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HOUSE OF REPRESENTATIVES
THE TWENTY-FIFTH LEGISLATURE
REGULAR SESSION OF 2009

Committee on Human Services

Comments on S.C.R. No. 90, S.D. 1, Urging the United States Congress to Oppose Specified Proposed Rule Amendments for the Developmental Disabilities Program

Friday, April 24, 2009, 11:35 a.m.
Conference Room 229

Chair Mizuno and members of the committee:

My name is John P. Dellera, Executive Director of the Hawaii Disability Rights Center (HDRC). I am testifying to offer comments on this measure.

This resolution would urge the Congress to limit the authority of protection and advocacy agencies to investigate abuse and neglect of individuals with developmental disabilities, including cases that present egregious threats to lives and safety.

This measure is seriously misguided. There is no question that the people of Hawaii support the national effort to protect and advocate for individuals who are unable to protect themselves. The most vulnerable members of our community are at risk of exploitation, abuse, and neglect, which is why Congress enacted laws to protect them and Hawaii established its own P&A agency to investigate violations of those laws; States are required to establish P&As as a condition to receiving federal funds. We have seen cases in Hawaii in which care home operators have failed to care for disabled residents with tragic results. No one can argue that those residents should not be protected or that providers should be beyond scrutiny.

The changes in federal law that this resolution would oppose have been proposed by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services, the federal agency with expertise in the field. The rules are carefully tailored to address problems that have arisen in the past, and there is no legitimate reason why the Hawaii Legislature should oppose them.

1. Definition of "Abuse" – The proposed change to 45 C.F.R. § 1386.19 ("Definitions") would retain the specific examples of abuse contained in present law and allow P&As to determine, in their discretion, whether "repeated and/ or egregious violations of an individual's statutory or constitutional rights amounts to abuse." The example provided in

the regulation is "significant financial exploitation that may prevent the individual from being able to provide for his or her basic needs such as food and shelter." SCR 90, SD1 does not explain why such cases should not be fully investigated, yet that would be the result if the resolution were implemented.

SCR 90, SD1 is inaccurate to the extent it says the federal amendments would allow P&As "wide discretion" in defining abuse. They would not. The amendments would retain current examples of abuse and neglect which have been construed by federal and state courts in decisions that are binding on P&As. The amendments add "significant financial exploitation that may prevent the individual from being able to provide for his or her basic needs such as food and shelter." It is difficult to imagine what legitimate public interest would be served by omitting the new language.

2. Definition of "Probable Cause" – The proposed rule would make two changes: first, probable cause would be expanded to include reasonable grounds for belief "that the health or safety of the individual is in serious and immediate jeopardy"; second, a sentence is added, stating, "[t]he P&A system is the final arbiter of probable cause between itself and the organization from whom it is seeking records."

   There is no legitimate reason to prevent P&As from investigating private providers where the facts show a reasonable basis to believe that an individual's health or safety is in immediate jeopardy. The issue, therefore, seems to be whether the proposed amendments "eliminate judicial review" of a P&A's finding of probable cause. They would not. The Preamble states that expressly:

   > "[t]he definition is not intended to affect the authority of the courts to review the determinations of P&As of whether probable cause exists."

   73 Fed. Reg. 19714 (Apr. 10, 2008). SCR 90, SD1 is fundamentally flawed because it is based upon a misconception of the proposed federal amendments.

3. Power of Guardians and Families – The resolution overstates the issue and is misleading to the extent it says that the federal amendments would "reduce the power of guardians and families." In fact, the proposed changes would dispense with a guardian or legal representative's permission to access confidential records only in case of the death of a disabled individual or where there is probable cause to believe an individual "is in serious or immediate jeopardy."

   We recognize that difficult questions may arise when guardians and legal representatives do not consent to give a P&A access to confidential records. Their wishes should be respected and in most cases followed, but there are exceptional cases where guardians or relatives could be responsible for abuse or neglect, and delay in obtaining information could jeopardize the health or safety of their ward. No legitimate public policy is served in such cases by allowing wrongdoers to hide behind claims of privacy.

4. Confidentiality of P&A Investigations – The resolution suggests that under proposed 45 C.F.R. § 1386.28, P&As may "continue to endanger persons by refusing to share vital information regarding abuse and neglect with state and local law enforcement agencies." The suggestion is unwarranted, and the interpretation of the proposed rule is mistaken.

   Contrary to SCR 90, SD1, the proposed rules actually authorize P&As to report confidential information to law enforcement agencies when (i) a complaint of abuse or neglect is filed, (ii) the P&A has probable cause to believe abuse and neglect has taken place or may occur, (iii) the P&A has probable cause to believe that the health or safety of a disabled individual is in serious jeopardy, or (iv) the death of an individual the P&A believes was developmentally disabled.

5. Redesignation of P&As – SCR 90, SD1 incorrectly states that the proposed federal rules would reduce the State's power to redesignate its P&A. The current rule, 45 C.F.R. § 1386.20, allows the Governor of Hawaii to redesignate the State's P&A agency "for good cause." The proposed rule is essentially the same.

Federal law allows States to designate state agencies as P&As, as long as they are not direct service providers. Nevertheless, most P&As are nonprofit organizations that are independent of state control. The reason for this is clear: in some cases, state agencies may share responsibility for mistreating individuals with developmental disabilities through inadequate funding, oversight, or enforcement. Agencies that are independent of the state may be best able to investigate such cases, rather than relying upon the state to investigate itself.

In any event, while the relationship between P&As and the State is a subject the Legislature may properly consider, we submit that SCR 90, SD1 is not the means to do so. The resolution apparently arises from a dispute between HDRC and a private provider which is within the jurisdiction of the federal court in a pending lawsuit. We submit that it is inappropriate for the Legislature to take sides in that dispute before the court has ruled.

Thank you for your consideration of our comments.

DATED: Honolulu, Hawaii, April 22, 2009.

HAWAII DISABILITY RIGHTS CENTER

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John P. Dellera
Executive Director

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From: hppr@hawaii.rr.com
Sent: Thursday, April 23, 2009 12:21 PM
To: HUStestimony
Subject: Testimony in support of SCR 90 SD1

TESTIMONY IN SUPPORT OF SCR #90 SD1

TO: House Committee on Human Services

FROM: Yvonne de Luna and Ronald Renshaw

RE: Senate Concurrent Resolution # 90 SD 1
URGING THE UNITED STATES CONGRESS TO OPPOSE SPECIFIED PROPOSED RULE AMENDMENTS
FOR THE DEVELOPMENTAL DISABILITIES PROGRAM, 73 FED. REG. 19,708 (APRIL 10, 2008) (TO BE CODIFIED AT 45 C.F.R. PT. 1385-88) THAT IMPLEMENT THE DEVELOPMENTAL
DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT OF 2000, AND TO SUPPORT NEW SECTIONS IN THE UPCOMING REAUTHORIZATION.

HEARING: Friday, April 24, 2009, 11:35 am
Conference Room 229, State Capitol

Dear Members of the House Committee on Human Services:

We are submitting this testimony in support of SCR # 90 SD 1, which urges Congress to oppose the specified proposed rule amendments published on April 10, 2008, in the federal register (73 Fed. Reg. 19,708) that implement the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) and to support new sections in the upcoming reauthorization.

We are in favor of this resolution for several reasons:

First of all, the resolution expresses the overall sentiment and reiterates concerns raised by state legislators, government agencies, service providers, families/guardians and individuals with disabilities over the last few years with regards to current federal laws and rules applicable to state designated protection and advocacy systems. The resolution concludes that there is a need for clarification and changes to the DD Act and suggests that Congress address these concerns in their deliberation of the DD Act's reauthorization.

The April 10, 2008, specified proposed rule amendments to the Developmental Disabilities and Bill of Rights Act (DD Act), aimed to expand the powers of protection and advocacy agencies, which we feel could have a negative impact on the environment in which people with disabilities and their families receive services and exercise their rights. These proposed rules prompted opposition from the American Health Care Association (AHCA) together with the National Center for Assisted Living (NCAL), which make up 11,000 non-profit and for-profit long-term care providers. These proposed rules also met opposition from a national advocacy organization representing individuals with mental retardation and developmental disabilities and their families, as well as local government entities, service providers and individuals from our state.

Although the specified April 10, 2008, proposed rules may currently be on permanent hold due to technicalities and administration changes at the federal level, there is a concern that these rules may be revived as the DD Act is considered for reauthorization by Congress this year.

Finally, if approved, we hope this resolution will draw Congress' attention to the DD Act's impact and potential conflicts with the state's oversight authority, other state entities, service and health care providers, and the rights of individuals with disabilities and their families/guardians.

Thank you and we hope to gain your support for this resolution.

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TESTIMONY IN SUPPORT OF SCR #90 SD1

TO: House Committee on Human Services

FROM: Peggy Oshiro

RE: **Senate Concurrent Resolution # 90 SD 1**
URGING THE UNITED STATES CONGRESS TO OPPOSE SPECIFIED PROPOSED RULE AMENDMENTS FOR THE DEVELOPMENTAL DISABILITIES PROGRAM, 73 FED. REG. 19,708 (APRIL 10, 2008) (TO BE CODIFIED AT 45 C.F.R. PT. 1385-88) THAT IMPLEMENT THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT OF 2000, AND TO SUPPORT NEW SECTIONS IN THE UPCOMING REAUTHORIZATION.

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I believe that our country was built on a check and balance within our government so no agency should be unchecked even if they are the agency that oversees service providers.

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