

SB 422



STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
919 ALA MOANA BOULEVARD, ROOM 113
HONOLULU, HAWAII 96814
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543

February 10, 2009

The Honorable Suzanne Chun Oakland, Chair
Senate Committee on Human Services

and

The Honorable David Y. Ige, Chair
Senate Committee on Health
Twenty-Fifth Legislature
State Capitol
State of Hawaii
Honolulu, Hawaii 96813

Dear Senators Chun Oakland and Ige and Members of the Committees:

SUBJECT: SB 422 – RELATING TO HEALTH

The position and views expressed in this testimony do not represent nor reflect the position and views of the Departments of Health (DOH) and Human Services.

The State Council on Developmental Disabilities (DD) **STRONGLY SUPPORTS SB 422**. The purpose of the bill is to reinstate funds that have been depleted by budget reductions in order to provide continued support for families of individuals with disabilities through the implementation of the DOH Respite Services Program.

As noted in Section 1 of the bill, the Legislature enacted Act 324 to address the needs of families and caregivers through various appropriations. Section 4 of the Act established a Task Force within DOH to advise the Department on the allocation and expenditures of moneys appropriated for respite services and broad policy statements related to respite services. Section 5 specifically appropriated \$1,000,000 for support services, training, and respite services for families providing home-based care for a family member who is:

1. an infant and toddler three years of age or younger;
2. an adult with a serious mental illness;
3. a child with a serious emotional disturbance;
4. a child with a serious or terminal illness; or
5. a child or adult with a developmental disability.

The Task Force is comprised of representatives from the Health Resources Administration (HRA); Early Intervention Section, Family Health Services Division; Adult Mental Health Division; Child and Adolescent Mental Health Division; DD Division; Disability and Communication Access Board; DD Council; and family members of the target group. The Task Force continues to meet monthly or on an as needed basis to review and discuss program expenditures and issues related to the provision of respite services.

The DOH Respite Program's budget has been administered under HRA. The budget has taken its share of reductions of \$375,872 during the past 18 years, resulting in \$624,128 for the program. Below is the breakdown of the budget and its reductions.

DOH Respite Program Budget
 Act 324, SLH 1990

\$1,000,000	Act 324, SLH 1990 Appropriation
(\$375,872)	Minus Budget reductions
\$624,128	Remaining in operating budget
(\$51,316)	Minus 4% legislative reduction, transfer of funds to cover payroll shortfall, adjustment for personal services
\$572,812	Remaining in operating budget (minus the above reductions)

\$572,812	Operating Budget
(\$412,024)	Minus the Governor's proposed adjustments in the Executive Budget Request for FY 2010 and FY 2011
\$160,788	Actual amount available for the Respite Program

During the past year, the budget was affected by the four percent legislative reduction (\$30,732), transfer of funds to cover the payroll shortage for HRA (\$16,165), and adjustment for personal services (\$4,419). Those reductions left the program with \$572,812 until the Governor's proposed adjustments to the Executive Budget Request for FY 2010 and FY 2011 included the deletion of \$412,024 for respite services. The total reduction in the respite budget is \$463,340. Current budget for respite services is \$160,788. That amount divided by each of the six program areas means \$26,798 for each target group. Information about the DOH Respite Program and impact of the reduction in the budget is included in the attached FACT SHEET.

The Honorable Suzanne Chun Oakland
The Honorable David Y. Ige
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The Council strongly feels that respite services are essential in supporting families to cope with the daily responsibilities of caring for their family member with a disability and preserve and maintain the family unit. Respite continues to be the number one requested service to support families caring for a family member with a disability. Moreover, with the economic crisis facing our State, increase in unemployment, reduction in basic services, and other cost cutting measures, families will be ultimately challenged and stretched to the limit just to survive.

The Council is hopeful that the passage of the Economic Recovery and Reinvestment Act by Congress and signed by President Obama will provide Hawaii with some level of fiscal recovery. We will benefit from the proposed enhanced Federal Medical Assistance Percentage. The increase in Federal reimbursements will result in a decrease in the State's share and would allow for State funds to be redirected to other priority areas not matched by Federal funds.

Should SB 422 be in jeopardy as a stand alone bill to address respite services, the Council asks for your Committee's consideration to incorporate the provisions of this bill into SB 1679 – Relating to the Emergency and Budget Reserve Fund.

Thank you for your consideration and the opportunity to present testimony strongly supporting SB 422.

Sincerely,



Waynette K.Y. Cabral
Executive Administrator

Attachment

FACT SHEET

The Department of Health Respite Program

What is Respite?

- Respite provides temporary relief for a family, which helps to preserve the family unit by decreasing the individual and family stresses associated with caregiving so that families can continue to care for their loved ones. It is beneficial not only for the family caregiver, but also for the child or adult with special needs. It allows the family to engage in daily activities, decrease a feeling of isolation, increase the ability to cope with daily caregiving responsibilities, and maintain stability during crisis situations.
- Respite provides substitute support for a child or adult with special needs in order to provide a period of relief or rest for the family caregiver. Respite can allow time for the family caregiver to address personal needs, other business, or an unexpected emergency.
- Respite is an important part of the continuum of services for families who care for an individual with special needs. This support for families prevents burnout of the caregiver and reduces the possibility for out-of-home placement.

Who Receives Respite?

Families caring for a family member who is:

- An infant or toddler three years of age or younger with a developmental delay
- A child or adult up to age 21 with a serious or terminal illness
- A child with a serious emotional disturbance
- A child or an adult with a developmental disability
- An adult with a serious mental illness

Who Provides Respite?

Currently, the Respite Program affords respite to the families of clients from six program areas of four divisions of the Department of Health per the intent of Act 324, SLH 1990. Each of these six program areas split the respite funds equally (approximately \$104,000 per program area - before budget reductions). In addition, the programs work together and have transferred funds between programs to cover shortfalls experienced by one or more of the other programs.

- **Family Health Services Division – Early Intervention Section (EIS)** - Provides respite support to families in two program areas - medically fragile children or youth up to age 21 and infants and toddlers with developmental delays three years of age or younger.
- **Child and Adolescent Mental Health Division (CAMHD)** - Provides respite support to families for children with a serious emotional disturbance.
- **Developmental Disabilities Division (DDD)** - Provides respite support to families in two program areas – respite is available to families of individuals (children and adults) with developmental disabilities and/or mental retardation (DD/MR) who are not in the DD/MR Home and Community-Based Medicaid Waiver Program.
- **Adult Mental Health Division (AMHD)** – Provides respite services via a single, statewide provider, Mental Health Kokua. A respite housing pilot was initiated that will present a valuable resource to families and providers in the community and a formal contract modification was completed. Due to the recent budget reduction of \$25 million to the AMHD budget, the contract with Mental Health Kokua was terminated effective January 15, 2009. Respite funds were being used to supplement funds provided through the AMHD operating budget (approximately 25 percent of the total contract expenditures).

What are the Budget Expenditures for Fiscal Year 2008?

Fiscal Year 2008

Division	FSHD – EIS	CAMHD	DDD	AMHD	Total
Amount Spent	\$202,627	\$ 104,021 (estimate)	\$156,110	\$423,208* (\$98,000 in respite funds)	\$560,768
Number of Families Served	544	73	194	34	845
Number of Families Waiting For Services	35	Data Not available	Data Not available	Not Applicable	Data Not available

*Total contract amount. Respite funds used to supplement small portion of the contract.

What is Extent of the Budget Reduction?

The respite program budget sustained a discretionary reduction for FY 2009 of approximately \$51,316. The Governor's recommendation in the executive budget for the FB 2009-2011 further reduces the amount for respite by \$412,024, resulting in a total appropriation of \$160,788 to be shared among the six program areas.

What is the Impact of a Budget Reduction?

Overall, the budget reduction would have an adverse impact on the provision of respite for families and individuals with special needs. As respite is reduced, families will become more "at risk" for out-of-home placement, foster care, and possibly higher levels of care. In addition, it is more cost effective to provide respite funds to families than to pay for foster care or out-of-home placement if families are unable to care for their loved ones at home.

- **Family Health Services Division – Early Intervention Section (EIS) –**
 - A determination will need to be made as to whether to reduce the number of families served or reduce the respite hours per month.
 - The waitlist for respite services is expected to increase.
 - Reduction in Federal grant funding – general funds from the respite appropriation have been used as a "match" required to leverage the Federal Community-Based Child Abuse Prevention Grant.
- **Child and Adolescent Mental Health Division (CAMHD) –**
 - Possible increases in out-of-home placements and higher levels of care, such as therapeutic foster care, community-based residential care, or hospital-based residential care, which are much more restrictive and costly.
- **Developmental Disabilities Division (DDD) –**
 - Allotments for respite services of children and adults would decrease, with a more significant reduction of respite allotment for Neighbor Islands.
 - Anticipates that it will be receiving more requests for respite services that will exceed their annual portion, particularly from families who do not qualify for Medicaid, are not eligible for the DD/MR Medicaid Waiver Program respite services, or have had a reduction in respite services under the waiver program.

- **Adult Mental Health Division (AMHD) –**
 - AMHD Respite services contract with Mental Health Kokua was terminated effective January 15, 2009. All consumers with open authorizations for respite as of January 1, 2009 were transitioned to AMHD Peer Coaching services, which provide similar support for consumers and respite for caregivers delivered by a peer.

**TESTIMONY TO THE TWENTY-FIFTH STATE LEGISLATURE, 2009
SESSION**

To: Senate Committee on Human Services
Senate Committee on Health:

From: Hawaii Disability Rights Center
Re: SB 422, Relating To Health

Hearing: Tuesday, February 10, 2009 1:15 PM
Conference Room 016, State Capitol

Members of the Committee on Human Services:
Members of the Committee on Health:

Thank you for the opportunity to provide testimony supporting Senate Bill 422.

We are the agency mandated by federal law and designated by Executive Order to protect and advocate for the human, civil and legal rights of Hawaii's estimated 180,000 people with disabilities.

We support this bill. We represent many individuals who are able to reside in their own home or with their family because they receive caregiver support from a friend or family member. Obviously, this is an improved quality of life for them and also is generally more economical than placing these individuals in care homes. The key element is that the family member must be able to provide the care. Caregiver burnout is a well recognized phenomenon in these cases. This is where respite care proves to be invaluable as it provides an opportunity for the caregiver to either perform other essential chores or simply avail themselves of a brief time out so they can rejuvenate themselves. This money is extremely well spent from a quality of life and economic perspective. For those reasons, we support this bill.

Thank you for the opportunity to testify.

KOKUA COUNCIL

Hawaii's Voice for a Better Future
597-8838

Testifier: Laura G. Manis, tel.

Joint Hearing of the Senate Committees on Human Services and Health

February 10, 2008, 1:15 p.m. Conference Room 016

Chair Suzanne Chun Oakland, and Members of the HMS Committee, and Chair David Y. Ige and Members of the HTH Committee

SB422 RELATING TO HEALTH.

Appropriates funds to the department of health to provide for continued respite services for family caregivers.

SUPPORT

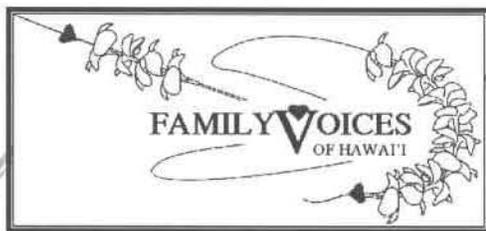
Kokua Council whose mission includes advocating for the health of the elderly and those vulnerable populations who cannot advocate for themselves supports this bill.

Numerous studies have demonstrated that caregiving takes an unusual toll on the health, and emotional well-being of caregivers.

Every survey of the needs of caregivers lists respite services as their number one requirement.

Since caregivers provide 85% of Long term care to our residents, thereby saving the state funds if these patients were cared by nursing homes financed by Medicaid, it is a money saving bill.

We urge you to pass this bill.



HILOPA'A

Family to Family Health Information Center

Date: February 7, 2009

To: COMMITTEE ON HUMAN SERVICES

Senator Suzanne Chun Oakland, Chair

Senator Les Ihara, Jr., Vice Chair

COMMITTEE ON HEALTH

Senator David Ige, Chair

Senator Josh Green, MD, Vice Chair

Fr: Leolinda Parlin, State Coordinator for Family Voices of Hawai'i

Re: **SUPPORT** – SB422 – Appropriates funds to DOH for state respite program

On behalf of Family Voices of Hawai'i, I offer testimony in strong support of SB422 - Appropriates funds to the department of health to provide for continued respite services for family caregivers.

As an organization, Family Voices is national grass roots organization of family of friends of child with special health care needs. In Hawai'i, we operate the federally funded Hilopa'a Family to Family Health Information Center.

Opponents to this measure would cite the tough economic times as being a reason to divert funds from the program. It is for this reason, that funding should be restored. Family resiliency is being challenged on all fronts, and for many families respite, is the thin thread that keeps our families together.

Prior to our national economic crisis, the National Survey of Children with Special Health Care Needs (CSHCN) 2005/2006 found that families in Hawai'i:

- 11% of our families of CSHCN spend 11 or more hours per week providing or coordinating child's health care
- 22% of our families of CSHCN have conditions which have caused family members to cut back or stop working
- 52% of our families of CSHCN did not receive the respite care that they needed

Cuts to programs and restrictive eligibility criteria will force more families to limit their employment opportunities, which will have an adverse effect on the family and the state's economy. Because of limited earning potential, families will be unable to support their own respite services. In fact, care giver burnout will be exacerbated because of the lack of respite options. Respite, is not a service covered through medical insurance policies – leaving the Department of Health, for many families the only resource available for respite.

Thank you for time and consideration in passing SB422.

Hawai'i Alliance for Retired Americans

An affiliate of the Alliance for Retired Americans
c/o AFSCME · 888 Mililani Street, Suite 101 · Honolulu, Hawaii 96813

AFT Hawaii Retirees

HGEA Retirees

HSTA – Retired

ILWU Retirees

Kokua Council

Machinists Union Retirees

UPW Retirees

ADA/Hawaii

Hawaii Family Caregivers Coalition

(Submitted by email to: HMSTestimony@Capitol.hawaii.gov February 7, 2009)

Joint statement of Al Hamai, President, and Carol Nitta, Legislative Committee
Member, Supporting SB 422, Relating to Health

Joint Hearing of the Senate Committees on Human Services and Health

February 10, 2008, 1:15 p.m. Conference Room 016

Chair Suzanne Chun Oakland, and Members of the HMS Committee,
and Chair David Y. Ige and Members of the HTH Committee,

We are submitting testimony on behalf of HARA in support of SB 422.

The purpose of this bill is to restore funds, already provided by law, to provide continued support for families of individuals with disabilities through the implementation of the Department of Health respite services program.

We clearly understand the need for family caregivers to have some respite from their 24/7 responsibilities of caregiving for much need rest and to take care of personal matters. This program has been an extremely beneficial program.

HARA urges the Senate Human Services Committee and the Senate Health Committee to approve SB 422. Mahalo.

HARA is a strong voice for Hawaii's retirees and seniors. HARA is an educator, a grassroots organizer, a communicator and a trusted source of information for decision-makers. HARA is a diverse community-based local organization with national roots where our members decide our priorities. We are 21,000 strong and growing.

TO: COMMITTEE ON HUMAN SERVICES
TO: COMMITTEE ON HEALTH
RE: Testimony on SB 422 RELATING TO HEALTH, SB 821 RELATING TO ELDER CARE, SB 824
RELATING TO LONG TERM CARE
HEARING: Tuesday, Feb. 10, 2009, 1:15 p.m.
State Capitol Conference Room 016

As a Social Worker with practice experience in gerontology and long term care and cognizant of increasing aging and longevity in our community, I wish to offer supportive testimony on these 3 bills.

SB 442: The appropriating of funds to the Dept. of Health for the continued provision of respite services for Family Caregivers is needed. More Family Caregivers are "on line" than last year, as kupuna continue to wish to live in their own homes and surrounded by family and friends and love.

SB 821: As our 75 and older population continue to grow, and demands for services means that "wait lists" inevitably grow, it is crucial that we develop a system of voluntary payments or a portion thereof. It is also crucial that we allow the system of services, focused on home and community-based care, to be more client-centered and client-directed. Thus "Cash and Counseling" is a process that needs to be implemented.

SB 824: We must continue the work of planning, and implementing a statewide system of ADRCs. The ADRC is not only the "new way and face" of delivering aging services, but makes such delivery more effective, timely and cost-effective.

Mahalo for your consideration of these bills, each of which contribute to the building of a home and community-based services infrastructure for a society in which people are living longer and longer.

John A. H. Tomoso, MSW, ACSW, LSW
51 Ku'ula Street
Kahului, Maui, Hawai'i 96 732-2906
jtomoso@hawaii.rr.com

BCC: Maui JACOSA ListServe, Maui County State Legislators

**Joe D'Alessandro
Colleen Pegg**

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joe@joedalessandro.com
Feb. 5 2009

The Honorable Suzanne Chun Oakland, Chair
Senate Committee on Human Services
and
The Honorable David Y. Ige, Chair
Senate Committee on Health
Twenty-Fifth Legislature
State Capitol
State of Hawaii
Honolulu, Hawaii 96813

SUBJECT/RE: SB 422 – RELATING TO HEALTH

Dear Senators Chun Oakland and Ige and Members of the Committee:

Our names are Joe D'Alessandro and Colleen Pegg. We have a son named Matthew D'Alessandro who is currently 8 years old, has been diagnosed PDD-NOS, doesn't speak at all and has behavioral problems and severe learning disabilities. We strongly support passage of SB 422

The passage of SB 422 will help reduce the threat of out of home placement, helps to preserve and strengthen our family by providing respite services we desperately need, and helps mitigate the threat of abuse or neglect our non verbal child would face in an out of home situation. We currently receive PA services from DD and will most likely need respite in the near future.

A cut in these services would severely impact our ability to survive financially and as a family unit. We would need to cut our work hours to care for our son, which would put our family in jeopardy of losing our home.

We therefore strongly support SB 422 and urge you and your committee to also. Thank you for your interest and concern about individuals with special needs and their families.

Aloha,

Joe D'Alessandro,
Colleen Pegg
808-242-1100

Jan M. Tateishi
7182 Kamilo Street
Honolulu, Hawaii 96825
Work Number: 586-8126

February 6, 2009

The Honorable Suzanne Chun Oakland, Chair
Senate Committee on Human Services

And

The Honorable David Y. Ige, Chair
Senate Committee on Health
Twenty-Fifth Legislature
State Capitol
State of Hawaii
Honolulu, Hawaii 96813

SUBJECT/RE: SB 422 – RELATING TO HEALTH

Dear Senators Chun Oakland and Ige and Members of the Committee:

My name is Jan Tateishi and I am the parent of Daren Tateishi, a young adult with a developmental disability. I strongly support the passage of SB 422.

Respite services have positively impacted our family over the years. It preserved our family unity, strengthened our marriage, and helped to create a nurturing environment for other family members. As a result of these services, our family has been able to give back to our community through volunteerism and civic service many times over.

I do believe that if respite services are reduced, families will be forced to make decisions that will create significant hardships for them, including, out-of-home placements, reducing their work hours or even being forced to quit their jobs. In the long run, this in itself would more costly for the state.

I strongly support SB 422 and urge you and your Committee to support the bill to preserve the 'ohana' of Hawai'i. Thank you for your concern and commitment to individuals with special needs and their families.

Warmest aloha,

Jan M. Tateishi

Susan Rocco
1716 Piikea Street
Honolulu, HI 96818

February 10, 2009

The Honorable Suzanne Chun Oakland, Chair
Senate Committee on Human Services

And

The Honorable David Y. Ige, Chair
Senate Committee on Health
Twenty-Fifth Legislature
State Capitol
State of Hawaii
Honolulu, Hawaii 96813

TESTIMONY: SB 422 – RELATING TO HEALTH

Dear Senators Chun Oakland and Ige and Members of the Committee:

I am a single parent with a 27 year old son, Jason, who has significant cognitive disabilities and serious health conditions. I'm writing in strong support of SB 422.

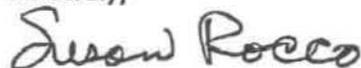
With the current economic downturn I, like so many other citizens, see the necessity of belt-tightening and personal sacrifice. However, with the Department of Health Respite Fund's reduction by 75% in the upcoming budget, I feel compelled to appeal to your committees to reconsider such a drastic cut to an essential family support service.

I like to think of my self as a competent employee, a responsible neighbor, and a nurturing parent, but in truth, I would never be able to manage a full time job and the medical and physical demands of caring for Jason at home without having period breaks from caregiving to catch my breath and replenish my batteries. For many families like mine, respite services allow us to keep the family together and have a reasonable quality of life.

The Department of Health's Respite Fund has served thousands of families since its creation in 1990 with relatively low amounts of funding. Most of the respite care is provided by friends and neighbors at an average reimbursement of \$5-10 an hour. Many families manage with as little as \$500 a year in respite reimbursement. This tiny investment in families pays off big dividends by preventing the need for more restrictive care facilities and additional social services.

I urge you to maintain this invaluable family support service. It's just not fair or fiscally responsible to yank this safety net from under us.

Sincerely,



Susan Rocco
(808) 422-5759