



DEPARTMENT OF HEALTH

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HAWAII RESIDENTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES CELEBRATE 30 YEARS OF SELF-DETERMINATION AT “DAY AT THE CAPITOL”

HONOLULU – Hawaii residents with intellectual and developmental disabilities have come a long way toward gaining more rights to be treated like other citizens in the past 30 years.

In the past, many with substantial intellectual and developmental disabilities were isolated from the community, and were admitted to Waimano Training School and Hospital (WTSH), which opened in 1921. WTSH served as the State’s only large intermediate care facility for persons with intellectual and developmental disabilities. However, an amendment to the state law in 1995 mandated Waimano’s closure.

With the final closure of Waimano Training School and Hospital in June 1999, Hawaii became the ninth state to completely shut down its publicly-operated institutions for individuals with intellectual and developmental disabilities. Currently, Hawaii is one of 15 states that no longer operates an institution for those with intellectual and developmental disabilities. The last state institution in the United States is projected to close within the next two decades.

The mandate came with a stipulation: all programs and services shall be provided in the community and the Hawaii State Department of Health shall maximize its funds for community services by using state-matching funds to match federal Medicaid funds through the Medicaid 1915 (c) Home and Community-Based Services Waiver.

The Medicaid Waiver makes it possible for individuals with intellectual and developmental disabilities to be integrated into the mainstream community, and allows Hawaii to leverage federal funding to better serve Hawaii’s citizens with intellectual and developmental disabilities.

Establishing the Developmental Disabilities Division within the Department of Health was the one of the positive results of the mandate. Today, the Developmental Disabilities Division provides services to people in their homes and in community-based settings that include personal assistance/habilitation, residential habilitation, emergency services, respite, employment supports, chore, training and consultation, specialized medical equipment, adult day health, skilled nursing, environmental accessibility and vehicular modifications, assistive technology, personal emergency response systems and non-medical transportation.

The statistics have been positive: Today, Hawaii ranks in the top quartile of states in supporting individuals in family homes. Currently, 99 percent of people served by the Department of Health's Developmental Disabilities Division live in residences serving one to six people, and 61 percent in settings with one to three people.

"Hawaii has been one of the most progressive states in empowering individuals with intellectual and developmental disabilities. We have many good reasons to celebrate the strides we have made as a state over the past 30 years," said Mary Brogan, Chief of the Department of Health's Developmental Disabilities Division. "However, we still have much more we can do to remove stigma and ensure those with intellectual and developmental disabilities have full access to the services and supports they need to and be fully integrated into the community to enjoy, rich, full and self-determined lives."

Despite progress in self-determination, new requirements are raising the bar to improve the quality of services for those with intellectual and developmental disabilities.

In 2014, the Centers for Medicare and Medicaid Services (CMS) finalized a new rule that dramatically shifted the emphasis to the nature and quality of the experience of beneficiaries and their desired outcomes. The new rule pertains specifically to home and community based services such as those provided through Hawaii's waiver for intellectual and developmental disabilities.

"The expectation is that people with disabilities and older adults receiving Medicaid home and community-based services have a right to live, work, and participate in the greater community," Brogan said.

"We're hoping that with appropriate federal support and state-matching funds, the Department of Health's Developmental Disabilities Division and its partners can continue to improve services and outcomes for individuals with intellectual and developmental disabilities," she said.

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Celebrating 30 Years Toward Self-Determination 1987 - 2017

Key Milestones for Hawaii Residents with Intellectual and Developmental Disabilities

1987:

Act 341 becomes a landmark law for people with intellectual and developmental disabilities. This new law establishes the Developmental Disabilities Division within the Hawaii State Department of Health and opens the door for Hawaii to move away from living in the institution at Waimano Training School and Hospital, and mandates a system of services in the community that is person-centered and ensures self-determination.

1995:

Act 189 takes a major step forward, going beyond a policy intent and mandates closure of the Waimano Training School and Hospital by 1998. Waimano Training School and Hospital had been in operation since 1921. Act 189 also clarifies that the Department of Health would maximize federal funds through the Medicaid 1915(c) Home and Community Based Services Waiver, paving the way to develop a wide array of services so people with intellectual and developmental disabilities residing at the Waimano institution could live in the community.

1998:

Act 133, an amendment to Act 189, codifies the principles of consumer choice for self-determination for individuals with intellectual and developmental disabilities. It stipulates the Department of Health to assist individuals with developing an individual service plan and to provide funds to implement these individual service plans. This Act establishes the rights of individuals with intellectual and developmental disabilities to manage a set amount of dollars to implement their own plan and to direct the resources, both paid and unpaid, to be fully integrated in the community, including employment.

1999:

Waimano Training School and Hospital closes and Hawaii becomes the ninth state to completely shut down its publicly-operated institutions for individuals with intellectual and developmental disabilities. Currently, Hawaii is one of 15 states that no longer operate an institution for those with intellectual and developmental disabilities.* The last state institution in the United States is projected to close within the next two decades.

2000 and 2005:

Two law suits (1998 and 2003) are filed by the Hawaii Disabilities Rights Center (HDRC) against the State for having waiting lists to provide services to those with intellectual and developmental disabilities.

A Hawaii Supreme Court ruling finds that Hawaii, with its population limits and resulting wait lists, failed to offer home and community-based services in the most integrated setting appropriate to individualized needs, which could force individuals with disabilities into institutions to receive needed services, in violation of the American Disabilities Act's integration mandate. In response, the State agrees to provide appropriate and needed home and community-based services, make the best effort to obtain appropriations from federal and state sources, and develop a comprehensive plan with public participation to move the waitlist at a reasonable pace.

The *Makin* settlement in 2000 and the Hawaii Disabilities Rights Center (HDRC) settlement in 2005 establishes timelines for waiver admissions and are instrumental in Hawaii having no waiting list for services to eligible individuals.

2011:

Following the passage of national legislation known as "Rosa's law" in 2010, Hawaii's individuals with intellectual and developmental disabilities and other advocates initiate state legislation to remove the "R word" from state statutes. Act 220 required that all references to "mental retardation" and "mentally retarded" be replaced by "intellectual disabilities." Individuals with IDD conveyed emphatically that the stigma of the R word provided barriers to inclusion and acceptance in their communities.

2014:

The Centers for Medicare and Medicaid Services (CMS) finalizes a new rule that dramatically shifts the emphasis to the nature and quality of the experience of beneficiaries and their desired outcomes. The new rule pertains specifically to Hawaii's waiver for intellectual and developmental disabilities. The expectation: people receiving home and community-based services will be able to receive services in their community to the same degree as people who do not receive Medicaid services.

2017:

Today, Hawaii is one of nine states that does not have a waiting list for home and community based services. Hawaii ranks in the top quartile of states in supporting individuals in family homes. Currently, 99 percent of people served by the Department of Health's Developmental Disabilities Division live in residences serving one to six people, and 61 percent in settings with one to three people. Hawaii ranks in the top quartile of states in supporting individuals in family homes.

By law, the Department of Health is mandated to develop, lead, administer, coordinate, monitor, evaluate, and set direction for a comprehensive system of supports and services for persons with developmental or intellectual disabilities in Hawaii. Current services include: personal assistance/habilitation, emergency services, respite, employment supports, chore, training and consultation, specialized medical equipment, adult day health, skilled nursing, environmental accessibility and vehicular modifications, assistive technology, personal emergency response systems and non-medical transportation.

The Developmental Disabilities Division has made significant progress, but there is much more that can be done with appropriate federal support and state-matching funds. *Possibilities Now!* is the core initiative that the Developmental Disabilities Division and its partners are implementing to improve services for individuals with intellectual and developmental disabilities.

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* The Case for Inclusion 2016, United Cerebral Palsy

<http://cfi.ucp.org/wp-content/uploads/2014/03/Case-for-Inclusion-2016-FINAL.pdf>

As of 2014, 15 States report having no state institutions to seclude those with ID/DD, including: Alabama, Alaska, Colorado, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, West Virginia and Washington, D.C. Another 9 States have only one institution each (Arizona, Delaware, Idaho, Montana, Nevada, North Dakota, South

Dakota, Utah and Wyoming). Since 1960, 205 of 354 state institutions have been closed, according to the University of Minnesota's Research and Training Center on Community Living.