# PROGRESS REPORT TO THE TWENTY-FOURTH LEGISLATURE STATE OF HAWAI‘I 2008

PURSUANT TO ACT 040, SESSION LAWS OF 2007 ENTITLED, “A BILL FOR AN ACT RELATING TO DEVELOPMENTAL DISABILITIES” REQUIRING THE STATE COUNCIL ON DEVELOPMENTAL DISABILITIES TO SUBMIT A PROGRESS REPORT ON THE NUMBER OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES OR MENTAL RETARDATION WHO CHOOSE TO LIVE INDEPENDENTLY AS PROVIDED BY ACT 303, SESSION LAWS OF HAWAII 2006 AND THE FINANCIAL IMPACT ACT 303 HAS HAD ON THE STATE.

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## I. INTRODUCTION

The Twenty-Third Legislature passed House Bill 2098, House Draft 1, Senate Draft 1, Conference Draft 1, entitled "A Bill for an Act Relating to Developmental Disabilities." It became law without the Governor's signature as Act 303, pursuant to Section 16 of Article III of the State Constitution.

The purpose of Act 303/2006 was to require provision of community residential alternatives for persons with developmental disabilities (DD) or mental retardation (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 also required 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 DD or MR who choose to live independently as provided by this Act; and

(2) The financial impact this Act has had on the State.

A workgroup consisting of representatives from Department of Health (DOH), DD Division, and Office of Health Care Assurance (OHCA); Department of Attorney General; and DD Council met during the interim to discuss the implementation of Act 303 and to address concerns conveyed by Governor Lingle in Governor's Message 861.

Governor Lingle expressed the following 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."

A preliminary report was submitted to the Twenty-Fourth Legislature, Regular Session of 2007. The report identified issues and dilemmas in the area of health and safety; the code of Federal regulations by Centers for Medicare and Medicaid Services (CMS); guidelines and procedures for assessment, managed/negotiated risk agreement, adverse reporting; and licensing and certification by DOH, OHCA, and DDD. Other areas identified for the workgroup to further discuss and address included:

(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) Establishment of 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 (adult residential care homes) that allows for an individual requiring professional health services provided in an intermediate or skilled nursing facility to remain in the ARCH.

(8) Development of 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 agreed that additional time was needed to fully address the issues and dilemmas, and above areas. Therefore, legislation was introduced during the 2007 Legislative Session to extend the repeal date in Act 303/2006. Senate Bill (SB) 820 - A Bill for an Act Relating to Developmental Disabilities was introduced by the Twenty-Fourth State Legislature Regular Session of 2007. The bill passed as SB 820, Senate Draft 1 and on April 25, 2007, it became law as Act 40 without the Governor's signature, pursuant to Section 16 of Article III of the State Constitution.

The workgroup to address Act 40 included representatives from DOH, DD Division, Case Management & Information Services Branch (CMISB) and Developmental Disabilities Services Branch, and OHCA; Department of Attorney General; DD Council; a parent of a son with developmental disabilities receiving services from DDD; and a service provider.

The Olmstead decision (Olmstead v. L.C., 119 S. Ct. 2176 - 1999 continues to provide the legal framework to enable individuals with disabilities to live in the most integrated setting appropriate to their needs. The ruling by the U.S. Supreme Court indicated that it is a violation of the American with Disabilities Act to discriminate against people with disabilities by providing services in institutions when individuals could be served more appropriately in community settings.

Olmstead and Chapter 333F, Hawaii Revised Statutes, provides direction for individuals with DD/MR to live in the most integrated setting and participate in the community. The significant legal directive and statute reinforces the basic civil rights for people with disabilities, that they have the right to be provided with opportunities to pursue the same quality of life as those without disabilities. This includes the civil and constitutional right to "life, liberty, and the pursuit of happiness."

## II. PURPOSE

The purpose of Act 40 was to extend the repeal date of Act 303, SLH 2006. Act 303 required the provision of community residential alternatives for persons with DD/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 was scheduled to sunset on June 30, 2008. Act 40 extends the sunset date to June 30, 2009. It also requires the DD Council to submit a progress report to the Legislature no later than twenty days prior to the convening of the Regular Session of 2008 and a final report to the Legislature no later than twenty days prior to the convening of the Regular Session of 2009.

## III. GOVERNOR'S MESSAGE NO. 798

Governor Lingle's concerns about Act 303/2006 were reiterated again in her message regarding Act 40/2007. Refer to the Introduction section of this report for her specific concerns. See attached Governor's Message 798.

## IV. IMPLEMENTATION OF ACT 303/2006

The current process in developing an Individualized Service Plan (ISP) addresses the Governor's concern regarding how the person's choice of residential setting is to be made and how DOH is to support the individual's choice.

DOH, DDD implements a person-centered process in developing an individual service plan (ISP). Throughout the year, the case manager will get to know the individual's preferences and goals, including his/her preference of where he/she may want to live. As part of the annual case assessment, the case manager administers the Inventory for Client and Agency Planning (ICAP) to gather information about the individual's skills in various areas. The ICAP has a

section that lists residential options which includes living with parents or relatives, living independently in own home or rental unit and various types of licensed/residential settings. The case manager indicates the individual's current residence and any recommended change within two years, if any, with input from the individual (as appropriate).

At the time of the ISP meeting, the current living arrangement and options should be discussed and whether it is the individual's desire/wish/goal to live in a different place. If another setting is preferred, the case manager and the circle of supports shall discuss "who will do what and by when" to assist the individual to move into/towards his desired residence, which is documented in the ISP. Some factors to be considered are health and safety issues, income, rent affordability, natural and paid supports that will be necessary in order for the person to succeed.

A new ISP format is currently being piloted that includes a section on "Where I Want To Live" as a necessary area to be discussed. An ISP committee was established in July 2006. It was composed of staff from the Program Supports Section, Contracts Section, Case Management Units, Staff Development from CMISB of DDD, and a parent. The committee's task was to look at the current ISP and make revisions to better address health and safety issues and quality of life outcomes, as well as to develop an effective tool for case managers to use for service planning, monitoring, and coordination. After several months of discussion, a format was decided on, and Case Management committee members implemented a pilot demonstration. From feedback gathered during the pilot demonstration, the committee again worked on the format. The second pilot demonstration also included case managers from the Neighbor Islands.

The ISP committee is currently working with the Outcomes Committee and developing a curriculum on the training on the new ISP format. The person-centered planning process remains the same. There is a specific area that addresses "Where I Want To Live." CMISB plans to begin training of case managers and providers on the new format by the end of the year.

The ISP format includes the following areas:

(1) CIRCLE OF SUPPORT

This section includes information about the individual (name, birth date and annual date), the names of individuals and their relationship that comprise the person's circle of support, and the case manager (name, address, unit, and telephone).

(2) THIS IS WHO I AM

This section includes great things about me, strengths, positive words that describe me, and how I communicate.

(3) WHAT'S IMPORTANT AND MEANINGFUL TO ME

This section includes areas to address: Control, Dignity, Respect, Choice, Relationships, Contributing to the Community, Responsibilities, and Dreams. Specific areas are:

- Where I Want To Live
- My Health and Well-Being
- My Safety
- Learning New Things/To Try New Things
- To Work/Generate Income for Myself
- Relationships with Family and Friends
- Leisure and Recreational Activities
- Things I Never Want in My Life Are
- Other Significant Things

(4) MY GOALS

This section includes based on what's important and meaningful to me, these are my priority goals for the coming year.

(5) ACTION PLAN

This section includes goals and outcomes for the individual.

(6) OTHER PERTINENT INFORMATION

This section includes information on guardianship status, guardian of the estate, legal issues, financial, representative payee, Medicaid eligibility, health insurance, where I live, health status, health supports, medications, adaptive equipment/assistive technology, medical supplies, and use of restraints.

Choice of residential setting, health and well-being, and safety issues are identified and addressed in Item (4), what's important and meaningful to me. As appropriate, the individual's circle of support with the case manager will identify what is needed and necessary to support the individual to achieve his/her goal(s) in the area of where he/she wants to live, his/her health, well-being, and safety. Specific concerns and supports will be noted in the ISP to address each area and identify the person and/or entity responsible to support the individual.

## V. NUMBER OF PERSONS WITH DEVELOPMENTAL DISABILITIES OR MENTAL RETARDATION WHO CHOOSE TO LIVE INDEPENDENTLY PROVIDED BY ACT 303/2006

In the report submitted to the 2007 Legislature, case managers from the DDD, CMISB were asked to provide the numbers of individuals in the following residential setting situations in addition to the number of individuals with DD/MR who choose to live independently as provided by Act 303 (addressed in Item 1). The data below represents an updated number of individuals living in various residential settings based on what was reported by the case managers.

(1) 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 = 18

(2) Persons living in a family owned home with a live-in caregiver who is paid. N = 7

(3) Persons living in a family owned home with supports, but there is no live-in paid caregiver. N = 5

(4) 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 = 10

(5) Persons living in a home that he/she rents from the landlord and receives paid support from someone coming into the home. N = 6

(6) Persons living in the home of another and does not receive paid Medicaid waiver supports in the home. N = 17

(7) One or two individuals rent a single apartment unit from a landlord. N = 113

(8) 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 = 9

(9) Persons who are not satisfied with their current living arrangement (whether licensed/certified or not). N = 14

(10) Persons currently living with family. N = 2,116

Based on the information above and in addressing this section, there are a total of 2,315 adults with DD who are living in various residential settings. Of that number, 2,116 live with their family and 199 live in settings other that with family. There are 18 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 Adult Foster Home (AFH), or are homeless, but remain in their current living situation due to limited resources to assist them to live independently. These 18 individuals are directly impacted by the implementation of Act 303/2006, as they desire to live in a residential setting other than what they currently reside in now.

The individual's ISP should identify their choice of residential setting and supports needed to transition from their current living situation to their desired residential option. Although the process may be in place to address the individual's choice of residential setting, reality takes hold in that there may be no resources to support the individual in that particular residential setting. There are rental considerations regarding deposits and monthly rental payments. Limited resources in the areas of Section 8 vouchers, low cost rentals, and rental subsidies, and the high cost of living in Hawaii make it challenging for individuals with DD to obtain housing to live independently.

## VI. NUMBER OF PERSONS WITH DEVELOPMENTAL DISABILITIES OR MENTAL RETARDATION WHO LIVE WITH PARENTS, FAMILY MEMBERS, GRAND-PARENTS, OTHER RELATIVES, SIBLINGS AND SPOUSE

The workgroup obtained data from DDD to identify the number of people living with parents and family members, grandparents, other relatives, siblings and spouses. The data included in the tables below account for 63% of the people served by DDD. The tables include information in five-year increments beginning at age 45 to 64 years old. This age group was of interest to the workgroup because it would provide useful information in future planning for individuals aging in place and pursuing other residential options for those individuals who may need placement in a setting other than their current one due to their caregiver's change in situation (aging, illness, death, etc.). For example, for an individual with DD/MR who is 44 years old, their caregiver may be 64 years old or older, or if the individual is in the age range of 65 + years, their caregiver may be 85 years old (taken into consideration that the caregiver is on the average 20 years older than the individual with DD/MR).

In light of the above and the data obtained, the workgroup emphasizes the urgency to build capacity in the community by pursuing other alternatives and funding sources to increase residential options other than the typical ARCHs, adult foster homes, DD domiciliary homes, residential alternatives community care homes, special treatment facilities, etc. Yet at the same time continue to support families who continue to care for their family member with DD/MR at home. According to DDD, over 60 percent of individuals served by the Division live with their family.

The following tables provide information on the number of individual living with parents, family, grandparents, other relatives, siblings and spouses. Data is also broken down by Case Management Units (CMU). The following case management units represent the following geographic areas:

(1) CMU 1 – Ward Avenue to Hawaii Kai
(2) CMU 2 – Waianae to Ewa Beach
(3) CMU 3 – Ewa Beach to Waipahu
(4) CMU 4 – Waimanalo to Kahuku
(5) CMU 5 – Waipahu
(6) CMU 6 – Wahiawa, Haleiwa, Turtle Bay, Mililani
(7) CMU 7 – Aiea, Pearl City, Salt Lake
(8) CMU 8 – Ward Avenue to Kalihi
(9) CMU 9 – East Hawaii
(10) CMU 10 – West Hawaii
(11) CMU 11 – North Hawaii
(12) CMU 12 – Maui
(13) CMU 13 – Molokai
(14) CMU 14 – Lanai
(15) CMU 15 – Kauai
(16) CMU 16 – Short Term Unit

TABLE 1
NUMBER OF INDIVIDUALS WITH DD/MR LIVING WITH PARENTS

| Category | Unit | 0-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65+ | Total |
|---|---|---|---|---|---|---|---|---|
| w/Parents | CM Unit 1 | 243 | 11 | 10 | 5 | 2 | 1 | 272 |
| | CM Unit 2 | 170 | 6 | 3 | 1 | 0 | 0 | 180 |
| | CM Unit 3 | 117 | 6 | 1 | 1 | 0 | 1 | 126 |
| | CM Unit 4 | 202 | 9 | 0 | 1 | 0 | 0 | 212 |
| | CM Unit 5 | 24 | 2 | 0 | 2 | 0 | 0 | 28 |
| | CM Unit 6 | 172 | 2 | 2 | 0 | 1 | 0 | 177 |
| | CM Unit 7 | 144 | 8 | 5 | 1 | 2 | 0 | 160 |
| | CM Unit 8 | 126 | 5 | 3 | 0 | 0 | 0 | 134 |
| | CM Unit 9 (East Hawaii) | 199 | 6 | 8 | 2 | 2 | 0 | 217 |
| | CM Unit 10 (West Hawaii) | 55 | 0 | 0 | 2 | 0 | 1 | 58 |
| | CM Unit 11 (North Hawaii) | 38 | 4 | 0 | 0 | 0 | 0 | 42 |
| | CM Unit 12 (Maui) | 121 | 4 | 1 | 3 | 0 | 0 | 129 |
| | CM Unit 13 (Molokai) | 11 | 0 | 0 | 0 | 0 | 0 | 11 |
| | CM Unit 14 (Lanai) | 2 | 0 | 0 | 0 | 0 | 0 | 2 |
| | CM Unit 15 (Kauai) | 118 | 3 | 6 | 3 | 3 | 0 | 133 |
| | CM Unit 16 (Short Term Unit) | 3 | 0 | 0 | 0 | 0 | 0 | 3 |
| | Total | 1,745 | 66 | 39 | 21 | 10 | 3 | **1,884** |

Table 1 represents individuals with DD/MR who live with their parents. There are 1,884 individuals who are currently living with their parents. Of the 1,884 individuals, 139 are between ages 45 and 65 years old. Of significance is that these 139 individual's caregivers may be between the ages of 65 to 85 years old. This is cause for concern in that within the next five years, these individuals may require placement in another residential option other than with family.

TABLE 2
NUMBER OF INDIVIDUALS WITH DD/MR LIVING WITH FAMILY (Except parents)

| Living w/ | Unit | 0-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65+ | Total |
|---|---|---|---|---|---|---|---|---|
| Family | CM Unit 1 | 8 | 0 | 1 | 0 | 0 | 3 | 12 |
| (except | CM Unit 2 | 21 | 4 | 1 | 4 | 2 | 0 | 32 |
| parents) | CM Unit 3 | 12 | 2 | 3 | 1 | 0 | 0 | 18 |
| | CM Unit 4 | 17 | 5 | 3 | 2 | 1 | 2 | 30 |
| | CM Unit 5 | 3 | 0 | 1 | 0 | 0 | 0 | 4 |
| | CM Unit 6 | 12 | 1 | 0 | 2 | 2 | 4 | 21 |
| | CM Unit 7 | 9 | 0 | 1 | 0 | 1 | 2 | 13 |
| | CM Unit 8 | 29 | 2 | 2 | 1 | 3 | 1 | 38 |
| | CM Unit 9 (East Hawaii) | 26 | 1 | 2 | 1 | 0 | 0 | 30 |
| | CM Unit 10 (West Hawaii) | 4 | 0 | 3 | 1 | 0 | 1 | 9 |
| | CM Unit 11 (North Hawaii) | 2 | 0 | 0 | 1 | 0 | 0 | 3 |
| | CM Unit 12 (Maui) | 11 | 2 | 0 | 2 | 0 | 1 | 16 |
| | CM Unit 13 (Molokai) | 2 | 0 | 0 | 0 | 0 | 0 | 2 |
| | CM Unit 15 (Kauai) | 9 | 4 | 1 | 2 | 1 | 3 | 20 |
| | CM Unit 16 (Short Term Unit) | 0 | 1 | 0 | 1 | 0 | 0 | 2 |
| | Total | 165 | 22 | 18 | 18 | 10 | 17 | **250** |

Table 2 represents the number of individuals living with family. This number does not include parents. There are 250 individuals that live with their family. Of this number, 85 individuals are between the ages of 45 to 65 years old.

TABLE 3
NUMBER OF INDIVIDUALS WITH DD/MR LIVING WITH GRANDPARENTS

| w/Grand- | Unit | 0-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65+ | Total |
|---|---|---|---|---|---|---|---|---|
| Parents | CM Unit 1 | 2 | 0 | 0 | 0 | 0 | 0 | 2 |
| | CM Unit 2 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 3 | 3 | 0 | 0 | 0 | 0 | 0 | 3 |
| | CM Unit 5 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 6 | 4 | 0 | 0 | 0 | 0 | 0 | 4 |
| | CM Unit 7 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 8 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 9 (East Hawaii) | 2 | 0 | 0 | 0 | 0 | 0 | 2 |
| | CM Unit 10 (West Hawaii) | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 13 (Molokai) | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | Total | 17 | 0 | 0 | 0 | 0 | 0 | **17** |

Table 3 represents the number of individuals living with their grandparents. There are 17 individuals that live with their grandparents between the ages of 0-44.

TABLE 3A
NUMBER OF INDIVIDUALS WITH DD/MR LIVING WITH GRANDPARENTS BY AGE AND CASE MANAGEMENT UNIT

Number of Persons With Developmental Disabilities Living with Grandparents by Age and CMU (Oct 2007)

| **Age of Individual** | **CMU** |
|---|---|
| 5 | 1 |
| 6 | 8 |
| 9 | 1 |
| 11 | 6 |
| 12 | East Hawaii |
| 13 | Molokai |
| 14 | 5 |
| 15 | East Hawaii |
| 16 | 7 |
| 16 | 6 |
| 18 | 2 |
| 19 | 3 |
| 21 | 3 |
| 22 | West Hawaii |
| 26 | 3 |
| 26 | 6 |
| 33 | 6 |

Table 3A represents the number of individuals living with their grandparents by age and CMU. There are 17 individuals between the ages of 5 and 33 years old living with their grandparent. These numbers also include grandparents who are caring for their children with DD/MR and their children's children with DD/MR.

TABLE 4
NUMBER OF INDIVIDUALS WITH DD/MR LIVING WITH RELATIVES

| w/Other | Unit | 0-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65+ | Total |
|---|---|---|---|---|---|---|---|---|
| Relatives | CM Unit 1 | 4 | 0 | 0 | 0 | 0 | 2 | 6 |
| | CM Unit 2 | 18 | 1 | 0 | 3 | 1 | 0 | 23 |
| | CM Unit 3 | 6 | 0 | 0 | 0 | 0 | 0 | 6 |
| | CM Unit 4 | 13 | 4 | 2 | 0 | 1 | 1 | 21 |
| | CM Unit 5 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 6 | 7 | 1 | 0 | 1 | 0 | 1 | 10 |
| | CM Unit 7 | 6 | 0 | 1 | 0 | 1 | 1 | 9 |
| | CM Unit 8 | 26 | 1 | 0 | 1 | 1 | 1 | 30 |
| | CM Unit 9 (East Hawaii) | 17 | 0 | 1 | 1 | 0 | 0 | 19 |
| | CM Unit 11 (North Hawaii) | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 12 (Maui) | 9 | 0 | 0 | 0 | 0 | 0 | 9 |
| | CM Unit 13 (Molokai) | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 15 (Kauai) | 7 | 2 | 0 | 1 | 1 | 3 | 14 |
| | Total | 116 | 9 | 4 | 7 | 5 | 9 | **150** |

Table 4 represents the number of individuals living with other relatives. There are 150 individuals living with other relatives. Of that number, there are 34 individuals who are between the ages of 45 to 65 years of age.

TABLE 5
NUMBER OF INDIVIDUALS WITH DD/MR LIVING WITH SIBLINGS

| w/Sibling | Unit | 0-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65+ | Total |
|---|---|---|---|---|---|---|---|---|
| | CM Unit 1 | 2 | 0 | 1 | 0 | 0 | 1 | 4 |
| | CM Unit 2 | 1 | 3 | 0 | 1 | 1 | 0 | 6 |
| | CM Unit 3 | 3 | 2 | 3 | 1 | 0 | 0 | 9 |
| | CM Unit 4 | 3 | 1 | 1 | 2 | 0 | 2 | 9 |
| | CM Unit 5 | 1 | 0 | 1 | 0 | 0 | 0 | 2 |
| | CM Unit 6 | 1 | 0 | 0 | 1 | 2 | 3 | 7 |
| | CM Unit 7 | 2 | 0 | 0 | 0 | 0 | 1 | 3 |
| | CM Unit 8 | 2 | 1 | 2 | 1 | 2 | 0 | 8 |
| | CM Unit 9 (East Hawaii) | 4 | 1 | 1 | 0 | 0 | 0 | 6 |
| | CM Unit 10 (West Hawaii) | 0 | 0 | 3 | 0 | 0 | 0 | 3 |
| | CM Unit 11 (North Hawaii) | 1 | 0 | 0 | 1 | 0 | 0 | 2 |
| | CM Unit 12 (Maui) | 2 | 2 | 0 | 2 | 0 | 1 | 7 |
| | CM Unit 15 (Kauai) | 2 | 2 | 1 | 1 | 0 | 0 | 6 |
| | CM Unit 16 (Short Term Unit) | 0 | 1 | 0 | 1 | 0 | 0 | 2 |
| | Total | 24 | 13 | 13 | 11 | 5 | 8 | **74** |

Table 5 represents the number of individuals living with their siblings. There are 74 individuals living with their siblings. Of this number, 50 individuals are between the ages of 45 to 65.

TABLE 6
NUMBER OF INDIVIDUALS WITH DD/MR LIVING WITH SPOUSE

| w/Spouse | Unit | 0-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65+ | Total |
|---|---|---|---|---|---|---|---|---|
| | CM Unit 2 | 0 | 0 | 1 | 0 | 0 | 0 | 1 |
| | CM Unit 3 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 4 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | CM Unit 9 (East Hawaii) | 3 | 0 | 0 | 0 | 0 | 0 | 3 |
| | CM Unit 10 (West Hawaii) | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| | Total | 6 | 0 | 1 | 0 | 0 | 0 | **7** |

Table 6 represents the number of individuals living with their spouse. There are 7 individuals living with their spouse. Of that number, all 7 individuals are between the ages of 0-44 years of age.

## III. FINANCIAL IMPACT ACT 303 HAS HAD ON THE STATE

The fiscal impact of Act 303 is still unknown at this time. The 18 individuals who have indicated that they would like to live independently in their own home have not yet been accomplished without financial assistance such as a rental subsidy. Until any of the 18 individuals transition to into a residential setting of their choice, the financial impact will not be known regarding the cost required to support them in their desired living arrangement.

## IV. FINDINGS AND RECOMMENDATIONS

Based on the review of the revised ISP process, current Adult Foster Home statutes, Hawaii Administrative Rules, data of individuals in various residential settings and number of individuals living with parents, grandparents, family, etc., the workgroup is considering the following initiatives to be pursued during the next year:

### 1. New Category of Residential Option

Implement a new category of residential option using the current Adult Foster Home Hawaii Administrative Rules and the new ISP format implemented by DDD, CMISB. The intent is to increase residential options for individuals on the neighbor islands and at the same time address potable (catchment) water policy issues in rural areas of the neighbor islands. This new category option would begin as a pilot project on Kauai, Hawaii, and Maui Counties by January 1, 2008. Details of the pilot project are still being discussed with the workgroup. It is not in final form. Once finalized, it will be submitted for review by the DD Division's Chief and assigned Deputy Attorney General. The following is summary of the new category of residential option.

- Any adult with developmental disabilities (or their designated representative) known to DOH, DDD can request to live with a particular person or family. This may be predicated on a pre-existing relationship between the individual and the homeowner.

- The individual's case manager would submit a request to DDD, Disabilities Services Branch, Certification Unit.

- Require a local criminal history check of all persons living in the home. Individual/guardian can waive a criminal history. The FBI and Child Welfare Services and Adult Protective Services checks would also be done, but not to deter the individual from initially moving into the home.

- Provide a functional assessment of the environment based on the individual's needs.

- Permit written attestation by the individual/guardian to substitute for a home study.

- The home would be certified as an "Adult Family Home" for one specific individual with developmental disabilities who has stated this is what he/she wants.

- Instead of stating the maximum number of foster adults, it will state the person's name the home is certified for.

- If something should happen to the specified individual there is no obligation to place another person in the home.

- The caregiver would receive Supplemental Security Income and Supplemental State Payment only for that one individual.

- Is targeted for persons who would require supports to live in the community. Waiver services could be provided in the home by persons not living in the same home.

2. Use of Existing Resources

For persons with developmental disabilities, limited income creates a barrier to independent living and relegates them to live in situations in which others exert control over their daily lives. Often times, their primary source of income is Social Security. While the Medicaid Home and Community Based Services Waiver program provides support services to prevent institutionalization and enable individuals to live in the community, it does not provide financial support for room and board. The amount of funding from SSI ($600.00 per month) does not provide sufficient dollars to pay for rental deposit, monthly rent and utilities for individuals in Hawaii's competitive rental housing market.

The process of utilizing flexibility within existing resources to create opportunities for individuals to live independently includes that once an individual budget for waiver services has been identified, flexibility is provided to convert a portion of the waiver budget to utilize the state portion (based on Federal Medical Assistance Percentage) for housing deposit and monthly rent. For example, given a waiver budget of $37,000, an individual might retain $22,000 for support services and use $5,000 (50% of the remaining $10,000) in state dollars for housing.

Several issues regarding the above have been identified to be resolved before the above can be implemented:

a. The process to identify a waiver budget that is equitable for all individuals.

b. The conversion should not deplete waiver services to endanger the health and safety of the person.

c. Request of budget increases merely to utilize the state's portion for housing.

3. Supported Housing/Bridge Subsidy Pilot Project

This pilot project would be modeled after the DOH, Adult Mental Health Division's Supported Housing/Bridge Subsidy program that has demonstrated success for individuals with mental illness to live independently in housing of their choice. The program provides rentals for persons with mental illness who are stabilized and can live in the community with appropriate supports. The individual selects housing, a rental subsidy is provided, and there is a 24-hr housing support team available for the individual.

This project could include the 18 individuals who choose to live independently, but require a rental subsidy to help pay for monthly rent costs. Additional funds would be required for implementation of this pilot project.

4. Coordination with Going Home Plus (Money Follows the Person) Demonstration Project

The Department of Human Services (DHS) was awarded a $10.2 million dollar "Money Follows the Person" Demonstration grant over five years by CMS to bring together the State's resources to support persons who have resided in a health care institution for at least six months but no longer than two years as they transition back to the community.

The workgroup will coordinate with the project staff and stakeholder group to identify if resources from this demonstration grant can be used to increase residential options for people with DD/MR. According to the proposed transition timelines, people with DD/MR will be transitioned from health care institutional settings into the community beginning in FY 2010. There are 10 individuals targeted to transition in the community during this time period with an additional 40 individuals in FY 2011.

The workgroup plans to continue to meet during he next year to pursue the above initiatives. A final report will be completed and submitted to the 2009 Legislature.