

PRELIMINARY REPORT TO THE
TWENTY-FOURTH LEGISLATURE
STATE OF HAWAI‘I
2007

PURSUANT TO ACT 303, SESSION LAWS OF 2006
ENTITLED, “A BILL FOR AN ACT RELATING TO
DEVELOPMENTAL DISABILITIES”.

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I. INTRODUCTION

In 2004, the Hawaii State Council on Developmental Disabilities (DD) convened a Residential Settings Task Force as requested by Senate Concurrent Resolution 79, Senate Draft (SD) 1, House Draft (HD 1). In 2005, the Legislature adopted House Concurrent Resolution 40 HD 1 requesting that the DD Council continue to convene the Residential Settings Task Force. The resolutions requested that the Task Force identify issues and solutions regarding individuals with DD and their choice of residential setting. The Task Force presented recommendations in its report to the Twenty-Third Legislature Regular Sessions of 2005 and 2006.

One of the recommendations and a priority of the Task Force was to amend Section 333F-2 (c)(9) that addresses provision of community residential alternatives for persons with DD or mental retardation (MR) to include language that enables an individual to live in a residential setting of choice provided that the individual can be sustained with supports, the supports are attached to the person and adequate consideration and recognition is given to the person's safety and well-being.

House Bill (HB) 2098 – A Bill for an Act Relating to Developmental Disabilities was introduced by the Twenty-Third State Legislature Regular Session of 2006 and passed as HB 2098, HD1, SD 1, Conference Draft 1.

As noted in a letter from the DD Council to Governor Linda Lingle, “the passage of the bill marks a significant commitment to provide individuals with DD opportunities to make their own decisions on their life. Furthermore, it recognizes and acknowledges that it is a basic human and civil right to make choices about one's life.” The passage of the bill also assists the State to comply with the Americans with Disabilities Act and the Supreme Court Decision in Olmstead v. L.C., 119 S. Ct. 2176 (1999).

The intent of Act 303 is to enable individuals with DD to exercise their civil rights to make choices about their residential setting. It does not repeal licensing and certification requirements. Furthermore, it does not give an individual “carte blanche” in choice of residential setting. Section 333F-2(d); Hawaii Revised Statutes (HRS) includes language that specifically states, “Provisions for supports and services shall be limited to the amount of resources allocated or available for the purposes of this chapter.”

On July 11, 2006 the bill became law as Act 303, Session Laws of Hawaii 2006 without the Governor's signature pursuant to Section 16 of Article III of the Constitution of the State of Hawaii.

II. PURPOSE

The purpose of Act 303 is to require provision of community residential alternatives for persons with DD or MR to be in a setting of the person's choice if the person with the help of family and friends, if necessary, determines that the person can be sustained with supports, the supports are attached to the person, and adequate consideration and recognition is given to the person's safety and well-being.

Act 303 requires the DD Council to submit a preliminary report to the legislature no later than twenty days prior to the convening of the regular session of 2007 and a final report no later than twenty days prior to the convening of the regular session of 2008. The reports shall contain but not be limited to:

- (1) The number of persons with developmental disabilities or mental retardation who choose to live independently as provided by this Act; and
- (2) The financial impact this Act has had on the State.

Act 303 took effect upon approval on July 11, 2006 and shall be repealed on June 30, 2008, provided that section 333F-2, Hawaii Revised Statutes, shall be reenacted in the form in which it read prior to this Act taking effect. The next two years is a critical period in determining the individual benefits and financial impact of the provisions of Act 303.

A workgroup consisting of representatives from Department of Health (DOH), DD Division and Office of Health Care Quality Assurance (OHCA); Department of Attorney General; and DD Council have met to discuss the implementation of Act 303 and to address the concerns expressed by Governor Lingle in Governor's Message No. 861.

III. GOVERNOR'S MESSAGE NO. 861

On July 12, 2006, Governor Lingle sent a message (Governor's Message No. 861) to Senator Robert Bunda, President of the Senate citing concerns about the need to amend Act 303 in the 2007 Legislative Session. Refer to attached Governor's Message No. 861. Governor Lingle's message includes the following two concerns:

"First, this bill does not state how the person's choice of residential setting is to be made and how the Department of Health (DOH) is to support the choice. Under the current system employed by the Developmental Disabilities Division (DDD) of the DOH, DDD assists clients to locate licensed or certified homes. This bill will create uncertainty over the DOH's role in selection of these residential alternatives even though State money would be spent supporting the individual.

Second, the bill does not specify how to determine whether “adequate consideration and recognition” has been given to the person’s safety and well-being. This bill does not mention licensing or certification requirements, an omission that could lead to an interpretation that this amendment to section 333F-2(c) allows placement in unlicensed or uncertified homes. Allowing placement in unlicensed or uncertified homes poses a risk for the safety and well-being of persons with developmental disabilities or mental retardation because it is only through licensing or certification requirements that safety standards such as criminal history background checks of the home operator and periodic monitoring or unannounced home visits are maintained. Any program that purports to assist the developmentally disabled under the care of the State must include a degree of accountability within the system.”

IV. IMPLEMENTATION OF ACT 303

Through its discussion of how to implement Act 303 and to address the Governor’s concerns, the workgroup identified several issues that have affected implementation.

Issues and Dilemmas

A. Health and Safety

The issue of health and safety continues to be a concern. As stated in Act 303, the statement, “and adequate consideration and recognition is given to the person’s safety and well-being” is open to an array of interpretations by individuals with DD, family members, advocates, service providers, DOH staff, and the state attorney general of what is adequate consideration and recognition. There is acknowledgement that there needs to be a common workable definition of what is adequate consideration and recognition.

The issue of balancing individual choice, assuring health and safety and having immunity from liability continues to be the focus of discussions. This issue has been at the forefront, however, continues to be unresolved.

B. Centers for Medicare and Medicaid Services (CMS) Code of Federal Regulations (CFR) Requirement

CMS does not prescribe to states how to assure and protect health and welfare of individuals in Home and Community-Based Services. Flexibility is given to states on what process is in place to assure that there are safeguards to address health and safety of individuals. In essence, quality assurance is required by CMS, not licensure.

As stated, the Code of Federal Regulations, Sub Part G-Home and Community-Based Services: Waiver Requirements, State Assurances (42 C.F.R. § 441.302) requires states to provide satisfactory assurances. In the area of health and safety, it states, “Assurance that necessary safeguards have been taken to protect the health and welfare of the residents of the services. Those safeguards must include:

- i. Adequate standards for all types of providers that provide services under the waiver;
- ii. Assurance that the standards of any State licensure or certification requirements are met for services or for individuals furnishing services that are provided under the waiver; and
- iii. Assurance that all facilities covered by section 1616(e) of the Act, in which home and community-based services will be provided, are in compliance with applicable State standards that meet the requirements of 45 C.F.R. Part 1397 for board and care facilities.”

(Source: National Archives and Records Administration, Code of Federal Regulations on the Government Printing Office Access site at: www.access.gpo.gov/nara/cfrl)

There are several guidelines and procedures used by OHCA and DD Division regarding assessment, managed/negotiated risk agreement, and adverse event reporting. Assessment information and managed/negotiated risk agreement are used for assisted living facilities. Adverse event reporting are used by DD/MR Medicaid waiver provider agencies, adult foster homes, adult residential care homes, DD domiciliary homes, and consumer-directed employers. Specifically, this form (DHS 519A revised 8/06) “is to identify and follow-up on critical events or incidents that bring harm, or create the potential for harm, to a participant. Event identification and follow-up is an essential component to assure the health and welfare of participants.”

The concern and dilemma surrounding the need to adhere to CMS requirements is that Act 303 will not compromise or jeopardize waiver reimbursements for those individuals opting not to live in only licensed or certified settings. This may not allow these individuals “choice” in selecting a setting of their choice and still receive assistance through federal waiver monies. Current state statutes and administrative rules require licensure and certification of various residential settings and do not address standards for settings other than regulated board and care settings.

The CMS Waiver application requires that states identify if waiver services will be provided in a facility (assisted living, group home etc.) that are subject to the Keyes Amendment. As a result, Hawaii identified the following six types of facilities where waiver services could be provided: 1) Adult Foster Home (AFH), 2) DD Domiciliary Home, 3) Adult Residential Care Home (ARCH), 4) Expanded ARCH, 5) Special Treatment Facility, and 6) Special Treatment Facility/Therapeutic Living Program. If people live in these facilities and receive waiver services, the rules established by the

state for these facilities must be met. If people do not live in any of these six facilities, there are no requirements for situations such as people living with their families, living independently, living with roommates in their own apartment, etc. The issue might be whether some of the living arrangements that people want to live in seem to meet the definition of one of the six listed facilities and be subject to state licensure or certification.

The present budget for Home and Community-Based waiver for persons with DD/MR is approximately \$95 million dollars. This amount includes federal reimbursements (about 58%) and state match funds. The State cannot afford to lose federal reimbursements. The loss of federal funds will result in the State having to provide federal reimbursable services with 100% general funds. Consequently, not maximizing federal funds will require State funds that could have been used to provide increased or additional services.

C. Licensing and Certification (OHCA and DDD)

Currently, the only recognized means of ensuring the health and safety of residents is licensing and certification of residential settings such as AFHs, ARCHs, Expanded ARCHS, Assisted Living Facilities, DD Domiciliary Homes, Intermediate Care Facilities for Persons with MR, Residential Alternatives Community Care Program, Special Treatment Facilities, and Therapeutic Living Programs. OHCA has initiated an enhanced training component to increase the skill level of care providers to address the specific needs of the DD/MR population and DOH is looking at having a training model for providers which would be consistently implemented statewide for individuals with DD/MR regardless of their residential setting or day program.

D. Challenges in finding placements for persons with DD/MR

1. Current residential options are limited to those that require licensure or certification should waiver monies be used.
2. Available residential settings may not be the least restrictive environment and most appropriate setting for an individual or in line with individual choice.
3. Shortage of licensed and certified placements, especially on the neighbor islands limits selection of residential options.

V. NUMBER OF PERSONS WITH DEVELOPMENTAL DISABILITIES OR MENTAL RETARDATION WHO CHOOSE TO LIVE INDEPENDENTLY AS PROVIDED BY ACT 303

Case managers from the DD Division, Case Management and Information Services Branch were asked to provide the numbers of individuals in the following residential setting situations in addition to the number of persons with DD/MR who choose to live independently as provided by Act 303. The data below represents 95% of the DD Division's caseload statewide, therefore, the number of individuals in each area may not represent the total number of individuals.

1. Persons living in a family owned home with a live-in caregiver who is paid.
N = 7
2. Persons living in a home that he/she rents from a landlord with no paid supports. In this situation, the landlord has no interest other than renting the home to the individual.
N = 13
3. Persons living in a home that he/she rents from the landlord and receives paid support from someone coming into the home.
N = 21
4. Persons living in the home of another and does not receive paid Medicaid waiver supports in the home.
N = 18
5. One or two individuals rent a single apartment unit from a landlord. The maximum number of individuals to live in a single apartment is two and rent is not paid by through the Medicaid waiver.
N = 32
6. A person living in the home of a caregiver (non-family) who is paid through the waiver to provide services in the home and the home is not licensed/certified.
N = 7
7. Persons who want to live independently in his/her own home (with or without supports) but would require a rental subsidy to help pay for rent.
N = 27
8. Persons who are not satisfied with their current living arrangement (whether licensed/certified or not).
N = 12

Based on the information above and in addressing this section, there are 27 individuals who want to live independently in his/her own home (with or without supports), but would require a rental subsidy to help pay for rent. These individuals live with their family, relatives, in an ARCH or AFH, are homeless, but remain in their current living situation due to limited resources to assist them to live independently.

VI. FINANCIAL IMPACT ACT 303 HAS HAD ON THE STATE

The fiscal impact of Act 303 is unknown at this time since it has not been implemented. Those 27 individuals who have indicated that they want to live independently in their own home would be able to accomplish this with financial assistance such as a rent subsidy. DOH, Adult Mental Health Division has a Supported Housing/Bridge Subsidy Program that has demonstrated success in allowing individuals with mental illness to live independently in housing of their choice. The program provides a temporary bridge subsidy to assist them with rent payments until they can obtain permanent funding from resources such as Section 8 rent subsidy.

For persons who are receiving waiver services and live in a setting that is not licensed or certified, federal reimbursements may be jeopardized. CMS does not require everyone receiving waiver services to live in a licensed facility, but does require people receiving waiver services and living in one of the six type of facilities designated in Hawaii's waiver to be in compliance with state rules.

The workgroup will further address the financial impact during the next year once implementation of Act 303 begins.

VII. FINDINGS AND RECOMMENDATIONS

The workgroup finds that additional time is needed to fully address the issues and dilemmas noted in Section IV – Implementation of Act 303 before implementation can begin. Discussion and considerations to amend Act 303 include:

1. Clarification of settings (in a setting that the person identifies).
2. Specific criteria to address health and safety.
3. State immunity from liability.
4. Establish a common workable definition of what is adequate consideration and recognition.
5. A certification process that includes criminal history background of potential caregivers.

6. A risk assessment of individuals to match compatibility with caregivers.
7. An "expanded care" option to the current DD domiciliary homes that would open up more placement options to higher level of care clients. This would be modeled after the Expanded ARCHs that allows for an individual requiring professional health services provided in an intermediate or skilled nursing facility to remain in the ARCH.
8. Develop criteria (negotiable and non-negotiable requirements) for a "new" category of a residential option. Such an option should be distinct from the current residential options in terms of benefits to care providers to prevent the risk of an exodus of licensed/certified providers to the lesser level homes.

The workgroup is in the process of drafting amendments to Act 303 and will submit its recommendations to the 2007 Legislature. Once the amendments are finalized, implementation of Act 303 will commence. The workgroup will continue to convene meetings during the next year to monitor implementation. Individuals with DD and family members will be included in the workgroup. A final report will be completed and submitted to the 2008 Legislature.