NEIL ABERCROMBIE GOVERNOR OF HAWAII



STATE OF HAWAII DEPARTMENT OF HEALTH P.O. Box 3378 HONOLULU, HAWAII 96801-3378

In reply, please refer to:

DIRECTOR OF HEALTH

House Committee on Health

#### H.C.R. 17, Requesting the Department of Health Developmental Disabilities Division to Establish a Task Force to Review Hawaii's Statutory Definition of Developmental Disabilities

## Testimony of Lynn N. Fallin Deputy Director, Behavioral Health Administration

#### February 26, 2014

**Department's Position:** The Department strongly supports this measure to create a task force to study
the implications and opportunities by revising the Statutory definition of Developmental Disabilities in

3 HRS 333F-1.

4 Fiscal Implications: None.

**Purpose and Justification:** Currently the Department interprets eligibility based upon the State's 5 definition to mean that not all persons with mental or physical disabilities are eligible for the Medicaid 6 7 Home and Community Based Alternative Services Waiver program (HCBS). Since 1986, the United 8 States Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS) has enforced a "related conditions" rule for Medicaid HCBS and ICF/MR (institutional) eligibility. This 9 rule decouples the eligibility for Medicaid programs from the Federal Definition of Developmental 10 11 Disabilities in the DD Act of 2000. This does not allow persons with mental illness or persons with physical disability not meeting the CMS amended functional limitations standards to participate in these 12 community based programs that replaced the institutional model of care at Waimano Traning School and 13 Hospital in Hawaii. This creates a delimma for the Department of Health finding that some persons are 14 Promoting Lifelong Health & Wellness

1	eligible for ca	se management but not the HCBS Medicaid program. The federal definition of			
2	developmental disabilities is a legal and not a clinical definition and was meant for states to further				
3	define. Hawaii is one of three States that solely utilize the Federal Definition of Developmental				
4	Disabilities found in USC. Many States have added categorical eligibility language to their statute.				
5	These options can both expand and restrict the designated population being served by the Department of				
6	Health Developmental Disabilities Division. The task force will need to determine the needs and costs				
7	of persons that could be served and make recommendations to the Legislature.				
8	Hawaii Revised Statute 333F-1 defines Developmental Disabilities as follows:				
9	"Developmental disabilities" means a severe, chronic disability				
10	of a person which:				
11	(1)	Is attributable to a mental or physical impairment or			
12		combination of mental and physical impairments;			
13	(2)	Is manifested before the person attains age twenty-two;			
14	(3)	Is likely to continue indefinitely;			
15	(4)	Results in substantial functional limitations in three or			
16		more of the following areas of major life activity; self-			
17		care, receptive and expressive language, learning,			
18		mobility, self-direction, capacity for independent living,			
19		and economic sufficiency; and			
20	(5)	Reflects the person's need for a combination and sequence			
21		of special, interdisciplinary, or generic care, treatment,			
22		or other services which are of lifelong or extended			
23		duration and are individually planned and coordinated.			

1	The Health Care Financing Administration (HCFA), now known as the Centers for Medicare and			
2	Medicaid Services (CMS) issued a proposed rule in February 1983[i] that was intended to: (a) decouple			
3	the definition of "related conditions" for purposes of Medicaid policy from the definition of the term			
4	"developmental disability" within the federal Developmental Disabilities Act; and (b) clarify the			
5	circumstances under which an individual could be considered eligible for ICF/MR services (and, by			
6	extension, home and community-based waiver services) on the basis of a "related condition." This new			
7	regulatory definition, which was finalized in a rule issued by HCFA on May 28, 1986, [ii] was based on			
8	the language of the DD Act, except that:			
9	• In addition to meeting the age of onset and modified functional criteria spelled out in the DD			
10	Act, an individual had to be diagnosed as having cerebral palsy, epilepsy, or " any other			
11	condition, other than mental illness, found to be closely related to mental retardation because			
12	this condition results in impairment of general intellectual functioning or adaptive behavior			
13	and requires treatment or services similar to those required by these persons" [emphasis			
14	added].[iii]			
15	• An individual must have substantial limitations in three out of six (rather than three out of			
16	seven) major areas of life functioning in order to qualify for Medicaid long-term care			
17	benefits. HCFA eliminated "economic self-sufficiency" from the list of major areas of life			
18	functioning on the assumption that, for the vast majority of persons with lifelong			
19	developmental disabilities who require ongoing long-term services, the capacity to become			

- 20 economically self-sustaining is not a reasonable life goal.
- 21 HCFA officials later issued interpretative guidance in an attempt to clarify the circumstances under

22 which a person with a developmental disability caused by a condition other than mental retardation,

23 cerebral palsy or epilepsy would qualify for Medicaid-funded long-term services.

24 Thank you for the opportunity to testify on this measure.



LATE

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES 919 ALA MOANA BOULEVARD, ROOM 113 HONOLULU, HAWAII 96814 TELEPHONE: (808) 586-8100 FAX: (808) 586-7543 February 26, 2014

The Honorable Della Au Belatti, Chair House Committee on Health Twenty-Seventh Legislature State Capitol State of Hawaii Honolulu, Hawaii 96813

Dear Representative Au Belatti and Members of the Committee:

#### SUBJECT: HCR 17– Requesting the Department of Health Developmental Disabilities Division to Establish a Task Force to Review Hawaii's Statutory Definition of Developmental Disabilities

The State Council on Developmental Disabilities (DD) **SUPPORTS HCR 17**. This concurrent resolution will address the current statutory definition of developmental disabilities in comparison to other states and study the impacts of changing the definition of DD.

In addition to comparing other states definitions and impacts of changing the definition of DD, the Council urges the task force to identify strategies to address how to best meet the growing demands for services in supporting individuals with DD and their families in light of ongoing competing and limited state resources.

The current statutory definition as noted on Page 1, lines 15-28, is consistent with the Federal definition as defined in P.L. 106-402 with the exception of the following clause, "An individual from birth to age nine, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described above, if the individual, without services and support, has a high probability of meeting those criteria later in life." We support the inclusion of this part of the definition to be addressed by the task force.

We bring to your attention a typo on Page 2, line 30, the word "of" should be "or" to read, "BE IT FURTHER RESOLVED the Director <u>or</u> the Director's designee…"

The Honorable Della Au Belatti Page 2 February 26, 2014

With respect to the membership of the task force, we respectfully ask that HCR 17 be amended to include the following entities to be specifically listed as members as they represent individuals with intellectual and developmental disabilities and families who have been directly impacted by the current definition, and who would be directly impacted by any change in the definition of DD:

- 1. Family Voices of Hawaii
- 2. Hawaii Self-Advocacy Advisory Council
- 3. Hilopa'a Family to Family Health Information Center
- 4. Special Parent Information Network

The Council looks forward to working with the Department of Health DD Division and the task force in carrying out the activities of the concurrent resolution.

Thank you for your consideration of the proposed amendment in our testimony in **support of HCR 17.** 

Sincerely,

Wayhette K.Y. Cabral, MSW Executive Administrator

J. Curtis Tyler, III Chair

# HAWAI'I SELF-ADVOCACY ADVISORY COUNCIL

February 26, 2014

The Honorable Representative Della Au Belatti, Chair House Committee on Health Twenty-Seventh Legislature State Capitol State of Hawaii Honolulu, Hawaii 96813

RE: HCR 17 – Requesting the Department of Health Developmental Disabilities Division to establish a task force to review Hawaii's statutory definition of developmental disabilities.

Hearing Date: Wednesday, February 26, 2014 Hearing Time: 10:00 AM Hearing Place: Conference Room 329 State Capitol 415 South Beretania Street

The Hawaii Self-Advocacy Advisory Council (SAAC) is testifying in **support of HCR 17**. SAAC consists of 118 people with a variety of intellectual and developmental disabilities. We work on improving the lives of persons with disabilities. The members of SAAC are leaders in their homes, community, agencies and advocacy groups.

We would like to be included in the task force as a member. As a Statewide advocacy group, we believe that it is important to review the definition of developmental disabilities. We know we can share the needs, supports and services of individuals with a developmental disability. We hope that our participation in this task force will help the people we support.

Respectfully submitted,

Shavanna Mahoe President Hawaii Self-Advocacy Advisory Council



## HAWAII DISABILITY RIGHTS CENTER

1132 Bishop Street, Suite 2102, Honolulu, Hawaii 96813 Phone/TTY: (808) 949-2922 Toll Free: 1-800-882-1057 Fax: (808) 949-2928 E-mail: info@hawaiidisabilityrights.org Website: www.hawaiidisabilityrights.org

## THE HOUSE OF REPRESENTATIVES THE TWENTY-SEVENTH LEGISLATURE REGULAR SESSION OF 2014

## Committee on Health Testimony in Opposition to HCR 17 Requesting the Department of Health Developmental Disabilities Division to Establish a Task Force To Review Hawaii's Statutory Definition of Developmental Disabilities

## Wednesday, February 26, 2014, 10:00 A.M. Conference Room 329

Chair Belatti and Members of the Committee:

The Hawaii Disability Rights Center testifies in opposition to this Concurrent Resolution.

In the wake of many very positive discussions this agency has had with the DD Division in the past few years it was extremely disappointing to see the introduction of this Concurrent Resolution. It might more be appropriately titled "How Can the DD Division Limit Its Legal Obligations to Support Individuals with Developmental Disabilities." In fact, as drafted, this is all that is the intent of this measure.

Hawaii law is very clear in its definition of "developmental disability". However, one problem has been that the Division does not like the definition. As a result, we have been through several administrative hearings with them as they have sought to exclude individuals from eligibility from services based on their different interpretation of what the law should be. Furthermore, they currently are in the process of attempting to promulgate rules which are outside the scope of the current statutory definition. We pointed that out in our testimony at their public hearing.

This, then is little more than an attempt to "warm up" the legislature and use a Task Force to return next session with a bill to change the law to exclude individuals from eligibility. The rationale put forth in the Resolution is that the legislature has not appropriated sufficient funds to the Division to enable them to serve these individual appropriately. However, the Makin Settlement Agreement which resulted from a lawsuit





brought by HDRC against the DD Division requires them to annually assess the needs of the DD population and to seek sufficient resources to fund the waiver programs properly. We submit that instead of seeking to weaken the law and exclude people from the DD system, it would be more appropriate to follow the law and serve these people.

Discussions with the Division in the past few years have centered around how can we ensure that all persons with disabilities receive appropriate services. If the Legislature were inclined to convene a Task Force, we submit that that would be a more appropriate focus. For example, instead of figuring out how to eliminate people from the system, the Task Force should focus on how those with physical vs. cognitive impairments can receive necessary services under the Medicaid Waiver. It could examine how to serve individuals who fall into a gap because they are slightly too high functioning under the current DD criteria. Yet their needs are very real. Their needs go unmet under the current system.

Since the measure references the Department of Human Services, it would be very illuminating to have cross agency meetings to see where we can use all the available waivers to fund and serve different populations. Our current system is so fragmented because of all the "silos" that exist at the federal funding streams. Yet here in Hawaii we are sufficiently integrated with each other than we ought to be able to develop methods and programs to cut across these barriers. If the Legislature wants to create a Task Force, then let's make this inclusive, rather than exclusive and see if we can actually accomplish something comprehensive and positive. Let not the focus of the Task Force be to help DD narrow the current law to exclude people. Let it be to assess the needs of the disability community and analyze the best way to provide services to them. We think that most of us really believe that is where we should be going.

Thank you for the opportunity to testify in opposition to this measure.

From: Sent:	mailinglist@capitol.hawaii.gov Monday, February 24, 2014 4:31 PM
To:	HLTtestimony
Cc:	toddhairgrove@hotmail.com
Subject:	Submitted testimony for HCR17 on Feb 26, 2014 10:00AM

#### HCR17

Submitted on: 2/24/2014 Testimony for HLT on Feb 26, 2014 10:00AM in Conference Room 329

Submitted By	Organization	<b>Testifier Position</b>	Present at Hearing
Todd Hairgrove	Individual	Support	Yes

Comments: As a Disabled person I strongly support this.

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

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