



STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
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March 13, 2008

The Honorable Suzanne Chun Oakland, Chair
Senate Committee on Human Services and Public Housing
Twenty-Fourth Legislature
State Capitol
State of Hawaii
Honolulu, Hawaii 96813

Dear Senator Chun Oakland and Members of the Committee:

**SUBJECT: HB 3352 HD2 - RELATING TO AN AUDIT OF THE HAWAII
DISABILITY RIGHTS CENTER**

The position and views expressed in this testimony do not represent nor reflect the position and views of the Department of Health.

The State Council on Developmental Disabilities (DD) would like to offer comments on **HB 3352 HD2**. The purpose of the bill is to require the Auditor to conduct a financial and management audit of the Hawaii Disability Rights Center (HDRC).

We appreciate the Legislature's concern about HDRC's handling of State funds and its approach to resolving the conflict between a patient's right to privacy and its need for access to patient and the patient's records. The Council does not feel that a financial and management audit is necessary for the following reasons:

- 1) The Council, HDRC and the University of Hawaii, Center on Disability Studies (UH-CDS) have specific roles and responsibilities under the DD Assistance and Bill of Rights Act of 2000 (P.L. 106-402). In summary, DD Councils are required to engage in advocacy, capacity-building, and systemic change activities; Protection and Advocacy (P&A) systems (HDRC) are required to protect the legal and human rights of individuals with DD and their families; University Centers for Excellence in DD education, research and service (UH-CDS) are required to provide interdisciplinary pre-service preparation and continuing education, community service, research, and disseminate information.

All three agencies are required to submit an annual program performance report and semi-annual financial status reports to the U.S. Department of Health and Human Services, Administration on DD.

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- 2) With regard to the P&A systems, the law [Sec.143. (a)(2)(A)(B)] provides that the system shall have the authority to: a) pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for the rights of individuals with DD; and b) to investigate incidents of abuse and neglect (see attached).
- 3) Sec. 143. (a)(2)(I) of the law provides access to all records of any individual with DD (see attached).

It is our understanding that HDRC also operates other P&A programs which require them to complete and submit program and financial reports. Should the Legislature decide that it is still necessary to add another financial and management review of HDRC, we are confident that they will fully cooperate in the audit.

Thank you for the opportunity to submit testimony in opposition to HB 3352 HD2.

Sincerely,



Waynette K.Y. Cabral
Executive Administrator

An Act

To improve service systems for NOTE: Oct. 30, 2000 - [S. 1809] individuals with developmental disabilities, and for other purposes.

Be it enacted by the Senate and House of NOTE: Developmental Disabilities Assistance and Bill of Rights Act of 2000. Representatives of the United States of America in Congress assembled.

SUBTITLE C- PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS

SEC. 143. NOTE: 42 USC 15043. SYSTEM REQUIRED.

- (a) System Required.--In order for a State to receive an allotment under subtitle B or this subtitle--
- (1) the State shall have in effect a system to protect and advocate the rights of individuals with developmental disabilities;
 - (2) such system shall--
 - (A) have the authority to--
 - (i) pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of such individuals within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements, with particular attention to members of ethnic and racial minority groups; and
 - (ii) provide information on and referral to programs and services addressing the needs of individuals with developmental disabilities;
 - (B) have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred;
 - (C) on an annual basis, develop, submit to the Secretary, and take action with regard to goals (each of which is related to 1 or more areas of emphasis) and priorities, developed through data driven strategic planning, for the system's activities;
 - (D) on an annual basis, provide to the public, including individuals with developmental disabilities attributable to either physical impairment, mental impairment, or a combination of physical and mental impairment, and their representatives, and as appropriate, non-State agency representatives of the State Councils on Developmental Disabilities, and Centers, in the State, an opportunity to comment on--
 - (i) the goals and priorities established by the system and the rationale for the establishment of such goals; and
 - (ii) the activities of the system, including the coordination of services with the entities carrying out advocacy programs under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the Older Americans

Act of 1965 (42 U.S.C. 3001 et seq.), and the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (42 U.S.C. 10801 et seq.), and with entities carrying out other related programs, including the parent training and information centers funded under the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.), and activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012);

- (E) establish a grievance procedure for clients or prospective clients of the system to ensure that individuals with developmental disabilities have full access to services of the system;
- (F) not be administered by the State Council on Developmental Disabilities;
- (G) be independent of any agency that provides treatment, services, or habilitation to individuals with developmental disabilities;
- (H) have access at reasonable times to any individual with a developmental disability in a location in which services, supports, and other assistance are provided to such an individual, in order to carry out the purpose of this subtitle;
- (I) have access to all records of--
 - (i) any individual with a developmental disability who is a client of the system if such individual, or the legal guardian, conservator, or other legal representative of such individual, has authorized the system to have such access;
 - (ii) any individual with a developmental disability, in a situation in which--
 - (I) the individual, by reason of such individual's mental or physical condition, is unable to authorize the system to have such access;
 - (II) the individual does not have a legal guardian, conservator, or other legal representative, or the legal guardian of the individual is the State; and
 - (III) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect; and
 - (iii) any individual with a developmental disability, in a situation in which--
 - (I) the individual has a legal guardian, conservator, or other legal representative;
 - (II) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect;
 - (III) such representative has been contacted by such system, upon receipt of the name and address of such representative;...

From: Linda Elento, Member of The Hawaii Down Syndrome Congress

To: COMMITTEE ON HUMAN SERVICES & PUBLIC HOUSING
Senator Suzanne Chun Oakland, Chair
Senator Les Ihara, Jr., Vice Chair

Re: HSP, March 13, 2008, 1:15p

HB3352 In Support

Relating to an Audit of the Hawaii Disability Rights Center.



The federal government provides non-profit agencies and state agencies money directly and expect these agencies (such as Hawaii Disability Rights Center (HDRC), Head Start organizations and the Department of Education) to report to the federal government that they comply with federal law.

The *Individuals with Disabilities Education Improvement Act of 2004* authorizes its grants to fund an advocacy agency to support children with disabilities who need special education and services. To my knowledge, HDRC is the named protection and advocacy center to provide services under the IDEA. But, HDRC selects priority needs that affect the services available to the public. When Free Appropriate Public Education for children with disabilities is not a priority for HDRC, the protection and services are hindered for families with children with disabilities who desperately need help (regardless of their income levels) in obtaining the services and accommodations they are mandated by federal and state laws to receive. My family has proven that the State spends thousands of dollars for us to take our matters to administrative hearings, court reporter services, and federal court). This process is a physical, mental, emotional, and financial drain on families and state resources.

We ask the Legislature to assure the State's needs are being met when these agencies are allowed to decide whom to serve, when to serve, how to serve, in spending federal and state tax dollars and reporting their own information. Please don't assume the federal government provides an audit to determine what our State's needs are and that the funded agency is serving such needs.

Over the past 3 ½ years I have contacted HDRC about four or five times, at least twice we were denied assistance. I found to have worked with HDRC personnel a waste of time when I sought help for my son's special education and medical and language needs. Even after the court allowed a settlement between Developmental Disability Division and HDRC (which applied to my son's case), it took months before I received the assistance of an HDRC representative, which in the end (7 MONTHS LATER) only served the purpose of attending meetings with DDD to apply for Medicaid through the Department of Human Services, receiving evaluations, completing forms, meetings, and then being denied all services and funding; DDD determines that a child's needs are the "parent's responsibility," so services that would ordinarily be provided for an adult would not be provided to a child with the same needs.

These great needs of our children with disabilities and their families warrant a thorough audit and complete support of the protection and advocacy agency which is given the money and authority to serve these children. Thank you for the opportunity to provide testimony.

TESTIMONY IN SUPPORT OF HB 3352 HD2
And SUGGESTED AMMENDMENT

TO: Senate Committee on Human Services and Public Housing

FROM: Ronald R. Renshaw

RE: House Bill 3352 HD2
Relating to an audit of the Hawaii Disability Rights Center

HEARING: Thursday, March 13, 2008 at 1:15 p.m.
Conference Room 016, State Capitol

Dear members of the Senate Committee on Human Services and Public Housing,

Thank you for this opportunity to provide **testimony in support of HB 3352 HD2**. I support this bill for the following reasons:

It is important that agencies expending state funds be subject to review by the state. Apparently, the agency designated by state law as Hawaii's Protection and Advocacy (P&A) System, the Hawaii Disability Rights Center (HDRC), has not been subject to any state review or oversight in the 30 years since its designation. An audit would ensure that the P&A system's use of public funds is appropriate, efficient, and in conformance with the expectations of the legislature. **However, I respectfully request that the Committee favorably consider amending HB 3352 HD2 to reinstate the effective date of July 1, 2008.**

A report from the Attorney General's Office, dated September 14, 2007, establishes that, "... *there is authority for the Legislature to direct the auditor to conduct an investigation ... under the DD Act and its regulations, the State (Governor) is responsible for designating a P&A system initially and can redesignate the P&A for 'good cause' Section 104(a)(4) of the DD Act: 45 CFR 1386..20 ... and in fact, the State is responsible for making the 'good cause' determination. If there is evidence that indicates a redesignation of HDRC as the State's P&A agency ought to occur, there are federal procedures which must be followed.*" An audit should provide the state with the information necessary for decision making in its provision of oversight.

The requested audit would also ensure that the legislature is aware of the manner in which the P&A system is carrying out its monitoring and advocacy activities. An audit could address the conflict between the P&A system's right to access people with developmental disabilities and their records, and an individual's (and that individual's family's) right to privacy. It could assess the P&A system's criteria for choosing between litigation and some alternative means of dispute resolution. It could also determine what the P&A system's procedure is for resolution of complaints and/or grievances.

Thank you again for this opportunity to provide testimony in support of HB 3352 HD2.

testimony

From: Ethel Yamane [ehy@hawaii.rr.com]
Sent: Tuesday, March 11, 2008 3:57 PM
To: testimony
Cc: HPPR@hawaii.rr.com
Subject: Testimony on HB#3352 HD 2 relating to an audit of HDRC. Hearing on 3/13/08, 1:15 pm. conf.rm016, Senate Human Services Com

Testimony on HB #3352 HD 2

Relating to An Audit of the Hawaii Disability Rights Center

As a concerned citizen, I have observed the struggles of private providers of services to persons with developmental disabilities in providing guidance, protection, education in an environment comparable to any other services for other citizens within the state. As a former administrator with the Department of Health which provided funding and oversight to these private providers of services, I have always marveled at the dedication, patience and sincere interest of the staff working with the clients. When I look back on the Waimano Institution for the mentally retarded and the care of the mentally challenged in the community today, there is no comparison. The clients in the community are really enjoying a normal life in the community.

The Hawaii Disability Rights Center has a right to advocate for persons with disabilities but the persons with developmental disabilities also have the right to privacy. Only when there are specific complaints on someone, the record should be open to HDRC. Otherwise, it will be like a witch hunt looking to find something to charge the providers with. The providers are regularly monitored for compliance by the licensing agency, the funding agencies, both Federal and State. Abuse cases are also reported to the Adult Protective Services of the Department of Human Services.

HDRC has hired attorneys to charge different programs with non-compliances and have made monetary settlements with the programs involved. The private agencies do not have the funds to be paying thousands of dollars to HDRC. Their funds really need to be used to care for the persons with disabilities.

In view of the ongoing disputes with HDRC, an audit of the agency's management and funding activities are warranted. I would also recommend that the audit be completed by January 1, 2010 rather than January 1, 2050.

Respectfully submitted,
Ethel Yamane

testimony

From: hppr@hawaii.rr.com
Sent: Tuesday, March 11, 2008 3:45 PM
To: testimony
Subject: Testimony in support of HB 3352 HD2 with suggested amendments

TESTIMONY IN SUPPORT OF H.B. # 3352 HD 2
With Suggested Amendments

TO: Senate Committee on Human Services and Public Housing
FROM: Yvonne de Luna
RE: House Bill # 3352, HD2
RELATING TO AN AUDIT OF THE HAWAII DISABILITY RIGHTS
CENTER
HEARING: Thursday, March 13, 2008, 1:15 pm
Conference Room 016, State Capitol

Dear Members of the Senate Committee on Human Services:

I am submitting this testimony in support of House Bill # 3352 HD2, which requires the auditor to perform a financial and management audit of the Hawaii Disability Rights Center (HDRC), currently the state's designated protection and advocacy (P&A) agency. I am also asking for you to reinstate the effective date to July 1, 2008, and to consider periodic audits of our P&A system as a means of oversight.

I support this bill for several reasons:

First of all, HDRC's overall financial accountability, operations, effectiveness of governance, and appropriate administration of programs and services has not been reviewed by the state since its inception 30 years ago. I believe our state needs to ensure the agency it designated is attaining the objectives and results expected of them while also examining how well they are organized and managed and how efficiently they acquire and utilize resources. Protection and Advocacy systems are required in order for a state to receive federal allotment for state councils on developmental disabilities or for the protection and advocacy of individual rights. Thus, appropriate and efficient utilization of these funds/resources in our state and an assessment of its direct impact on our community should be reviewed by our state on a regular basis.

The Developmental Disabilities Act, a federal law, which led to the creation of P&A agencies such as HDRC, requires a review by Congress every 7 years. It seems even Congress felt it was necessary to do a periodic review on its laws.

Secondly, I support the idea that, through this audit, the Legislature and the Governor, will have the opportunity to receive a thorough assessment and hopefully, recommendations, which could reinforce or help to change and/or improve our P&A system, its policies, financial, program, operation and/or administration management. Although HDRC has some federal oversight, our state should conduct its own evaluation.

Families/guardians, persons with disabilities, service providers and concerned individuals have raised their concerns as to how HDRC resolves conflicts between a patient and their rights to privacy, conflicts on the service providers' obligations to disclose patient information and records to HDRC, and conflicts on the justification and manner in which HDRC demands from service providers and their families/guardians unrestricted and unaccompanied access to the patient and the patient's records. Moreover, how HDRC handles abuse and neglect complaints, how it determines the merit of litigation as opposed to other means of dispute resolution and how it handles complaints/ grievances against it, needs to receive its overdue evaluation.

"There is authority for the Legislature to direct the auditor to conduct an

investigation," according to our state's Attorney General (AG) report in Sept. and Oct. 2007. Since our public agencies are subject to state audits, there should be no reason to exempt HDRC from such oversight.

It had been suggested in the AG's report that perhaps our P&A's efforts should focus on augmenting current services and not duplicating them. Regulations do not directly address this potential redundance in service with other statewide advocacy programs. This certainly is something that auditor can look into.

I feel it is the right time for government and the community to re-visit and discuss the values we hold with regards to the care and protection of people with disabilities, the intent of the laws, and to determine if the law or the manner in which it is implemented need to change. I believe it is also the right time for a fresh pair of eyes to look at what HDRC is doing and how well it is performing its job. Without an audit, there would be no gauge for our Governor and the legislature to determine if the system it created really works.

Thank you and I hope to gain your support for this bill.

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