Help or Hinder: Recent HCBS programs and their impact on “Aging in Place”

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Tied for Fourth Place
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I. INTRODUCTION

Over the next several decades, the demographics of our country will be significantly altered. A dramatic increase in the elderly population will require a response by both federal and state legislatures to address the impact these changes will have on our long term care programs and supports. Many initiatives being implemented now may provide examples in the future of programs that are successful and sustainable for the long term. This paper will address many of the recent efforts by the United States and Minnesota Legislatures, and discuss whether they are helping or hindering the elderly from remaining in their homes and in their community. Part II will provide a background for the paper, Part III will evaluate recent federal programs, and Part IV discusses several Minnesota programs that impact aging in place.

II. BACKGROUND

A. THE GROWING ELDERLY POPULATION
B. According to a report by the United States Census Bureau, the United States is projected to experience rapid growth in its older population between 2010 and 2050. The number of Americans ages 65 and older is projected to be 88.5 million in 2050, more than double its population of 2010. Nearly one in five U.S. residents will be aged 65 and older in 2030.

Much of this growth is because of the aging baby boomer population. In 2010, the baby boom generation was 46 to 64 years old. By 2030, all of the baby boomers will be over the age of 65. Projected immigration trends into the working age group will mitigate the impact, but there is little doubt that the aging population will influence public policy and legislative decisions for the next several decades. It is important to implement and test federal and state programs now, in order to ensure that we have a comprehensive and flourishing home and community-based services system when the baby boomers reach retirement.

C. AGING IN PLACE

“Aging in place” is the desire of older people to live in their own housing and communities as long as possible. This idea has gained popularity with the aging of the American population. In an AARP survey from 2000, more than 80% of respondents aged 45

2 Id.
3 Id.
4 Id.
5 Id.
6 Id.
7 Id.
9 Id.
and older wished to stay in their current homes for as long as possible.\textsuperscript{10} In another survey of
Minnesota baby boomers, 89% of respondents indicated that they wanted to remain living at
home, 1% wanted to live in assisted living, 0% wanted to live in a nursing home, and 10% didn’t
know.\textsuperscript{11}

The elderly wish to remain in their homes for several reasons. First, the elder’s home is a
comfortable and familiar environment. A sense of identity is created from living in a home for
an extended period of time.\textsuperscript{12} In 1996, 65% of elderly homeowners had been living in the same
home for more than thirty years.\textsuperscript{13} In that time, deep ties are created with family members and
friends.\textsuperscript{14} They identify the home as a harbor of family traditions.\textsuperscript{15} The elder also has his
regular and familiar community locations, such as shops, restaurants, and health services.\textsuperscript{16}

Second, the elder can remain in close proximity to family. Sixty-six percent of elders
live within thirty minutes of a family member.\textsuperscript{17} Relationships with neighbors and family
traditions can continue, as they have in the past. Family support and the assistance of family
members make independent living much easier to manage for a person with a disability.\textsuperscript{18}
Relatives may also provide uncompensated care, or informal support, to the individual at home.\textsuperscript{19}

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\textsuperscript{11} The Ecumen Age Wave Study (2007), http://www.ecumendev.org/app/webroot/files/file/White\%20Papers/Age-Wave-Study.pdf
\textsuperscript{12} Pynoos, supra note 8, at 79.
\textsuperscript{13} Id. at 80.
\textsuperscript{14} Id. at 79.
\textsuperscript{15} Id.
\textsuperscript{16} Id.
\textsuperscript{18} Lawrence A. Frolik & Richard L. Kaplan, Elder Law in a Nutshell, 152 (2d ed. 1999).
\textsuperscript{19} Id.
\end{flushleft}
Third, living in the community promotes feelings of independence. Like other Americans, elderly in this country cherish their freedom, autonomy, and privacy.\textsuperscript{20} A survey of the Minnesota baby boomer population found that 100% of respondents considered independence an important factor in the decision of where they live. Ninety-nine percent considered privacy an important factor.\textsuperscript{21} Recognizing that living in a nursing home may involve sacrificing these ideals, the majority of older people try to postpone and avoid moving into a nursing home to the fullest extent possible.\textsuperscript{22}

Nevertheless, aging in place also presents some challenges and risks. One of the major challenges, and the focus of this paper, is having supportive services available to older adults living in the community that need them. Those in the oldest ages often require additional caregiving and support.\textsuperscript{23} Of non-institutionalized adults 65 and older, 22.1 million, or 61%, have at least one basic actions difficulty or complex activity limitation.\textsuperscript{24} This shows the challenge presented to the elderly who endeavor to stay in their homes as they continue to age.

**D. AMERICANS WITH DISABILITIES ACT**

The Americans with Disabilities Act of 1990 (ADA) defines a person with a disability as an individual with a physical or mental impairment that substantially limits one or more major life activities of such individual, an individual with a record of such impairment, or a individual who is regarded as having such an impairment.\textsuperscript{25} The ADA prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial

\textsuperscript{20} \textit{Id.}
\textsuperscript{21} Ecumen, supra note 11.
\textsuperscript{22} \textit{Id.}
\textsuperscript{23} Vincent & Velkoff, supra note 1.
\textsuperscript{25} 42 U.S.C.A. § 12102(1)(A-C).
facilities, transportation, and telecommunications.\textsuperscript{26} The Rehabilitation Act (RHA), which articulates similar standards to the ADA, prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors.\textsuperscript{27}

In the ADA, Congress found that unjustified isolation and segregation of persons with disabilities is a form of discrimination, and that it is a serious and pervasive social problem.\textsuperscript{28} The ADA states, “… 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 entity.”\textsuperscript{29}

A provision that relates specifically to aging in place is the “integration regulation.” This states that a public entity shall administer its services, programs, and activities in the most integrated setting appropriate to the needs the qualified disabled individual.\textsuperscript{30} The preamble to the Attorney General’s Title II regulations defines “the most integrated setting appropriate to the needs of qualified individuals with disabilities” to mean “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.”\textsuperscript{31}

Furthermore, 28 CFR § 35.130(b)(7) requires a “public entity to make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid

\textsuperscript{27} \textit{Id.} at 16.
\textsuperscript{28} 42 U.S.C.A. § 12101(a)(2).
\textsuperscript{29} 42 U.S.C.A. § 12132.
\textsuperscript{30} 28 CFR § 35.130(d).
discrimination of the basis of disability.” If these modifications fundamentally alter the nature of the program, they are not required to modify it under this rule.

1. Olmstead v. LC

In Olmstead v. L.C. ex rel. Zimring, 527 U.S. 591 (1999), an iconic Supreme Court decision, the Court concluded that “states are required to provide community-based treatment for persons with mental disabilities when the State’s treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonable accommodated.” This case has the potential to change the social response to people with physical or mental disabilities who need assistance in daily life, including ever-increasing numbers of elderly Americans.

In Olmstead, two women were being treated in institutional settings for their mental disabilities. One woman had schizophrenia and the other woman was diagnosed with a personality disorder. Those providing treatment to the women determined that their needs could be appropriately met in a community-based setting. Despite that determination, the women remained institutionalized. They filed suit to challenge their continued confinement in a segregated environment, claiming that the state violated Title II of the ADA. The Court agreed.

32 28 CFR § 35.130(b)(7).
33 Id.
34 Olmstead, supra note 31, at 607.
36 Id., supra note 31, at 593.
37 Id.
38 Id.
39 Id.
40 Id.
41 Id. at 594.
The Court concluded that “when a disabled individual’s treating professionals find that a community-based placement is appropriate for that individual, the ADA imposes a duty to provide treatment in a community setting – the most integrated setting appropriate to that patient’s needs. Where there is not such finding, nothing in the ADA requires the deinstitutionalization of the patient.” The Court holds that unjustified segregation reflects the position that institutionalized individuals are incapable or unworthy of participating in community life. The Court also holds that institutional confinement severely diminishes individuals’ everyday life activities, including family life, social contacts, work options, economic independence, educational advancement, and cultural enrichment. The Olmstead decision did not require that individuals who will not benefit from community-based services be treated in the community. Moreover, under Olmstead, community-based services will not be imposed on someone who does not want them.

The integration regulation of the ADA is not absolute. Title II regulations require reasonable modifications, but only if the modifications do not fundamentally alter the program. Meeting the fundamental alteration test takes into account three factors: 1) the cost of providing services in the most integrated setting, 2) the resources available to the state, and 3) how the provision of services affects the ability of the state to meet the needs of others with disabilities.

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42 Id. at 595.
43 Id. at 600.
44 Id.
45 Id. at 583.
46 Id.
47 Id. at 595.
48 28 CFR § 35.130(b)(7), supra note 32.
In the current fiscal crisis, it would appear that a state could make cuts to a program to save money and subsequently argue that the cuts do not violate the integration regulation of the ADA because of the fundamental alteration defense. In *Crabtree v. Goetz*, No. 3:08-0930 (M.D. Tenn.), the court considered the fundamental alternation test. In this case, the court holds that cuts made to home care hours was a violation of the ADA.\textsuperscript{50} Tennessee’s Medicaid program, called TennCare, limited the amount of hours of home health and nursing services that enrollees could receive each week.\textsuperscript{51} The court holds that the cuts would result in isolating and deleterious effects, such as the loss of individual lives, community activities, and separation from their communities and loved ones.\textsuperscript{52} The defendants asserted the fundamental alteration defense, arguing that the cuts were necessary to save money in the current financial crisis, and that the cuts would make it possible to expand other long term care programs.\textsuperscript{53} The court rejected this defense, holding that increased state expenditures may be necessary to provide home medical services and accommodations required by the ADA and RHA.\textsuperscript{54}

The *Olmstead* decision has led to many changes on both a federal and state level. The removal of the institutional bias in government funding has made progress.\textsuperscript{55} The Kaiser Commission on Medicaid and the Uninsured reported that the national percentage of Medicaid spending on home and community based services (HCBS) has more than doubled in recent

\textsuperscript{50} *Crabtree v. Goetz*, No. 3:08-0930 (M.D. Tenn.)

\textsuperscript{51} *Id.*

\textsuperscript{52} *Id.* at 25.

\textsuperscript{53} *Id.* at 28.

\textsuperscript{54} *Id.* at 26.

\textsuperscript{55} Johnson & Bowers, supra note 35.
years. Only 19% of Medicaid long term care money was devoted to HCBS in 1995. In 2008, 42% of Medicaid long term care dollars were spent on HCBS. Furthermore, many new programs are increasing the flexibility and effectiveness of community services. The influence of *Olmstead* is evident in many of the federal and Minnesota programs that this paper will explore.

### III. FEDERAL PROGRAMS

#### A. COMMUNITY FIRST CHOICE OPTION

Made available through the Affordable Care Act, the Community First Choice Option (CFC) is a federal program that offers a modernized version of Personal Care Assistance (PCA) services. It requires services and supports to be provided in the most integrated setting without regard to type of disability, age, and the type of assistance needed to lead an independent life. CFC is a Medicaid state plan option, which offers enhanced Medicaid matching payments for HCBS in exchange for state adoption of initiatives designed to increase the proportion of their total long term services and supports devoted to non-institutional services.

States are required to develop and implement CFC in collaboration with the Development and Implementation Council, which has a majority membership of persons with disabilities,

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57 Id.
58 Id.
59 Johnson & Bowers, supra note 35.
60 Anne Henry, *Medicaid Funded Options for Home and Community-based Services*, Disability Law Center, (Oct 2010)
older people, and their representatives.\textsuperscript{62} The state must also establish and maintain a comprehensive and continuous quality improvement program.\textsuperscript{63} In addition to these requirements, CFC must be provided on a statewide basis.\textsuperscript{64} Furthermore, the state cannot put limits on the amount of people receiving the benefits; if an individual meets the eligibility requirements, they can receive the services and supports of CFC.

As an incentive for the states to implement the program, CFC provides a 6\% higher Federal Medicaid Match for at least a 5 year period, and possibly permanently.\textsuperscript{65} In the first year of the program, states must not spend less on Medicaid HCBS than prior years.\textsuperscript{66} There is also no budget neutrality required and state spending will not be held to an amount that would have otherwise been spent on institutional care.\textsuperscript{67} This program will take effect on October 1, 2011.\textsuperscript{68}

1. Services and Supports

CFC finances home and community based attendant services and supports to assist eligible persons.\textsuperscript{69} Services include assistance with activities of daily living (ADLs), such as eating, toileting, grooming, dressing, bathing, and transferring, instrumental activities of daily living (IADLs), such as meal planning and preparation, shopping, and travel, and health-related...

\textsuperscript{62} Id.
\textsuperscript{64} Id. at 10750.
\textsuperscript{65} Id. at 10736.
\textsuperscript{66} Henry, supra note 60.
\textsuperscript{67} Justice, supra note 61.
\textsuperscript{68} CFC Proposed Rules, supra note 63, at 10736.
\textsuperscript{69} Henry, supra note 60.
tasks, such as administering medication.\textsuperscript{70} The type of assistance may include hands-on, supervision, and prompting and cuing.\textsuperscript{71}

CFC also provides for the acquisition of skills and training to accomplish daily living activities.\textsuperscript{72} This assistance includes helping a person to acquire, maintain, or enhance skills and functioning, not just training for a maintenance level of service.\textsuperscript{73} For example, eating utensils can be fitted with oversized handles for easier gripping, which would enable an individual to with limited hand function to prepare meals by himself.\textsuperscript{74} CFC also provides for back-up systems and voluntary training for managing attendants.\textsuperscript{75} To help individuals transition from institutions, CFC covers expenditures for one month in rent, utility deposits, and household furnishings.\textsuperscript{76} It also covers expenditures that increase independence or substitution for human assistance.\textsuperscript{77} Supports not included are medical supplies and equipment, home modifications, vocational rehabilitation, and room and board.\textsuperscript{78} Assistive technology is also not included, unless it can substitute for human assistance.\textsuperscript{79}

2. \textbf{Eligibility}

An individual must need an institutional level of care to be eligible for CFC’s services and supports.\textsuperscript{80} CFC also requires financial eligibility. This program uses a two-tiered approach

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\textsuperscript{70} CFC Proposed Rules, supra note 63, at 10750.
\textsuperscript{71} \textit{Id}.
\textsuperscript{72} Justice, supra note 61.
\textsuperscript{73} CFC Proposed Rules, supra note 63, at 10750.
\textsuperscript{74} \textit{Id}. at 10740.
\textsuperscript{75} \textit{Id}. at 10750.
\textsuperscript{76} \textit{Id}.
\textsuperscript{77} \textit{Id}.
\textsuperscript{78} \textit{Id}.
\textsuperscript{79} \textit{Id}.
\textsuperscript{80} \textit{Id}. at 10736.
\end{flushleft}
to financial eligibility.\textsuperscript{81} First, individuals are eligible if they are financially eligible for medical assistance under the state plan and have income of less than 150\% of the federal poverty level.\textsuperscript{82} Second, an individual is financially eligible if he has been determined to have income applicable for an institutional level of care, typically 300\% of SSI, and meets the institutional level of care criteria.\textsuperscript{83}

3. \textbf{Strengths}

CFC provides greater opportunities for individuals to get services they need, where they prefer to live.\textsuperscript{84} The program includes all types of disabilities, and the services and supports are tailored to the needs of the individual.\textsuperscript{85} The program provides for a large range of services, beyond ADLs, IADLs, and health-related tasks. CFC provides for skill development and enhancement. This type of support will allow an individual to gain independence, and the ability to complete tasks on their own. This may lead to deceased need of services by that individual in the future.

Another strength of the CFC is individual entitlement to the program. States cannot put a limit on the number of individuals that can enroll in the program. States must also provide CFC statewide. This is unlike the HCBS waiver program, which has a cap on the number of individuals receiving the services and a long waiting list of those who are eligible. If an individual is eligible for CFC, he will receive the services and supports of CFC.

\textsuperscript{81} Justice, supra note 61.
\textsuperscript{82} Id.
\textsuperscript{83} Id.
\textsuperscript{84} Id.
\textsuperscript{85} Henry, supra note 60.
From a budget perspective, the 6% higher Federal Medicaid match is a strength of this program. This match will be provided for a five year period, with the possibility of being implemented permanently.

4. **Weaknesses**

There are several weaknesses to CFC. First, this program does not give the states the ability to control the program’s growth through cost containment strategies.\(^{86}\) Enrollment caps, for example, have allowed the state to budget for a specific number of enrollees of the HCBS waiver program. Some states have geographical limits, a cap on the number of hours an individual can receive services, or a limit on the amount of expenditures per enrollee, all of which allow a state to contain the cost and growth of the HCBS waivers. Without these strategies, the cost of implementing CFC could be deemed too expensive for a state.

In addition, the cost of this program’s benefits per-person, compared with the cost the HCBS waivers per-person, is unknown.\(^{87}\) It might be more cost-efficient to provide for a greater number of people under the HCBS waivers, instead of under CFC.\(^ {88}\) However, states may determine that the 6% Federal Medicaid match would off-set any additional costs of CFC and the risk of the program growing too rapidly.\(^ {89}\) As states implement this program in the coming years, the cost and benefits of this program will become much clearer.

5. **Help or Hinder?**

If a state chooses to implement CFC, it significantly helps the elderly age in place. This program provides a range of services and supports, from skill development to medical supplies. CFC provides support tailored to an individual’s needs. More importantly, this program does not

\(^{86}\) Justice, supra note 61, at 8.
\(^{87}\) *Id.*
\(^{88}\) *Id.*
\(^{89}\) *Id.*
have a cap on the amount of people who can receive the services and supports of the program. Once an individual is eligible, he or she can receive CFC; unlike the waiver program, which has enrollment limits and waiting lists. CFC is a great step forward to assisting individuals in their endeavor to remain in the community.

B. STATE BALANCING INCENTIVE PAYMENTS PROGRAM

The State Balancing Incentive Payments Program was passed as a part of the Affordable Care Act. It provides enhanced federal matching funds to states that implement programs and strategies to increase the proportion of their total Medicaid long-term services and supports spending devoted to HCBS. The state must also implement delivery system reforms to increase consumer accessibility to needed services and supports. This is a temporary program, which will run from October 1, 2011 to September 30, 2015.

States that devote less than 50% of their total Medicaid long term services and supports spending to HCBS are eligible.

1. **Strengths**

This program is providing incentives for the state to increase the number of services and the number of individuals served in the community. States will be able to compete for up to $3 billion in enhanced matching payments. States with less than 25% of their Medicaid long term services and supports expenditures allocated to non-institutional services and supports would receive a 5% increase in Federal Medicaid Assistance Payments. State with less than 50%
would receive a 2% increase.\footnote{Id.} This money could be used for HCBS waivers, home health, and personal assistance.\footnote{Id. at 2.} States that are eligible are expected to vigorously compete to participate in the program.\footnote{Id. at 3.} Hopefully, this added incentive will allow states that are lacking in HCBS programs to focus their long term services and supports on programs that allow individuals to stay in the most integrated setting possible.

2. Weaknesses

The State Balancing Incentives Payments Program will only be provided for four years. This may provide enough time for a state to get a new program up and running, but the state may lack the funding to continue it once the incentives program is over.

3. Help or Hinder?

Overall, the State Balancing Incentive Payments Program will help the elderly age in place. This program will give a state the opportunity and funding to enhance the long term services and support that it provides. By providing increased funding, states can create new programs that boost the number of individuals receiving HCBS. A state could expand the availability of its waivers, for example. Although the benefit may be short term, and end when the program concludes on September 30, 2015, states have the chance to transform their long term services and possibly provide the rest of the country with successful examples of HCBS.

C. MONEY FOLLOWS THE PERSON

Money Follows the Person Rebalancing Demonstration was established by the Deficit Reduction Act of 2005.\footnote{Id. at 4.} This program encourages states to pinpoint Medicaid recipients who

\footnote{Id.}
have been living in an institution and want to return to the community to live.\textsuperscript{100} By July 2010, 9,000 people across the country have transitioned back to the community through Money Follows the Person, and another 4,000 transitions are currently in process.\textsuperscript{101}

Once a state has assisted in an individual’s transition back into the community, the federal government provides an enhanced Federal Medicaid Assistance Payment for the Medicaid HCBS provided to program participants during their first year living back in the community.\textsuperscript{102} The funds provided must be used in the state’s long term services and supports system to expand the availability of community-based options.\textsuperscript{103} Twenty-nine states and the District of Columbia are participating in the program, and an additional 14 states have expressed their intent to apply.\textsuperscript{104}

1. \textbf{Eligibility}

For a person to qualify the state for Money Follows the Person, his or her institutional length of stay must be 90 days, minus Medicare covered rehabilitation days.\textsuperscript{105} States can transition many different categories of institutionalized persons, including older people, people with intellectual, developmental, or physical disabilities, mental illness, and those with a dual diagnosis.\textsuperscript{106}

2. \textbf{Help or Hinder?}

\textsuperscript{100} Id.
\textsuperscript{101} Id.
\textsuperscript{103} Id.
\textsuperscript{104} Money Follows Snapshot, supra note 101.
\textsuperscript{105} Id.
\textsuperscript{106} Id.
The Money Follows the Person Rebalancing Demonstration helps the elderly age in place. This program meets the housing preferences of an institutionalized individual and provides an added funding incentive for states to assist the individual in his or her transition back into the community. In addition, the reinstitution rate of the individuals transitioned through this program is very low. Only 322 individuals of 9,000 have moved back into an institution. This program exemplifies the integration regulation of the ADA, by providing an avenue for an institutionalized individual to transition back into the community, the most integrated setting available.

D. HCBS WAIVERS

Section 1915(c) of the Social Security Act authorizes HCBS waivers. This program provides an alternative to providing long term services in an institutional setting. Most states use HCBS waivers to finance the majority of their long term services and supports system. In 2009, annual program expenditures were more than $33 billion. 1,175,220 individuals received HCBS waivers in 2007. Currently, 287 HCBS waivers are in place throughout the country, and 48 states and the District of Columbia operate services through the waivers. States are not limited in the number of waivers they provide.

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107 Money Follows Snapshot, supra note 101.
108 Id.
109 U.S. Dep’t of Health and Human Services, Medicaid State Waiver Program Demonstration Projects- General Information, Center for Medicare and Medicaid Services, https://www.cms.gov/MedicaidStWaivProgDemoPGL/01_Overview.asp (herein after “Waiver Demonstration Projects”)
110 Id.
111 Justice, supra note 61.
112 Id.
113 Medicaid HCBS Program Update, supra note 56, at 5.
114 Waiver Demonstration Projects, supra note 109.
115 Id.
Eligibility for HCBS waivers, the services provided, and the process to receive the waivers is determined by each state, not the federal government. They can target particular areas of a state, and do not have to provide the waivers on a statewide basis. States also determine financial eligibility and income requirements.

In addition, states do not have to provide waiver services to everyone that is eligible. A state can target specific groups of individuals, such as those with developmental disabilities or the elderly. It may target based on disease or conditions, such as those with a traumatic brain injury or AIDS. States may also limit the number of individuals who receive the waiver services. Consequently, an individual may qualify for a waiver, but may not receive services. This enables a state to budget for the number of persons who will be enrolled in the program and establish participant waitlists when that level is reached.

1. **Eligibility**

The federal government does have a few requirements for the state it chooses to create a HCBS waiver. First, the program must be budget neutral. This means that providing waiver services to individuals must be less expensive than the cost of providing services to those same individuals in an institution. Also, the state must ensure that the health and welfare of

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116 *Id.*
117 *Id.*
118 *Id.*
119 *Id.*
120 *Id.*
121 *Id.*
122 *Id.*
123 *Id.*
124 *Id.*
125 Wavier Demonstration Projects, supra note 109.
126 *Id.*
consumers are protected and ensure that the services are provided according to a care plan.\textsuperscript{127} Lastly, the state must provide adequate and reasonable provider standards to meet the needs of the target population.\textsuperscript{128}

The state must submit an application for a HCBS waiver to the Center for Medicare and Medicaid Services for approval.\textsuperscript{129} Initially, HCBS waivers are approved for a three-year period, and are renewed every five years.\textsuperscript{130}

2. \textbf{Strengths}

Complying with Title II of the ADA, and also with the \textit{Olmstead} decision, the HCBS waiver provides services and supports to a disabled individual in the most integrated setting appropriate. Individuals who wish to live in the community can do so, with the help of a HCBS waiver.

In addition, states are not limited in the number of waivers they provide. Residents of New York have 12 HCBS waivers available.\textsuperscript{131} Illinois, Wisconsin, Missouri, Florida, and Colorado each provide 9 or more HCBS waivers.\textsuperscript{132}

States have also begun to include forms of consumer direction in the HCBS waivers.\textsuperscript{133} Individuals can choose how to allocate their service budget, and also have the ability to hire and fire service providers.\textsuperscript{134} In 2009, 94 waivers provided some form of consumer direction and

\begin{flushright}
\textsuperscript{127} \textit{Id.} \\
\textsuperscript{128} \textit{Id.} \\
\textsuperscript{129} \textit{Id.} \\
\textsuperscript{130} \textit{Id.} \\
\textsuperscript{131} U.S. Dep’t of Health and Human Services, \textit{Medicaid Waivers and Demonstration List}, Center for Medicare and Medicaid Services, http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp \\
\textsuperscript{132} \textit{Id.} \\
\textsuperscript{133} Medicaid HCBS Program Update, supra note 56. \\
\textsuperscript{134} \textit{Id.} at 12.
\end{flushright}
another 15 waivers required consumer direction for all or some services within the waivers.\textsuperscript{135} The incorporation of consumer direction in the waivers allows the individual to manage the services and support they receive.

3. **Weaknesses**

Despite its ability to provide services to individuals in the community, the HCBS waivers have several weaknesses. For starters, states may impose a cap on the amount of individuals who can participate in the program. Once the cap is met, remaining individuals are put onto a waitlist, sometimes for a long period of time. Thirty-nine states reported the use of waiting lists in 2009, and 365,553 individuals were on these lists.\textsuperscript{136} Waivers for the aged, and for the aged and disabled reported the second largest amount of individuals on a waiting list.\textsuperscript{137} Furthermore, it can take up to two years for an individual to be removed from a waitlist and receive a HCBS waiver.\textsuperscript{138} These waitlists leave many eligible individuals unable to receive the proper services and supports that they need to live in the community. As a result, thousands of elderly individuals may have to enter a nursing home or similar institution to get the care that they need. This may be a violation of the integration regulation of the ADA.

Secondly, the HCBS waivers do not have to be provided on a statewide basis and can target certain diseases, conditions, or categories. Similar to the program cap on the number of individuals who can receive a waiver, this program feature leaves many individuals without needed services and supports in the community. Alarmingely, 11 HCBS waivers have more restrictive functional eligibility criteria than the criteria necessary to receive institutional care.\textsuperscript{139}

\textsuperscript{135} *Id.*
\textsuperscript{136} *Id.*
\textsuperscript{137} *Id.*
\textsuperscript{138} *Id.* at 14.
\textsuperscript{139} *Id.* at 11.
This means that it is easier for an elder to qualify to live in a nursing home than receive one of the waivers and services in his or her home.

Lastly, two individuals with the exact same disability and exact same need for services can be treated very differently under the HCBS waiver. Person A and Person B both are diagnosed with a mental disability. If Person A receives the waiver and Person B does not, Person B may be forced to live in an institution to get adequate care to meet their needs, whereas Person A may live in their home and community with the waiver services. Similarly situated individuals are treated differently, and this is a major weakness of the HCBS waiver program.

4. Help or Hinder?

The HCBS waivers help the elderly age in place by providing services and supports to individuals within their home. The increased use of consumer direction and the ability of states to provide many different types of waivers allow the elderly to remain in their homes and community. However, the program has several limitations. A state may impose participant limits, condition or disease requirements, or location targets, all of which make it more difficult for an individual who is financially and functionally eligible for the program to receive the assistance that he needs. A person may be on a waitlist for two years before receiving services. In that amount of time, an individual may have already had to move out of his or her home to seek care and support elsewhere, possibly in an institution. If an individual does qualify despite the limitations of the program, the services he or she will receive will assist and support that person to remain in their home and community. Overall, this program helps the elderly age in place, and has provided over a million people in recent years with the services and supports they need.

IV. MINNESOTA PROGRAMS
A. HCBS WAIVERS

1. HCBS Waivers Available in Minnesota

Authorized by the federal government, under 1915(c) of the Social Security Act, Minnesota provides six HCBS waivers to individuals within the state.\(^{140}\) Two of the waivers, Elderly Waiver and Alternative Care, are only provided to elderly individuals, age 65 and older.\(^{141}\)

   a. Alternative Care Program

   The Alternative Care program provides funding for HCBS for Minnesotans, age 65 and older. This program aims to prevent and delay transitions to a nursing facility.\(^{142}\) The program prevents the “impoverishment of eligible seniors and shares the cost of care with clients by maximizing use of their own resources.”\(^{143}\) In 2010, 5,279 individuals received services through the Alternative Care program.\(^{144}\)

   Many services are provided under the Alternative Care program. Covered services include adult day service, care-related supplies and equipment, case management, chore services, companion services, consumer-directed community supports, home health aides, home-delivered meals, homemaker services, environmental accessibility adaptations, nutrition services, personal

\(^{140}\) Minnesota Dep’t of Human Services, *Minnesota’s home and community based waivers*, http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_003726

\(^{141}\) Id.


\(^{143}\) Id.

\(^{144}\) Id.
care, respite care, skilled nursing, specialized equipment and supplies, training and support for family caregivers, and transportation.\footnote{Id.}

The Alternative Care program has several eligibility requirements. First, a person must need a nursing facility level of care.\footnote{Id.} Also, the person must choose to receive services and supports in the community, instead of in an institution.\footnote{Id.} There are also income and asset eligibility requirements. A person’s income and assets must be lower than the cost to fund a nursing home stay for more than 135 days.\footnote{Id.} The monthly cost of Alternative Care services must be less than 75\% of the average Medicaid payment limit for older people with a comparable case mix classification.\footnote{Id.} Lastly, in order to receive Alternative Care, there must be no other funding source available for the individual’s community services.\footnote{Id.}

To receive Alternative Care, the individual must pay the assessed monthly fee.\footnote{Id.} In 2010, the average monthly cost per enrollee was $775.\footnote{Id.} Because Alternative Care is used as a last resort to remain in the community, the probable alternative is a stay in a nursing facility, which costs on average of $4,888 per person, per month.\footnote{Id.}

b. Elderly Waiver
The Elderly Waiver (EW) provides funding for HCBS for individuals age 65 and older.\textsuperscript{154} In 2010, EW provided services to 26,779 people.\textsuperscript{155}

EW provides many services to the elderly in their homes and communities. These services include adult day service, caregiver assessment, chore services, companion services, consumer-directed community supports, home health aides, home-delivered meals, homemaker services, customized living services, family foster care, residential care, environmental accessibility adaptations, PCA services, personal emergency response system, respite care, skilled nursing, specialized equipment and supplies, training for informal caregivers, transitional supports, and transportation.\textsuperscript{156}

EW has several eligibility requirements. An individual must be 65 and older, and he or she must be eligible for Medical Assistance.\textsuperscript{157} The individual must need a nursing facility level of care, and must choose to reside in the community.\textsuperscript{158} Lastly, the cost of services for an enrollee of EW must be less expensive than the estimated cost for that person to stay in a nursing facility.\textsuperscript{159}

2. Help or Hinder?

For those eligible, the HCBS waivers in Minnesota help an elderly individual remain in their home and community. The average number of waivers provided within states across the

\textsuperscript{154} Minnesota Dep’t of Human Services, \textit{Elderly Waiver Program}, http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_137092

\textsuperscript{155} Minnesota Dep’t of Human Services, \textit{Elderly Waiver Program}, https://edocs.dhs.state.mn.us/lfserver/Public/DHS-5357-ENG

\textsuperscript{156} Elderly Waiver Program, supra note 154.

\textsuperscript{157} Id.

\textsuperscript{158} Id.

\textsuperscript{159} Id.
country is six.\textsuperscript{160} Therefore, the number of waivers provided in Minnesota is average. Twenty-two other states, including our neighbors Wisconsin, Iowa, and North Dakota, provide more waivers than Minnesota.\textsuperscript{161} Certainly, there is room for improvement. By providing additional waivers or increasing the number of people who can receive each waiver, more individuals can enroll and receive the necessary services and supports they need to remain in their homes.

B. NEW ACCESS CRITERIA FOR PERSONAL CARE ASSISTANCE

Personal Care Assistance (PCA) is a service option that provides assistance to individuals within their home and community.\textsuperscript{162} In 2010, the Minnesota Department of Human Services administered PCA services to 25,762 individuals.\textsuperscript{163}

PCA provides services and supports to people who need assistance with activities of daily living (ADLs), health-related procedures and tasks, observation and redirection of behaviors, and instrumental activities of daily living (IADLs).\textsuperscript{164}

Minnesota recognizes seven ADLs- dressing, grooming, bathing, eating, transferring, mobility, positioning, and toileting.\textsuperscript{165} To qualify for an ADL is dressing, the individual requires assistance with the application of clothing and special appliances or wraps.\textsuperscript{166} A grooming ADL requires assistance with basic hair care, oral care, shaving, basic nail care,
applying cosmetics and deodorant, and the care of eyeglasses and hearing aids. To qualify for
a bathing ADL, the individual requires assistance with basic personal hygiene and skin care. An ADL in eating requires assistance with completing the process of eating, including application of orthotics, hand washing, and transfers. If an individual requires assistance to transfer from one seating or reclining area to another, the individual has an ADL in transferring. To qualify for an ADL is positioning, the person requires assistance with positioning or turning for necessary care and comfort. Lastly, a person has an ADL in toileting if the person needs help with bowel or bladder elimination and care, including transfers, mobility, positioning, feminine hygiene, use of toileting equipment or supplies, cleansing the perineal area, inspection of the skin, and adjustment of clothing.

Other services provided by PCA are health-related procedures and tasks. Examples of these services include assistance with self-administered medications, interventions for seizure disorders, including monitoring and observation, and range of motion to maintain a person’s strength and muscle functioning. These tasks must be delegated by a licensed health care profession, and the PCA must be trained and demonstrate competency to safely complete the task.

PCAs may also assist adult clients with IADLs. A PCA may accompany the individual to medical appointments and to participate in the community. They may also assist with paying bills, planning and preparing meals, completing household tasks, and shopping for food, clothing, and other essential items. A PCA may also assist an adult client with communication by telephone, internet, and other media.

Lastly, a PCA can observe and redirect behaviors of an individual. PCA services may include observation of a person who has episodes of behavior or needs redirection to remain safe in his or her environment.
1. Eligibility Criteria Then and Now

Prior to July 1, 2011, an individual is required to have a dependency in one ADL, or qualify as having a Level 1 behavior in order to qualify for PCA services. A person has a “dependency” in an ADL if the individual has a need on a daily basis, or on the days during the week the task is completed, for hands on physical assistance to complete the task or cuing and constant supervision to complete the task. A Level 1 behavior is physical aggression towards self or others, or the destruction of property which requires the immediate response of another person.

Beginning July 1, 2011, it will be more difficult for an individual to meet the eligibility criteria for PCA services. Recipients will need two or more dependencies in ADLs to qualify for PCA services. In addition to the higher number of ADLs required, a Level 1 behavior will no longer qualify someone for PCA services.

2. Strengths

PCA services provide needed in home care for eligible individuals. A PCA comes into a person’s home and assists for a designated number of hours based on that individual’s assessed needs. These services can be extremely vital to a person wanting to remain in their homes. Although the new access criteria makes it more difficult for a person to qualify for PCA services, those that do take a major step towards achieving their goal of independent living.

In addition, the new access criteria for PCA services have a substantial impact on Minnesota’s budget. In the fiscal year 2010-2011, Minnesota is projected to save $63 million due to the PCA changes. Minnesota is also projected to save $109 million for the fiscal year 2012-2013. Obviously, with the current budget concerns, the amount of money saved was a major motivation for passing the modified PCA access criteria.
Furthermore, the former PCA system was experiencing incidents of fraud and abuse, which warranted changes by the Minnesota legislature.\textsuperscript{188} A 2009 legislative auditor’s report revealed that within one month, more than 200 cases billed for more than 24 hours in a day.\textsuperscript{189} The new PCA changes will hopefully provide more oversight and support to limit similar incidents in the future.

3. **Weaknesses**

With the PCA changes to access criteria, many people are seeing their PCA hours and services get cut or completely eliminated. In 2010, 4,044 Minnesotans had a decrease or loss in PCA services.\textsuperscript{190} Another 2,789 people will lose PCA services once Level 1 behaviors are eliminated from the access criteria on July 1, 2011.\textsuperscript{191}

The impact on the families of an individual who has their PCA services eliminated or reduced may be significant. The National Alliance of Mental Illness, Minnesota (NAMI-MN) conducted a study of PCA users in Minnesota who were losing their services due to the new access criteria.\textsuperscript{192} This study found that many family members indicated that they will have to quit their job or reduce their work hours to care for the individual.\textsuperscript{193} Half of those surveyed said that the individual would most likely end up in residential or foster care.\textsuperscript{194} Some respondents even felt that the individual will have to move into a nursing home to get the care that they needed.\textsuperscript{195}

The same survey also found that the profile of those who will remain eligible and those who are terminated in terms of mental illness and behavioral issues are strikingly similar.\textsuperscript{196} Approximately 50\% of those remaining eligible for PCA services have behavior challenges and/or mental illness. In other words, those terminated are not so different from those who will remain eligible.\textsuperscript{197}
Another study conducted by the Courage Center found that the loss of PCA services has caused increased medical issues and costs, job and income loss, and decreased independence in individuals with disabilities. The cut to PCA services has cost the state millions in hospitalizations alone, and has also caused deteriorated health and a decrease in the quality of life for individuals and their families.

Of the surveys collected, 78% of respondents reported negative health and medical consequences due to the PCA cuts. The number of trips to the Emergency Room and hospital increased. Respondents also indicated an increase in medications, medical services, and secondary conditions. On a statewide level, the extra trips to the Emergency Room and hospital have cost Minnesota an extra $9.9 million. “These cuts are not only causing increased cost; it has led to hardship and deteriorating health for many in this vulnerable population.”

In addition to impacts on an individual’s health, the PCA cuts have also financially impacted families. Thirty-eight percent of participants reported loss in family income, because of forced retirement, loss of jobs or hours because of increased demand on their time, and the loss of benefits because they had to cut their hours or quit their jobs.

Lastly, participants of the survey indicated a negative impact and decrease in quality of life for the client and the family. Seventy-eight percent of recipients and families reported negative effects on their relationships, mental health, and stress levels, and have reported an increase in mental health and behavioral concerns. Some families have experienced divorce, depression, induced seizures, and increased behavioral episodes with injuries.

It is clear that the PCA cuts have been a major step backwards for the elderly and other disabled individuals trying to remain in their home and community. With the new access
criteria, it may be more difficult to get PCA services than to enter an institution. That result may have implications for Minnesota under Title II of the ADA, and under the decision in *Olmstead*. If an individual has to move out of his or her home in the community because of cuts to PCA services, and that person has to enter an institution to get necessary services and supports, that individual may have a civil rights claim under the ADA. People should not have to live in more restrictive settings when they are able to living in their homes and communities with proper supports.

4. **Help or Hinder?**

After reviewing all of the strengths and weaknesses to the new access requirements, the PCA cuts hinder the elderly from aging in place. Although budget considerations are a major consideration for the cuts, the individuals whose PCA services are reduced or eliminated have reported deteriorated health and quality of life. The individual’s families have also been impacted, forced to quit jobs or reduce their hours to provide for the individual. The PCA cuts have been a major step backwards for the state of Minnesota and its capacity to provide HCBS to individuals in their home and community.

C. **MODIFICATION OF NURSING FACILITY LEVEL OF CARE**

In 2009, the Minnesota legislature modified the nursing facility level of care (NF LOC). NF LOC impacts several services and programs, including Medical Assistance payment for nursing home services. It also applies to the eligibility requirements of the HCBS waivers that Minnesota provides, including Alternative Care and EW. These changes will take effect on July 1, 2011.
To meet the new criteria of NF LOC, an individual must be assessed for at least one of the following: a high ADL need, an ongoing clinical need, a cognitive impairment or behavioral need, or at institutional risk.\(^{213}\)

An individual is considered to have a high ADL need if they need assistance in four or more ADLs, or need assistance that cannot be scheduled in toileting, transferring, or positioning.\(^{214}\) If the person needs clinical monitoring at least once a day, he or she is considered to have an ongoing clinical need.\(^{215}\) A cognitive impairment or behavioral need is indicated by significant difficult with memory, using information, daily decision-making, or behavior needs that require at least occasional intervention.\(^{216}\) Lastly, a person is considered an institutional risk if he or she has had a qualifying nursing facility admission of at least 90 days, or he or she lives alone and is at risk of a fall related fracture, maltreatment or neglect, self neglect, or a sensory impairment that substantially impacts functional ability and maintenance of a community residence.\(^{217}\)

1. **Strengths**

One of the benefits to the NF LOC is the implementation of objective criteria.\(^{218}\) Prior to 2009, the NF LOC criteria required a determination of unstable health, special treatment, restorative or rehabilitative treatment, or complex management.\(^{219}\) The new NF LOC is much clearer about what is required for a determination of NF LOC, improving equality throughout Minnesota with objective criteria.\(^{220}\)

In addition, the Minnesota Legislature has enacted the Essential Community Support program to target the individuals who no longer meet the NF LOC.\(^{221}\) Although the services under this program are limited, it does provide some assistance to an elderly individual to help them avoid transitioning into an institution. Services include homemaker services, chore
services, caregiver education and training, and a Personal Emergency Response System. By offering at least the basics of community support for an elder, the program provides some services for the elderly.

2. **Weaknesses**

A major weakness of the modification to NF LOC is the impact on eligibility for HCBS waivers. The Alternative Care, EW, and two other waivers in Minnesota are affected by the modified criteria. Fewer individuals will be eligible for the HCBS waivers. Those that no longer qualify under the criteria may have to seek services and supports elsewhere, possibly in an institution.

An individual may be able to bring a civil rights suit under Title II of the ADA. Unjustified institutionalization of an individual, who, with proper supports, can live in the community, is discrimination. If a person loses their eligibility for a HCBS waiver and cannot receive services and supports in the home through other programs, they may be forced to enter an institution to meet their needs. According to the decision in *Olmstead*, this is discrimination.

3. **Help or Hinder?**

The modification to the NF LOC hinders the elderly from aging in place. Many elders will lose their eligibility for the two HCBS waivers that are provided for the elderly, EW and Alternative Care.

V. **CONCLUSION**

The recent programs and initiatives by the United States and Minnesota Legislatures provide many illustrations of efforts that both help and hinder the elderly from remaining in their homes and in their communities. By evaluating the strengths and weaknesses of each program, the legislatures can create a comprehensive system that addresses the needs and desires of the
elderly population, as well as the budgetary concerns of the current fiscal crisis. It is crucial to test federal and state programs now, in order to ensure that we have a flourishing home and community-based services system when the baby boomers reach retirement.