

Hawai`i & Pacific Deaf-Blind Project

Parent Guidebook



*a resource for parents and
service providers*

A`ohe hana nui ka alu`ia

No task is too big when done together

When you found out your child had a hearing and vision loss, did you feel lost and alone? You are not alone. There are other parents like you, who know what you are going through, and are here to offer their support. Our children are very special and raising them is a task that is not too big when done together. This guidebook will help you navigate this journey.

All about _____

Birth History

Date of Birth: _____

Weight/Length: _____

Primary Diagnosis: _____

Significant events during pregnancy (illnesses, injuries): _____

Degree of hearing loss:

unaided: left ear _____ right ear _____

aided (if applicable): left ear _____ right ear _____

Type of hearing loss: _____

Type of vision loss: _____

Functional vision: left eye _____ right eye _____

Glasses: yes no

Medical Information

Primary doctor

name: _____

phone number: _____

address: _____

Audiologist

name: _____

phone number: _____

address: _____

Optometrist

name: _____

phone number: _____

address: _____

All about _____

Neurologist

name: _____

phone number: _____

address: _____

Other Important Contacts

name: _____

phone number: _____

name: _____

phone number: _____

name: _____

phone number: _____

All about _____

In Case of Emergency

name: _____

phone number: _____

email: _____

name: _____

phone number: _____

email: _____

name: _____

phone number: _____

email: _____

name: _____

phone number: _____

email: _____

All about _____

School: _____

Grade/Year: _____

Teacher: _____

Other Service Providers: _____

School: _____

Grade/Year: _____

Teacher: _____

Other Service Providers: _____

School: _____

Grade/Year: _____

Teacher: _____

Other Service Providers: _____

All about _____

Other Important Information

Our dreams for our child are...

What my child likes best is...

What my child does not like is...

Notes

Notes

Notes

All about _____

Medications:

Prescription One

name: _____

number: _____

dose: _____

prescribing doctor: _____

reason for medication: _____

Prescription Two

name: _____

number: _____

dose: _____

prescribing doctor: _____

reason for medication: _____

Prescription Three

name: _____

number: _____

dose: _____

prescribing doctor: _____

reason for medication: _____

Medications:

Prescription Four

name: _____

number: _____

dose: _____

prescribing doctor: _____

reason for medication: _____

Prescription Five

name: _____

number: _____

dose: _____

prescribing doctor: _____

reason for medication: _____

Known Drug Allergies/Allergies: _____

All about _____

Medical Equipment

item: _____

vendor: _____

phone number: _____

last service date: _____

item: _____

vendor: _____

phone number: _____

last service date: _____

item: _____

vendor: _____

phone number: _____

last service date: _____

Important Questions for My Child's Doctor(s)

What is my child's primary diagnosis?

What is my child's prognosis?

What are the side effects of medication(s)?

What are the options for treatment?

Is the condition progressive?

Important Questions for My Child's Teacher(s)

What are my child's strengths?

What are areas of need for my child?

What support services will be provided?

How often? Minutes/week?

Who will be responsible for practicing those skills with my child when the specialist is not there?

What are the projected outcomes for my child after leaving the school system?

Independent living?

Post-secondary education?

Job training?

Employment?

How will my child be supported in the classroom?

What modes of communication will be used?

How will communication on my child's progress be maintained?

Daily communication log?

Weekly email communication?

Monthly meetings?

Definitions

Deaf-Blindness

The term deaf-blind refers to a combination of vision and hearing loss, not necessarily complete deafness and complete blindness. Most children who qualify as deaf-blind have some useful vision and/or hearing. There is a wide range of cognitive and developmental ability among individuals who are deaf-blind. Since deaf-blindness is a combination of vision and hearing losses, there are as many possible combinations as there are individuals. For this reason, no two children with deaf-blindness are alike.

Critical factors which affect the severity and development of deaf-blind children:

- Age of onset
- Degree and type of vision and hearing loss
- Stability of each sensory loss (whether the loss will progress over time)
- Age of identification and intervention provided

Hearing Loss

Hearing loss is being partially or totally unable to hear sound in one or both ears. There are two main types of hearing loss:

- Conductive hearing loss occurs because of a mechanical problem in the outer or middle ear
- Sensor-neural hearing loss occurs when the tiny hair cells (nerve endings) that detect sound in the ear are injured, diseased, do not work correctly, or have died.

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Definitions

Vision Loss

Vision loss, or low vision, means that even with eyeglasses, contact lenses, medicine or surgery there is a reduction in the ability to see, including blurred vision, cloudy vision, double vision, blind spots, poor night vision, and loss of peripheral vision (tunnel vision). It may be caused by many different conditions that affect the brain or even the whole body. The vision loss may affect one or both eyes, it may occur gradually or suddenly, and it may be partial or complete.

Individuals with Disabilities Act (IDEA):

The Individuals with Disabilities Education Act (IDEA) is a United States federal law that governs how states and public agencies provide early intervention, special education, and related services to children with disabilities. It addresses the educational needs of children with disabilities from birth to age 18 or 21.

Individualized Family Service Plan (IFSP):

An Individual Family Service Plan (IFSP) is a plan for special services for young children with disabilities. An IFSP only applies to children from birth to three years of age. The IFSP is developed with a service coordinator and is set up to identify individualized supports and services that will enhance the child's development. An IFSP revolves around the family since it is the only constant a child has in their life at this age.

Individualized Education Plan (IEP):

An Individualized Education Plan (IEP) is specially designed instruction to meet the educational needs of a child with a disability ages three to 18 or 21. The IEP must be tailored to the individual student's needs as identified by the evaluation process, and should describe how the student learns. Key considerations are how the disability affects the student's learning, developing goals and objectives that correspond to the needs of the student, and choosing a placement in the most appropriate environment for the student.

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Individualized Transition Plan (ITP):

An Individualized Transition Plan (ITP) is a plan, if applicable, for students with a disability aged 14 and over from secondary school to adult life. The ITP is included as part of an Individualized Education Program, and is intended to ensure that students are prepared when they leave high school. Areas of focus include such things as postsecondary education, vocational education, employment, and independent living.

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"My comfort is knowledge. As the diagnosis/conditions keep piling up, never stop learning about them and never stop asking questions! You are the expert in your child's life! Speak up and speak loud and make them listen."

~ Natasha Kaiwi

Words of Wisdom from Parents

"Parents are the captain of this ship...we steer our children, providers, doctors and teachers in this journey. It is our job to make sure the journey is as smooth as possible.

~ Hoku Defeo

YOU are your child's best advocate

- * You play an important role in your child's development through early interactions.
- * You foster trust and form the foundation for your child's exploration and understanding of their world.
- * You have specific information regarding your child's development, abilities and disabilities.
- * You will be the constant presence in your child's life. Doctors, educators, therapist, and other professionals will come in and out of your lives.
- * You are allowed to say "no". It's okay to tell your child's doctor/service provide/therapist "no" if you do not feel comfortable in anything they want to do with your child.
- * You have the right to know what degree, education and/or work experience the teachers and service providers working with your child have.

Working with the medical professionals

- * Find the best doctors in your area to help with medical issues. Talk with other families to find the best doctors in your area. Do not settle for average!
- * Look for doctors, audiologists, and therapists that have experience working with children who are deaf-blind.

- * Be prepared for doctor appointments by taking copies of articles you have found on the Internet, in publications, or other sources to your child's doctor appointments to discuss.
- * Take another person with you to appointments to be another set of ears to hear and write down the information the doctor will be giving you.
- * When you meet with doctors and professionals, ask questions and expect answers.
- * Remember that your child is unique, and their medical care may be different than another child that is deaf-blind.
- * Allow yourself to not worry about education or other areas as you deal with the medical issues.
- * There may be several therapists working with your child. Pace yourself and prioritize the therapies that you can focus on at the time.
- * Know that the medical choices you make for your child may be different than other people's choices, but they are the best decisions you can make for you and your family.
- * Keep a file with records of shots, tests, doctor's visits, letters from doctors and teachers, notes from meetings.

Reaching out and getting support

- * It is not easy being the parent of a deaf-blind child. Be sure to surround yourself with people who support you and the decisions you make. Remember there are other people on this journey and they can help each other along the way.
- * Build friendships with other families:

- * You can find support by connecting with other families that have children similar to yours.
- * You can learn how to support and advocate for your child by sharing experiences with other families, both successes and challenges.
- * Find support in your community.
- * There are several pages of resources included in this guidebook.
- * Consider having your child join a group for children that don't have special needs. They may need some accommodations like an intervener or assistant.
- * Your child could participate in after-school activities, such as play, cultural events, and peer groups.
- * Church groups and community centers may have programs that your child could join as well. The members often volunteer to provide the support that a deaf-blind child needs.
- * It may be a good idea to seek out an advocate to be at your IEP meetings with you, especially in the beginning or when you feel your child needs more services. An advocate might be another parents with more experience or a person from an advocacy agency.

“ I like to tell other parents (not all with special needs children) “I can't promise it will be easy, but I can promise that I will be here every step of the way”.

~ Leanna Larinaga

Pace yourself

- * Don't wear yourself out rather accept help when it is offered. Keep a list of tasks that others can do for you when they offer.
- * Caring for your child can be physically and emotionally draining. Take advantage of respite care from friends, family or social services.
- * You can energize yourself everyday by doing something for yourself, like taking a walk, reading a book, or having a cup of tea.
- * Take care of your health by getting regular check-ups for yourself as prolonged stress can threaten your well-being.
- * Find support for yourself through groups and professional counseling.
- * Holiday activities may be difficult for your child. You may have to adjust your expectations and participation by staying for a shorter time, having a sitter stay with your child, or host events at your home.

"Please take advantage of professional help. Find doctors and other help wherever you can and coordinate it with your child's primary doctor."

~ Liana Genovese

Siblings need attention too

- * Siblings may feel that all of your attention is given to their deaf-blind sibling and you don't have time for them. Try to set aside time just for them.
- * Siblings may think the disability is their fault. Help them

Teaching Your Child

You are your child's first teacher, become the expert on your child

- * Watch how your baby reacts when you feed, hold, play, change their diaper, and do the day-to-day care.
- * Learn how to identify their emotions – fear, pain, anger and contentment.
- * Look for the ways in which your baby tries to communicate, and how they react to the ways in which you communicate – verbal, visual, and tactile.
- * Adapt the environment to best match your child, such as more lighting or eliminating clutter and obstacles.
- * Be aware and ready to take advantage of teachable moments that happen with your child.

Communicate, Communicate, Communicate

- * Provide your child with a feeling of security with routines and repetitive activities so they know what is about to happen.
- * Have a consistent routine for daily activities. For example, when feeding, touching the bottle nipple to their cheek, lifting them up, putting on a bib/cloth, and inserting the bottle into their mouth.
- * Supplement your normal communication with cues to let them know what is about to happen by flashing lights or gently shaking their bed to let them know you are in the room, or rubbing their arm with a washcloth to let them know it is time for a bath.

- * Touch is often a main way a deaf-blind child will communicate and learn about their world. Parents need to show their children that touch can be a pleasant experience. It builds a connection of trust and safety between parent and child.
- * Provide opportunities for your child to make choices, such as which toy to play with.
- * Remember to allow pauses so your child can process the communication and have an opportunity to respond.
- * Sensory Cues can be used depending on the abilities of your child.
 - Touch – rubbing their arm with a washcloth (bath time)
 - Smell – the smell of soap (bath time)
 - Sound – squeaking a toy (play time)
 - Sight – a flashing toy (play time)
- * Object cues, such as a bottle or a diaper

Communication systems for persons who are deaf-blind

- * Touch cues
- * Gestures
- * Object symbols
- * Picture symbols
- * American Sign Language
- * Fingerspelling
- * Signed English

- * Pidgin Signed English
- * Braille writing and reading
- * Tadoma method of speech reading
- * Large print writing and reading
- * Speechreading

Sensory Integration Therapy

- * A child's senses begin to form before they are even born. While a deaf-blind child has limited input from two of their senses. Stimulating their remaining senses and the environment provides additional information for the child to understand their world.
- * Sensory integration therapy or approach program is usually developed by a trained occupational therapist.
- * Some behaviors of deaf-blind children that are seeking more sensory input are:
 - Self-biting, slapping, pinching, or scratching, spinning, rocking, picking their skin, bouncing, leg swinging, hand flapping, light gazing, teeth grinding. Enjoying being bounced, rocked, or swung by an adult.
 - Sensory defensiveness – withdrawing from touch, certain textures, or turning away from light.
 - Abnormally low or high pain thresholds.
 - Variable or inconsistent sensory abilities – biting on non-food items but refusing to bite or chew food; inappropriate pressure when touching or grasping.

- Unusual postures – twisted, head hanging down or needing support.
- * Sensory integration therapy incorporates four principles:
 - The right amount of challenge in the child-selected activity to guarantee success.
 - The child has to adapt their response to the challenge, thus increasing their knowledge base.
 - The child must be actively engaged and motivated by the activity.
 - The activity must be child directed.
- *The goals for using a sensory integration approach are:
 - To have a child with a balanced state of emotion to be able to learn.
 - To help organize the senses to enable learning.
 - To provide a child the ability to control the input from their environment.
 - To increase their base of knowledge, essentially to learn.
- *Some sensory integration techniques are:
 - Deep pressure massage
 - Rhythmic joint compression
 - Large muscle movements
 - Use of weighted clothing
 - Brushing or stroking the skin

- A sensory integration approach requires careful monitoring of the child to ensure the intended outcome. Bottom line is, if the child is not behaving in a positive way stop using that stimulus!

Additional educational concerns

- * Some deaf-blind children use sign language to communicate, and may need a sign language interpreter. A sign language interpreter can sign what is being said to the child, and voice what the child says.
- * Some deaf-blind children need an intervener, someone who works consistently with the child to be their eyes and ears in the classroom.

“ I highly recommend reaching out to parents who have “been there” and can help you navigate the world of medical specialists, special education and all those come with it. They are usually more than willing to share their experiences and help! Also, sometimes when I get overwhelmed with meetings, appointments, goals etc. I just sit and hug my child and just be with him and enjoy the special blessing he is!

~ Carol Bigelow

Resources

National/International



American Association of the Deaf-Blind (AADB)

www.aadb.org

301-495-4403 (voice)

301-563-9107 (videophone)

The American Association of the Deaf-Blind (AADB) is a nonprofit national consumer organization of, by, and for deaf-blind Americans and their supporters. “Deaf-Blind” includes all types and degrees of dual vision and hearing loss. Their mission is to ensure that all deaf-blind persons achieve their maximum potential through increased independence, productivity, and integration into the community.

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American Foundation for the Blind (AFB)

www.afb.org

212-502-7600

The American Foundation for the Blind is a national organization that promotes independent and healthy living for individuals with vision loss; broadens access to technology; improves the information and tools available to the professionals who work with blind or visually impaired individuals; and advocates on behalf of the rights and interests of Americans with vision loss.

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Resources

National/International



CHARGE Syndrome Foundation

www.chargesyndrome.org

516-684-4720

800-442-7604 (toll free)

The CHARGE Syndrome Foundation provides support to individuals with CHARGE syndrome and their families; to gather, develop, maintain and distribute information about CHARGE syndrome; and to promote awareness and research regarding its identification, cause and management.



Keller National Center for Deaf-Blind Youths and Adults

www.hknc.org

516-944-8900 (main switchboard)

516-944-8637 (TTY)

516-570-3626 or 866-351-9089 (videophone)

The Helen Keller National Center serves adults who are deaf-blind and provides support services for youth and adults who are deaf-blind, their families and the professionals who serve them across the country. Their mission is to enable each person who is deaf-blind to live and work in their community of choice.



Perkins School for the Blind

www.perkins.org

617-924-3434

Perkins School for the Blind is an innovative leader in serving people with visual impairments. Perkins is committed to providing education and services that build productive, meaningful lives for children and adults around the world who are blind, deaf-blind or visually impaired with or without other disabilities.

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National Family Association for Deaf-Blind

www.nfadb.org

800-255-0411

The National Family Association for Deaf-Blind (NFADB) is the largest nonprofit national organization of families of individuals who are deaf-blind, and exists to empower the voices of families of individuals who are deaf-blind and to advocate for their unique needs. NFADB believes that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of their community.

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Don't compare your child's progress with anyone else's. They will surprise you - enjoy it!

~ Cene Logsdon

Resources

National/International



Consortium on Deaf-Blindness for Children and Young Adults Who are Deaf-Blind (NCDB)

www.nationaldb.org

Telephone: 800-438-9376 (toll free)

800-854-7013 (TTY)

The National Consortium on Deaf-Blindness (NCDB) is a national technical assistance and dissemination center for children and youth who are deaf-blind. NCDB conducts initiatives and activities to increase the capacity of state and local early intervention and education agencies to improve policies and practices for children and youth who are deaf-blind; promote the use of evidence-based practices; and increase the capacity of families to develop relationships with fellow families, service providers, and others, and expand their knowledge of deaf-blindness and skills in self-advocacy and self-empowerment.



DB Link

www.nationaldb.org

800-438-9376 (toll free); 800-854-7013 (TTY)

NCDB is home to DB-LINK, the largest collection of information related to deaf-blindness worldwide. A team of information specialists makes this extensive resource available in response to direct requests, via the NCDB web site, through conferences and a variety of electronic medium.



A-Z to Deafblindness

www.deafblind.com

This website offers information and links to resources for blind or deaf people, especially deaf-blind people, and those who provide specialized services for those who are deaf-blind.

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Described and Captioned Media Program (DCMP)

www.dcmp.org

800-237-6213

800-237-6819 (TTY)

The Described and Captioned Media Program (DCMP) is a unique educational accessible media resource serving the United States and its territories. The DCMP provides a collection of free-loan accessible media, a database of accessible media available for purchase, guidelines for educational description and captioning, and training and feedback for beginning description and captioning agencies. In addition, the DCMP is a resource for educational description and captioning information, providing its own clearinghouse along with a gateway to additional resources provided by partners and collaborators.

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Resources

National/International



National Dissemination Center for Children with Disabilities

www.nichcy.org

800-695-0285 (toll-free, voice/TTY)

202-884-8200 (voice/TTY)

The National Dissemination Center for Children with Disabilities (NICHCY) serves the nation as a central source of information on disabilities in infants, toddlers, children, and youth. You'll find easy-to-read information on IDEA, the law authorizing early intervention services and special education, and State Resource Sheets that will help you connect with the disability agencies and organizations in your state.



Deafblind International (DbI)

www.deafblindinternational.org

902-737-1453

Deafblind International (DbI) is the world association that supports and promotes the development of services to enable a good quality of life for deaf-blind children and adults. DbI brings together professionals, researchers, families, deaf-blind people and administrators to raise awareness of deaf-blindness.





Bookshare

Bookshare

www.bookshare.org

650-352-0198

Bookshare's goal is to raise the floor of access so that people with print disabilities can obtain a broad spectrum of print materials at the same time as everyone else. People with visual impairments, physical disabilities and/or learning disabilities can look to Bookshare to dramatically increase the quantity and timely availability of books and newspapers in accessible formats. Bookshare's vision encompasses new technological developments as well as new applications of widely available technologies to stretch the power of technology for increased access to content.

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Social Security Administration – Supplemental Security Income

<http://www.socialsecurity.gov/pgm/ssi.htm>

1-800-772-1213

Supplemental Security Income (SSI) is a Federal assistance program designed to provide income to aged, blind, or disabled people who have limited assets with which to support themselves. The SSI program is managed by the Social Security Administration (SSA), but financed by the general tax fund. Because the program is not financed by Social Security taxes, there are no work requirements necessary to qualify for SSI.

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Resources

National/International



The Sibling Support Project

www.siblingsupport.org

800-695-0285 (toll-free, voice/TTY)

202-884-8200 (voice/TTY)

The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.



Family Village

www.familyvillage.wisc.edu

The Family Village is a global community that integrates, information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities for their families, and for those that provide them services and support.



Sense for Deafblind People

www.sense.org.uk

Sense was established in 1955 out of a family support group made up of parents whose children were born with rubella. It is a national charity that supports and campaigns for children and adults who are deafblind.



“Fight for what you want from doctors/school. Don’t let them overlook your child and make sure they help you. Also to love your child, continue to be patient and enjoy every moment you have with them. We were blessed with the special ones!

~ Korina Leong

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WonderBaby.org

www.wonderbaby.org

help@wonderbaby.org

Wonderbaby.org, a project funded by Perkins School for the Blind, is dedicated to helping parents of young children with visual impairments as well as children with multiple disabilities. It has a database of articles written by parents who want to share with others what they’ve learned about playing with and teaching a blind child, as well as links to meaningful resources and ways to connect with other families. Additional resources such as Dots for Tots, Seedlings and NBP for free/cheap Braille books can be found on the Wonderbaby.org website

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Resources

National/International



American Samoa Community College - University Center for Excellence on Developmental Disabilities

[http://www.amsamoa.edu/
academicssupportucedd.htm](http://www.amsamoa.edu/academicssupportucedd.htm)

The ASCC UCEDD seeks to support, enhance, and improve the quality of life for persons with developmental disabilities. This is accomplished through cooperation, coordination, and collaboration among disability agencies to develop programs that promote self-determination, integration, full inclusion, and person-centered planning with family involvement and family advocacy. The ASCC UCEDD contributes to improving the lives of individuals with disabilities through a variety of initiatives and activities focused on education, research, and service. This includes trainings such as the “Use Your Voice” Parent Workshop which provide parents with information and knowledge to help parents understand and seek appropriate services for their children; “Accessing Services” which was a training geared towards introducing parents and families to the various agencies of the government that provides services for children with DD; and trainings on People-First Language and Signs of Abuse (Quality Assurance)





Northern Marianas College - University Center for Excellence on Developmental Disabilities

[http://www.nmcnet.edu/content.php?
id=146&cat=151&mnu=148](http://www.nmcnet.edu/content.php?id=146&cat=151&mnu=148)

The NMC UCEDD Program is committed to the development of culturally complimentary outcomes while promoting equal opportunity, independence, productivity, promoting self-determination, and supporting an improved quality of life for people with developmental disabilities in their villages, the Commonwealth, and the world around us.

Our Goals and Responsibilities are to provide training, technical assistance, and information-sharing with the focus on building the capacity of the CNMI to fully include persons with developmental disabilities. We are an in-direct service provider, collaborating and coordinating with all the agencies serving people with DD in the CNMI. The purpose of UCEDD programs remains concise to meet the dynamic needs of a group of people historically unserved and underserved in our country.

NMC-UCEDD has an awesome opportunity and privilege to support and empower wonderful individuals and this community-based program is very dynamic in its changing and progressive focus.

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Resources

State of Hawai'i

Department of Health – Early Intervention Section (0-3)

www.Hawai'i.gov/health/family-child-health/family-child-health/eis

808-594-0066

800-235-5477 (Neighbor Islands)

The Early Intervention Section (EIS), otherwise known as the 0-3 Program, of the State Department of Health is a program that provides developmental services for any eligible child from birth to three years of age in five areas: physical, cognitive, communication, social or emotional and adaptive. Services are available on all islands and there is no cost to families.

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Department of Health – Hawai'i Keiki Information Services System (H-KISS)

www.hawaii.gov/health/family-child-health/family-child-health/eis

808-594-0066

800-235-5477 (Neighbor Islands)



The Hawai'i Keiki Information Services System (H-Kiss) is a free information and referral service of the Early Intervention Section. A care coordinator can help answer questions and get your child evaluated for developmental delays or other special needs, get needed services (like speech therapy and physical therapy), and link to other parents and services (such as child care, family support, respite, and community services).

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Resources

State of Hawai'i



Department of Health – Developmental Disabilities Division (DDD)

<http://hawaii.gov/health/disability-services/developmental/index.html>

808-586-5840

The Developmental Disabilities Division (DDD) assures there is a state system of supports and services for persons with developmental disabilities or mental retardation (DD/MR), which includes principles of self-determination and incorporates individualized funding, person-centered planning and community services.

Department of Health – Children with Special Health Needs Branch (CSHNB)

<http://hawaii.gov/health/family-child-health/cshcn/index.html>

808-733-9070

Children with Special Health Needs Branch (CSHNB) works to ensure that all children and youth with special health care needs will reach optimal health, growth, and development, by improving access to a coordinated system of family-centered health care services and improving outcomes, through systems development, assessment, assurance, education, collaborative partnerships, and family support.

Department of Health – Public Health Nursing Branch (PHNB)

<http://hawaii.gov/health/family-child-health/publichealthnursing/index.html>

808-832-5765

Public Health Nursing Branch (PHNB) administers the public health nursing services statewide. The staff of PHNB is made up of Public Health Nurses, who are Registered Nurses, Licensed Practical Nurses, Para-medical Assistants, and Health Aids in the public schools. Public Health Nursing services are focused on public health issues which include care coordination services for infants and toddlers for EIS and facilitate access to services for special needs populations with medical/health and their caregivers.

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Department of Health – Women, Infants and Children (WIC)

<http://hawaii.gov/health/family-child-health/wic/index.html>

808- 586-8175



The Special Supplemental Nutrition Program for Women, Infants and Children (WIC), is a federally funded program which provides Hawai'i residents with nourishing supplemental foods, nutrition education, breastfeeding promotion and health and social service referrals. The participants of WIC are either pregnant, breastfeeding, or postpartum women, and infants and children under age five who meet income guidelines and have a medical or nutritional risk.

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Resources

State of Hawai'i



**Department of Education – Hawai'i
School for the Deaf and the Blind
(HSDB)**

www.hsdb.k12.hi.us

808-733-4999

The Hawai'i School for the Deaf and Blind (HSDB) is a public education facility that provides statewide services to students that are deaf, blind, and deaf-blind. The HSDB's array of services are designed to assist each student in the target populations to maximize his or her potential with high expectations of success including support services by uniquely qualified personnel, support for families, post-secondary transition services and adapted educational materials.



Department of Education – Special Education Section (SES)

<http://www.doe.k12.hi.us/specialeducation/index.htm>

808-203-5560

The Special Education Section (SES) of the Department of Education focuses on the need of students with disabilities. Special education is specially designed instruction to meet the unique learning needs of students who require individualized education programs. Special education services (e.g. speech and language therapy, occupational therapy, etc.) may be delivered in a variety of settings based on the student's needs.





Department of Education – Comprehensive Student Support Services Section (CSSS)

<http://doe.k12.hi.us/programs/csss/index.htm>

808-205-5515

The Comprehensive Student Support System (CSSS) provides overarching support to the standards-based curriculum and programs. CSSS is based on the belief that given the appropriate support and interventions, every student will learn and succeed. It links students and families to the resources of the Department of Education, as well as those of their neighborhood, their community and other governmental and private agencies, emphasizing proactive, timely prevention and intervention services.

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Department of Education – Hawai'i State Library for the Blind and Physically Handicapped (LBPH)

<http://hawaii.sdp.sirsi.net/custom/web/>

808-733-8444

The Library for the Blind and Physically Handicapped (LBPH) provides services to U.S. citizens statewide and is part of two library systems: the Hawai'i State Public Library System and the National Library Service for the Blind & Physically Handicapped, Library of Congress. LBPH serves as the regional library and machine lending agency for the blind and physically disabled throughout the state and the outlying Pacific Islands.

EW

Resources

State of Hawai'i

Department of Human Services – Vocational Rehabilitation and Services for the Blind – Ho'opono

<http://hawaiivr.org/hoopono/index.php>

808-586-9744

Ho'opono provides statewide comprehensive and specialized services to meet the varied needs of persons who are blind, deaf-blind, or visually impaired. There is no fee for services, and you do not have to be totally blind to use the services of Ho'opono. The goal of Ho'opono is to enable visually impaired adults to attain maximum vocational and functional independence with its team of skilled professionals providing varied services to meet the participant's individual needs.



QUEST HAWAII
More Choices For Your Healthcare

Department of Human Services – Med-QUEST Division

<http://hawaii.gov/dhs/health/medquest/>

808-587-3521

Medicaid is the United States health program for certain people and families with low incomes and resources. It is jointly funded by the state and federal governments, and is managed by the states. People served by Medicaid are U.S. citizens or legal permanent residents, including low-income adults, their children, and people with certain disabilities. The Hawai'i Med-QUEST Program (QUEST) is a Medicaid managed care program where the State pays health plans to provide coverage of medical and mental health services. Dental Services are provided on a fee-for-service

income Hawai'i residents since January 1966. The program provides coverage for individuals who are age 65 and over, or under age 65 who are blind or disabled. All other individuals are covered by QUEST.

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Department of Human Services – Developmentally Disabled/ Mentally Retarded Home and Community-Based Services Program (DD/MR HCBS)

[http://hawaii.gov/dhs/health/medquest/Document.
2009-04-14.2024](http://hawaii.gov/dhs/health/medquest/Document.2009-04-14.2024)

808-733-9303

The Developmentally Disabled/Mentally Retarded Home and Community-Based Services Program (DD/MR HCBS) is a Departments of Human Services and Health collaboration to administer and implement this program through Medicaid. The DD/MR HCBS Program provides individuals with developmental disabilities, mental retardation, and the medically fragile with support and services that will enable them to live as independently as possible in the least restrictive environment. Some services include: assistive devices, DDMR emergency services, Personal Assistance/Habilitation, respite care, and skilled nursing.

EW

"Always treat your child in a normal way. Never hurt them.

~Mario Gandeza

Resources

State of Hawai'i

Department of Human Services – Supplemental Nutrition Assistance Program (SNAP)

<http://hawaii.gov/dhs/self-sufficiency/benefit/FNS#What>

808-643-1643

The Supplemental Nutrition Assistance Program (SNAP) is a federal program funded through the U.S. Department of Agriculture. As of October 1, 2008, SNAP is the new name for the federal Food Stamp Program. Each state administers a SNAP.



Isle Interpreting

<http://www.isleinterpret.com>

Isle Interpret is a kama'aina interpreting agency dedicated to promoting successful communication with deaf and hard of hearing persons. Isle Interpret offers affordable, convenient, and secure interpreting and captioning services statewide.

Services include:

- On-site and Video Remote (VRI) interpreting in American Sign Language
- On-site and remote Real Time Captioning (RTC) services
- On-site and remote Computer Assisted Notetaking services (CAN)

To request an interpreter/captioner or to find out more about Isle Interpret's services, please visit the web site.

Resources

Community



Center on Disability Studies – Hawai'i & Pacific Deaf-Blind Project (HPDBP)

<http://www.pdb.hawaii.edu/>

Telephone: 808-956-5861 or 808-956-9855

The Hawai'i & Pacific Deaf-Blind Project provides technical assistance to children and youth who are deaf-blind, birth through 21 years of age, and to their families and service providers here in Hawai'i and outlying Pacific Island nations/jurisdictions of American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia (Kosrae, Pohnpei, Chuuk, and Yap), Guam, Republic of Palau and Republic of the Marshall Islands. Technical assistance may include:

- in-home consultation,
- school consultation,
- family support,
- networking,
- in-services,
- bi-annual statewide trainings,
- referrals to other agencies,
- and resources.

Services may be requested by families of children and youth with deaf-blindness, school personnel, and agencies providing services to children and youth with deaf-blindness.

Resources

Community



Gallaudet University Regional Center (GURC)

<http://kapiolani.hawaii.edu/object/kdc.html>

Telephone: 808-734-9210

The Gallaudet University Regional Center and the Intensive Preparatory Program for Deaf and Hard of Hearing, provides services for KCC students and other members of the deaf community in Hawai'i and the Pacific Rim.



UNIVERSITY of HAWAII*
KAPĪ'OLANI
COMMUNITY COLLEGE

Kapiolani Community College Interpreter Training Program

<http://kapiolani.hawaii.edu>

Telephone: 808-734-9891

The Kapiolani Community College Interpreter Training Program prepares American Sign Language interpreters that work with deaf and deaf-blind people in a variety of settings. Once trained, these interpreters work with clients in community and educational settings.



Hawai'i
Interpreting
Services

Hawai'i Interpreting Services (HIS)

www.interpretinghawaii.com

Telephone: 808-394-7706

Hawai'i Interpreting Services (HIS) is a comprehensive, one-stop service

center providing quality sign language interpreters, real-time captioners, and computer-assisted notetakers to facilitate communication between deaf, hard of hearing, deaf-blind, and hearing individuals. These services are available 24 hours a day, 7 days a week on six islands in the state of Hawai'i (Kauai, Oahu, Molokai, Lana's, Maui, and the island of Hawai'i).

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Signs of Self (SOS)

www.signsofself.org

Telephone: 808-382-3881 (voice); 808-442-6449 (videophone)

Signs of Self (SOS) is a nonprofit 501(c)3 contracted through the Hawai'i Department of Human Services, Vocational Rehabilitation and Services for the Blind Division (VR). Signs of Self serves the needs of people who are deaf, hard-of-hearing, and/or deaf-blind, staffed by trained professionals and community members. SOS believes that all individuals have the right to as much say as possible in the direction of their own lives - regardless of individual ability. Their goal is to help clients make the most of their lives.

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Resources

Community



Assistive Technology Resource Centers of Hawai'i (ATRC)

www.atrc.org

Telephone: 808-532-7110

Assistive Technology Resource Centers of Hawai'i (ATRC) is a 501(c)3 nonprofit, resource center that provides access to assistive technology (AT) for people with disabilities of all ages, enabling independence and participation in every aspect of community life, including employment and education. As a resource center, ATRC's mission is to link persons with technology and as such, ATRC will utilize demonstrations, outreach, technical assistance, public awareness, device loans and trials, financial loans and other programs to meet that mission.



Aloha Special Technology Access Center, Inc. (Aloha STAC)

www.alohastac.org

Telephone: 808-523-5547

The mission of Aloha Special Technology Access Center (Aloha STAC) is to provide individuals with disabilities, and their families, access to computers, peripheral tools, and appropriate software. Aloha STAC aims to increase awareness, understanding, and implementation of assistive technology by establishing a program of activities and events to educate the community about what technology makes possible for persons with disabilities.



Disability and Communication Access Board (DCAB)

www.hawaii.gov/health/dcab

Telephone: 808- 586-8121

The Disability and Communication Access Board (DCAB) serves as a public advocate of persons with disabilities by providing advice and recommendation on legislation, rules, policies, procedures, and plans relating to persons with disabilities and their civil rights or service needs. DCAB establishes and disseminates guidelines for the utilization of Sign Language Interpreters in state programs and activities, provides systems advocacy for issues related to persons who are Deaf, hard of hearing or deaf-blind, and administers the Hawai'i Quality Assurance System to credential Sign Language Interpreters.

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Special Parent Information Network (SPIN)

www.spinhawaii.org

Telephone: 808-586-8126 (voice/TTY)

The Special Parent Information Network (SPIN) is a parent to parent organization in Hawai'i that provides information, support and referral to parents of children and young adults with disabilities and the professionals who serve them. SPIN tries to keep families of a child with a disability linked to important information through its annual conference, quarterly newsletter, legislative updates, Special Education Advisory Council, fact sheets and parent guidebook.

EW

Resources

Community



Island Skill Gathering (ISG)

www.isghawaii.com

Telephone: 808-733-4622 (voice/TTY)

Island Skill Gathering (ISG) facilitates the learning of independent living skills which empower people to create a life situation of their own choice. ISG seeks to inspire people with disabilities to discover assistive technology solutions while serving as a role model, a trusted mentor, and end-user of technology, and in the process providing support services and product sales. ISG's technology specialists can help configure a computer system, and then assist with the acquisition, set up and training of its use.



Hawai'i Association of the Blind (HAB)

www.acb.org/hawaii

Telephone: 808-521-6213

The Hawai'i Association of the Blind (HAB) is an affiliate of the American Council of the Blind. They strive to advocate independence, equality and opportunities for the blind in Hawai'i.





Learning Disabilities Association of Hawai'i (LDAH)

www.ldahawaii.org

Telephone: 808-536-9684

The Learning Disabilities Association of Hawai'i (LDAH) is a non-profit organization founded by parents of children with disabilities. LDAH supports Hawai'i parents of children with any disability and the professionals who serve them through information/referral, education, training, mentoring and advocacy.

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Easter Seals Hawai'i

www.hawaii.easterseals.com

Telephone: 808- 536-1015; 888-241-7450 (Neighbor Islands)

Easter Seals Hawai'i serves families of children with disabilities through education, advocacy, referral, direct service, counseling, and care coordination to ensure that their children have equal opportunities to live, learn work and play in their communities. Easter Seals Hawai'i has been serving special needs children, youth and adults for over 60 years.

EW

Resources

Community



Help, Understanding and Group Support (HUGS)

www.hugslove.org

Telephone: 808-732-4846

Help, Understanding and Group Support (HUGS) serves families with children up to the age of 21 who have been diagnosed with any illness or disease that could rob a child of his or her life. The organization is the only one of its kind in the state that provides programs designed to improve the quality of life for families as they deal with the emotional and financial hardships of caring for a seriously ill child. HUGS' services are designed to strengthen families in the face of overwhelming adversity.



Special Olympics

www.specialolympicshawaii.org

Telephone: 808- 943-8808; 888-531-1888 (toll free)

Special Olympics is founded on the belief that people with disabilities, who are at least eight years old, with proper instruction and encouragement, can learn, enjoy and benefit from training, participating and competing in individual and team sports, adapted as necessary to meet the needs of those with special mental and physical limitations. Special Olympics also permits individual programs to accept children from age six to seven for training, but these children may not compete.





United Cerebral Palsy Association of Hawai'i (UCPA)

www.ucpahi.org

Telephone: 808-532-6744; 800-606-5654 (toll free)

The United Cerebral Palsy Association of Hawai'i (UCPA) is part of a nationwide network of approximately 93 state and local affiliates that provide services, conduct public and professional education programs and support research in cerebral palsy. UCPA of Hawai'i is also one of four independent non-profit organizations involved in an innovative collaboration called DiverseAbilities. The purpose of this partnership is to combine resources, reduce costs and expand services in pursuit of strengthening each organization's mission. In addition to UCPA of Hawai'i, DiverseAbilities includes Assistive Technology Resource Centers of Hawai'i, Hawai'i Centers for Independent Living and Abilities Unlimited.

EW

STRIDE Hawai'i

Successful Transitions in Diverse Environments

Successful Transitions In Diverse Environments (STRIDE) Hawai'i

www.hawaii.edu/stride

Telephone: 808-592-5900; 808-592-5906 (TTY)

The Successful Transitions In Diverse Environments (STRIDE) Hawai'i is a collaborative mentoring project to design, implement, and evaluate an effective vocational rehabilitation model for mentoring culturally diverse youth and young adults with disabilities as they transition into meaningful community environments, postsecondary education or employment.

Resources

Community

Collaborators include state agencies, university, and disabilities organizations. The STRIDE research project is funded by a grant from the United States Department of Education, Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration.



Hawai'i Centers for Independent Living (HCIL)

www.cil-hawaii.org

Telephone: 808-522-5400

The Hawai'i Centers for Independent Living (HCIL) is a non-profit organization operated by and for people with disabilities to ensure their rights to live independently and fully integrated into the community of their choice, outside of institutional care settings. To accomplish this, HCIL promotes self-advocacy and continues to provide statewide resources for peer counseling, outreach and public education, independent living skills, housing assistance, deaf and blind Services, and personal assistant services.



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