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I. INTRODUCTION – MEET JON

Imagine Jon, a forty-one year old man with Down’s Syndrome and moderate retardation. For the past twenty-five years, Jon has lived at Waimano Training School and Hospital (“Waimano”), Hawaii’s main institution for the developmentally disabled. In 1999, Waimano closed by order of the Hawaii Legislature. Jon was placed by the State into a developmental disabilities domiciliary care home in Kalihi. This home is owned and operated by a husband and wife team that provides care to persons with disabilities. In addition to Jon, the caregivers take care of four other people with disabilities. All seven live together in the four-bedroom house.

Initially, the transition from Waimano into the care home was difficult for Jon, as he had grown accustomed to life separate from the community. Jon has gotten used to his new home, but occasionally misses the familiarity of the staff and the daily contact with friends at Waimano. But what Jon misses most is painting nature scenes, a hobby he learned while living at Waimano. Jon’s window had overlooked Aiea Heights, and he really liked painting the mountains and trees.

Jon spends most of his time at an adult day program run by a private non-profit agency contracted by the State. He attends the program five times a week from eight in the morning until two in the afternoon. Jon is limited to participating in activities with others at the day program, which includes cooking classes, puzzles and games, or even walking around Ala Moana Center. Jon does not enjoy participating in all of the activities offered at the day program, although he is allowed to paint occasionally. Unfortunately, the day program is located in the heart of Honolulu, surrounded by buildings and cement, not the mountains and trees Jon is so fond of painting.

Occasionally, Jon becomes frustrated when he does not want to participate in the designated activity for the day and screams and stomps his feet. On such occasions, Jon’s new friend Sally helps to calm him down. Sally, a retired school teacher, works as a volunteer personal assistant at the day program and even visits Jon during her free time.

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outside of the day program. Jon really likes Sally, and wishes there were some way that she could help him with his painting hobby on a more regular basis. Unfortunately, Jon lives in Kalihi, and Sally lives in Kaneohe, so Sally is not able to visit Jon at his home very often. Jon wishes they could spend more time together and less time at the day program.

Although Jon and Sally are fictitious persons, this situation does occur in Hawaii. Many people moved from Waimano into more community-based setting after decades of living in segregation. The State of Hawaii Department of Health (“DOH”), Developmental Disabilities Division (“DD Division”) is responsible for providing case management and coordinating services to over 3000 persons with developmental disabilities or mental retardation (“DD/MR”). The DD Division is responsible for creating, implementing, and monitoring a “state system of supports and services for persons with developmental disabilities or mental retardation ....” Once admitted into the Hawaii “DD System,” DOH shall “administer or may provide available supports and services based on a client-centered plan, which resulted from client choices and decision-making that allowed and respected client self-determination,” as mandated by Hawaii Revised Statute § 333F (“H.R.S. § 333F”). But does this system truly allow individuals with DD/MR to direct the expenditure of funds and assist them with living a life in the community rich in association and contribution?

Advocate groups, such as the Hawaii Disability Rights Center (“HDRC”) and councils such as the State Planning Council on Developmental Disabilities and Commission on Persons with Disabilities (“DD Council”), are vigilantly monitoring the current DD System. HDRC has filed two class action lawsuits against the Hawaii State Department of

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Health on behalf of individuals with DD/MR. On September 29, 2003, HDRC sued the State for “failure to deliver necessary and appropriate services to hundreds of children and adults with [DD/MR],” misuse of funds appropriated by the Legislature, and for “violat[ing] State law which requires that federal monies be used before state funds are expended on programs and services.” In 1999, HDRC sued the State in Makin v. Hawaii (“Makin”) for “failing to move people with developmental disabilities from its waitlist for community services in a timely manner.” Makin was settled in April of 2000.

In addition, DD Council has commissioned studies to evaluate the DD System and make suggestions on how to improve the provision of services to persons with developmental disabilities. One such study criticizes the DD System as needing to “be far more responsive to the needs of people with developmental disabilities and their families.”

The State has responded by taking action to implement a variety of programs and services designed to further individual choice and self-determination in community-based services. One of these services is consumer-directed personal assistance, where individuals with DD/MR have more control over the direction of funding for their personal assistance services offered through the DD/MR Medicaid waiver.

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5 Id.

6 114 F. Supp. 2d 1017 (D. Haw. 1999)

7 See HRDC Website, supra note 4.


10 See Doyle Interview, supra at note 1.
as a Medicaid Home and Community Based Services (“HCBS”) waiver amendment to Centers for Medicare and Medicaid Services (“CMS”), formerly the Federal Health Care Financing Administration (“HCFA”). If approved, consumer-directed services will be a reality for individuals with DD/MR in Hawaii, and Jon will have more control over his budget, and increased flexibility to hire and supervise support workers of his choice, and thereby live a more self determined life.

Section II of this paper addresses the problems of institutionalization and the call to end disability discrimination. Section III of this paper addresses the State’s response to this criticism by initiating a paradigm shift toward deinstitutionalization and the enactment of statutes that advocate for community-based services, increased client participation and choice, and self-determination. Section IV analyses the criticism that the DD System has faced by advocates groups and councils that have sued the State on behalf of individuals with DD/MR for failure to effectively provide a system of supports and services as mandated by law. Section V discusses consumer-directed services in detail, and the State’s efforts to implement these services to further the goals set forth by H.R.S. § 333F and the ADA. Section VI contains the author’s concluding remarks and suggestions to improve the Hawaii DD System.

II. INSTITUTIONALIZATION AND DISABILITY DISCRIMINATION

Jon was forced to leave Waimano, the State’s main ICF-MR institution for the developmentally disabled, because of its legislatively mandated closure in 1999. This was in line with the national trend toward deinstitutionalization, a social movement that encouraged the transition of people “out of institutions and back into their communities.”

“Until the late 1960’s, the dual attitudes of paternalism and fear ensured a segregated, institutionalized existence for people with

\[\text{COPY ON FILE WITH AUTHOR}\]
disabilities.”

Institutions often provided a congregate “warehouse” setting that limited both rights and privacy; in some extreme cases, residents were showered with hoses, while being offered little or no training for community living.

During the later part of the nineteenth century, large institutions took the form of schools whose purpose was to train children with DD/MR so that they could eventually return into the community. But by the end of the nineteenth century, school-like institutions began to resemble asylums because of the enhanced perception of academic and medical professionals that individuals with DD/MR had criminal tendencies, were immoral, and were potential menaces to society.

In response to these misconceptions about the disabled and institutional atrocities, Congress and many States began to implement legislation toward deinstitutionalization. After closing its main institution for people with DD/MR, Hawaii was the first state to include concepts of self-determination and a planning process that focused on the individual with DD/MR in its statutes.

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III. THE HAWAII DEVELOPMENTAL DISABILITY SYSTEM

Over the past two decades, the State of Hawaii has initiated a paradigm shift through legislation away from institutionalization and toward community-based services that focus on individualized needs, desires, and choices of persons with disabilities. This shift is the result of changing attitudes locally and nationally that recognize disability discrimination as a thing of the past, and advocates for freedom and equality for individuals with DD/MR.

The following section outlines chronologically the Hawaii and Congressional legislation that serves as the impetus for changing the DD System. In addition, the United States Supreme Court through the Olmstead Decision and the President of the United States through Executive Order 13217 solidify the nation’s commitment to end disability discrimination and promote programs that support community-based services and self-determination for individuals with DD/MR.

A. ACT 341 – THE ORIGIN OF THE HAWAII DD SYSTEM

House Bill 598 of the 1987 Hawaii Legislative Session, which became Act 341, was “a landmark bill for the rights and needs of the developmentally disabled population of our state and their parents and guardians.”19 The purposes of Act 341 were fiscal responsibility of state and federal funds; a continuation of the policy of deinstitutionalization for “those who would best thrive in smaller, community-based, care homes; and to clarify the responsibilities of the DOH in the licensing, monitoring, and maintenance of programs and standards for community services.”20

Act 341 was especially significant to the DD/MR independence movement because it included clear language that focused on community-based services “to allow persons with [DD] or [MR] to live in the least restrictive, individually appropriate environment.”21 This language perpetuates similar language used in the Federal Developmentally Disabled Assistance and Bill of Rights Act (“DDABRA”) of 1975,22

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20 Id. at 1244.


22 29 U.S.C. §§ 6000-6083 (1976). Although the DDABRA was repealed by the Disabilities Assistance and Bill of Rights Act (“DABRA”) of
which has “played a major role in disability litigation during the past twenty-five years.”

The DDABRA also created and authorized funding for Protection and Advocacy Systems in each state to ensure the safety and well being of individuals with DD. In Hawaii, the DDABRA laid the groundwork for HDRC and DD Council.

Similar to the DDABRA, Act 341 established a bill of rights for individuals with DD/MR that included the right to receive services and live in residences in the least restrictive, individually appropriate manner located as close as possible to the person’s home community within the State, and the right to live in a setting that is closely similar to those available to non-disabled persons of the same age.

Act 341 became codified in the Hawaii Revised Statutes as Section 333F (“H.R.S. § 333F”) and laid the foundation for DOH’s policy away from institutionalization and towards community-based services and supports.

2000, 42 U.S.C. §§ 15001-15115 (2000), the least restrictive language from the DDABRA remained substantively the same. The DABRA of 2000 states in relative part, “the treatment, services, and habilitation for a person with DD . . . should be provided in the setting that is least restrictive of the person’s personal liberty.” 42 U.S.C. § 6010(2) (2000).


25 See Act 341, Session Laws of Hawaii, 1121, 1123 (1987). In addition, Act 341 provided for individualized service plans (ISPs) for each person with DD/MR prepared by an interdisciplinary team, consisting of the individual, any appropriate family member, professionals in the field, direct-care/direct contact staff, and any other who could contribute to identifying the needs of the individual and ways to fulfill those needs. Id. at 1120. The ISP would function to identify “the nature of the needs of the person, treatment and care goals, and specific services to be offered to the person to attain these goals.” Id. at 1122.
B. THE FEDERAL AMERICANS WITH DISABILITIES ACT

Three years later in 1990, Congress passed the Americans with Disabilities Act ("ADA") for the purpose of ending discrimination for a person with disabilities.26 "Designed as a comprehensive statutory scheme, the ADA seeks to eliminate disability discrimination on the following fronts: employment,27 public services offered by public agencies,28 and public services and accommodations offered by private entities.29 In addition to the areas covered above, ADA also addresses telephone relay services to allow individuals with DD/MR to communicate more effectively, and also other miscellaneous provisions that address "retaliation and coercion and the abrogation of state immunity under the Eleventh Amendment."30

Title II of the ADA has been frequently used in litigating for community-based services. It provides in pertinent part, "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such agency."31 In addition, the ADA explicitly recognized "institutionalization" and "segregation" as forms of discrimination against disabled individuals.32

ADA authorized the Department of Justice to create regulations for implementation.33 Two especially important regulations are the Integration


32 42 U.S.C. §§ 12101(a)(2), (3), and (5).

33 42 U.S.C. § 12134(a).
Mandate and the Reasonable Modifications Regulation. The Integration Mandate is derived from the following language: “A public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”³⁴ It is followed by the Reasonable Modifications Regulation that states, “[a] public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate conclusively that making the modifications would fundamentally alter the nature of the service, programs, or activity.”³⁵ This language has been the focus of much of the litigation involving the provision of home and community-based services.³⁶

Embedded in the Reasonable Modifications Regulation is the Fundamental Alteration Defense, which also has been subject to much debate. In Helen L. v. DiDario, the 3rd Circuit “held that under the ADA individuals are entitled to receive treatment in the most integrated setting appropriate and that a public entity violates the ADA when it requires an individual to receive nursing home care against her wishes when she is qualified to receive home-based care.”³⁷ The U.S. Supreme Court denied certiorari, leaving the 3rd Circuit’s legal precedent for community-based services under the ADA.

C. ACT 189 – THE END OF WAIMANO AND INCORPORATION OF PERSON-CENTERED PLANS WITHIN THE DD SYSTEM

Hawaii Senate Bill 1461 was approved by the Governor on June 21, 1995, and became Act 189.³⁸ This bill was the result of a collaborative effort between the DD Division, DD Council, people with DD/MR and

³⁴ 28 C.F.R. § 35.130(d) (emphasis added).

³⁵ 28 C.F.R. § 35.130(b)(7) (emphasis added).

³⁶ See Karger, supra note 23, at 1239.


their family members, and also private service providers.\textsuperscript{39} Act 189 superseded the legislature’s previous notion that there would always be a need for an institution by calling for the closure of Waimano by January 1, 1998.\textsuperscript{40} Furthermore, the legislature mandated all services and programs to be provided by the private sector by June 30, 1998, although it accounted for an interim period of transition where DOH would be responsible to provide services if need be.\textsuperscript{41}

An additional amendment to the bill called for the creation of a panel, including persons with developmental disabilities and their families, to create a plan to ensure that the transition of residents would be “client-centered, taking into consideration the health, safety, and happiness of the residents and the concerns of their families.”\textsuperscript{42}

Act 189 further clarified that the provision of services and care were “within the limits of the state and federal resources allocated or available,”\textsuperscript{43} and that DOH maximize its funds for community services as state matching funds for Title XIX Medicaid waiver programs.\textsuperscript{44} Act 189 also mandated that assessments, plans, and services would be “person-centered and community-based.”\textsuperscript{45} DOH’s responsibilities were amended to “lead, administer, coordinate, monitor, evaluate, and set direction for a comprehensive system of supports and services.”\textsuperscript{46} In addition, DOH was required to provide case management independent of the private direct service providers, separating any conflict of interest that

\textsuperscript{39} E-mail from Waynette Cabral, Executive Director, State Planning Council on Developmental Disabilities and Commission on Person with Disabilities, to Jason Minami, Law Student, William S. Richardson School of Law (Apr. 30, 2004) (on file with author).


\textsuperscript{41} Id.

\textsuperscript{42} Id.

\textsuperscript{43} Id.

\textsuperscript{44} Id.

\textsuperscript{45} Id. at 359.
may occur. DOH case managers were required to determine eligibility for services to qualified individuals with DD/MR within 30 days of receipt of an application to expedite access to services.

In a mere seven years, the legislature moved from identifying their support for a policy towards community-based services for persons with DD/MR, to the mandated closure of the State’s main institution and the inclusion of person-centered ideals in the planning process for services.

D. ACT 133 – THE BEGINNING OF CONSUMER-DIRECTED SERVICES

House Bill 2862, which later became Act 133 after it was signed into law by the Governor on June 24, 1998, had two purposes: to extend the deadline initiated by Act 189 to close Waimano for another year until June 30, 1999, and to recognize the principles of consumer choice for self-determination for the developmentally disabled. DD Council played an integral role in the drafting and initiating of HB 2862. DOH supported the intent of the bill, and expressed concerns that it needed more time to transition services and programs from Waimano into the community due to limited resources.

Act 133 made profound changes to H.R.S. § 333F by amending its language to provide for consumer-directed services. H.R.S. § 333F-7 “Provision of Services” was amended to place the individual in the forefront, stipulating that DOH will assist the individual to develop the individualized service plan (“ISP”) with the help of family and friends. In addition, DOH was mandated to identify funds to effectuate the ISP, and “allow consumers to direct the expenditure of the identified funds.”

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47 Id.

48 Id.


50 See Email from Waynette Cabral, supra note 39.


53 Id. (emphasis added).
The bill of rights in H.R.S. § 333F was also amended to include the rights of the person with DD/MR to “control, with the help of family and friends as necessary, an identified amount of dollars to accomplish the plan . . . to direct the provision of resources, both paid and unpaid, that will assist an individual with a disability to live a life in the community rich in community association and contribution,” and to have a valued role in the community through employment, participation in community activities, volunteering, including being accountable for spending public dollars in ways that are life enhancing.

Act 133 shifted the focus from generic policy support for self-determination to the inclusion of specific person-centered language that provided for control by persons with DD/MR over the identification and provision of services. H.R.S. § 333F clearly and unequivocally opens the door for consumer-directed services in Hawaii.

E. THE OLMSSTEAD DECISION AND PRESIDENTIAL EXECUTIVE ORDER NO.13217

While Hawaii was altering its laws to close its main institution and provide for more self-determination initiatives, the United State Supreme Court and the Federal government were busy altering its own polices on institutionalization and community-based services for people with DD/MR. The Supreme Court’s 1999 decision in Olmstead v. L.C. has been described as the Brown v. Board of Education for disability rights. The Olmstead decision is summarized into two basic principles:

1. Unnecessary institutionalization of people with DD/MR who are eligible for state community-based programs constitutes discrimination under the ADA; and

2. A court must carefully examine the state’s legitimate interest in providing various services for persons with DD/MR, including institution-based services, as well as the allocation of state resources fairly and evenlyhandedly, when considering the fundamental alteration defense.

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54 Id. (Emphasis added).
55 Id.
56 See Cerreto, supra note 15.
Advocates and persons with DD/MR hailed the *Olmstead* decision as a tremendous victory in the disability rights movement. The Supreme Court’s message was clear: “unjustified institutionalization of persons with disabilities constitutes discrimination.”58 As one scholar adequately put it, “no sweeter words could reach the ears of the community of person with disabilities.”59

The *Olmstead* decision resonated throughout the Federal Government. On June 18, 2001, President George W. Bush issued Executive Order on Community-Based Alternatives for Individuals with Disabilities.60 In it he declared:

Section 1. Policy. This order is issued consistent with the following findings and principles:

(a) The United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interests of America.

(b) The United States seeks to ensure that American’s community-based programs effectively foster independence and participation in the community for Americans with disabilities.

(c) Unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination prohibited by Title II of the ADA. States must avoid disability-based discrimination unless doing so would fundamentally alter the nature of the service, program, or activity provided by the State.

(d) In *Olmstead v. L.C.* ... the Supreme Court construed Title II of the ADA to require States to place qualified individuals with mental disabilities in community settings, rather than in institutions, whenever


treatment professionals determine that such placement is appropriate, the affected person does not oppose such placement, and the State can reasonably accommodate the placement, taking into account the resources available to the State and the needs of others with disabilities.

(e) The Federal Government must assist States and localities to implement swiftly the Olmstead decision, so as to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life.\footnote{61 Id.}

Section 2 of the Executive Order emphasized swift implementation of the \textit{Olmstead} decision by ordering the Attorney General, the Secretaries of Health and Human Services, Education, Labor, Housing and Urban Development, and the Commissioner of the Social Security Administration to work cooperatively in its implementation.\footnote{62 Id.} In addition, the President ordered them to evaluate the policies, programs, statutes, and regulations of their respective agencies to improve on the availability of community-based services for qualified individuals with disabilities, while including the involvement of consumers, advocacy organizations, providers, and relevant agency representatives.\footnote{63 Id.} Finally, the Executive Order mandated the cooperation of the Department of Justice and the Department of Health and Human Services to the furthest extent possible in investigating and resolving complaints brought under Title II of the ADA.\footnote{64 Id.}

The Executive Order was issued in conjunction with the President’s New Freedom Initiative,\footnote{65 Whitehouse News (Feb. 1, 2001),http://www.whitehouse.gov/news/freedominitiative/freedominiative.html, (copy on file with author).} which was designed to “increase access to assistive technology, expand educational opportunities, increase
the ability of people with disabilities to integrate into the workforce, and promote increased access to daily community life.” 66 These policy changes drastically affected the focus of programs and services away from institutions and toward home and community-based services.

IV. CHALLENGES TO THE DD SYSTEM: ADVOCATES, REPORTS, AND LAWSUITS

A. HDRC AND THE MAKIN WAITLIST SETTLEMENT

Although the State of Hawaii has made great progress in recognizing and expanding the rights of persons with DD/MR through legislation, there are some who keep a watchful eye over its implementation by the DD System. One such group is the Hawaii Disability Rights Center (“HDRC”), formerly the Protection and Advocacy Agency of Hawaii, which is the State’s federally funded protection and advocacy center.67 HDRC was designated as Hawaii’s Client Assistance Program under the Federal Rehabilitation Act in 1984,68 and also was granted such authority by the Governor and by statute.69 HDRC’s mission is “to protect and promote the human, civil and legal rights of individuals with disabilities through the provision of information and advocacy.”70

HDRC has filed two lawsuits on behalf of individuals with developmental disabilities against the State. Makin v. State of Hawaii (“Makin”)71 was settled in April, 2000, and the case was dismissed by

66 Cerreto, supra note 15, at 60.


69 HDRC website, supra note 67.

70 Id.

United States District Court, District of Hawaii, upon approval of the settlement agreement.\textsuperscript{72}

In \textit{Makin}, the State was sued because the waitlist for Medicaid Home and Community-Based Services ("HCBS") allegedly violated ADA mandates, Federal Medicaid law, and the \textit{Olmstead} decision. Typically, waitlist lawsuits assert that a State has failed to provide long-term services funded by Medicaid with reasonable promptness to individuals with developmental disabilities who would have otherwise been eligible to receive services.\textsuperscript{73}

The district court held that "the State need not provide HCBS services to listed individuals on the wait list until vacant slots become available under the HCBS Waiver program."\textsuperscript{74} However, the court also "found that the State’s Medicaid statute, with its population limits and resulting wait lists, failed to offer HCBS in the most integrated setting appropriate to individualized needs, potentially forcing individuals with disabilities into institutions to receive needed services, in violation of the ADA’s integration mandate."\textsuperscript{75} After the cross-motion ruling by the district court, both sides came to an agreement in April 2000.\textsuperscript{76}

According to the \textit{Makin} settlement agreement, the State agreed to provide “appropriate and needed home and community services to at least 700 qualified developmentally disabled or mentally retarded people from the waitlist for Medicaid funded home and community-based services by June 30, 2003.”\textsuperscript{77} In addition, the State agreed to use its best efforts to obtain appropriations from the Legislature and Federal approval from


\textsuperscript{73} Margaret K. Feltz, \textit{Playing the Lottery: HCBS Lawsuits and Other Medicaid Litigation on Behalf of the Developmentally Disabled}, 12 Health Matrix 181, 189 (2002).

\textsuperscript{74} See Kubo, \textit{supra} note 72, at 746.

\textsuperscript{75} \textit{Id.} at 747.


\textsuperscript{77} \textit{Id.} at 3.
CMS, and to develop a comprehensive plan with public participation to move the waitlist at a reasonable pace after the aforementioned June 30, 2003, deadline.\(^7\)

In May 2000, the Hawaii Legislature passed House Concurrent Resolution 196 ("HCR 196") to address the *Olmstead* decision and the DD System waitlists for services. HCR 196 requested "the Governor to establish a task force to develop and implement a statewide, comprehensive, and effective working plan for placing qualified persons with disabilities in the most integrated setting possible and to keep waiting lists that move at a reasonable pace."\(^7\)

The task force, led by the Department of Human Services, the Department of Health, and the Hawaii Centers for Independent Living, met over the an 18 month period with "[i]ndividuals with disabilities, their family members and representatives from advocacy groups, non-profit groups, businesses, and government agencies who assist people with disabilities . . . to identify principles, design strategies and outcomes, and work together on successive drafts"\(^8\) to create a planned response to the *Olmstead* decision. The plan was issued on September 13, 2002, and outlined five goals to keep Hawaii in compliance with *Olmstead* with oversight charged to existing councils and agencies including DD Council, the Executive Office on Aging, and the Disability and Communication Access Board.\(^8\) The DD System is currently attempting to implement these strategies to comply with CMS and the Olmstead decision.

*S.M. v. State of Hawaii* ("SM") was filed on September 29, 2003, and alleges failure of compliance with the *Makin* Waitlist Settlement.\(^8\) In *SM*, HDRC alleges that the State failed to comply with the terms of the settlement agreement, and renewed their complaints in *Makin*, with

\(^7\) *Id.* at 3-5.


\(^8\) *Id.*

additional claims. Gary Smith, president of HDRC, is quoted by the Honolulu Star Bulletin as saying, “The new lawsuit is the outcome of the state’s failures to meet the requirements of the settlement agreement of the Makin lawsuit.” According to the complaint, the lawsuit is brought on behalf of over 300 eligible individuals with DD/MR applying for the Medicaid HCBS Waiver Program. HDRC alleges that the State violated the terms of the settlement agreement by admitting 336 new additions into the HCBS Waiver Program ahead of 309 individuals out of the 700 named on the original waitlist.

The State asserts that 688 individuals were on the waitlist in fiscal year 2002, but 423 of them, including many children in the State Department of Education system, chose to defer admissions to the DD/MR Waiver Program during that year. According to data provided by to HDRC by the State, others were “removed from the waitlist due to death, relocation, Medicaid ineligibility or by request.” In addition, “727

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85 Id.


88 See HDRC Report, supra note 86, at 3.
persons had been admitted to Medicaid waiver services in the 3-year period from March 2000 to March 2003.\footnote{89} This indicates that the State admitted more than 700 individuals who were on the waitlist either at the time of the Makin settlement, or during the three-year period thereafter. Janice Okubo, spokeswoman for the DOH, said that the State has complied with the agreement and that “in the spirit and intent of the Makin settlement, we are continuing to reduce the waitlist for disabilities services.”\footnote{90}

The discrepancy arises over the deferral of admission by those previously on the waitlist at the time of the settlement. HDRC argues that the State’s deferral procedure violated plaintiffs’ rights to “procedural due process, integration into the community, and appropriate and necessary medical treatment,” and the State has “also wrongfully obtained consent by coercion and misrepresentation.”\footnote{91} HDRC supports its allegations through data collected from a series of investigations conducted from 2001 through mid-2003.\footnote{92} The investigations included follow-up mailers to all of the class members in Makin, telephone surveys of individuals, caregivers, or guardians, and a review of several hundred case files kept by the DD Division.\footnote{93}

If the State can show that the individuals from the original waitlist openly and consensually deferred admission into the Waiver Program, then HDRC’s argument seems to be without merit. Even HDRC concedes, “If a waitlisted person defers HCBS, isn’t it entirely logical that other waitlisted persons with power priorities who haven’t ‘deferred’ will receive waiver services before them?”\footnote{94} However, the outcome of this case is yet to be seen, as settlement negotiations are currently taking place.

\footnote{89} Id.

\footnote{90} See Bernardo, supra note 84.

\footnote{91} See First Amended Complaint, supra note 83.

\footnote{92} See HDRC Report, supra note 86, at 1.

\footnote{93} Id. at 1-2.

\footnote{94} Id. at 10.
B. **DD Council’s Report of the DD System**

The Federal DDABRA mandated that every state have a Council on Developmental Disabilities. The Hawaii Legislature established the State Planning Council on Developmental Disabilities and Commission on Persons with Disabilities (“DD Council”) through Act 198, Session Laws of Hawaii, 1975, which became codified as Hawaii Revised Statutes § 333E (“H.R.S. § 333E”), to comply with the DDABRA. The DD Council is comprised of approximately 30 people appointed by the Governor, a majority of whom are persons or family members of persons with disabilities. The remainder of the members is from state agencies, private service providers, and the community.

H.R.S. § 333E requires the DD Council to “plan, coordinate, evaluate, monitor, and advocate on behalf of individuals with developmental disabilities.” In addition, the Council must “assure that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports, and other assistance and opportunities that promote independence, productivity, and integration, and inclusion into the community.”

The mission of the DD Council is to “support people with developmental disabilities to control their own destiny and determine the quality of life they desire.” The DD Council strives to “work for self-determination, advocate for systems change, provide information, education, planning, serve as conscience/monitor of the State; and promote best practices.”

In this pursuit, the DD Council has commissioned various reports conducted by outside consultants to analyze and review the DD System.

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96 Id.

97 Id.

98 Id.

99 Id.

100 Id.

101 Id.
The 1999 Harkins and Head report is of particular significance, as it acknowledges that the DD System must conform to the statutory mandate in Act 133 that amended H.R.S. § 333F to “enable each person with a developmental disability to direct the expenditure of funds available for his/her support, and to assist each person to be involved with and play valued roles within his/her communities.”  

The report cites inadequacies within the DD System, specifically finding faults in the Medicaid Waiver Program utilized by the DD System to obtain federal reimbursement money to provide home and community-based services for people with DD/MR. It states, “[w]aiver-covered

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In 1981, former President Ronald Reagan signed into law Public Law 97-35. Section 2176 of PL 97-35 established section 1915(c) of the Social Security Act [hereinafter SSA], which became the Medicaid Home and Community-Based Services (“HCBS”) Waiver program administered by the Centers for Medicare and Medicaid (“CMS”). This legislation allowed States to administer Medicaid services to people in their homes and communities who would otherwise receive services in an institutional setting, such as hospitals, nursing facilities or intermediate care facilities for persons with mental retardation (“ICF-MRs”).

States now had the ability to design an array services to meet the needs of Medicaid eligible target populations in a community setting. The provision of such community services was found to cost no more than institutional placement. The waiver program also afforded people the ability to remain in their home, fostering independence and relationships with their family and friends.

Congress has subsequently amended the SSA to:

1. Expand the waiver authority to individuals who absent the waiver would require hospital level of care;
2. Extend the renewal authority from three years to five years;
services definitions are narrowly designed, professionally driven, and easily result in people being offered programs segregated from meaningful community participation.” In addition, the report finds very little of the statutory mandates of Act 133 currently available through the Medicaid Waiver Program.

The report recognizes, however, that the current Medicaid Waiver Program was created prior to the statutory changes made by Act 133. The report suggests amending the Medicaid Waiver Program to include

3. Limit waivers of Medicaid statutes to section 1902(a)(10)(B) rather than the broad section 1902(a) waiver offered in the original legislation;
4. Added, with exceptions, prevocational, educational and supported employment to habilitation services; and
5. Include day treatment or other partial hospitalization services, psychosocial rehabilitation services and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness.

The additional legislation broadened the spectrum of community services that states could provide in their waiver program. Essentially, states can tailor waiver programs to offer more services that assist people to actively participate in the community.

See also CMS Program Design, available at http://www.cms.hhs.gov/medicaid/1915c/design.asp, (last visited Aug. 27, 2004) (copy on file with author). States may identify a target population, such as persons with DD/MR, and create a waiver program of services designed to fit their needs in the community. States are limited, however, by the requirement that people in the waiver program qualify for institutional level of care. In other words, individuals receiving services under a HCBS waiver program must be at or exceed the following levels of care: hospitalization, nursing facility, or ICF-MR. While there are no specific services or limits on the number of services that must be offered in a single HCBS waiver program, the waiver must retain cost-neutrality and the services must be necessary to avoid institutionalization.

104 See Harkins & Head, supra note 102, at 22.

105 Id. The report states, “There are no obvious avenues within current Waiver arrangements which promote accomplishing plans that speak directly to what needs to happen to support a person in his/her desired life, if that desired life does not include participation in a segregated program or a licensed residential facility. Likewise, no avenue exists which allow the person to control, with the help of family and friends as necessary, an identified amount of dollars to accomplish that plan.”
services that comply with the statutory mandates in H.R.S. § 333F. These amendments “should promote freedom, choice and control for individuals who require support from the developmental disabilities system.” The addition of consumer-directed personal assistance services in the Medicaid Waiver Program would bring the DD System closer to compliance with Act 133.

V. CONSUMER-DIRECTED SERVICES

A. INTRODUCTION TO CONSUMER-DIRECTED SERVICES

“‘Consumer-direction’ is a philosophy and orientation to the delivery of home and community-based long-term care that puts informed consumers and their families in the driver’s seat with respect to making choices about how best to meet their disability-related supportive services needs.” Persons with a wide range of disabilities, some with the help of friends and family representatives, will be able to choose who they want to provide various levels of care. In addition, the individual with a disability will be able to make more decisions about their non-medical care without excessive reliance on professional personnel for all decisions. The level of consumer-direction, including choice and responsibility, can vary significantly. While programs may differ, the outcome remains consistent in that the individual makes decisions appropriate to their needs.

106 Id. at 23.


108 Id.


110 Id.

111 AOA Information Memorandum, To State and Area Agencies on Aging and Tribal Organizations Administering Plans Under Titles III and VI of the Older American Act of 1965, As Amended, Subject: Cash and Counseling
conceptualized as a “continuum of approaches based on the level of decision-making, control, and autonomy allowed in a particular situation.” At the furthest end of the continuum, “professionally managed service packages” with limited consumer-direction would allow for the person to choose their workers and replace them when necessary. These workers, although chosen by the individual, would remain employees of a more traditional provider agency. The opposite end of the consumer-directed continuum would follow a “cash model” where persons with disabilities receive cash benefits directly and can then manage and purchase services on their own or with the help of friends and family.

With such a wide array of consumer-direction programs that offer a variety of avenues to meet the needs of individuals with disabilities, it is no wonder that consumer-directed services are gaining recognition and interest around the nation. While its origins are found in the 1970s, the number of programs utilizing consumer-direction has significantly increased over the last three decades. In a 2002 review, there were 139 programs offering a consumer-directed service. Tennessee and the District of Columbia are the only states that do not offer at least one consumer-directed program.

The number of consumer-directed programs continues to rise. Sixty-five percent of consumer-directed HCBS reviewed have been implemented since 1990, twenty-three percent during the 1980s and

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112 See Stone, supra note 109.

113 Id.

114 Id.


116 See Doty & Flanagan, supra note 107, at 1.

117 Id. at 2.
eleven percent before 1980.\textsuperscript{118} Of the 139 programs reviewed, sixty-five percent utilize Medicaid funding.\textsuperscript{119}

A.E. Benjamin, professor and chair of the Department of Social Welfare, School of Public Policy and Social Research at the University of California at Los Angeles, cites five motivating factors that drive the growth of CD services:

1. Three decades of aggressive advocacy by non-elderly persons with chronic impairments has increased political pressure to expand publicly funded personal assistance services that give recipients more autonomy over their own care;

2. Consumer movements have called for “demedicalization” of some conditions (such as disability, old age, and pregnancy) and services (such as supportive home care and child birth) so the message of consumer-direction has a broader context;

3. Concerns about cost and long-term care have made federal and state policymakers receptive to home care service approaches considered to be less costly;

4. The Supreme Court’s 1999 Olmstead decision has put additional pressure on states to consider diverse approaches to providing community placements and services for persons with disabilities; and

5. The recent shortage of front-line workers also has increased receptivity to new strategies for recruiting long-term care providers.\textsuperscript{120}

\begin{enumerate}
\item \textsuperscript{118} \textit{Id.} at 3.
\item \textsuperscript{119} \textit{Id.}
\item \textsuperscript{120} Benjamin, \textit{supra} note 115, at 81. \textit{See also} Batavia, \textit{supra} note 7, at 270, who cites five significant events as being responsible for the propulsion of CD services in long-term care:
\begin{enumerate}
\item The Olmstead Decision citing discrimination under the ADA for unnecessary institutionalization as well as the need for the provision of services to be in the most integrated setting;
\item Following court decisions, advocacy efforts and state initiatives and government assistance in adhering to Olmstead requirements in a way that promotes consumer direction;
\item Assistance from the federal government in creating consumer-directed methods for practice;
\end{enumerate}
The provisions tailoring consumers’ needs to the “most integrated setting appropriate” cited in the DDABRA, RA, and ADA, are used by individuals with disabilities to further access personal assistance services consistent with the independent living model.121 “The very foundation of consumer direction lies in the independent living movement led by individuals with physical disabilities during the 1960’s and 1970’s who demanded their rights to be full participants in mainstream society and to live independently in their communities.”122 This is contrary to the traditional agency model where care is coordinated by a case management entity and provided through a service provider agency.123

Additionally, the ADA states, “[t]he Nation’s proper goals regarding individuals with disabilities are to assure equal opportunity, full participation, independent living, and economic self-sufficiency for such individuals.”124 “By allowing individuals to live at home according to their own needs, desires, and schedules, the independent living model promotes all four goals of the ADA.”125

B. Benefits of Consumer-Directed Services to Hawaii

Regardless of which program on the consumer-direction continuum Hawaii chooses to follow, the implementation of consumer-

4) Culmination of state efforts in integrating consumer-directed approaches in programs;
5) Co-sponsorship by the Department of Health and Human Services and Robert Wood Johnson Foundation of a national conference to discuss consumer-direction for the elderly and people with disabilities.


123 See AOA Information Memorandum, supra note 104.

124 Id., citing 42 U.S.C 12101(a)(8).

125 Id.
directed services by the DD System will address issues brought up by HDRC and DD Council, while providing people with DD/MR with more choice and control over needed services and supports. Consumer-directed services will help alleviate some of the problems that led to Makin and SM.

As stated previously, the Makin lawsuit focused on an excessive waitlist for Medicaid waiver services. Waitlists are caused by a variety of issues, including a lack of adequate funding. Studies have shown that consumer-directed services cost substantially less than traditional provider service programs. “In a home care industry in which workers make low wages, a substantial share of traditional home care cost involves agency overhead. When that overhead is minimized or eliminated because the self-directing consumer assumes the employer role, the hourly cost to public programs can drop sharply.”

Another major cause of the formation of waitlists is inadequate provider capacity. Experts recognize that “there is a growing shortage of frontline workers to deliver long-term care in all settings.” Consumer-directed services offer a potential remedy, as they “afford much more flexibility in hiring workers (including relatives and friends), thus expanding the potential pool of caregivers.” Individuals who live in rural areas, where it is difficult and expensive for providers to maintain workers, will be able to hire family members and other people who live in their communities.

The DD System is also currently taking steps to implement consumer-directed services. The DD Division, working in conjunction with the State of Hawaii Department of Human Services (the State’s Medicaid agency), submitted a waiver amendment in October of 2003 that provided for consumer-directed services. Making matters easier, the Federal government is currently simplifying the process and alleviating

127 See Benjamin, supra note 108 at 90.
128 See Stone, supra note 102, at 1.
129 Id.
130 Id.
131 Doyle Interview, supra note 1.
much of the bureaucratic red tape that states must cut through to include the provision of consumer-directed services in their Medicaid Waiver Programs.

On May 9, 2002, Tommy Thompson, Secretary of the Department of Health and Human Services, unveiled two new waiver templates that will assist states to better enhance their Medicaid programs in an attempt to enable people with disabilities to choose services in their own homes and communities.\(^{132}\)

The initiative provides for consumer-direction by allowing the participant “to hire, fire, train, and supervise personal assistance attendants, as well as the opportunity to directly purchase services.”\(^{133}\) In addition, the initiative offers a budget that the individual may control and arrange for services.\(^{134}\)

Once approved, the new Waiver Program will implement the mandates of Act 133 by allowing consumers to exercise more direct control over the expenditure of funds available for their support. Cost and provider capacity issues are also addressed which reduce waitlists for services and allow more people with DD/MR to remain in the community, thereby satisfying the least restrictive setting mandate of the ADA. The provision of consumer-directed services will enhance the quality of a

\(^{132}\) Press Release FOR IMMEDIATE RELEASE, Thursday, May 9, 2002: NEW FREEDOM INITIATIVE PROGRESS REPORT RELEASED, HHS Announces Steps to Facilitate State Programs to Foster Community Integration, available at http://www.hhs.gov/news/press/2002pres/20020509a.html, (last visited Aug. 27, 2004) (copy on file with author). Secretary Thompson states, “Never before have so many federal agencies devoted so much time and attention toward eventually eliminating the barriers that keep people with disabilities from enjoying the freedoms that so many of us take for granted. These barriers have been years in the making and will take much effort to address, but we are fully committed to the task.” The Press Release further states, “HHS’ new ‘Independence Plus’ waiver templates will give States tools to create programs that will allow people with disabilities and their families to decide how best to plan, obtain and sustain community-based services, placing control into the hands of the people using the services.”


\(^{134}\) Id. at 12.
person’s life by increasing their independence, allowing them to direct their workers according to their needs, preferences, and desires.

C. CONCERNS WITH CONSUMER-DIRECTED SERVICES

Although consumer-directed services are a potential remedy to some of the issues of compliance with Act 133 by the DD System, there are various concerns that need to be addressed. Those opposed to enhancing consumer control fear that the quality of services will decline, the amount of applicants needing benefits will increase, and many consumers will have trouble navigating the issues related to directing their personal care services.\footnote{See Batavia, supra note 110, at 22.} A variety of additional concerns exist over the implementation of consumer-direction, including issues relating to the cognitive ability of the consumer to make adequate choices,\footnote{See Benjamin, supra note 108, at 84.} liability considerations,\footnote{Marisa A. Scala & Pamela S. Mayberry, Consumer-Directed Home Services: Issues and Models, at 17, Scripps Gerontology Center, Miami University (1997), (copy on file with author).} and costs related to consumer-directed services.\footnote{See Stone, supra note 102.}

Discussions on these issues focus on the ability of persons with disabilities, particularly cognitive disabilities, to make choices regarding care.\footnote{See Benjamin, supra note 108, at 84.} The question of eligibility often arises, and is based on the need to make decisions and the ability to incur responsibility, including “employer related tasks such as recruiting, screening, interviewing, hiring, training, supervising, paying, withholding taxes, and if necessary firing assistants.”\footnote{See Scala & Mayberry, supra note 137, at 3.} Some programs impose restrictions based on the person’s ability to self-direct.\footnote{See Doty & Flanagan, supra note 100, at 2.}

Cognitive ability to make decisions about preferences in service delivery, however, should not be a restriction to the utilization of a
consumer-directed model. This concern can be addressed through the use of a surrogate. Surrogates are “typically family members who conduct all the functions and tasks the individual would perform in managing the personal assistance relationship.” The University of Maryland Center on Aging found that persons with cognitive impairments as well as those with severe to moderate disabilities were able to express their preferences about their care themselves or through a person close to them who understands their non-verbal communication.

In addition to concerns over a person’s cognitive ability, there is an issue regarding the quality assurance of the workers hired by the individual or her surrogate. The traditional service provider agency/adult day program model provides safeguards in the form of licensure, certification, and qualifications for its employees. In cases of poor service delivery, based on agency supervision, workers may be dismissed or reprimanded. Reports have been compiled that evaluate outcomes and experiences, and were compared by users of agency models against consumer-directed models of care. In the area of client safety and unmet needs, no major variation in outcomes between the two groups was revealed. In fact, “clients in the consumer-directed model who

142 See Benjamin, supra note 108, at 82. See also Scala and Mayberry, supra note 132, at 3.

143 See Batavia, supra note 7, at 282.

144 Id.


146 See Benjamin, supra note 108, at 88.

147 Id.

148 Id.


150 Id.
hired family members as their personal care attendants had better outcome measures related to safety and sense of security.\textsuperscript{151}

Research suggests services supporting a consumer-directed model may have a beneficial effect on the participant’s health.\textsuperscript{152} Several other studies suggest, “the actual risks to consumers associated with self-direction seem no greater than those with agency based services.”\textsuperscript{153} Another study conducted by the Federal Department of Health and Human Services and the University of California, Los Angeles, found that participants reported increased satisfaction using a consumer-directed model in the areas of service quality and impact and in the interpersonal and technical sense as well.\textsuperscript{154}

Liability for personal injury to clients is increasingly expressed as a concern when the person with a disability has increased control over the service worker and provision.\textsuperscript{155} However, “in reality . . . there has been very little litigation for negligence against agencies or privately hired assistants.”\textsuperscript{156} States may address these concerns in many ways including, identifying the consumer as the employer of record, providing training in the area of employer tasks, identifying the responsibilities of each party, providing support to the person controlling their service, requiring criminal history checks for workers, and providing a workman’s compensation in a general benefits package.\textsuperscript{157}

Employment tax and benefit liability is another area that is cause for discussion. It is suggested that state programs identify the consumer as the employer, using a fiscal intermediary for tax withholding and payment purposes.\textsuperscript{158} The use of fiscal intermediaries can also alleviate concerns

\textsuperscript{151} Id.

\textsuperscript{152} See Batavia, supra note 110, at 21-22.

\textsuperscript{153} Benjamin, supra note 108, at 88-89.

\textsuperscript{154} See Squillace & Firman, supra note 145, at 17.

\textsuperscript{155} See Scala & Mayberry, supra note 137, at 17.

\textsuperscript{156} Id.

\textsuperscript{157} See Scala & Mayberry, supra note 137, at 17.

\textsuperscript{158} Id. at 19.
over the misuse of funds.\footnote{See Squillace & Firman, \textit{supra} note 145, at 13.} Fiscal intermediaries can assist persons in a variety of ways to participate in consumer-direction, including assistance with budget management and employee responsibilities such as accounting related to taxes.\footnote{\textit{Id.}}

Although there are legitimate concerns over the functionality of consumer-directed services, scholars and advocates insist that consumer-direction will remain a viable tool in implementing home and community-based services.

VI. CONCLUSION

The rights of persons with disabilities are stated in the ADA, interpreted in Olmstead, and mandated by Presidential Executive Order and the New Freedom Initiatives. Hawaii has shown clear support for community-based, person-centered services and supports as set forth in H.R.S. § 333F. The implementation of consumer-directed services will bring the DD System closer to achieving what is set forth in law.

Although cost-effectiveness, potential for abuse of the system, and the health, safety, and well-being of the individuals with DD/MR will always be concerns to all involved, these should not serve as impenetrable barriers that hinder change. In order to effectuate change, the belief and willingness to try is paramount. Even if the system does not succeed, the lessons learned can be used to make the next attempt stronger and better.

Through consumer-directed services, Jon will be able to direct the expenditure of moneys used to provide him services and supports. Jon can hire Sally on a permanent basis so that she can help him explore his hobby of painting. Jon can spend more time outdoors, explore volunteer opportunities with park rangers, tune his painting skills by taking classes and attending workshops. Whatever he decides to do, Jon will be able to live a more independent life with services tailored to his needs and desires.