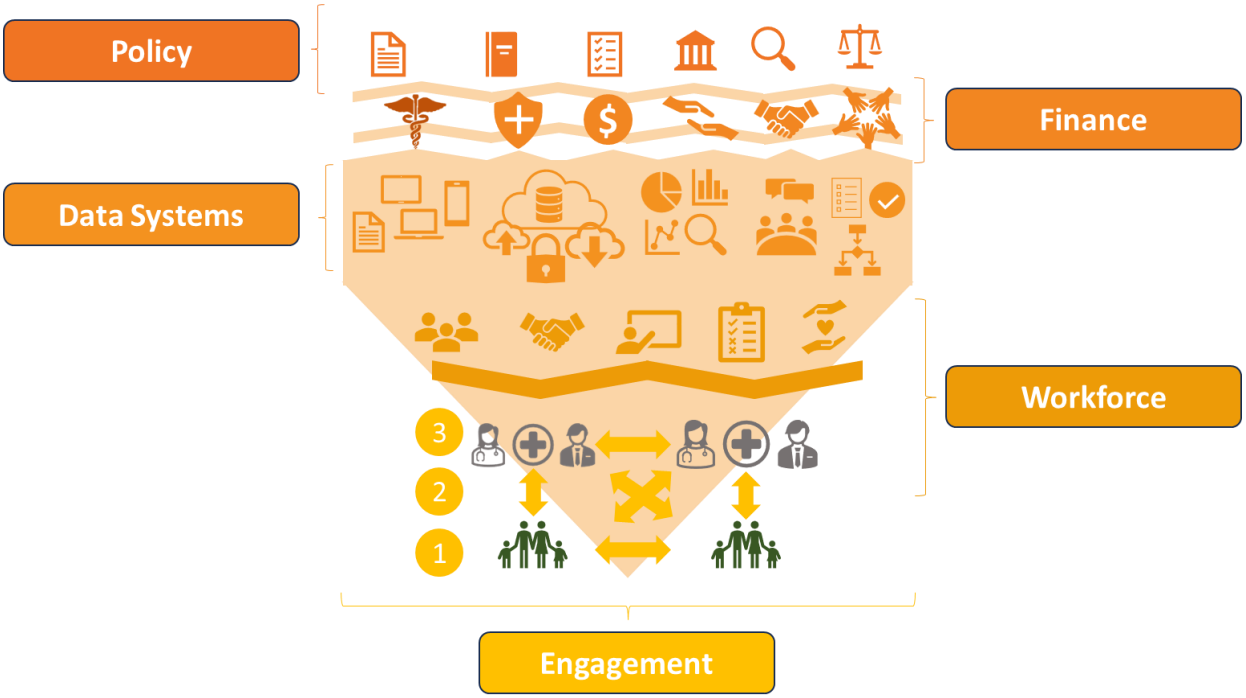
The prior themes will all rely on funding to maintain services and care for CYSHCN and their families. This includes utilization and optimizing the potential for insurance coverage, as well as exploring other funding sources that may provide opportunity to expand scope and breadth of service coverage. This can be done through better engagement with philanthropic or commercial organizations across the state, as well as with charitable or religious organizations with strategic program needs. The point here is to minimize the already additional cost most families encounter in regular day-to-day expenses, which are often higher due to the unique needs of CYSHCN. The nature of CYSHCN conditions necessitate additional resources or accommodations beyond what is typically needed by the general pediatric population. This includes costs for things such as food (e.g., special diets or tube feeds); transportation (e.g., adapted vehicle for assisted devices, travel to Honolulu from the neighbor island for specialist care, etc.); or even performing basic personal activities of daily living (e.g., feeding, toileting, cleaning, activity/mobility exercises, etc.) for the child. These expenses also imply additional cost beyond specialist visits to care providers as well. This financial support for services and care is meant to protect families from financial burden for the care of CYSHCN. Financing models and structures will benefit from some level of guidance, policy, law, or regulation to ensure availability of funds, set expectations for coverage and support, and establish limits on costs, among other things. CSHNB will utilize its available resources and assist families in navigating other agencies that can provide support for these additional expenses.

5. Policy: Inform and shape policies, structures, and mechanisms that support CYSHCN across the state. Engage all relevant stakeholders and apply the best available evidence to create an environment in which CYSHCN and their families thrive.

This overarching theme provides for the structure and expectation, as well as protections, for all the other priorities encapsulated in this conceptual model. This priority encompasses policies, laws, rules, guidelines, regulations, agreements, contracts, and advocacy positions that affect CYSHCN and their families. Much of this will originate from the community, including lawmakers, lobbyists, and other interest groups. The CSHNB will collaborate with legislators to inform developing bills that may be put to a vote for legislative consideration. Resulting statutes that impact CYSHCN will also be supported by the CSHNB in the development of administrative rules, as well as their

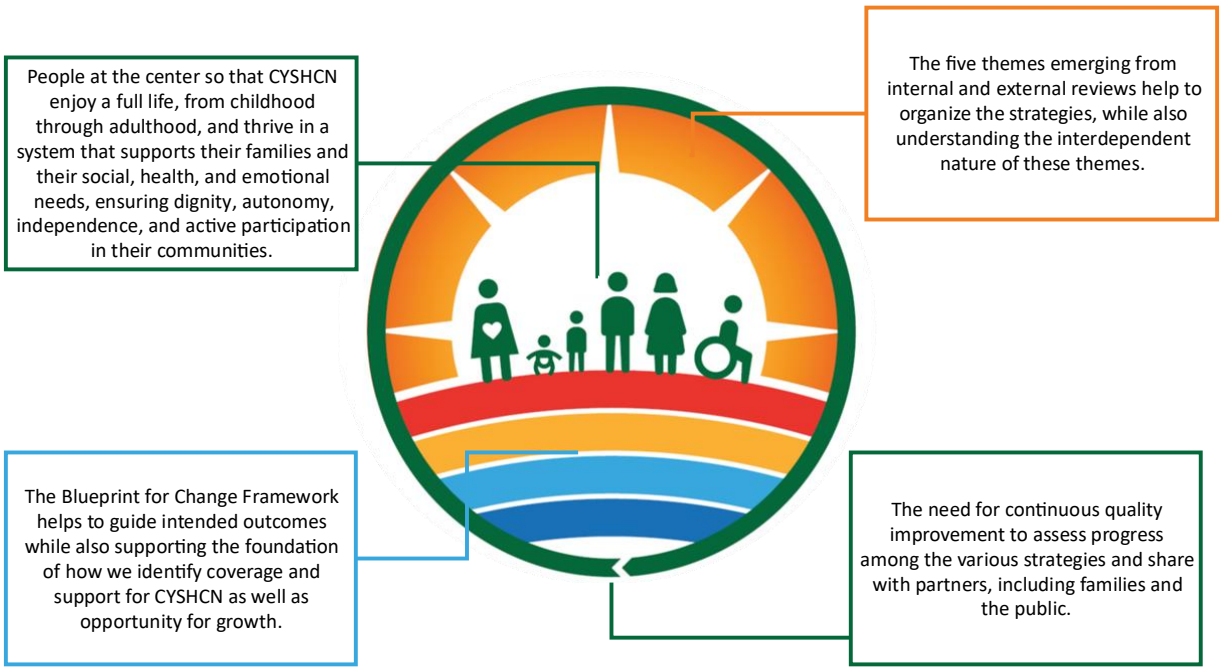
implementation, oversight, or contribution. Our programs also work broadly with the partners who engage with CYSHCN and families through their respective area of service or interest. The CSHNB has the unique opportunity to look holistically across the physical, developmental, behavioral, or emotional conditions, analyzing statewide data in terms of the needs of the community. This includes considering the cost applications—not only of the medical or behavioral health needs, but also the social and environmental needs that impact the well-being of the child and family. For this reason, it is critical for the CSHNB to maintain broad relationships with our partners in the community, as well as other state departments and programs, health systems and providers, insurers, educators, and families, in order to utilize the diverse coalition of vested partners.

Collectively, these strategic priorities provide a wider view of the system, as well as the interactions and interdependent nature of each priority in the system. It is important that family and people with lived experience contribute at all levels, from the care and service provided to thoughts on how providers can improve. Their input is essential in appreciating data and understanding how the system is responding at scale, ensuring accountability for the funds allocated to these services and the policies that impact their children and families. The workforce providing care and services to children and families need to be adequately staffed with qualified professionals who are skilled in engaging with CYSHCN and their families. It is crucial that these professionals have the time they need to provide quality care, are aware of the services available to support these children, and can coordinate effectively among colleagues to ensure comprehensive care. The data from the system can inform how we can improve the workforce effectiveness and efficiency, as well as how we can better support our workforce so that they may be able to work with balance as they support their own personal families and community. Data inherently permeates to all levels, including to inform how to best utilize public funds to support the workforce and services needed for children and families, as well as the policy that drives decisions on programs and initiatives that merit funding or regulations to maintain standards and equity for access to care and services. Finance also requires input from families and people with lived experience to ensure that insurers are aware of their needs and can work with policymakers to better address the needs of CYSHCN and to utilize all available resources. The most distal, yet all-encompassing priority, relates to the policies, laws, rules, guidelines, regulations, agreements, contracts, and advocacy positions that will impact what gets funding and how. These decisions are informed by the data systems and support the workforce that provides the essential care and services that CYSHCN and their families rely on.


Policy
Finance
Data Systems
Workforce
3
2
1
Engagement

Bring it together

The strategic plan incorporated the three frameworks/models noted above into a cohesive plan that organizes the various strategies developed in collaboration with CSHNB staff and partner input, including from families, people with lived experience, and advocates for the CYSHCN community. This is illustrated by the image that captures all three approaches into one symbolic strategy.



This plan is divided into two main sections. The first focuses on existing programs within the CSHNB, presenting strategies aimed at improving or optimizing ongoing or developing work. Each strategy includes clear measures to assess progress, aligns with the BFC to reflect intended outcomes, and connects to the five strategic priorities to show its relevance within the broader framework.

The second section highlights systemic and emerging strategies that extend beyond the CSHNB and require collaboration across the broader system. These strategies are organized by the five strategic priorities and include specific objectives and measurable indicators, similar to the first section.

Strategies: Optimizing existing programs

The strategies that help to support and improve existing programing are organized by the corresponding program/section. Section supervisors will be expected to work with their teams to develop and define operational plans to implement and deliver each respective strategy. Although not always explicitly listed as partners, clients, families, and community members, individuals with lived experience—or their designated representatives—should be engaged in all CSHNB program efforts. At a minimum, feedback should be gathered from those who use services, with documentation of how that input informs improvements or changes to service delivery. When individuals serve in a formal role through an organization or group, they will be identified in the corresponding tables.

Genomics

Birth Defects Surveillance Program

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Improving staffing to enable the program to maintain data collection and surveillance functions.	HRO Cogent	Workforce	Services
Maintain timely abstractions within at least one quarter from current DOH fiscal quarter.	Birthing Facilities	Workforce; Data Systems	Services
Data actively reviewed to assess population trends with quarterly reports to define status and concerns.	Genetics consultant Birthing Facilities Hawai‘i Genetics Counseling	Engagement; Data Systems	Service
Define opportunities for active case surveillance analysis to define associations and instigating factors to population findings.	Funders Legislature Research / Academic Institutions (Iowa University)	Finance; Data Systems	Service
Quarterly data review to assess program trends to respond to pending public health concerns (including, but not limited to, total monthly abstractions completed, birth defects trend data and cross-variable analysis using potential risk data collected, etc.).	Genetics consultant Research / Academic Institutions (Iowa University)	Data Systems	Service
Identifying funding opportunities to optimize the infrastructure or function of the BDSP to better identify potential public health concerns leading to preventable birth defects.	Federal Grantors Philanthropic enterprises/agencies	Finance	Finance
Improving public awareness of concerning trends of birth defects across the state for better prevention.	Community Partners	Engagement	Service

Newborn Hearing Screening Program

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Enhance recruitment and retention to enable a fully staffed program to monitor and support newborn hearing screening to comply with 1-3-6 approach.	Birthing Facilities PCP/Midwives Audiologists Community Partners Early Intervention Programs	Workforce	Services
Identify case clusters where screening is not achieved to close the gap, with the goal being to screen all newborns by 1 month of age.	Birthing Facilities PCP/Midwives Audiologists Community Partners	Engagement; Workforce	Services; Equity
Identify case clusters where diagnostic evaluation is not completed to close the gap, with the goal being to diagnose all newborns by 3 months of age.	PCP/Midwives Audiologists Community Partners Early Intervention Programs	Engagement; Workforce	Services; Equity
Identify case clusters where referral and enrollment into Early Intervention is not achieved to close the gap, with the goal being to refer and enroll all babies by 6 months of age.	Early Intervention Programs PCP/Midwives Audiologists Community Partners	Engagement; Workforce	Services; Equity
Enhance the language acquisition scores for DHH children by age 3 for school readiness among those who would benefit from DHH services.	Early Intervention Programs Community Partners	Engagement	Services; Equity
Optimize the data system to support monitoring cases referred to EI for children who are DHH to receive appropriate services to achieve language acquisition by age 3.	Early Intervention Programs Salesforce/TCS (HiTrack/Neometrics)	Data Systems	Equity; Quality
Quarterly data review to assess program trends to respond to pending public health concerns (including, but not limited to, progress of 1-3-6 approach, impact of referral and enrollment of cases to EI with respect to language acquisition, etc.).	Advisory Committee (annually?) Hawai‘i P-20	Data Systems	Service
Identifying funding opportunities to optimize the infrastructure or function of the NHSP to better identify potential public health concerns leading to preventable birth defects.	Federal Grantors Philanthropic enterprises/agencies	Finance	Finance
Improving public awareness of concerning trends of newborn hearing screening or needs for DHH children across the state for better support.	Community Partners	Engagement	Service

Newborn Metabolic Screening Program

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Enhance recruitment and retention to enable a full staffed program to monitor and support newborn metabolic screening of all newborns in a timely manner.	HRO Cogent	Workforce	Services
Screening all newborns appropriately using blood spot collection kits in a timely manner.	Birthing Facilities Midwives Washington State Laboratory	Data Systems; Engagement	Service
All positive screens complete additional screen testing with appropriate referrals for diagnostic management.	PCP HPH HCG Washington State Laboratory	Data Systems; Engagement	Service
Optimize the data system to support monitoring cases for follow-up with PCP and specialists, as appropriate, including referral to EI and/or CYSHNS.	Early Intervention Programs Salesforce/TCS (HiTrack/Neometrics)	Data Systems	Equity; Quality
Quarterly data review to assess program trends to respond to pending public health concerns (including, but not limited to, blood spot screens competed, cases followed-up, confirmed diagnosis, appropriate referrals for EIS/CYSHNS, respectively, etc.).	Advisory Committee (Annually?) HPH HCG Washington State Laboratory	Data Systems	Service
Identifying funding opportunities to optimize the infrastructure or function of the NMSP to better identify and support referrals for children found with metabolic or other genetic disorders.	Federal Grantors Philanthropic enterprises/ agencies	Finance	Finance
Improving public awareness of concerning trends of newborn metabolic screening, importance of screening and potential need for additional care as a result of screening to support a thriving child.	Community Partners	Engagement	Service

Early Intervention

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Improving staffing to enable the program to maintain EI services in an efficient and effective manner – particularly for direct services and social work.	HRO Cogent	Workforce	Services
Enhance measures to support staff wellness as a means to strengthen retention and morale among EI staff.	HRO	Workforce	Services
Provide reflective supervision / consultation to optimize staff performance, well-being and promote a supportive work environment.	AIMH-HI	Workforce	Services
Enhance outreach to identify children who would benefit from EI services for evaluation/assessment and enrollment.	PCP Medical Specialist Behavioral and Mental Health Providers	Engagement; Workforce	Service; Equity
Optimize public and private insurance for EI services support providing EI services and supports at no cost to the family.	State/ Federal Legislature Medicaid/Quest Private Insurance	Finance; Policy	Finance; Equity
Optimizing salaries for positions to be competitive through salary study.	HRO	Finance; Policy	Finance
Optimize the data system to support monitoring cases, case management and reporting, as appropriate, including referrals received, particularly from NMSP, NHSP and CYSHNS through the use of digital tools to phase out paper-based forms – including medical records.	Early Intervention Programs Salesforce/TCS (HiTrack/Neometrics)	Data Systems	Equity; Quality
Using family input through surveys, focus groups or other means to improve the family experience with EI services and assure the needs of children and families are appropriately being addressed.	Community Partners Family	Data Systems; Engagement	Quality; Equity
Support family linkage with their medical home and strengthen the coordination of care among the services received by the child and family.	PCP Medical Specialists Therapists / Counselors Support services (social work, case management, DHS, DDC, etc.)	Engagement	Access; Quality
Provide services in the lived environment, which may include intake, observations, or follow-up visits to gain better understanding to context of the child in their family environment.	Client/Family	Engagement	Access, Equity
Quarterly data review to assess program trends to respond to pending public health concerns (including, but not limited to, referrals received, evaluated	N/A	Data Systems	Services

and assessed, cases followed up, conditions/needs of children enrolled, appropriate referrals to CYSHNS, transition planning to DOE, graduating from EI services, etc.).			
Identifying funding opportunities to optimize the infrastructure or function of EI to better identify and support children enrolled in EI services.	Federal Grantors Philanthropic enterprises/agencies	Finance	Finance
Improving public awareness of concerning trends among children referred to EI and the impact of EI services in their development to support a thriving child.	Community Partners PCP Medical Specialist Behavioral and Mental Health Providers	Engagement	Service
Improve information on transitions for CYSHCN moving between Early Intervention to the Department of Education and from pediatric to adult providers.	Health Providers Early Intervention Programs IT developer/designer DOE	Data Systems	Quality; Services

Children and Youth with Special Health Needs: Specialty Support Program

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Improving staffing to enable the program to maintain data collection and surveillance functions.	HRO Cogent	Workforce	Services
Support needs for CYSHCN by providing data, expertise and stories of family to inform proposed bills, guidelines, policies or regulations.	Community Partners Advocacy Groups State Legislature Federal Agencies	Policy; Data Systems	Quality; Equity; Access
Strengthen the utility of central referral and resource systems, such as “No Wrong Door”, among programs to maximize the navigation support for families to access the full range of services available to them (including but not limited to SSI/TANF, Pre-K, etc.).	DHS DOE DDC/IDD DDD Community Partners	Policy; Workforce	Access; Quality
Reinforce neighbor island campaigns, support, and response to meet island specific needs (including Maui wildfire recovery efforts, Kauaʻi homeless care coordination partnership, etc.)	DHO (Kauaʻi, Hawaiʻi, Maui) Community Partners Medical Providers Housing Authority (i.e., Kauaʻi) Philanthropy / Charity	Engagement	Access; Quality; Equity
Support family linkage with their medical home and strengthen the coordination of care among the services received by the child and family.	PCP MCHB Adolescent Health Program Medical Specialists Therapists / Counselors Support services (social work, DHS, DDC, etc.)	Engagement	Access; Quality
Enhance the utilization and contribution of youth in outreach, health promotion, and career path enrichments to support the health needs of youth, with and without special health needs, to include transition from pediatric care to adult health care	TeenLink Hawaiʻi Community Partners Medical Home DOE MCHB Adolescent Health Program Health Plans Youth and family	Engagement	Services; Equity
Support EPSDT to share information across agencies to coordinate capacity building efforts, troubleshooting common interest needs and address changes and modifications to enhance beneficiary experience (including palliative services, etc.).	EPSDT Partners, including DHS/MedQuest; DOH; DOE; Aloha Care; HMSA; Kaiser; ʻohana; United HealthCare	Engagement	Quality; Access
Enhance outreach to better find children who would benefit from CYSHNS services for assessment and enrollment.	PCP Medical Specialist Health Provider Associations	Engagement; Workforce	Service; Equity

	Behavioral and Mental Health Providers Community Partners PHN Other State programs/departments: CAMHD, DDD, DOE,		
Optimize the data system to support monitoring cases received, case management for support and appropriate receipt of referrals from NMSP, NHSP and EI, respectively.	Early Intervention Programs Salesforce/TCS (HiTrack/Neometrics/HEIDS)	Data Systems	Equity; Quality
Quarterly data review to assess program trends to respond to pending public health concerns (including, but not limited to, referrals received, evaluated and enrolled, active case load, conditions/needs of children enrolled, appropriate referrals to other CYSHN programs and external programs, including DOE, DHS, DDC, etc.).	Parent and Youth Advisory Groups	Data Systems	Service
Identifying funding opportunities to optimize the infrastructure or function of CYSHCN to better identify and support children enrolled in services or who could benefit from services.	Federal Grantors Philanthropic enterprises/agencies	Finance	Finance
Improving public awareness of concerning trends among children referred to CYSHN and the impact of CYSHN services in their development to support a thriving child.	Community Partners State partners: DDD, CAMHD, DOE, PHN	Engagement	Service
Supporting availability of specialist clinics on neighbor islands (including cardiac, neurology, behavioral development, etc.).	HPH Kapiʻolani DHO Kaiser Queens	Engagement	Service; Equity; Quality
Supporting transportation and accommodation needs for neighbor island children's family/caretaker accompanying child requiring care in Honolulu, not covered by Insurance (to support a total of 2 adult care takers with/without insurance) – includes ground and air.	DHO DHS/MedQuest Ronald McDonald House Charity Hawaiian Airlines	Engagement	Service
Supporting nutritional needs of children requiring special diets, formula feeds, or other dietary intervention to optimize their ability to thrive.	PCP Medical Specialist Medical Supplies Provider Pharmacy / Formula Supplier DHS/MedQuest	Engagement	Service
Enhancing client and family support by conducting home visits or other field visits (which may include IFSP, school, medical visit, etc.) to address and aid in attaining resources, services or benefits that the child and family are entitled to and would benefit from.	PCP Medical Specialist Behavioral and Mental Health Providers Community Partners	Engagement	Service

Supporting specialty clinics (behavioral, cranial facial, pediatric specialty, etc.) at health facilities by providing resources and services to benefit child and family	Kapiʻolani Kaiser Shriner's Medical Specialist	Engagement	Service
Data actively reviewed to assess population trends with quarterly reports to define status and concerns.	Genetics consultant Birthing Facilities Hawaiʻi Genetics Counseling	Engagement; Data Systems	Service

Hawaii Childhood Lead Poisoning Prevention Program

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Improving staffing to enable the program to maintain operational functions.	HRO Cogent	Workforce	Services
Assessing all cases of children with elevated blood lead levels for environmental exposures of lead.	PCP Section 8 and HPHA (Housing) Families with Young Children	Engagement	Services
Improving public awareness of lead poisoning and prevention.	PCP Health plans Community groups	Engagement	Services
Data actively reviewed to assess population trends with quarterly reports to define status and concerns.	Section 8 and HPHA (Housing)	Data Systems	Service

Hi'Ilei Developmental Screening Program

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Assessing all cases of children self-screened and identified with a developmental delay are referred for appropriate support.	PCP Medical Specialist Health Provider Associations Behavioral and Mental Health Providers Community Partners EIS HI-CLPPP	Engagement; Data Systems	Services
Data actively reviewed to assess population trends with quarterly reports to define status and concerns.		Engagement; Data Systems	Service

Hearing and Vision Screening Program

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Providing standards/guidelines to support hearing and vision screening in schools to identify and correct or support intervention in order to optimize the development of the child and providing training for hearing and vision screeners.	PCP Medical Specialist Health Provider Associations DOE Community organizations	Policy; Data Systems	Services; Quality
Data actively reviewed to assess population trends with quarterly reports to define status and concerns.	Parent and Youth Advocacy Groups	Data Systems; Engagement	Service

Early Childhood Program

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Building capacity in the workforce to support mental health needs for children 0-5 (through Project LAUNCH).	PMHCA Program PCP Professional Associations Behavioral and Mental Health Providers Academic Institutions Community Partners	Workforce; Engagement	Service; Equity
Optimize referral networks and provider consultation to facilitate client and family access to services.	PCP Medical Specialist PMHCA Program Professional Associations Behavioral and Mental Health Providers Academic Institutions Community Partners	Policy; workforce; Engagement	Service; Quality
Data actively reviewed to assess population trends with quarterly reports to define status and concerns.	Genetics consultant Birthing Facilities Hawai‘i Genetics Counseling	Engagement; Data Systems	Service

Youth Transition to Adult Health Care

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Providing information to guide youth and their parents or providers to prepare them for how to be informed health care utilizers as young adults (utilizing approaches such as “Got Transition”, “Footsteps”, etc.).	Adolescent Groups (Serteens Hawai‘i, TeenLink Hawai‘i, etc.) Community Partners Parent Groups	Engagement	Quality

	PCP Professional Associations DHS/MedQuest IDD/DDC DOE		
Improve the support for special needs youth with disability or medical complexity as they transition to adulthood who may require medical legal aid, coordinated adult specialist care, special nursing care, etc.	Community Partners Parent Groups PCP Professional Associations DHS/MedQuest IDD/DDC DOE	Engagement	Quality
Data actively reviewed to assess population trends with quarterly reports to define status and concerns.	Adolescent Groups Community Partners Parent Groups PCP Professional Associations DHS/MedQuest IDD/DDC	Engagement; Data Systems	Service
Support for youth entering early adulthood (including health care transition, education/scholarships, job-training, life skills training).	Grantors Philanthropic organizations State Agencies (e.g., DOE, DOH, DHS, etc.) State Legislature Advocacy groups Health care providers Health Plan Providers Nutrition/Health Comprehensive Training	Policy	Service

Strategies: Systems optimization and emerging needs

The work of the CSHNB depends on strong collaboration with partners across the state to meet the needs of CYSHCN and their families. These partners include, but are not limited to: state agencies (e.g., DHS, DOE, DDC); academic institutions (e.g., UH schools such as JABSOM and the Office of Public Health Studies, HPU's Physician Assistant program, and Chaminade's FNP, PNP, and PMHNP programs); health systems (e.g., HPH, Kaiser, Shriners); health insurers (e.g., HMSA, AlohaCare, Kaiser); provider associations (e.g., HAAP, HAFP); community organizations (e.g., Hilopa'a, Roots Reborn, Family Voices, Hands & Voices); and families and individuals with lived experience. Aligning with these partners is essential to working effectively and efficiently toward the systemic changes needed to improve care, services, and outcomes for CYSHCN and their families.

This section is shaped by input from partners—including families and individuals with lived experience—and helps guide the development of strategies that address needs currently outside the direct scope of CSHNB's work. These emerging needs are important and merit support through collaboration, shared expertise, and resources.The strategies are organized under five overarching themes that reflect their crosscutting relevance to most, if not all, CSHNB programs. Given the interdisciplinary nature of these themes, the plan also highlights how they intersect with each other and align with the Blueprint for Change.

Engagement

Strategic Objectives	***Partner(s)***	***Theme***	***Domain***
Promote medical home models that work to achieve coordinated care for CYSHCN and facilitate the multidisciplinary care needed for the child and family.	PCP FQHC HPH KMC CMC Clinic Kaiser Queens Professional Associations Case Managers/Coordinators	Engagement; Workforce	Service
Improve collaboration among partners to support CYSHCN, focusing on building relationships, trust, as well as awareness of efficient use of all available resources.	State/City/County agencies/offices Community organizations Philanthropic organizations Religious institutions FQHC's/Health Providers Parents/families/children Policy Makers Public/ Private Schools For Profit/Nonprofit Healthcare Providers Insurance	Engagement; Workforce	Service; Quality
Work closely with children with behavioral health needs, particularly autism, and their families to help coordinate services with corresponding agencies.	DDD DD Council CAMHD Childcare services (Community) Interpreter services (community) SSI Insurance companies Public/Private Advocacy Orgs LDAH, ABA Services	Engagement	Services; Quality

	DOE Health Plan/Health Coordinator CDS Medical Homes Parent Support Groups Children's Justice Center		
Improve access and utilization of respite/ self-care (including social-emotional training) for families, teens, adults, and caregivers.	Queen Lili‘uokalani Children’s Center Doula Healthy Mothers Healthy Babies DDD Health Insurance Plans Technical Assistance Providers Community support groups/ programs Family support groups Military Mental Health services for caregivers Health Care Providers Religious Orgs OWR Governor’s office DOE/DOH	Engagement	Quality; Services
Engage with youth, particularly dependent youth with special health needs, to support essential life skills, their transition to adult life, and help them become as independent as possible to thrive in adulthood.	Community partners Youth groups Health providers Military Health Insurance providers State/ county/ city agencies State Agencies (CAMHD, DDD, DOE, DOH, DDD, DHS, DVR, CJC) State Attorney General Medical Legal Partnerships Leadership in Disabilities & Achievements of Hawai‘i Juvenile justice Domestic Violence Action Center YMCA Mentorship programs Assistive Technology Resource Centers of Hawai‘i For Profit/Nonprofit Programs (Businesses, volunteer, interns)	Engagement	Quality; Services
Ensure that materials provided to families are clear, accurate, informative, and accessible for building health literacy and effectively supporting the care of CYSHCN.	State agencies DOE/DHS Translation agency Community agencies Churches	Engagement; Workforce	Equity; Services

	State/ County/ City partners Native Hawaiian Health System OHA Advocate groups/agencies Care Coordinators ASL/Braille Healthcare Providers		
Support families, service providers and healthcare professionals engage with policymakers to better understand and fund the needs and challenges of CYSHCN and their families.	Community partners Child and Family Special interest/ advocacy representatives State Legislators County law makers Family Voices (Lived Experience) DD Council HCAN Budget Policy Center State Agencies (DCAB, HCRC, DOE, Task Force) Healthcare professionals Insurance companies	Engagement; Policy; Finance; Workforce	Finance; Equity
Engage with diverse community organizations, parent advocates, and community representatives from various ethnic and cultural backgrounds to prioritize children with special health needs as well as building trust and strengthen relationships.	Community partners Immigrant groups Families and people with lived experiences Leadership Education in Neurodevelopmental and Related Disabilities We Are Oceania Religious Organizations DEI Orgs OLA interpreter/translators Equity and justice organizations (e.g., PREL) University of Hawai‘i Pacific Gateway Center HCIR Social Services United Way FQHCs	Engagement	Equity

Workforce

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Focus on finding and hiring qualified people for vacancies, making sure job descriptions are updated, that salaries are competitive.	State Agencies (i.e. HRO) State Legislature HEICC Community partners Recruitment firms Provider association Universities, job fairs, online postings Social Media	Workforce	Service; Equity
Promote the recruitment of professions/disciplines that are lacking in practice across the state (particularly on neighbor islands) to meet the need of CYSHCN (including disciplines such as medical (primary and specialist), dental, technical, behavioral health, public health, community health and social work).	Community partners Provider association Universities, job fairs, online postings Social Media	Workforce	Service; Equity
Support the access to interpreters for both real-time support to families for non-English speaking families/communities, with particular interest to supporting in-person engagements.	Interpretive Service Agencies OLA Community Organizations Advocacy Groups	Workforce; Engagement	Service; Equity
Improve communication skills of workers on how to help families and to guide them to the right resources in a kind and supportive manner to create an enabling environment to build trust and make families feel confident about using state or program services.	Care Coordinators / Case Managers Direct service providers Quality Assurance Teams Technical Assistance Providers	Workforce; Engagement	Quality; Service; Equity
Use telehealth more effectively to provide support and services for CYSHCN and families.	Telehealth program (State Library supported) Providers and health systems (specialty care, including behavioral health) Programs using remote/ telehealth services Pacific Basin Telehealth Resource Center Recruiters (to recruit for telehealth) Grantors for telehealth infrastructure Telehealth platforms UH/Area Health Education Center	Workforce; Engagement	Service; Equity
Support program staff's well-being and quality of life by offering wellness activities, team building, help with their workload, and time for personal development.	Direct service providers Care coordinators Program Managers Partner programs Businesses / Philanthropies	Workforce	Quality; Service

Support and strengthen the skills of CYSHN program staff and partners to deliver effective, consistent, and evidence-based services to improve care for families and children.	AIMHI First responders Health care providers Case Managers/Coordinators Advocacy Groups Cultural/ traditional practitioners/ associations High school CTE programs & Post secondary education/ training programs Health insurance plans	Workforce; Engagement	Service; Quality
Improve upon the scope of the services provided for CYSHCN across the state – which currently include: Early Intervention services; Specialist access; Midwives/home birth community screenings; Pediatric audiology; Behavioral health; Developmental/ASQ screening; Increase time for counseling and screening; Home visits; Transition to adult health care; Nutrition support; Case Management/Support	Direct service providers Care coordinators Health care providers National technical assistance centers DHRD Provider groups/ associations Health plans WIC staff	Workforce; Engagement	Service
Support rural and neighbor island residents access necessary services, like specialists and labs, using visiting clinics, mobile clinics, or remote/virtual visits when local services are not available, so children and families can live and thrive.	Health care providers State Legislators Community partners Care Coordinators DHO offices Midwives Community Health Workers Nurses/APRN Social Workers Early intervention Providers	Workforce; Engagement	Service

Data Systems

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Identify and track family needs for services that may be needed for their child and for the family's well-being as well as the experience with the service provided.	Service/ Care Coordinators Home visiting program Community organizations Family Advocacy Groups DOE Homeless shelters Health plans Medical Facilities	Data Systems	Quality
Invest in online tools or databases to keep track of resources for children with special health needs, ensuring they are up-to-date and helpful for making referrals and providing support.	Health Providers Early Intervention Programs IT developer/designer	Data Systems	Quality; Services
Improve how data is collected and used to make decisions about programs. This includes looking at data to find any gaps or disparities, tracking referrals and services provided, and monitoring changes in clients' care.	Health Providers Early Intervention Programs IT developer/designer	Data Systems	Quality; Services
Enhance how data is shared to help programs understand community needs, how services are used and delivered, and how satisfied families are.	State agencies (DOH, DOE, DHS) P-20 Hawai'i Health Information Exchange State Chief Information Officer State Chief Data Officer State Legislature	Data Systems	Services; Quality; Equity

Finance

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Assist families in applying for Medicaid/MedQUEST insurance and work with MedQUEST health coordinators to make sure children get the services they need.	DHS/MedQUEST Philanthropic organizations Grants State Legislature Community Health Workers	Finance	Equity; Finance
Financial help for families of CYSHCN: (i) access to financial aid services through Community Health Centers (ii) improve access to health coverage for uninsured and under-insured children (iii) Have alternative payment methods, such as sliding scale fee for services (iv) Assistance with paying for lead abatement services.	Community Health Centers DHS/MedQUEST State Legislature HUD/Public Housing Agency Grants/philanthropy	Finance	Finance; Equity
Improve health insurance coverage and services for children with complex medical needs to limit out-of-pocket expenses.	DHS/MedQUEST Kapiʻolani Medical Center Complex Care Federal Grantors State Legislature	Finance	Equity; Finance
Increase payments to programs and providers that help CYSHCN, including Early Intervention, from both private and public health insurance companies to include more types of needed care, like rehabilitation services, respite services.	Health plans (public/private) Health care providers Advocacy groups State/Federal Legislature	Finance	Finance
Support expanding MedQuest eligibility to include all CYSHCN regardless of income eligibility.	Governor Federal/State Legislature Advocacy Groups Researchers	Finance	Equity; Finance
Funding for neighbor islands to support specialty care providers travel, invest in specialty equipment per county and expand preventive screening access particularly in rural areas.	Health Providers/Specialists Insurance payors Airlines CBOs	Finance; Workforce	Equity; Finance
Pay and reimbursement parity between comparable EIS and DOE services.	DHS/MedQUEST Private Insurers DOE	Finance; Workforce	Finance
Support to have private insurers pay for EIS and habilitative services.	Private Insurers	Finance; Workforce	Finance

Support financial mechanisms (i.e. loan reimbursement and tuition waivers) to facilitate the workforce pipeline from public universities and community colleges into shortage disciplines such as PT, OT, Speech, RBT, BCBA, and LCSW.	Academic Institutions Grantors Philanthropists	Finance; Workforce	Finance; Service
Support the financing of care coordination/ case management for families and their respective service needs.	DHS/MedQUEST Private Insurers FQHCs / Health Providers (PCP)	Finance; Workforce	Finance; Service
Advocate for financing support of telehealth services as an option to expand care access.	DHS/MedQUEST Private Insurers FQHCs / Health Providers (PCP)	Finance Engagement	Finance; Service
Promote funding opportunities for recreational activities and equipment that are accessible for children of varying abilities to promote physical activity and social engagement.	University and Community Colleges DOE Advocacy groups Philanthropists	Finance; Engagement	Quality; Equity

Policy

Strategic Objectives	*Partner(s)*	*Theme*	*Domain*
Enhancing participation in Equity working groups at Division level to better address the needs among populations disproportionately impacted by adverse health outcomes.	FHSD	Policy; Engagement	Service; Equity
Create a childcare policy that includes support for children with special health needs, with inclusion and sensitivity training for other children.	Childcare providers Families Advocacy organizations County Early Childhood Coordinator Medical Providers Dental Providers Health Pans DHS DOE State Legislature	Policy	Service; Quality; Equity
Strengthen partnerships between CSHNB programs and other agencies, sharing resources openly to better facilitate service access to children and families - includes attending Initial IEP meetings, working with agencies on events and projects, and coordinating with MedQUEST health coordinators.	State agencies (i.e. DOE, DHS, OWR) Other DOH Div Progs (Dev Disabilities, Clean Water, Environmental) Health/service coordinators Healthcare providers (e.g., Kapiʻolani Medical Center clinics) Health Insurance Companies Community organization Philanthropic organizations	Policy	Service
Encourage and support families with CYSHCN to meaningfully participate in advisory groups and councils, such as the Council on Developmental Disabilities.	HEICC State programs with advisory councils (e.g., DOH, DHS, DOE, etc.) Advocacy groups Legislature Faith Based Organizations Cultural Leaders/groups Community Service Providers & Navigators Peer Support Specialists Childcare Providers Translation Services	Policy	Quality; Equity
Support all people by making sure they have what they need, like good information and services that are sensitive to their language and culture.	State Agencies (e.g., Office of Language Access, DOE, etc.) State Legislature Advocacy groups	Policy	Equity; Service

	Philanthropic groups Interpreters / Translators (including for visual and hearing impaired) Faith based groups Translation, immigration, community leaders/champions, state legislature, immigration policy legality		
All children and families should be aware on how to avoid lead exposure, access to childhood lead blood level testing, ASQ screening and nutrition to mitigate harms from lead poisoning, and advocate for Federal Housing and Urban Development to adopt CDC lead safety rules.	State/Federal Legislature Federal agencies (e.g., HUD, CDC) State Programs (e.g., WIC, Early Head Start program, DOE/health screenings, etc.) Med Providers Health Provider Associations (e.g., AAP Hawai‘i, HAFP, etc.) Health plans/Insurance companies Health Academies at High Schools Early Childhood Education & Early Care	Policy	Service
Increase support options for upgrades with coverage for equipment and supplies for children with special health needs, like mobility devices, diapers, braces, medical and hygiene items.	State Agencies (e.g., Medicaid [DHS], etc.) Federal Agencies (e.g., CMS, etc.) Legislative Partners Health insurance companies (public/private) Philanthropic organizations *Community Health Worker/Navigator	Policy	Equity; Finance; Service
Develop guidance and opportunities for families to have recognizable roles within CSHNB, particularly to support quality improvement and accountability into the system.	Families State/County agencies Family Engagement Centers Civic Engagement Hapa-Kuleana Hawai‘i Alliance for progressive action DD Council Head Start Policy Council	Policy; Engagement	Equity

Monitoring and Follow-up

The CSHNB will monitor the progress of all outlined strategies and develop an operational plan to guide implementation over the next five-year period. An annual external brief will be made publicly available to share updates. If funding allows, the Branch also plans to host annual meetings with partners to present progress, gather feedback, and, if necessary, adjust direction during this period.

A final report will summarize progress over the five-year period and inform the next strategic cycle, using preliminary data and findings to build on current efforts. Ongoing engagement with partners and the community is essential to strengthening both individual and collective responses. This approach also supports accountability and transparency in the CSHNB's service to CYSHCN and their families.

Annex 1. Partner List

This list catalogs current partners with a working relationship or partners identified for engagement.

Section(s)	Partner Organization/Agency	Type of Partner	Location (County)
CYSHNS	AlohaCare - EPSDT Coordinator	Insurer	Oʻahu
CYSHNS	American Academy of Pediatrics (AAP) Hawaiʻi Chapter	professional association	Oʻahu
Genomics	Audiologist	health providers/systems	Oʻahu
CYSHNS	Association for Infant Mental Health Hawaiʻi (AiMHHI)	community organization	Oʻahu
CYSHNS	Autism Support and Disabilities Center (ASDC)	community organization	Hawaiʻi
CSHNB	Catholic Charities	community organization	Oʻahu
CYSHNS	C&C Honolulu	State government agency	Oʻahu
Genomics	Clinical labs of Hawaiʻi	health providers/systems	Oʻahu
CYSHNS	Cradles n' Crayons	health providers/systems	Oʻahu
Genomics	Deaf HoH specialist	health providers/systems	Oʻahu
CYSHNS	DHS	State government agency	Oʻahu
EIS	DHS – Childcare	State government agency	Oʻahu
EIS	DHS-CWS	State government agency	Oʻahu
CYSHNS	DHS – MedQUEST	State government agency	Oʻahu
CYSHNS	DHS – MedQUEST-EPSDT	State government agency	Oʻahu
CYSHNS	DHS – Office of the Director – FRC Coordinator	State government agency	Oʻahu
CYSHNS	DHS – Office of Youth Services	State government agency	Oʻahu
Genomics	Diagnostic Laboratory	health providers/systems	Oʻahu
CYSHNS	DOE	State government agency	Oʻahu
CYSHNS	DOE – Community Children's Council	State government agency	Oʻahu
CYSHNS	DOE – Homeless Liaison	State government agency	Oʻahu
CYSHNS	DOE – Preschool Special Education	State government agency	Oʻahu
CYSHNS	DOH-CAMHD	State government agency	Oʻahu
CYSHNS	DOH – Communicable Diseases & Public Health Nursing Division	State government agency	Oʻahu
CYSHNS	DOH – Harm Reduction	State government agency	Oʻahu
CYSHNS	DOH – Hazard Evaluation and Emergency Response (HEER) Office	State government agency	Oʻahu
FHSD	DOH-OPPPD	State government agency	Oʻahu
CYSHNS	DOH – Public Health Nursing Branch	State government agency	Oʻahu
CYSHNS	DOH – Special Parent Information Network	State government agency	Oʻahu
EIS	Early Childhood Action Strategy (ECAS)	community organization	Oʻahu
CYSHNS	Early Childhood Resources Coordinator – Maui County	community organization	Maui
EIS	Easter Seals Hawaiʻi	community organization	Oʻahu
EIS	Easter Seals Hawaiʻi - Kauaʻi	community organization	Kauaʻi
CYSHNS	Executive Office on Aging	State government agency	Oʻahu
CYSHNS	Executive Office on Early Learning (EOEL)	State government agency	Oʻahu

CYSHNS	Family Hui	community organization	Oʻahu
EIS	Family Support Services of West Hawaiʻi (FSSWH) - Child Development Program (Kona & North Hawaiʻi)	community organization	Hawaiʻi
EIS	Family Support Services of West Hawaiʻi (FSSWH)	community organization	Hawaiʻi
CYSHNS	Hawaiʻi Academy of Family Physicians	professional association	Oʻahu
EIS	Hawaiʻi Appleseed/ Parent	community organization	Oʻahu
CYSHNS	Hawaiʻi Children's Action Network (HCAN)	community organization	Oʻahu
CYSHNS	Hawaiʻi Community Foundation (HCF)	community organization	Oʻahu
CYSHNS	Hawaiʻi Island Community Health Center (FQHC)	health providers/systems	Hawaiʻi
CYSHNS	Hawaiʻi Keiki - DOE Clinical Consultant	health providers/systems	Oʻahu
CYSHNS	Hawaiʻi ʻohana Support Network	health providers/systems	Oʻahu
CYSHNS	Hawaiʻi Primary Care Association	community organization	Oʻahu
CYSHNS	Healthy Mothers, Healthy Babies Hawaiʻi	community organization	Oʻahu
CYSHNS	Hilopaʻa	community organization	Oʻahu
CYSHNS	HMSA – EPSDT Coordinator	Insurer	Oʻahu
CSHNB	Kaiser	health providers/systems	Oʻahu
CYSHNS	Kaiser – EPSDT Coordinator	Insurer	Oʻahu
Genomics	Kaiser – Genetics	health providers/systems	Oʻahu
CYSHNS	Kauaʻi Planning and Action Alliance	health providers/systems	Kauaʻi
CYSHNS	Keiki Injury Prevention Coalition	community organization	Oʻahu
CYSHNS	KKV	community organization	Oʻahu
CYSHNS	KMC	health providers/systems	Oʻahu
Genomics	KMC – Children's Specialty Clinic Hawaiʻi Community Genetics	health providers/systems	Oʻahu
CYSHNS	KMC – Developmental Behavioral Pediatrics	health providers/systems	Oʻahu
Genomics	KMC – ENT	health providers/systems	Oʻahu
CYSHNS	KMC – Multi-Disciplinary Clinic	health providers/systems	Oʻahu
Genomics	KMC – Neonatologist	health providers/systems	Oʻahu
CYSHNS	KMC – Pediatrics	health providers/systems	Oʻahu
EIS	Leadership in Disabilities & Achievement of Hawaiʻi (LDAH)	community organization	Oʻahu
CYSHNS	Lions Club - hearing	community organization	Oʻahu
CYSHNS	Lions Club - vision	community organization	Oʻahu
CYSHNS	MCH LEND	health providers/systems	Oʻahu
CYSHNS	Office of Wellness and Resilience	State government agency	Oʻahu
CYSHNS	ʻohana Healthcare - EPSDT Coordinator	Insurer	Oʻahu
CYSHNS	ʻohana Healthcare	Insurer	Oʻahu
EIS	PACT Head Start/Early Head Start	community organization	Oʻahu
CYSHNS	Palama Settlement	community organization	Oʻahu
CYSHNS	DD Council Member	Parent	Oʻahu
Genomics	CSC/Advisory Board member	Parent	Oʻahu
Genomics	Hands and Voices HI Chapter	Parent	Maui
CYSHNS	PATCH	community organization	Oʻahu
EIS	PCDC Wahiawa Program	community organization	Oʻahu
CYSHNS	Queen’s	health providers/systems	Oʻahu

CYSHNS	Ronald McDonald House Charities	community organization	O‘ahu

Annex 2. Birth Defects Surveillance Program: Birth Defects Monitored

This list provides the current birth defects that are identified through medical records across the state of Hawai`i.

Cardiovascular

- Atrioventricular septal defect
- Atrial Septal Defect
- Aortic Valve Stenosis
- Coarctation of the Aorta
- Common Truncus
- Double Outlet Right Ventricle
- Ebstein Anomaly
- Hypoplastic Left Heart Syndrome
- Interrupted Aortic Arch
- Pulmonary Valve Atresia and Stenosis
- Single Ventricle
- Tetralogy of Fallot
- Total Anomalous Pulmonary Venous Connection
- Transposition of the Great Arteries
- Tricuspid Valve Atresia and Stenosis
- Ventricular Septal Defect

Chromosomal

- Deletion 22 Q11.2
- Trisomy 13
- Trisomy 18
- Trisomy 21 (Down Syndrome)
- Turner Syndrome

Central Nervous System

- Anencephaly
- Encephalocele
- Holoprosencephaly
- Spina Bifida without Anencephaly

Eye

- Anophthalmia/ Microphthalmia
- Congenital Cataracts

Ear

- Anotia/ Microtia

Gastrointestinal

- Biliary Atresia
- Esophageal Atresia/Tracheoesophageal Fistula
- Rectal and Large Intestinal Atresia/Stenosis
- Small Intestinal Atresia/Stenosis

Genitourinary

- Bladder Exstrophy
- Cloacal Exstrophy
- Congenital Posterior Urethral Valves
- Hypospadias
- Renal Agenesis/Hypoplasia

Orofacial

- Choanal Atresia
- Cleft Palate Alone
- Cleft Lip with Cleft Palate
- Cleft Palate Alone
- Musculoskeletal
- Clubfoot
- Craniosynostosis
- Diaphragmatic Hernia
- Gastroschisis
- Limb Deficiencies
- Omphalocel

Annex 3. Newborn Metabolic Screening Program: Metabolic Disorders Screened

This list provides the current genetic and metabolic disorders that are screened through the newborn blood spot testing in the state of Hawai`i.

- **Endocrine (hormone) disorders:** Congenital adrenal hyperplasia in which the adrenal glands are unable to produce normal amounts of certain hormones.
- Congenital hypothyroidism in which the thyroid gland cannot make enough thyroid hormone for normal body and brain growth.

Hemoglobin (blood) disorders:

- Sickle cell disease and other hemoglobinopathies in which abnormal hemoglobin in the red blood cells may cause anemia.

Other disorder:

- Cystic Fibrosis
- Severe Combined Immunodeficiency (SCID)
- Pompe
- Mucopolysaccharidosis Type 1 (MPS I)
- Spinal Muscular Atrophy (SMA)
- X-linked Adrenoleukodystrophy (X-ALD)

Metabolic (metabolism) defects:

- Biotinidase deficiency in which the body is unable to use biotin, a B-vitamin.
- Galactosemia in which the body cannot break down a sugar (galactose) found in milk.
- **Amino acid (protein) disorders: a group of hereditary disorders caused by enzymatic defects, which result in the toxic accumulation of certain amino acids in the blood.**
    - Homocystinuria
    - Maple Syrup Urine Disease (MSUD)
    - Phenylketonuria (PKU)
    - Tyrosinemia (Types I)
- **Fatty acid oxidation disorders: a group of hereditary disorders caused by defects in enzymes which are involved in the breakdown of dietary and stored fats to energy.**
    - Medium chain acyl-CoA dehydrogenase deficiency (MCADD)
    - Long chain 3-hydroxyacyl-CoA dehydrogenase deficiency (LCHADD)
    - Very long chain acyl-CoA dehydrogenase deficiency (VLCADD)
    - Carnitine uptake/transport defects
    - Trifunctional Protein Deficiency (TFP)
- **Organic acid disorders: a group of hereditary disorders caused by enzymatic defects which result in a toxic accumulation of certain organic acids in the blood.**
    - Beta-ketothiolase deficiency (BKD)
    - Glutaric acidemia Type I (GA-1)
    - Isovaleric acidemia (IVA)
    - Methylmalonic acidemia (MMA)
    - Multiple carboxylase deficiency (MCD)
    - Propionic acidemia (PA)
- **Urea cycle disorders: a group of hereditary disorders, caused by enzymatic defects which result in a toxic accumulation of ammonia in the blood.**
    - Citrullinemia (ASAS)

Newborn Screening for Critical Congenital Heart Defects (including but not limited to):

- Hypoplastic left heart syndrome
- Pulmonary atresia
- Tetralogy of Fallot
- Total anomalous pulmonary venous return
- Transposition of the great arteries
- Tricuspid atresia
- Truncus arteriosus

Annex 4. Early Intervention: Mandated Services

This list provides the current mandated services under IDEA Part C which supports the Early Intervention Services provided.

- Assistive Technology
- Audiology
- Family training, counseling and home visits
- Health Services (necessary to enable the infant or toddler to benefit from the other early intervention services)
- Medical Services by a Physician (only for diagnostic and evaluation purposes)
- Nursing Services
- Nutrition Services
- Occupational Therapy
- Physical Therapy
- Psychological Services
- Service Coordination (care coordination)
- Sign Language/Cued Language
- Social Work Services
- Special Instruction
- Speech-Language Pathology
- Transportation (direct/and related costs of travel necessary to enable the child/family to receive early intervention services)
- Vision Services