

**HAWAII WAIVER PROVIDERS ASSOCIATION (HWPA)**  
Developmental Disability Service Coalition  
*Hawaii's Developmental Disability Service System: Problems & Solutions*

**BACKGROUND**

According to the U.S. Administration on Developmental Disabilities, approximately 5 million people in the United States have a developmental disability defined in the Developmental Disabilities Act (P.L. 106-402), Section 102(8)<sup>1</sup>, as a severe, chronic disability of an individual that:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Is manifested before the individual attains age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more major life activities: (self care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency); and
- Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

According to the Hawaii State Council on Developmental Disabilities, using the nationally established prevalence rate of 1.58%<sup>2</sup>, approximately 21,500 people in Hawaii have a developmental disability and will require life-long supports. The Department of Health (DOH) Developmental Disabilities Division (DDD) serves approximately 3,500 people with developmental disabilities. These statistics indicate Hawaii is under serving this population; likely due to current eligibility criteria in the Hawaii Revised Statutes (HRS), Chapter 333F, and Hawaii Administrative Rules (HAR) and/or a lack of public information and outreach.

**SERVICE SYSTEM PRIORITY CONCERNS & RECOMMENDED SOLUTIONS**

**I. Lack of Inter-Departmental & Community Collaboration and Planning**

The Department of Human Services (DHS), the State's single Medicaid agency is responsible for all Medicaid programs. This includes the administration of the Medicaid Home and Community Based Services (HCBS) waiver program that provides long-term care services that are not included or limited in the current Medicaid state plan services for people with developmental disabilities.

The DOH-DDD, per Chapter 333F, Hawaii Revised Statutes (HRS) is responsible for developing, leading, administering, coordinating, monitoring, evaluating, and setting direction for a comprehensive system of supports and services for persons with developmental disabilities. The Hawai'i State Council on Developmental Disabilities (DDC) is mandated by federal law (P.L. 106-402) and State law (Chapter 333E, HRS) to plan, coordinate, evaluate, monitor, and advocate on behalf of individuals with developmental disabilities.

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<sup>1</sup><http://www.acf.hhs.gov/programs/add/adddocs/act.pdf>

<sup>2</sup> Larson, S.A., Lakin, K.C., Anderson, L., Kwak, N., Lee, J.H., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106, 231-252.

Other state departments involved in the coordination and implementation of services include the Department of Education (DOE) and the DHS Division of Vocational Rehabilitation (DVR). Within each of the aforementioned State departments there are several divisions and units involved in disability service development and implementation. Additionally, there are numerous private sector health and human service agencies engaged by the state to provide direct services.

The majority members of the Developmental Disabilities Service Sector Coalition, which represents both the private and public sector, have spent decades in this system and are of the strong opinion that the multiple layers of State departments, divisions, and units is one of the many reasons we have a fragmented system of service delivery. The system in its current state is plagued with inconsistent interpretation and application of policies, duplication of services, lack of accountability and transparency, and is extremely difficult to navigate.

### **Recommendation:**

That the Administration support collaboration and innovation through the establishment of a statewide task force that includes private sector experts and leaders from State departments who have the authority to make decisions and take the necessary actions to remove systemic barriers that prevent individuals from accessing needed services on a timely basis. The task force would make recommendations regarding policy, administrative rules, and statutory provisions that would lead to an efficient seamless system of services for people with developmental disabilities and their families that reflect best practice design and approaches. Should the work of this task force result in the consolidation of departments, divisions, and units, this coalition is of the strong opinion the State will save money, increase competencies and efficiencies, and ultimately provide a sound person-centered system of support.

## **II. Medicaid Waiver Reduced Funding/Managed Care Roll-In**

In December 2008, the DOH-DDD informed approximately 2,500 recipients of Medicaid HCBS waiver program services of a mandatory 15% reduction in services. The DOH-DDD stated publicly that the reduction in services was necessary because service utilization was out of control, suggesting recipients were receiving services they did not really need thereby causing a budget shortfall. While there has always been concern regarding inconsistent assessment and utilization policies and practices, department officials stated the DOH-DDD “had to do its part to help balance the overall state budget”. The reduction or loss of Medicaid HCBS waiver program services regardless of reason has consistently resulted in people with developmental disabilities being isolated and confined in their homes with minimal supervision and inadequate care.

Historically, Waimano Training School and Hospital served as a safety net with a “no reject” policy and was expected to serve individuals for whom there were no providers. Waimano was finally closed in 1999 due to the commitment of advocates, families, the State administration, and the Legislature to support people with developmental disabilities in the community. Promises were made to the families of residents (as far back as the 1970’s when the deinstitutionalization movement began) that there would be quality community based services to replace the institutional services. The Medicaid HCBS waiver program has served as the vehicle to deliver on that promise. Medicaid HCBS waiver program services are designed to provide people with developmental disabilities opportunity to live full and meaningful lives in the least restrictive setting. Future reduction or loss of Medicaid HCBS waiver program services potentially places Hawaii in a vulnerable position to regress to institutional based services. Returning to institutional based services is not an option and is simply unacceptable.

Hawaii is one of only ten states and D.C. that have closed their large (16+ individuals) public state-operated institutions for people with intellectual and developmental disabilities and relies on the Medicaid HCBS waiver program to provide support services in the community. Hawaii's per capita cost for individuals in the Medicaid HCBS waiver program is \$40,943 (2009)<sup>3</sup>. The average per capita Medicaid HCBS waiver program spending for individuals in similar sized states that have closed their large public state-operated institutions reflects a higher average per capita cost ranging from \$53,800 (Vermont)<sup>4</sup> to \$79,425 (Maine)<sup>5</sup>. The average annual institutional cost on the mainland for large institutions is \$191,260. It is critical to maintain Hawaii's level of Medicaid HCBS waiver program funding.

In addition to potential service reductions for individuals in this program, we are concerned with the possibility of Medicaid HCBS waiver program services being rolled into the State's Medicaid QUEST Expanded Access managed care program. We do not recommend this as the current health insurance plans and providers have not demonstrated the interest or the capacity to serve this targeted high-needs population.

Typical health insurance care coordinators do not have the education, experience or training to address the needs of individuals with developmental disabilities. These needs include but are not limited to: seeking appropriate homes in which to live, finding employment, supporting choice and self-determination, developing relationships with people in the community, transitioning from public and private schools, responding to behavioral crisis situations, fostering relationships with family and guardians, and coordinating services with public schools and other State departments. This type of intensive interdisciplinary service coordination is atypical of a managed care plan. Furthermore, the current case loads of the managed care health insurance care coordinators in Hawaii are approximately four to five times larger than the national recommended waiver case load of 35 individuals. As it is, many of our individuals with developmental disabilities do not see their managed health care insurance care coordinator as required.

**Recommendations:**

- 1) Introduce legislation that prohibits unilateral service reductions to all recipients in the Medicaid Home & Community Based Services waiver program.
- 2) Introduce legislation that exempts the State's Medicaid Home and Community Based Services waiver program for people with developmental disabilities from submission into the State QUEST Expanded Access managed care program.

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<sup>3</sup>Braddock, D. et al. (2011). *The State of the States in Developmental Disabilities 2011*. University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities: Boulder, CO. Table 8.

<sup>4</sup> *ibid.*

<sup>5</sup> *ibid.*

### III. Limited & Fragmented Residential Options

While many Hawaii residents are challenged by the lack of affordable housing, the challenges for people with developmental disabilities are even greater. In addition to the shortage of affordable housing, there is also a shortage of accessible and integrated housing options.

Approximately 30% of individuals in the Medicaid HCBS waiver program do not live with family members and are dependent on paid caregivers to provide shelter and support<sup>6</sup>. This is due to the passing of parents, elderly family members, limited natural supports, and the physical and behavioral demands of care giving. As a result, a significant number of individuals live in licensed or certified settings which are licensed and regulated by multiple state departments and agencies.

The Department of Health is responsible for the licensure of Adult Residential Care Homes, DDD Adult Foster Homes and Developmental Disabilities Domiciliary Homes while the Department of Human Services is responsible for the licensure of Community Care Foster Family Homes for people at the Intermediate Care Facility (ICF) and Skilled Nursing Facility (SNF) level of care, Residential Alternatives Community Care Program (RACCP) homes, and other non-disabled homes all of which are regulated by separate HAR. Although the governing HARs are separate, there is a significant amount of duplication and varied interpretations. Additionally the HARs are in dire need of updating to reflect current legal and best practice home licensure requirements. One of the many issues relates to the payment for services.

People with developmental disabilities typically receive \$1,325.90 per month in benefits all of which is used to pay a paid caregiver for room, board and general supervision. The amount received is partially from Supplemental Security Income (SSI) and a State Supplemental Payment (SSP) commonly referred to as a *level of care* payment. Because individuals are left with no discretionary money after paying their room and board costs, many of them desire employment. However, if individuals living in a licensed or certified home start to work or receive income through Social Security Disability Insurance (SSDI) survivor benefits, their income increases above \$1,325.90 and the individual must pay a cost share toward their Medicaid services. This will reduce their available income to \$469/month to pay for room, board and general supervision. The reduction from \$1,325.90 to \$469 will greatly jeopardize their continued placement in the home.

This will be a growing issue as (1) the State and Federal government encourage individuals to work and reduce dependence on services and (2) as aging parents start to get Social Security benefits or die and their adult children with disabilities become eligible for SSDI benefits. This predicament will negatively impact the health and safety of individuals without family support and in a worse case scenario, render them homeless.

As previously stated, this coalition is of the strong opinion that the multiple layers of State departments, divisions, and units, in the home licensing and monitoring arena is a major reason why this system is also plagued with inconsistent interpretation and application of policies, duplication of services, lack of accountability and transparency, and a system that is extremely difficult to navigate.

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<sup>6</sup>State of Hawai'i, Department of Health, Developmental Disabilities Council. (2009). *Report to the twenty-fifth Legislature, state of Hawai'i, 2009*.  
<http://gen.doh.hawaii.gov/sites/LegRpt/20091/Act%2040%20Report%20to%202009%20Legislature%2012-08.pdf>

**Recommendations:**

- 1) Introduce legislation that requires the review of all Hawaii Administrative Rules as they relate to the licensure and regulation of Adult Foster Homes, Developmental Disabilities Domiciliary Homes, small community-based ICF/MR Homes, Adult Residential Care Homes, Community Care Foster Family Homes for people at the Intermediate Care Facility (ICF) and Skilled Nursing Facility (SNF) level of care, Residential Alternatives Community Care Program (RACCP) homes, and other non-disabled homes and make recommendations for the licensure and regulation of these homes to be the responsibility of one State department.