

REPORT TO THE  
TWENTY-FOURTH LEGISLATURE  
STATE OF HAWAI'I  
2008

PURSUANT TO CHAPTER 333E-3 (5)(A),  
HAWAII REVISED STATUTES,  
HAWAII STATE COUNCIL ON DEVELOPMENTAL  
DISABILITIES 2007 ANNUAL REPORT

PREPARED BY:  
STATE OF HAWAI'I  
DEPARTMENT OF HEALTH  
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES  
DECEMBER 2007

# Hawai'i State Council on Developmental Disabilities 2007 ANNUAL REPORT



## Mission Statement

The mission of the Council is to support people with developmental disabilities to control their own destiny and determine the quality of life they live.

## Vision Statement

People with disabilities are treated equally and enjoy fundamental human rights, among them life, liberty and the pursuit of happiness. They have choices about where they live, work and play, and they receive the supports they need to do so.

## Implementation Statement

To this end, the Council will:

- ✿ work for self-determination;
- ✿ advocate for systems change;
- ✿ provide information, education and planning;
- ✿ serve as conscience/monitor of the State; and
- ✿ promote best practices.

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## FROM THE CHAIR...

*Aloha!*

*This has been my first year as your DD Council Chair and I feel honored to have been given an opportunity to work with such dedicated and talented individuals as those we have as Council Members.*

*We have continued our tried and true activities, such as Partners in Policymaking and Day at the Capitol. We have also participated in planning of the Pacific Rim Conference on Disabilities.*

*We went through another busy session at the Legislature and were able to successfully advocate for important items such as a self-advocacy network.*

*Our committees have been busy as well. The Community Supports Committee worked diligently on Position Papers regarding such topics as positive behavioral supports. The Employment & Education Committee has agreed to serve as an advisory group for the State Employment Leadership Network (SELN). All committees worked on finalizing their 5 year plans and a list of activities that will help them achieve their goals.*

*This year we have also changed the format of Council meetings. Previously, a lot of time was spent listening to reports from various committees and agencies. Through the suggestion of the Executive Committee, these reports are now submitted in writing prior to meetings and opportunity is given to Council members to ask questions regarding the written reports. This now frees up time for presentations on various topics that Council members have interests in. The meetings have been turned into learning experiences that empowers Council members to advocate knowledgeably for issues of importance.*

*This past year has been an exciting one, and I look forward to another year of learning and advocating together.*

*Mahalo,*

*Liz Ann K. Salvador*

*Liz Ann K. Salvador  
Chair*

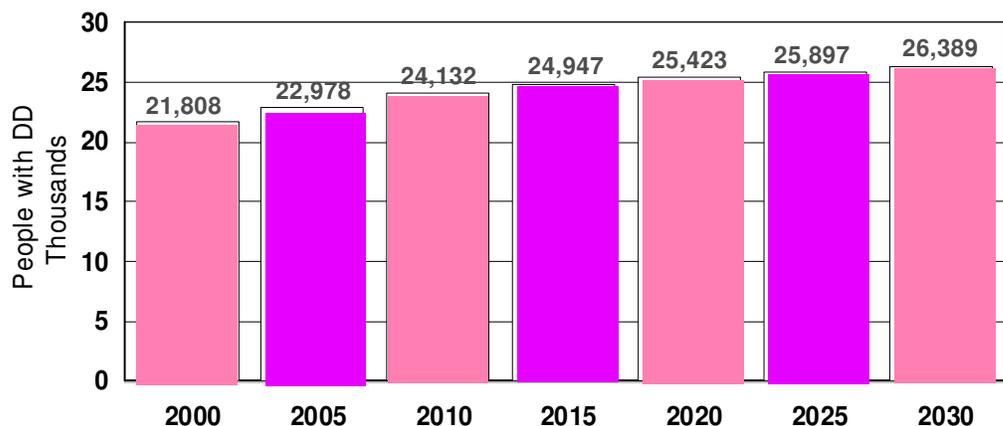
## COUNCIL MEMBERSHIP...

Maggie Baxter	Elvira Lee
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Oralie Carter	Sheryl Nelson
Ann Collins	Dr. Patricia Nishimoto
Dr. David Fray	John Noland
Naomi Grossman	Debbie Rivers
Martha Guinan	Mark Romoser
Dr. Patricia Heu	Liz Ann Salvador
Paul Higa	Michael Tada
Dr. Jean Johnson	Charlene Tarr
Charlotte Kamauoha	J. Curtis Tyler III
Bernadette Keliiaa	Paul Vargas
Jean Kiyabu	Betsy Whitney



*Representative Mizuno plays host to Evan Murakami and Leolinda Parlin during Day at the Capitol.*

### Developmental Disability Prevalence in Hawaii \*



\* Using Gollay 1.8% estimate and US Census projections



## THE COUNCIL...

State Councils were established in response to the federal *Developmental Disabilities Services and Facilities Construction Act of 1970* (PL 91-517). Hawai‘i’s Council was established in State Law by Act 198, Session Laws of Hawai‘i, in 1975.

The Council is administratively attached to the Department of Health (DOH). The department serves as the designated state agency, providing fiduciary and administrative support.

The Council engages in activities which change the system of services for people with developmental disabilities and conducts systems change, capacity building, and advocacy activities that...

- ✿ Provide training for individuals with developmental disabilities and their families including legislative advocacy, training on the legislative process, and leadership development;
- ✿ Demonstrate new approaches to services, supports, and assistance;
- ✿ Inform federal, state, and local policymakers;
- ✿ Foster interagency collaboration and coordination;
- ✿ Eliminate barriers and enhancing the design and redesign of systems;
- ✿ Maintain a resource library with articles, books, research studies, and videos that may be borrowed free of charge;
- ✿ Develop and support coalitions;
- ✿ Educate the public; and
- ✿ Coordinate and support community activities that follow the Council’s mission.

The Council, appointed by the Governor, is a group of individuals dedicated to improving the lives of Hawai‘i’s citizens with developmental disabilities. The philosophy of membership is that all key stakeholders are represented at the Council table: individuals with developmental disabilities; their family members, advocates; representatives of state and private agencies who provide services; representatives of the Hawai‘i Disability Rights Center (HDRC), the state’s Protection and Advocacy agency; University of Hawai‘i’s Center on Disability Studies (CDS) and other key community interests. The beauty of this composition is in the skills and experience that each brings to the table and shares with other Council members.

*Legislators representing Maui get together with their constituents during Day at the Capitol.*

## DEVELOPMENTAL DISABILITY

[from PL 106-402, Sec. 102. Definitions, (8)]

(A) IN GENERAL.—The term “developmental disability” means a severe, chronic disability of an individual that—

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency; and

(v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN.—

An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.



## MAJOR ISSUES IN DEVELOPMENTAL DISABILITIES...

In the wake of the 9/11 terrorist attacks and the more recent disasters of Hurricanes Katrina, Rita and Wilma of 2005, the inability of the system to respond to the needs of persons with disabilities or other special health needs became more apparent as a major deficiency in our overall community emergency preparedness and response system. Hawaii would fare no better than mainland locations in meeting the needs of persons with disabilities were similar events to occur tomorrow. The disasters, coupled with the growing recognition that people with disabilities or special health needs are a more vulnerable population in an emergency or natural disaster when their daily survival mechanism, coping skills, and support systems are interrupted, have emphasized the need to prepare a strategic plan which addresses the unique circumstances of persons with disabilities and special health needs in disaster preparedness planning. In 2005, a working group, consisting of various government and private organizations, was convened to address the issue of emergency preparedness of people with disabilities and special health needs. The group developed an action plan to ensure that efforts are made to include the issues of individuals with disabilities or special health needs in the overall community effort to prepare for an emergency. The action plan focuses on those individuals with disabilities whose ability to respond or respond as effectively in an emergency, and addresses emergency preparedness, notification, and sheltering as those were identified as the most

urgent issues. It identifies goals and objectives as well as lead and supporting agencies responsible for implementing the objectives. An emergency preparedness simulation exercise is scheduled for October 2007 and will serve as a test as to how effective the current procedures are. Community input forums in all counties are also planned for October 2007.

Hawaii's DD Division continues to move individuals to the DD/MR waiver increasing their number to 2,337 by July 2007. The state legislature provided an emergency appropriation of \$4.9 million to insure the continuation of funding for waiver services. The early intervention program is identifying more children needing services and finding that the cost for services is also increasing. This year they served 4,000 children. The legislature provided \$4.4 million this past session to meet existing demands. In May 2007, Hawaii was awarded a 5-year \$10+ million Money Follows the Person grant by CMS.

The project will be directed on discharging individuals with complex medical issues who have remained in hospitals and nursing facilities for 6 months or more. The projected number of people to be transitioned over the course of the grant is 415 of whom 58 will be DD/MR. The state also received an \$11 million Mental Health Transformation grant. The Council and DD Division will participate in the planning to improve the services available to those with a dual diagnosis of DD and mental illness.



### Health



Dental care services continue to be a priority issue for the disability community. In 2006 and again in 2007, the Council supported the state Medicaid agency in getting legislation passed to provide preventive and restorative dental services to adults on Medicaid. However, finding dentists willing to participate in Medicaid has been a major problem. The Neighbor Islands continue to have limited services. The situation has actually been exacerbated because state funds that were previously used for dental services are now not available since they would supplant services "available" through Medicaid. Finding a provider for those individuals who require anesthesia for dental procedures continues to be difficult. Legislation that would have funded a pilot hospital dentistry program did not pass. The contract for the \$90,000 appropriated in 2006 to look at improving dental services to persons with disabilities is in the process of being awarded. The Council in collaboration with the National Foundation on Dentistry for the Handicapped was able to obtain \$47,000 for an additional two-years worth of funding for the Donated Dental Services Program. Access to children's dental services although covered under EPSDT has

not been well-utilized especially in rural areas.

In 2004, the state Medicaid agency unveiled a plan to move the Aged, Blind and Disabled (ABD) population into managed care. The Council participated both in the public roundtables and the advisory committee. Currently, the ABD population, approximately 40,000, is served by a fee-for service program that has not been very effective in delivering health care services especially in rural areas where providers and specialists are scarce. Often, Neighbor Islanders require transportation to Oahu to receive services. Although the current system has flaws, individuals with DD and their families remain apprehensive about the proposed delivery system. Major concerns include the continuity of services during the transition period, the breadth of physician recruitment (including specialists), and the ability to provide services in rural areas. Dental services for adults on Medicaid, reinstated at the end of 2006, will remain as fee-for-service rather than be included in a managed care plan.





## Quality Assurance



*Note: The term “quality assurance” is defined broadly in DD Council’s enabling statute, PL 106-402, to include “advocacy, capacity building, and systemic change activities;” “self-advocacy, and self-determination for individuals with developmental disabilities, their families, and their guardians;” and “activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life, of individuals with developmental disabilities.”*

The Council continued its support of the implementation of Act 133/1998 incorporating the principles of self-determination into state law. The challenge associated with implementing self-determination is the person-centered planning process which must reflect a person’s choices, preferences, and strengths while balancing the state budget. As the state moves toward consumer-directed services, more options in residential settings and housing options will continue to be explored and other funding opportunities pursued.

The Council initiated legislation to fund a self-advocacy network organization in accordance with its state plan objective “Support the formation of a statewide self-advocacy organization and its ongoing activities.” The Council received a biennium appropriation from the 2007 state legislature of \$115,255 for a self-advocacy coordinator and operating funds to support a self-advocacy network (Year 1 funding: \$44,618; Year 2 funding: \$70,637). Based on the appropriation, the Council has initiated the process to recruit a half-time coordinator with the position expected to become full-time in the second year.

The annual Council-sponsored Day at the Capitol continues to be successful. More than 350 participants representing all counties had the opportunity to meet with legislators and their staff to share their personal stories and express

concerns about available DD services and issues such as dental care, disability access, employment, family support, waiver services, residential services, funding for DD and early intervention services, housing, education, and emergency/disaster preparedness. They attended floor sessions and had an opportunity to tour the Capitol and network with others.

The Council completed production of a public awareness Storyteller Project. The DVD features six storytellers with disabilities talking about experiences during their teen and young adult years with the purpose of promoting disability awareness to high school students. The stories focus on the issues of inclusion and diversity. The DVD was previewed at the 2007 PacRim conference and received extremely positive feedback. The Council’s Public Awareness, Self-Determination & Training Committee is developing a curriculum to accompany the DVD.

The Council collaborated with private agencies and the Medicaid Infrastructure Grant to present training for direct support workers. The November 2006 trainings were held over a four-day period on Oahu, Maui, and the Big Island and reached a total of 373 participants.

The Council continued to conduct regular legislative advocacy training statewide for persons with disabilities, family members, and service providers upon request.



## Employment



The Council has participated on the Advisory Council for the Medicaid Infrastructure Grant (Hire Abilities Hawaii). The first year of the grant focused on an analysis of barriers and solutions through data gathering and focus groups. The grant is currently focusing on the development of Medicaid Buy-In program; benefits planning; and the use of personal assistance services for individuals with disabilities to obtain and sustain employment. The Council

obtained preliminary data on employment outcomes of individuals with developmental disabilities from the Division of Vocational Rehabilitation (DVR). The Council also obtained data on consumer awareness and utilization of work incentive programs through the Medicaid Infrastructure Grant. The Council plans to continue to work with DVR and other agencies to obtain additional employment data.



## Education



The Council monitored and tracked the federal regulations proposed for the Individuals with Disabilities Education Improvement Act of 2004 (IDEA Reauthorization). The Council was part of a workgroup that was established to address inconsistencies, if any, between the proposed federal regulations and the State administrative rules of the Department of Education (DOE). The workgroup completed its analysis and recommendations for amendments. The IDEA 2004 final regulations were published in the Federal Register in August 2006. During the 2006 Legislative session, legislation was introduced that attempted to clarify concerns about which party has the burden of proof in appealing administrative hearings brought under IDEA. The Council supported legislation placing the burden of proof on the DOE. Although no legislation was passed, the Council continues to work with advocacy agencies regarding this concern. The Council has participated on the

Advisory Council for the Family Support 360 Project (Kokua I Holomua) since January 2005. The project is part of a three-year grant that aims to assist students with developmental disabilities transitioning from high school to adulthood and their families in Windward O’ahu with locating appropriate and available services and supports in the community. The grant focuses on collaboration between partner agencies toward the creation of a navigational one-stop system where navigators assist students and families with identifying needed supports and in determining and reaching their goals. The grant is in its second year of implementation and has provided essential training for families, created navigators who have assisted families to successfully navigate the complex service and support systems in the community, and is nearing completion of the development of competencies for the navigational one-stop system.



## Housing



The 2005 State Legislature adopted HCR 40 HD 1 – Requesting the Hawaii State Council to Continue to Convene the Residential Settings Task Force to Identify Issues and Solutions Regarding Individuals with Developmental Disabilities and Their Choice of Residential Setting. This resolution provided the basis for the Council to reconvene the Task Force. The Task Force continued its work and submitted a follow-up report (Phase 2) to the 2006 Legislature. The report described residential options currently available for individuals with developmental disabilities, addressed individual choice and self-determination in increasing residential options, identified statutes, administrative rules, policies, and directives that if revised would allow settings that do not require licensure and reflect individual choice, assure civil rights, health and safety. The report also required that adequate consideration be given to the person’s safety and well-being, and outlined additional recommendations.

The Council advocated for and supported legislation to address two of the task force recommendations, and both pieces of legislation were enacted into state law by the 2006 legislature. The first, Act 261 (2006) appropriated \$1.2 million to provide for continued operation of DD domiciliary homes and apartment complexes thereby maintaining current residential options for those individuals. The second, Act 303 (2006) amended the provisions of Chapter 333F, Hawaii Revised Statutes, to clarify that an individual be afforded with the choice of residential settings, provided that the person can be sustained with supports. Act 40 (2007) requires the Council to submit a report to the legislature on the number of persons with developmental disabilities or mental retardation who choose to live independently and the financial impact of Act 303 and extended the Act’s sunset date to June 30, 2009. Act 213 (2007) increased the previous appropriation of \$1.2 million by \$600,000 per year.



*Day at the Capitol participants attend House and Senate floor sessions.*



# HIGHLIGHTED ACTIVITIES

## Neighbor Island Activities

### Kaua'i

The Kauai DD Committee sponsored community forums bringing individuals with developmental disabilities as well as family members and State and County officials. The forum focused on available resources and services to individuals with disabilities, access to recreation, school to community transition, dental services, income received by individuals who live below income levels, supported employment, housing and legislation. The members also attended a "Day at the Capitol" event in which they were able to meet with legislators, tour the Capitol, meet the Governor, and attend hearings throughout the day. Members also worked with the Mayor's Committee on emergency preparedness, as well as the county Parks and Recreation Committee to increase accessibility and accommodations in the area of recreation. Members also were involved with the Children's Council of Kauai working on areas of education and equal access for all children of Kauai in schools and school based activities.

### Maui

The Maui Disability Alliance, a coalition of 16 different disability provider agencies and support groups, held its 11<sup>th</sup> Annual Legislative Forum in October 2006. The focus of the forum was small groups working to examine and address issues facing individuals with disabilities. Each group recorded what success they've had and what barriers they faced. The Mayor, members of the County Council, and state legislators participated. The Maui County budget for public transportation tripled. As a result of the increase, there will be Sunday service, longer hours and increased frequency on all existing routes. The committee supported an amendment to the County Charter to use 2% of the Real Property Tax to create an affordable housing fund, and participated in the Maui Nui Affordable Housing Task Force. A tri-isle planning retreat sponsored by the Community Children's Councils of Hana, Lana'i, Moloka'i and Maui identified and explored educational issues in these communities.

### Hawai'i

The East and West Hawaii DD Committees held their annual legislative forums and introduced legislation to implement hospital dentistry services on the Big Island. The East and West Hawaii DD Committees continue to collaborate with community stakeholders regarding the critical need for access to dental care for children and adults with DD on the Big Island and bring this critical issue to the public's attention. Despite these challenges three adults with developmental disabilities received on-island hospital dentistry services due to the great collaborative effort and volunteer hours of those involved locally in community health care.

The Committees collaborated with the County of Hawaii on the successful implementation of Project Lifesaver, as well as the development and planning of the Aging & Disability Resource Center (ADRC) planned for East Hawaii.

Both DD Committees sponsored presentations in collaboration with the Disability and Communication Access Board on the Inter-Agency Plan for the Emergency Preparedness of People with Disabilities and Special Health Needs.

A critical need for improved services and supports for people with dual diagnoses was identified. The use of aversive behavioral interventions including pharmaceutical and physical restraints continues to be a concern. The use of best practice approaches in crisis intervention, behavioral assessments and positive behavioral supports remains a high priority. Other issues raised on the Big Island were EPSDT services, housing, public transportation, inclusive education, accessible recreation, and the need for improved employment options.

## Partners in Policymaking

*Partners in Policymaking* is an innovative program for individuals with developmental disabilities and their family members. The program is designed to provide information, training, resources and skills, to develop productive partnerships between people who need and use services and those in a position to make policy and law. It teaches people to be community leaders and educates participants about current issues and best practices in the disabilities field, and informs them about the policymaking and legislative process.

Eighteen individuals from across the state completed the 13th Partners training in 2006. Presently, there are 212 Hawai'i *Partners* graduates. Many graduates are serving the community in leadership roles on councils, commissions, and coalitions and as service providers and as self-advocates. The planning has already started for the Partners Fourteenth Session. Partners are selected from all geographic areas across the State.

## Legislative Update

The Council actively monitored, tracked and supported measures related to community placement; dental care; disability access; early intervention services; education; emergency and disaster preparedness; emergency appropriations for DD home and community-based waiver services and for early intervention services; family caregivers; individual choice of residential setting; long-term care; Medicaid & Medicare services including medical/dental care; residential services; residential personal needs allowance; consistent statewide policies on the use of restraint and seclusion; respite care; and self-advocacy.



*The Partners in Policymaking 13th Academy participants pose at the Pagoda Hotel.*



## HOW WE CAN BE REACHED...

### Hawai'i State Council on Developmental Disabilities

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#### From the Neighbor Islands:

Call O'ahu toll-free ...

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Hawai'i: 974-4000, x68100  
Moloka'i: 1-800-468-4644, x68100  
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#### Kaua'i DD Committee

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Secretary  
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Clerk Typist  
Erin Ota Alvarez,  
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## Acronyms

ABD	Aged, Blind, and Disabled
ADRC	Aging & Disability Resource Center
CD	Conference Draft
CDS	Center on Disability Studies (University of Hawai'i)
CMS	Centers for Medicare & Medicaid Services
DD	Developmental Disabilities
DD/MR	Developmental Disabilities/Mental Retardation
DOE	Department of Education
DOH	Department of Health
DVD	Digital Video Disc
DVR	Division of Vocational Rehabilitation
EPSDT	Early & Periodic Screening, Diagnosis, & Treatment
HB	House Bill
HCR	House Concurrent Resolution
HD	House Draft
HDRC	Hawai'i Disability Rights Center
IDEA	Individuals with Disabilities Education Improvement Act
PL	Public Law
SB	Senate Bill
SD	Senate Draft
SELN	Statewide Employment Leadership Network