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Funding Long-Term Services and Supports (LTSS) for Working Aged Disabled Americans

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I. INTRODUCTION

World renowned scientist Stephen Hawking is said to have the greatest mind in physics since Albert Einstein.[1] Now 72 years old, Hawking has enjoyed success as a researcher, university professor and best-selling author.[2] His estimated net worth is

*Helen Rapp received her J.D. degree from Cleveland Marshall College of Law in Cleveland, Ohio in May 2017. Helen would like to thank her entire family for their constant support especially her remarkable daughter Jane who was the inspiration for this note.

[1] PBS: A Science Odyssey, People & Discoveries, http://www.pbs.org/wgbh/aso/databank/entries/bphawk.html.. *See also*, KITTY FERGUSON, STEPHEN HAWKING AN UNFETTERED MIND 3 (2012).

[2] Nola Taylor Redd, Stephen Hawking Biography 3 SPACE.com, May 30, 2012, available at http://www.space.com/15923-stephen-hawking.html (last visited February 14, 2015). Stephen Hawking's first book, "A Brief History of Time," was published in 1988 and became an international best seller.

$20 million dollars.[3] Hawking comes from a family of modest means and his fortune is completely the result of more than 50 years of hard work.[4] Hawking also has Amyotrophic Lateral Sclerosis (ALS).[5] As a result, he is almost completely paralyzed, has been confined to a wheelchair since the late 1960's and speaks using a computer-based speech synthesizer.[6] He requires personal care assistants (PCAs) to perform all activities of daily living. Hawking is a British citizen, which means that his medical needs are covered by the British National Health Service (NHS)[7]. Under the care of the NHS, as a disabled person, Hawking is entitled to free medical care and medicine, and he is eligible for home adaptations, equipment and personal care to allow him to live at home.[8] Had he been a US citizen living in the United States, he may not have had the opportunity to accomplish the amazing things that he has, because in order to qualify for Long-Term Services and Supports (LTSS) such as PCAs, he would have to be Medicaid eligible. This means that his income would need to be significantly below the middle-class standard.

John Robertson was born with a condition called spinal muscular dystrophy.[9] John uses a wheelchair and relies on complex rehabilitation technology (CRT) in order to live independently.[10] When John graduated from law school, he was offered a job at

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[3] Travelers Today, Stephen Hawking Net Worth: How Much is the World's Smartest Human Being Worth?, updated December 20, 2014, available at http://www.travelerstoday.com/articles/16890/20141225/stephen-hawking-net-worth-how-much-is-the-worlds-smartest-human-being-worth.htm.

[4] KITTY FERGUSON, STEPHEN HAWKING AN UNFETTERED MIND 20, 25 (2012). Stephen Hawking was the oldest of 4 children born to Frank and Isobel Hawking. *Id.* The family was close and believed strongly in the value of education, but they were not wealthy. *Id.*

[5] *Id.* at 3. ALS is commonly referred to as Lou Gehrig's disease in the United States, after New York Yankee first baseman Lou Gehrig who died from ALS in 1941. *Id.*

[6] *Id.*

[7] The NHS is a rare example of truly socialized medicine. Health care is provided by a single payer — the British government — and is funded by the taxpayer. All appointments and treatments are free to the patient. Eben Harrell, *Is Britain's Health-Care System Really that Bad?*, TIME.COM (Aug. 18, 2009), available at http://content.time.com/time/health/article/0,8599,1916570,00.html (last visited Feb. 12, 2015). *See also The NHS in England, The NHS, About the NHS*, NHS CHOICES, available at http://www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx (last visited Feb. 12, 2015).

[8] Daniel Martin, *UK's top doctors write letter to U.S. politicians to battle 'lies' about the NHS*, THE DAILY MAIL (September 16, 2009), http://www.dailymail.co.uk/news/article-1213783/UKs-doctors-write-letter-U-S-politicians-battle-lies-NHS.html (last visited Jan. 17, 2015). *See also* Claudia Dreifus, *Conversation With | Stephen Hawking Life and the Cosmos, Word by Painstaking Word*, THE NEW YORK TIMES (May 9, 2011), available at http://www.nytimes.com/2011/05/10/science/10hawking.html?pagewanted=all (last visited Feb. 12, 2015).

[9] Laphonza Butler, Henry Claypool, Judith Feder, Lynnae Ruttledge, Judith Stein, *A Comprehensive Approach to Long-Term Services and Supports*, LONG-TERM CARE COMMISSION 4-5 (Sep. 23, 2013), available at http://www.aapd.com/resources/press-room/ltss-alternative-report.pdf (last visited Feb. 14, 2015). John Robertson is one of several individuals featured in this report to demonstrate the issues caused by the current funding scheme for LTSS.

[10] *Id.*

a prestigious law firm in another state with an annual salary of $120,000.[11] John's personal care costs are approximately $90,000 per year, which are not covered by his employer-sponsored insurance. Although John relied on Medicaid to cover his personal care needs while he was a student, Medicaid is not portable to the state in which he would work and even if it was, his income would make him ineligible. John must now decide whether to forego a job at a prestigious law firm in order to maintain access to LTSS. This reality denies John the ability to live as independently as possible and become a taxpayer.[12]

19-year old Jane has Cerebral Palsy.[13] She has lived in Cleveland, Ohio her entire life. Although Jane cannot walk, stand or use her right hand and arm, she has always been mainstreamed[14] in school and has recently graduated from a private, college prep high school. Jane has excellent verbal skills and uses a power wheelchair for mobility. Jane is attending a 4-year college and aspires to live independently and support herself. Jane will also need lifetime support from PCAs. When meeting with a social worker from the County Board of DD, Jane was "reassured" that they would help her make sure her income never jeopardizes her Medicaid eligibility. What a demoralizing experience for a young woman on the brink of starting her adult life to realize that she would be resigned to low income if she wanted access to the support she needed to live.

These are some of the dilemmas faced today by the over 3 million significantly disabled Americans, many of whom depend on Medicaid for LTSS, in obtaining the services they need to simply live.[15] While the landmark 1990 Americans with Disabilities Act (ADA)[16] has done a lot to improve the lives of people with disabilities,

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[11] *Id.*

[12] *Id.*

[13] Jane is the youngest daughter of the author of this note. She was born 10 weeks prematurely at Rainbow Babies & Children's Hospital in Cleveland, Ohio and suffered a grade IV brain bleed which resulted in her Cerebral Palsy. Jane's story as presented in this note comes entirely from the author's personal knowledge.

[14] Mainstreaming refers to placement of a student with disabilities into ongoing activities of regular classrooms so that the child receives education with nondisabled peers — even if special education staff must provide supplementary resource services. *Special Education Rights and Responsibilities (SERR) Manual, Chapter 7, Information on Least Restrictive Environment*, DISABILITY RIGHTS CALIFORNIA 7-2, available at http://www.disabilityrightsca.org/pubs/504001Ch07.pdf (last visited Feb. 12, 2015). Some students with disabilities are mainstreamed for only portions of the school day.

[15] Donald Redfoot & Wendy Fox-Grage, *Medicaid: A Program of Last Resort for People Who Need Long-Term Services and Supports*, INSIGHT ON THE ISSUES 81, AARP PUBLIC POLICY INSTITUTE 1 (May 2013), available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2013/medicaid-last-resort-insight-AARP-ppi-health.pdf (last visited January 14, 2015).

[16] Americans with Disabilities Act of 1990 (ADA), 42 U.S.C. §§ 12101-12213 (2000). The Americans with Disabilities Act was signed into law by President George H.W. Bush on July 26, 1990. The ADA provides

> civil rights protection to people with disabilities and guarantees those protected by the law equal opportunity in the areas of employment, state and local government services, public transportation, privately operated transportation available to the public, places of public accommodation and telecommunications services offered to the public.

the reality is that using Medicaid as the vehicle for funding LTSS, places unreasonable restrictions on disabled people who want to live independent lives and be as successful as possible.

The Federal Government must change funding for LTSS in order to provide disabled Americans with real choices regarding living arrangements and maximize their earning potential without fear of being deprived of support they cannot live without. Part II of this note provides background information on LTSS (what they are, who uses them, what they cost and how they are currently funded). Part III examines the Medicaid Program and specifically Medicaid HCBS[17] Waiver Programs which provide the bulk of LTSS funding today. A brief history of the federal laws, amendments and policies that have impacted Medicaid LTSS will be provided. Part IV analyzes an alternative to Medicaid for LTSS funding for those working age disabled individuals who would not otherwise be Medicaid eligible. This section will specifically focus on recommendations from the congressionally established Commission on Long-Term Care and a Pilot Program proposed by the American Association for People with Disabilities (AAPD). Finally, Part V concludes that the Federal government must take action to establish a stand-alone, non-Medicaid Program to provide LTSS for working age, disabled Americans who are capable of working and living independently.

II. BACKGROUND ON LTSS

A. What are Long Term Services and Supports?

Long-Term Services and Supports (LTSS) are defined as assistance with activities of daily living (ADL) such as bathing, dressing, eating, transferring and walking or instrumental activities of daily living (IADL) such as money management, meal preparation, house cleaning, transportation and medication management.[18] LTSS services include residential care in facilities like nursing homes, but also include home and community-based service options (HCBS) such as home health care, personal care assistance (PCA), adult day care and homemaker services that help meet peoples' needs without institutional placement.[19] During the past two decades, there has been a major shift toward serving more people in home and community-based settings

Understanding the (ADA) Americans with Disabilities Act, UNITED SPINAL ASSOCIATION, 7, available at http://www.unitedspinal.org/pdf/understanding_the_ada.pdf (last visited Jan. 17, 2015).

[17] HCBS are Home and Community Based Services as opposed to services provided in a residential institution like a nursing home.

[18] Bruce Chernof & Mark Washawsky, *Commission on Long-Term Care Report to the Congress*, GPO.GOV 7 (Sep. 30, 2013), available at http://www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf (last visited Feb. 15, 2015). Examples of HCBS LTSS include home health care, personal care assistance (PCA), adult day care and homemaker services. Evin Isaacson, Eric Carlson & Anna Rich, *Medicaid Long Term Services & Supports 101: Emerging Opportunities and Challenges*, NATIONAL SENIOR CITIZEN'S LAW CENTER, 3 (Sep. 2012), available at http://www.nsclc.org/wp-content/uploads/2012/09/Medicaid-LTSS-Guide-Final.pdf (last visited Feb. 5, 2015).

[19] Isaacson, Carlson & Rich, *supra* note 18 at 3.

rather than institutions.[20] This shift is the result of a combination of individual preferences and states' obligations under the Supreme Court's 1997 *Olmstead* decision.[21] LTSS does not include medical or nursing services needed to manage an individual's underlying health condition. [22] People may need LTSS for a variety of reasons including physical, cognitive, or developmental disability, chronic health issues or simply old age.[23] LTSS can be provided formally by people who are paid for these services or informally by family members and friends of people who need them. Properly defining ADLs and IADLs and assessing each individual's ADL and IADL needs is critical, because it factors into determining whether a person is eligible for LTSS benefits or not.[24] Typically a person needs to show that they need assistance with two or more ADLs in order to be eligible for LTSS benefits.[25]

B. Populations that use LTSS in the United States

In the United States, there are currently over 12 million people who require some level of LTSS.[26] This includes people who rely strictly on the loving support of unpaid caregivers (family and friends) as well as those who utilize paid caregivers.[27] Approximately 3.2 million of these people are considered eligible for LTSS benefits because they need assistance with two or more ADLs. [28] Although people need LTSS for a variety of reasons, it is useful to break the group into 3 broad categories and examine the issues associated with each. These categories are (1) children (18 years and under), (2) working age adults (19 – 64 years) and (3) the elderly (65 and older).[29] The largest and the fastest growing of these populations is the elderly group. As advances in medicine allow people to live longer, the number of elderly people in need of some level of LTSS will grow dramatically. Some estimates predict that by 2050, the number of Americans in need of LTSS will more than double from 12 million to 27 million (see figure 1), largely driven by the rapidly growing elderly population.[30]

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[20] Erica L. Reaves & MaryBeth Musumeci, *Medicaid and Long-Term Services and Supports: A Primer*, THE HENRY J. KAISER FAMILY FOUNDATION, 1 (Jul. 30, 2014), available at https://kaiserfamilyfoundation.files.wordpress.com/2014/07/8617-medicaid-and-long-term-services-and-supports_a-primer.pdf (last visited Feb. 13, 2015).

[21] *Id* at 2. Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999). The Olmsted court found that the unjustified institutionalization of persons with disabilities violates the Americans with Disabilities Act.

[22] *America's Long-Term Care Crisis: Challenges in Financing and Delivery*, BIPARTISAN POLICY CENTER 15 (Apr. 2014), available at http://bipartisanpolicy.org/wp-content/uploads/sites/default/files/BPC%20Long-Term%20Care%20Initiative.pdf (last visited Feb. 15, 2015).

[23] *See* Isaacson, Carlson & Rich, *supra* note 18 at 3.

[24] *See* America's Long-Term Care Crisis, *supra* note 22.

[25] *Id.*

[26] *Id.* at 7.

[27] *Id.* at 17.

[28] *Id.* at 15.

[29] *Id.* at 9.

[30] *Id.* at 4.

The other two demographic groups are not inherently likely to grow significantly in numbers and should be considered to be steady in size. Of the 12 million Americans currently requiring LTSS, 3% are children, 47% are working age adults (19 – 64 years) and 50% are elderly (over 65).[31] The type of LTSS care required varies extensively within and across groups.

C. Costs of LTSS

LTSS can be very costly. It is difficult to capture the total cost of LTSS in the United States because the majority of it is provided by unpaid family and friends. In 2012, the estimated cost of paid LTSS was $219.9 billion dollars, which represents 9.3% of personal health care spending in the United States. [32] The value of unpaid, family caregiving was estimated to be worth $450 billion in 2009.[33] Some individuals require only minimal support (transportation to doctor's appointments or help paying bills)[34] and their care maybe financially manageable, but for some LTSS costs are overwhelming. Examples of the more costly type of LTSS include nursing home and other institutional care facilities and PCA support for home and community based individuals. The average annual cost for a semi-private room in a nursing home is $90,520. [35] A wheelchair bound person living at home who needs PCA support to shower, dress, transfer and go to the bathroom can expect to spend $21/hour for this level of care.[36] For a person requiring 40 hours/week of PCA support this translates to $44,000 per year.[37]

D. Funding History

Since its inception, Medicaid has been the single largest payer of LTSS in the United States.[38] In 2012, almost two thirds (63%) of LTSS funding ($140 million) came from Medicaid.[39] This represented 34.1% of the total Medicaid funding for the year.[40] About half of this funding was spent in institutional settings and half for home

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[31] *Id.* at 15.

[32] Carole V. O'Shaughnessy, *National Spending for Long-Term Services and Supports (LTSS), 2012*, NATIONAL HEALTH POLICY FORUM (March 27, 2014), available at http://www.nhpf.org/library/the-basics/Basics_LTSS_03-27-14.pdf (last visited Feb. 14, 2015).

[33] L. Feinberg, S. Reinhard, A. Houser, R. Choula. *Valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving*, AARP PUBLIC POLICY INSTITUTE 2, available at http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf (last visited Feb. 16, 2015).

[34] *See* Reaves & Musumeci, *supra* note 20, at 2.

[35] *Id.* at 3.

[36] *Id.*

[37] *Id.*

[38] Steve Eiken, *Medicaid Expenditures for Long-Term Services and Supports in FFY 2012*, TRUVEN HEALTH ANALYTICS 1 (April 28, 2014), available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/LTSS-Expenditures-2012.pdf (last visited Feb. 16, 2015).

[39] *Id.*

[40] *Id.*

and community based services (HCBS).[41] After Medicaid, the next largest source of funding for LTSS is out-of-pocket funding paid by individuals and their families. This burden to the families was over $45 billion in 2012.[42] Other private and public sources accounted for the remaining $34 million spent on LTSS in 2012.[43]

III. HISTORY OF MEDICAID AND HCBS WAIVER PROGRAMS

In 1965, Congress created the Medicaid Program as Title XIX of the Social Security Act.[44] Medicaid is jointly funded by federal and state governments to provide health care services to low income Americans and people with disabilities.[45] Medicaid is currently the single largest provider of health coverage in the United States and covers over 66 million Americans.[46] Medicaid Programs are administered by the states within broad federal requirements.[47] The federal government contributes between 50 and 83% of the states total annual Medicaid expenditures.[48] States with high per capita income receive less support from the federal government than states with low per capita income. The average federal contribution across all states for 2012 was 58.8%.[49] States have flexibility to determine what benefits to cover, who is eligible and how much to pay health care providers.[50] In general, in order to be Medicaid eligible, individuals must have low income and limited financial assets.[51] Although eligibility varies from state to state, income restrictions are normally tied to the federal poverty level (FPL).[52] The 2014 federal poverty level is $11,670 for

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[41] *Id.*

[42] *See* America's Long-Term Care Crisis , *supra* note 22, at 19.

[43] *Id.*

[44] *Implementing Olmstead by Outlawing Waiting lists*, 49 TULSA L. REV. 713, 721 (2013-2014).

[45] *Id.*

[46] *Medicaid Moving Forward*, THE HENRY J. KAISER FAMILY FOUNDATION 1 (Jun. 17, 2014), available at http://files.kff.org/attachment/fact-sheet-medicaid-moving-forward (last visited Feb. 16, 2015).

[47] *Id.*

[48] *See* Kaiser Family Foundation, *supra* note 44, at 722. Every year the Center for Medicare and Medicaid Services (CMS) calculates the Federal Medical Assistance Percentage (FMAP) for each state based on its relative wealth. *Id.*

[49] *Id.*

[50] *Id.*

[51] *Find Your Path Forward, Medicaid Eligibility*, US DEPARTMENT OF HEALTH AND HUMAN SERVICES, LONGTERMCARE.GOV, available at http://longtermcare.gov/medicare-medicaid-more/medicaid/medicaid-eligibility/ (last visited January 19, 2015). While Medicaid eligibility requirements vary from state to state, all states have income requirements tied to the Federal Poverty Level (FPL) and all states have asset limitations which typically limit countable assets to $2,000 per individual or $3,000 per married couple.

[52] Keeping America Healthy, Medicaid.gov, http://www.medicaid.gov/medicaid-CHIP-Program-Information/By-Topics/Eligibility/Eligibility.html.

individuals and $23,850 for a family of 4.[53] The Patient Protection and Affordable Care Act (ACA) of 2010 contains an optional Medicaid expansion provision.[54] States

[53] The U.S. Department of Health and Human Services issues federal poverty guidelines on an annual basis which are used to determine eligibility for Medicaid and CHIP. *Federal Poverty Guidelines*, FAMILIES USA, February 2015, available at http://familiesusa.org/product/federal-poverty-guidelines (last visited Feb. 14, 2015).

2014 Federal Poverty Guidelines – issued February 10, 2014

Household Size	**100%**	**133%**	**150%**	**200%**	**250%**	**300%**	**400%**
1	$11,670	$15,521	$17,505	$23,340	$29,175	$35,010	$46,680
2	$15,730	$20,921	$23,595	$31,460	$39,325	$47,190	$62,920
3	$19,790	$26,321	$29,685	$39,580	$49,475	$59,370	$79,160
4	$23,850	$31,721	$35,775	$47,700	$59,625	$71,550	$95,400
5	$27,910	$37,120	$41,865	$55,820	$69,775	$83,730	$111,640
6	$31,970	$42,520	$47,955	$63,940	$79,925	$95,910	$127,880
7	$36,030	$47,920	$54,045	$72,060	$90,075	$108,090	$144,120
8	$40,090	$53,320	$60,135	$80,180	$100,225	$120,270	$160,360

2015 Federal Poverty Guidelines – anticipated release February 2015

Household Size	**100%**	**133%**	**150%**	**200%**	**250%**	**300%**	**400%**
1	$11,770	$15,654	$17,655	$23,540	$29,425	$35,310	$47,080
2	$15,930	$21,187	$23,895	$31,860	$39,825	$47,790	$63,720
3	$20,090	$26,720	$30,135	$40,180	$50,225	$60,270	$80,360
4	$24,250	$32,253	$36,375	$48,500	$60,625	$72,750	$97,000
5	$28,410	$37,785	$42,615	$56,820	$71,025	$97,710	$113,640
6	$32,570	$43,318	$48,855	$65,140	$81,425	$110,1900	$130,280
7	$36,730	$48,851	$55,095	$73,460	$91,825	$110,190	$146,920
8	$40,890	$54,384	$61,335	$81,780	$102,225	$122,670	$163,560

[54] 42 U.S.C.A. § 1396.

that elect to adopt this provision can offer Medicaid to all state residents with income up to 138% of the FPL.[55] This is far more inclusive than prior Medicaid eligibility criteria that would only provide coverage to people with incomes up to 100% of the FPL and often times much less. To date, 28 states plus the District of Columbia have adopted the ACA Medicaid expansion.[56] This means that for states that have expanded their Medicaid coverage under the ACA, individuals earning up to $15,521 per year and families of 4 with income up to $31,721 are now Medicaid eligible, assuming their assets are less than $2,000.[57]

States also have the ability to decide what services they will cover through Medicaid. Medicaid Programs are required to cover inpatient and outpatient hospital services, services provided by physicians and laboratories, and nursing home and home health care.[58] In addition to these traditional acute health care services, Medicaid covers a broad spectrum of LTSS that Medicare and most private insurance plans exclude or tightly limit.[59]

In the early days of Medicaid, LTSS funding was only available to individuals in institutional settings.[60] This institutional bias has eroded over the decades and funding for home and community based services has greatly expanded.[61] In 1995, only 20.8% of Medicaid LTSS dollars were spent for HCBS, but by 2011 HCBS represented 50.6% of Medicaid LTSS.[62] This shift toward HCBS began in 1981 with the enactment of the Omnibus Budget Reconciliation Act which created the 1915(c) HCBS Waiver Program as part of Medicaid. Additional shifts were driven by the 1990 Americans with Disabilities Act, the 1999 Supreme Court decision in Olmstead v. L.C., the Deficit Reduction Act of 2005, and most recently the Affordable Care Act in 2010. A brief overview of these important legislative acts and judicial decisions is provided here.

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[55] *Id.*

[56] *Status of State Action on the Medicaid Expansion Decision*, THE HENRY J. KAISER FAMILY FOUNDATION (Aug. 28, 2014), available at http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/ (last visited Feb. 15, 2015).

[57] *See* Health and Human Services, *supra* note 51.

[58] *An Overview of the Medicaid Program*, CONGRESSIONAL BUDGET OFFICE (Sep. 18, 2013), available at http://www.cbo.gov/publication/44588 (last visited Feb. 15, 2015).

[59] *See* Kaiser Family Foundation, *supra* note 46.

[60] *See* Kaiser Family Foundation, *supra* note 44, at 726.

[61] *Id.*

[62] Kirsten J. Colello, *Medicaid Coverage of long-Term Services and Supports*, CONGRESSIONAL RESEARCH SERVICE 2 (Dec. 5, 2013), available at https://www.fas.org/sgp/crs/misc/R43328.pdf (last visited Feb. 13, 2015).

A. 1981 Omnibus Budget Reconciliation Act (OBRA-81) – HCBS Waiver Programs

When first enacted in 1965, Medicaid funding for LTSS was limited primarily to people who were institutionalized.[63] Coverage for LTSS was mandatory for people 21 or older if they resided in a skilled nursing facility (SNF).[64] Only very limited funding was available for people who required LTSS, but chose to stay in their homes or a community setting.[65] To obtain Medicaid funding, states are required annually to develop a State Plan which describes how the state plans to spend their Medicaid dollars. The plan needs to detail what services are covered and who is covered. State Plans are submitted to the federal government every year for approval by the Centers for Medicaid and Medicare Services (CMS).[66] State Plans are required to be implemented uniformly throughout the state which is called the "statewideness" requirement.[67] Once a State Plan is approved, states are required to provide the elements of the program to all eligible residents of the state – this is an entitlement program.[68]

In 1981, when Congress enacted the Omnibus Budget Reconciliation Act (OBRA-81), they established Home and Community Based Waiver programs as part of Medicaid through section 1915(c).[69] Waiver Programs differ from State Plans in that States can request that the Secretary of Health and Human Services (HHS) "waive" certain Medicaid requirements in order to test new ways to provide care in Medicaid.[70] The 1915(c) Home and Community Based Waiver Programs specifically give states the flexibility to provide additional services not typically covered by Medicaid so that individuals can remain in their home or a community setting.[71] States can also use waivers to target specific populations, to limit the number of people they would serve and to negate the "Statewideness" requirement.[72] The creation of the 1915(c)

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[63] Gary Smith et al., *Understanding Medicaid Home and Community Services: A Primer*, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES 8 (2010 Edition), available at http://aspe.hhs.gov/daltcp/reports/2010/primer10.htm (last visited Feb. 16, 2015).

[64] *Id.* at 13.

[65] *Id.* at 14.

[66] Dee Mahon, *State Plan Amendments and Waivers: How States Can Change Their Medicaid Waiver Programs*, FAMILIES USA 1 (Jun. 2012), available at http://familiesusa.org/sites/default/files/product_documents/State-Plan-Amendments-and-Waivers.pdf.

[67] *Id.* at 3.

[68] Paul M. Johnson, *A Glossary of Political Economy Terms – Entitlement Program*, DEPARTMENT OF POLITICAL SCIENCE, AUBURN UNIVERSITY, available at http://www.auburn.edu/~johnspm/gloss/entitlement_program (last visited Feb. 12, 2015). An entitlement program is defined as a program where beneficiaries have a legal right whenever they meet eligibility conditions that are specified by standing law that authorizes the program.

[69] Mary Jean Duckett, M.S.P., and Mary R. Guy, M.S.Ed., M.S.W., *Home and Community-Based Services Waivers*, HEALTH CARE FINANCING REVIEW 123 (FALL 2000), available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4194688/pdf/hcfr-22-1-123.pdf (last visited Feb. 16, 2015).

[70] *See* Johnson, *supra* note 66.

[71] *Id.* at 4 – 6.

[72] *Id.*

HCBS Waiver Programs represented the greatest advance in the delivery of LTSS since the inception of Medicaid. It is important to note however, that unlike benefits provided by the Medicaid State plan, HCBS are not an entitlement.[73] In other words, it is possible to be eligible for a waiver but end up on a waiting list because not enough funding exists for all of the eligible applicants.

B. Americans with Disabilities Act – 1990

On July 26, 1990, President George H.W. Bush signed into law the Americans with Disabilities Act.[74] This comprehensive federal civil-rights statute was designed to protect the rights of people with disabilities.[75] It affects access to employment; state and local government programs and services; access to places of public accommodation such as businesses, transportation, and non-profit service providers; and telecommunications.[76] The adoption of the ADA had huge implications on HCBS Waiver Programs. States are now required to show that they have implemented changes to policies, practices and procedures to avoid discrimination on the basis of disability.[77] Under the ADA, disabled individuals who were not able to gain access to necessary LTSS finally had a statutory basis to litigate. Previous attempts to argue constitution based discrimination were not successful since disability is not considered a suspect class under the "equal protection" clause of the 14th amendment.[78] After the adoption of the ADA, more and more states began developing HCBS Waiver Programs for specific groups of people. In 1990, the year that the ADA became law (almost 10 years after HCBS Waiver Programs were introduced), there were less than 50,000 people receiving waivers, but by 2010 there were over half a million people benefiting from HCBS waivers.[79]

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[73] *Understanding Medicaid Entitlements and Long-Term Care*, PAYING FOR SENIOR CARE (July 2014), http://www.payingforseniorcare.com/longtermcare/resources/medicaid-explanation.html.

[74] United States Department of Justice, Civil Rights Division, *Information and Technical Assistance on the Americans with Disabilities Act*, available at http://www.ada.gov/ada_intro.htm (last visited Jan. 18, 2015).

[75] *Id.* The ADA was modeled after the Civil Rights Act of 1964, which prohibits discrimination on the basis of race, color, religion, sex, or national origin – and Section 504 of the Rehabilitation Act of 1973 -- the ADA is an "equal opportunity" law for people with disabilities. *Id.*

[76] *A Guide to Disability Rights Laws*, UNITED STATES DEPARTMENT OF JUSTICE, CIVIL RIGHTS DIVISION 2 (Jul. 2009), available at http://www.ada.gov/cguide.htm (last visited Feb. 6, 2015).

[77] Cynthia Shirk, *Rebalancing Long-Term Care: The Role of the Medicaid HCBS Waiver Program*, NATIONAL HEALTH POLICY FORUM 10 (Mar. 3, 2006), available at http://www.nhpf.org/library/background-papers/BP_HCBS.Waivers_03-03-06.pdf (last visited Feb. 16, 2015).

[78] Marcie Straus, *Reevaluating Suspect Classifications*, 35 SEATTLE U. L. REV. 135, 146 (2011). *See also*, Plyler v. Doe, 457 U.S. 202, 215-21 (1982).

[79] *See* Kaiser Family Foundation, *supra* note 44, at 726.

C. Olmstead v. L.C. decision – 1999

In 1999, the U.S. Supreme Court ruled on what is now considered to be the landmark case for people with disabilities – Olmstead v. L.C.[80] The *Olmstead* case involved two mildly mentally retarded[81] women, Lois Curtis (L.C.) and Elaine Wilson (E.W.) who had each been voluntarily admitted for treatment to the psychiatric unit of Georgia Regional Hospital (GRH).[82] After appropriate treatment, medical professionals for both women determined that they could continue treatment in community-based settings.[83] Despite these recommendations both women remained institutionalized at GRH.[84] In May of 1995, seeking placement in a community setting, L.C. filed suit in the U.S. district Court and E.W. joined the case likewise seeking placement in a community setting.[85] In *Olmstead*, the Court held that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the ADA.[86] Writing for the Court, Justice Ginsberg noted that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life."[87] The Court found that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.[88]

As a result of the Olmstead decision, federal and state governments have worked to expand HCBS to persons with disabilities.[89] Since *Olmstead*, every state now offers either Medicaid 1915(c) HCBS Waiver Programs or comparable waivers to provide HCBS to certain groups of people who are eligible for LTTS.[90] While this certainly represents progress in providing necessary LTSS to disabled Americans, the fact that states are able to limit enrollment in waiver programs has created another serious problem – waiting lists. By 2011 there were over 300,000 disabled Americans on waiting lists for HCBS waivers in the United States.[91] While some states have managed to keep the time spent on waiting lists to a minimum, others have not. In

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[80] Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (Jun. 22, 1999).

[81] *Id.* The term 'mentally retarded' is now referred to as an intellectual disability.

[82] *Id.*

[83] *Id.*

[84] *Id.*

[85] *Id.*

[86] *Id.*

[87] *Id.* at 600.

[88] *Id.* at 607.

[89] *See* Health and Human Services, *supra* note 51, at 28.

[90] *Id.*

[91] *See* Kaiser Family Foundation, *supra* note 44, at 730.

Oklahoma, for example, the average time on the waiting list is over eight years.[92] Because waiver programs are state specific, they do not transfer from state to state.[93] If a person receives a waiver in one state and elects to move to another state he/she will lose their waiver and have to start all over again in the new state. Spots on waiting lists are likewise not transferable – a person who needs to move one or more times could literally spend the majority of their life on waiting lists for services.

D. Deficit Reduction Act of 2005

The Deficit Reduction Act ("DRA") of 2005 allowed states to make significant reforms to their Medicaid Programs.[94] Under § 6086 of the DRA, states were allowed for the first time to offer HCBS through their Medicaid State Plans rather than requiring them to establish 1915(c) Waiver Programs.[95] States were given the ability to do this by establishing a 1915(i) waiver-like HCBS State Plans which do not require a secretary-approved waiver.[96] The DRA was also introduced the Money Follows the Person (MFP) Program, which could be used to help Medicaid beneficiaries who needed LTSS move out of institutions (nursing homes) back to their homes or community residential settings without losing their support funding.[97] Although in theory giving states the ability to provide HCBS through their Medicaid State Plans rather than requiring them to use Waiver Programs should be very beneficial to the over 300,000 Americans on HBCS Waiver Program waiting lists, the reality is that this has not been the case. Some states are reluctant to move from waiver programs where they had the discretion to decide what the enrollment numbers would be to a State Plan Program, which would be an entitlement.

E. Patient Protection and Affordable Care Act of 2010

The Affordable Care Act of 2010 provided improvements to the Medicaid amendment initiatives introduced by the Deficit Reduction Act of 2005. Under the DRA, although states could now offer HCBS under Medicaid State Plans through section 1915(i), there were restrictions. Under the DRA, individuals had to have incomes at or below 150% of the FPL and states could offer some but not all of the services available under the 1915(c) waiver programs and states were not able to target certain populations within the state. [98] The ACA expanded coverable services available under 1915(i) and increased the income limit to 300% of the SSI federal benefit level.[99] Starting in 2014, the Affordable Care Act expands Medicaid eligibility

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[92] *Id.*

[93] *Id.*

[94] *The Deficit Reduction Act: Important Facts for State Government Officials*, CENTERS FOR MEDICARE & MEDICAID SERVICES 1, available at https://www.cms.gov/Regulations-and-Guidance/Legislation/DeficitReductionAct/downloads/checklist1.pdf (last visited Feb. 6, 2015).

[95] *Id.* at 5.

[96] *Id.*

[97] *See* Colello, *supra* note 60, at 28.

[98] *Id.*

[99] Carol V. O'Shaughnessy, *Medicaid Home- and Community-Based Services Programs Enacted by the ACA*, NATIONAL HEALTH POLICY FORUM 10 (Nov. 19, 2013), available at

to all people under 65 with incomes below 133% of the FPL.[100] Before this, although Medicaid required states to cover certain groups of individuals—such as pregnant women, people with disabilities, seniors, and children—at certain income levels, states could decide to simply not cover other categories of people such as adults without dependent children regardless of income. The Medicaid expansion will standardize eligibility across states and base it on income alone. As a result, Medicaid will cover many more people, but the federal government will pick up nearly all the costs of this expansion. To lay the foundation for the Medicaid expansion in 2014, the Affordable Care Act requires states to maintain Medicaid eligibility levels at least at the March 2010 level. Additionally, enrollment processes cannot be made more restrictive.

Despite the fact that ACA provides states with an unprecedented ability to cover more of their neediest residents under Medicaid with the bulk of the costs paid for by the federal government, to date, only 28 states plus the District of Columbia have adopted the Medicaid expansion provision.[101]

In the nearly 50 years since it was created, there have been huge improvements in Medicaid's ability to provide LTSS to some Americans. The above overview of federal laws and policies highlights this progress. At the end of the day, however, Medicaid is and always will be a needs based program with income and resource limits that preclude the middle class[102]. By continuing to utilize Medicaid as the only significant provider of LTSS, we are essentially denying disabled Americans the right to maximize their earning potential and live the type of lives that all Americans should be entitled to strive for.

III. THE NEED FOR A NEW AND INNOVATIVE APPROACH TO LTSS

The issues associated with LTSS have been known and heavily debated for decades. [103] A number of proposals have been offered at the federal level to address the financing and delivery of LTSS.[104] Some suggested solutions such as the Pepper Commission Report and the CLASS Act were comprehensive in nature, while others

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http://www.nhpf.org/library/background-papers/BP86_ACAMedicaidHCBS_11-19-13.pdf (last visited Feb. 15, 2015).

[100] *Id.*

[101] *Status of State Action on the Medicaid Expansion Decision*, THE HENRY J. KAISER FAMILY FOUNDATION (Aug. 28, 2014), available at http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/ (last visited Jan. 30, 2015).

[102] There is no universally accepted definition of "middle class" in the United States. Robert Reich, a noted economic analyst, has suggested that the middle class be defined as "those with income levels 50 percent above and below the median income. Median is a term that means the 'middle of the middle.' Median earnings are a key indicator of how the middle class is doing." Karin Kamp, *By the Numbers: The Incredibly Shrinking Middle Class*, MOYERS & COMPANY (Sep. 20, 2013). http://billmoyers.com/2013/09/20/by-the-numbers-the-incredibly-shrinking-american-middle-class/ (last visited Feb. 16, 2015).

[103] Beatrice S. Braun, *Long-Term Care and the Challenge of an Aging America: An Overview*, 1 QUINNIPIAC HEALTH L.J. 113, 115-18 (1997) available at http://www.quinnipiac.edu/prebuilt/pdf/SchoolLaw/HealthLawJournalLibrary/13_1QuinnipiacHealthLJ113%281996-1997%29.pdf (last visited Feb. 14, 2015).

[104] *See* America's Long-Term Care Crisis, *supra* note 22, at 5.

suggested incremental changes to the regulation and tax treatment of private insurance, or provided new state options to expand the availability of home and community-based care through the Medicaid program.[105] Although political posturing maybe responsible for some of the inability to move forward on the issue and to identify a feasible solution, the reality is that this is a complicated situation and when viewed in its entirety, may not be solvable with one solution. A better approach would be to parcel the population of LTSS users into at least the 3 broad categories defined by age and identify unique solutions for each one. The remainder of this note will focus on the middle group – working age disabled (ages 18 – 65).[106] Within this population, there is a subset of individuals who have the potential to work and live independent lives. Developing a LTSS Program for this group is a solvable problem and one the federal government should prioritize. This analysis section will explore the feasibility of proposals made by a dissenting group of Commissioners from the 2013 Commission on Long-Term Care and a subsequently proposed AAPD (American Association for People with Disabilities) Pilot Program[107] to determine how these proposals could lead to an improved LTSS Program for the working age disabled.

On January 2, 2013, President Obama signed into law the American Taxpayer Relief Act (ATRA) of 2012.[108] Section 643 of this Act created the Commission of Long Term Care.[109] The Commission consisted of 15 members who were selected 3 each by the President, The Majority and Minority Leaders of the Senate, the Speaker of the House of Representatives and the Minority Leader of the House of Representatives. 3 apiece.[110] Dr. Bruce Chernoff was elected by the Commission to serve as Chairman.[111] The Commission was directed to develop a plan for

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[105] *Id.*

[106] The other two demographic groups include the elderly and children. Each of these populations of LTSS users have unique needs that differ from the issue of working age people who are capable of and desiring of independence. Solutions for these two populations will not be analyzed in this note.

[107] Henry Claypool, Executive Vice President, American Association for People with Disabilities (AAPD) was one of the 6 dissenting Commissioners from the 2013 Long-Term Care Commission and part of the group of 5 Commissioners to author the Alternative Report. Subsequently the AAPD offered details for a proposed pilot program that expound on some of the recommendations put forth in the Alternative Report.

[108] *See* Chernof &Washawsky,*supra* note 18 at 1.

[109] *Id.* The Commission was created to study the issues of long-term care after Congress repealed the Community Living Assistance Services and Supports (CLASS) Act from the Affordable Care Act. Susan Jaffe, *Long-Term Care Panel Releases Recommendations But Fails to Offer Plan to help Pay for Services*, KAISER HEALTH NEWS 3 (September 13, 2013), available at http://kaiserhealthnews.org/news/long-term-care-commission-recommendations/ (last visited February 16, 2015). CLASS had been a voluntary long-term care program that was ultimately determined to be financially unfeasible because high premiums would have discouraged people from participating. *Id.*

[110] *See* Chernof &Washawsky, *supra* note 18, at 1. Hence this was a bipartisan commission with 9 democrats and 6 republicans. *See also*, Jaffe, *supra* note 108.

[111] Chernof &Washawsky, *supra* note 18, at 1. Bruce Allen Chernof, MD, FACP, currently serves as the President & Chief Executive Officer of The SCAN Foundation, whose mission is to advance a coordinated and easily navigated system of high-quality services for older adults

establishing, implementing and financing a comprehensive system for LTSS.[112] The Commission was given an aggressive timetable with a deadline of voting on proposals and presenting a detailed report by September 12, 2013.[113] The formation of this Commission and its charter were a direct response to the repeal of the CLASS ACT from the Affordable Care Act.[114]

Ultimately, nine of the fifteen Commission members endorsed a package of 28 recommendations which were summarized on September 12, 2013 and detailed in a formal report published on September 30, 2013.[115] These recommendations did not include a consensus on how to finance long-term care services.[116] Although the recommendations included some good ideas, the report "did little to change the perception that substantial relief for caregivers will be a long time coming." [117] Five of the six Commission members who voted against the proposals subsequently released their own proposal in a report dated September 23, 2013.[118] Speaking for this group of five Commissioners, Judith Feder[119] said "The fundamental issue in getting people the long-term services and supports they need is an issue of financing…[a]nd this Commission did not address that issue."[120] In explaining the elements of the alternative proposal that her group offered, Feder further emphasized that individuals and families needed help with funding LTSS, stating that "Medicaid is there for them only after they impoverish themselves,…[w]e can do better than that."[121] This alternative report and an affiliated plan put forth by the American

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that preserve dignity and independence. The SCAN Foundation is one of the largest foundations in the United States focused entirely on improving the quality of health and life for seniors. http://www.thescanfoundation.org/who-we-are/foundation-staff/dr-bruce-chernof.

[112] Chernof &Washawsky, *supra* note 18 at 1.

[113] *Id.* at 2. This task was made more challenging by the fact that it took 3 months for all of the commission members to be appointed and the Commission did not have its first meeting until June 27, 2013.

[114] Howard Gleckman, *Fiscal Cliff Deal repeals CLASS Act, Creates Long-Term Care Commission*, FORBES (Jan. 1, 2013), available at http://www.forbes.com/sites/howardgleckman/2013/01/01/fiscal-cliff-deal-repeals-class-act-creates-long-term-care-commission/ (last visited Feb. 6, 2015).

[115] Judith Graham, *No Easy Answers on Financing Long-Term Care*, NY TIMES (Sep. 19, 2013), available at http://newoldage.blogs.nytimes.com/2013/09/19/no-easy-answers-on-financing-long-term-care/?_r=0 (last visited Jan. 29, 2015).

[116] *See* Jaffe, *supra* note 108 at 1.

[117] *Supra* note 115.

[118] Butler et al., *supra*note 9.

[119] Judith Feder, a health policy scholar at Georgetown University Public Policy Institute was appointed by Senate Majority Leader Harry Reid (D-Nev.). *See* Jaffe, *supra* note 109 at 1-2.

[120] Chernof &Washawsky, *supra* note 18, at 1-2.

[121] *Id.*

Association for People with Disabilities (AAPD) [122] will be the subject of this analysis.

A. An Alternative Report: A Comprehensive Approach to Long-Term Services and Supports

Five of the six Commissioners who voted against the proposal submitted by the Commission subsequently drafted an alternative plan.[123] This plan offered novel and intriguing ideas about how to implement, deliver, and finance a long-term care program. These Commissioners assert that "no real improvements to the current insufficient, disjointed array of LTSS and financing can be expected without committing significant resources, instituting federal requirements, and developing social insurance financing."[124] The Commissioners acknowledged that building a new LTSS system and delivering on the statutory requirements given to the Commission would be time consuming, but they also recognized that people who need LTSS can't afford to wait.[125] Their proposal, therefore, represents short term improvements to existing LTSS funding approaches while building a completely new system.[126] The alternative plan is presented as six recommendations, the last two of which specifically address the issues regarding using Medicaid as the funding vehicle for disabled Americans who are able to work and live independently.[127]

1. Recommendation Five

Recommendation Five suggests ways to strengthen and improve Medicaid which essentially represent a continuation of the great progress that has been made in Medicaid in the past 50 years with respect to LTSS.[128] While sensible, this recommendation in and of itself does not solve the problem - Medicaid remains a means-tested system and as long as income and resource limits exist, disabled Americans who are able to work will continue to have to make choices that limit their ability to reach their full earning potential. The major thrust of this recommendation is to provide incentives to states to rebalance their Medicaid Programs towards HCBS (away from institutional care) and to improve Medicaid LTSS benefits.[129] Key elements of Recommendation Five include:

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[122] *Proposals to Bolster Access to LTSS for Working Americans with Disabilities, Families of People with Disabilities and Current Beneficiaries*, AMERICAN ASSOCIATION FOR PEOPLE WITH DISABILITIES, *available at* http://www.aapd.com/resources/alternative-report.pdf. Henry Claypool one of the dissenting commissioners who authored the alternative report is the Chairperson of the AAPD.

[123] Butler et al., *supra* note 9.

[124] *Id.* at 1.

[125] *Id.* at 6.

[126] *Id.*

[127] *Id.*

[128] Reaves & Musumeci, *supra* note 20 at 12–15.

[129] *Id.* at 15.

> 1. Require coverage of HCBS in Medicaid and raise asset standards for community residents and spouses, addressing what is commonly referred to in the disability rights advocacy community as the "institutional bias."[130]
> 2. Rebalance Medicaid financing to support community living.[131]
> 3. Gradually increase the federal share of Medicaid financing for LTSS, thereby reducing burdens on the states.[132]
> 4. Broaden access to LTSS in the community by expanding the existing infrastructure of one-stop shopping and worker registries for people not eligible for Medicaid; fully fund and implement these programs at a national level.[133]

2. Recommendation Six

Recommendation Six directly addresses the inadequacy of Medicaid as the vehicle for funding LTSS. The Commissioners recognize that Medicaid is an "imperfect solution" [134] with structure and eligibility rules that make it difficult or impossible for working individuals with significant disabilities to achieve a middle-class lifestyle for themselves and their families.[135] Although there are provisions in Medicaid such as the Medicaid Buy-In Program that allow people with income somewhat above the income and resource limits to participate, these exceptions typically only extend to incomes of up to 250% of the federal poverty level.[136] For an individual, this still restricts annual income to $29,175.[137] Recommendation Six presents a plan for providing LTSS for people whose income is above 250% of the federal poverty level and therefore represents the type of innovative solution that the working age disabled population needs. If implemented, this plan would represent the most significant improvement in quality of life for disabled Americans since the passage of the ADA. This recommendation proposes three distinct elements which are[138]:

> 1. Tax-preferred savings accounts for disabled Americans and their families not currently receiving LTSS through Medicaid.[139]
> 2. An expansion of the Medicaid Buy-In Program to allow more disabled Americans to participate in Medicaid.[140]

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[130] Butler et al., *supra* note 9, at 17. While Medicaid is required to pay for LTSS in institutional settings, it remains optional for states in HCBS.

[131] *Id.*

[132] *Id.*

[133] *Id.*

[134] *Id.* at 16.

[135] *Id.*

[136] *Id.*

[137] *Supra* Part III at 7.

[138] Butler et al., *supra* note 9, at 16-17.

[139] *Id.*

[140] *Id.*

> 3. A new Federal Pilot Program that would allow workers with significant disabilities who earn above 250% of the federal poverty level to obtain funding for LTSS without participating in Medicaid.[141]

Element (3) of Recommendation Six is the game-changer that the working-age disabled population has been waiting for. This would allow disabled people to not only take jobs that maximize their income, but would also give them the ability to relocate from one state to another without fear of losing the supports they need to live independently.

To better understand the specifics of how element (3) would work, it is useful to examine the related Pilot Program suggested by the American Association for People with Disabilities (AAPD).[142]

A. AAPD Proposed Pilot Program

The AAPD Pilot Program outlines the issues that working age disabled Americans face with obtaining LTSS funding through Medicaid. These issues are described by the Pilot Program as:[143]

> 1. Upper limits on income and resources for program eligibility are often the drivers of career decisions rather than opportunities.[144]
> 2. Variations in state Medicaid programs (e.g. income and resource limits for MBI participation, income limits for eligibility, types of waivers and whether slots are available, and the package of services and supports available) make relocating for a better opportunity difficult, if not impossible.[145]
> 3. SSI/Medicaid's resource limits (e.g. a person can have no more than $2000 in assets for an individual or $3000 for a couple to be Medicaid eligible) are often problematic making it impossible for people with disabilities who work to save for emergencies and retirement, let alone save to purchase a home or start a business.[146]
> 4. People with significant disabilities often have extraordinary support needs that make it difficult, if not impossible, to get those needs met outside of public programs.[147]

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[141] *Id.* at 17.

[142] Henry Claypool, who serves as the Chairperson of AAPD and was one of the six dissenting Commissioners and an author of the alternative report, put together this Pilot Program.

[143] *Giving Hardworking Americans With Disabilities A Chance At A Middle Class Life*, AAPD FACT SHEET, available at http://www.aapd.com/what-we-do/health/aapd-pilot-program-fact-sheet.pdf (last visited February 6, 2015).

[144] *Id.*

[145] *Id.*

[146] *Id.*

[147] *Id.*

The AAPD believes that because of these issues, Medicaid is an inappropriate program for people to rely on as they earn more.[148] The AAPD further asserts that the US must provide people with disabilities a pathway to access services and supports that allow them to earn to their potentials, save for their futures, achieve a middle class lifestyle, and achieve the vision of the ADA.[149] To achieve this, AAPD proposes the following new federal program.

B. AAPD Proposed Pilot Program Solution[150]

A pilot program that provides access to the services and supports needed by employed individuals with significant disabilities (meet SSA definition of disability absent the inability to work assessment) combined with a waiver of rules that prevent people with disabilities to earn income and accumulate assets without jeopardizing access to services and supports. This program is designed to wrap-around health insurance products (offered by employer or through the state Marketplaces) and modeled on the 1619(b) program, specific program design elements include:

> 1. Eligibility: To be eligible to receive wrap-around services and supports through this program, a person would have to be a working individual with a disability defined as:
>
> a..Meeting or equaling the Social Security disability listings or qualify for quick disability determination/compassionate allowances for eligibility for the Social Security disability programs.
>
> b. Be working, defined as earnings at or above 250% FPL.
>
> 2. Pay applicable cost sharing based on income, employment –related disability expenses, as well as level of services needed.
>
> 3. Wrap around Package:[151] The program would offer access to services and supports that people with disabilities need to become and stay employed, fill coverage gaps that between what is offered by health care insurance products and the unique health care needs of individuals with significant disabilities. Services and support package available through the program would include: personal attendant care, assistive technology, durable medical equipment and other services and supports.

To summarize, the alternative report from the dissenting Commissioners on the Long-Term Care Commission and the AAPD Pilot Plan propose a program that essentially allows people with income up to 250% of the FPL to continue to participate in Medicaid and would establish a new federal program to provide funding for LTSS for people with income above 250% of the FPL. This new Program would be completely separate from Medicaid and would wrap-around health insurance secured by these individuals either privately or through the ACA exchanges. This plan would

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148 *Id.*

149 *Id.*

150 *Id.*

151 Wrap-around benefits are benefits that provide assistance to beneficiaries who are enrolled in private health insurance. They serve to ensure that the beneficiary's coverage is equivalent to what he or she would have received in a traditional Medicaid plan. KANSAS HEALTH INSTITUTE at khi.org.

establish cost sharing so that disabled Americans with higher incomes would make contributions towards this benefit.

C. A Real Life Example of how this new Program would look

To analyze how such a Program could look financially for the government, we return to Jane, the 19-year old young woman with Cerebral Palsy featured in the Introduction.[152] Jane is currently a college freshman. She plans to major in Social Work or Communications and would ultimately like to serve in a leadership role in a university Office for Students with Disabilities. Jane's State of Ohio BVR[153] Vocational Counselor has researched this career goal with Jane and has assured her that this is a growing field with good job prospects and that she can expect to earn a salary of $42,000 - $47,000/year. [154] This salary range would put Jane at ~400% of the federal poverty level (FPL), which would make her ineligible for Medicaid in all current scenarios.[155] Jane's estimated annual PCA expenses are ~$44,000.[156] If Medicaid continues to be the only source of funding for LTSS (here PCAs) and Jane is Medicaid ineligible because of income, she will essentially spend more than her entire income (after tax) paying for her PCA care. This is of course not feasible and in order to be Medicaid eligible, Jane would have to take a lesser job restricting her income potential in the best case to ~$29,000 – far below her potential. Jane would then be Medicaid eligible and the government would pay her PCA expenses and her health care through Medicaid.

If, instead, Jane had access to the proposed new federal Program to fund her PCAs, she could take this higher paying job, live independently, and be a taxpayer and utilize private health insurance. Jane would access the new federal program to wrap-around her private health insurance. The wrap-around federal program would cover the cost of Jane's PCAs. Although not detailed by the AAPD proposal, there is a reference to the fact that as incomes increased, individuals would be responsible for covering more of their LTSS costs.[157] Most likely at this entry level starting salary of $42,000 - $47,000 Jane would not be expected to contribute to her LTSS costs, but perhaps a

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[152] *Supra* Part I.

[153] The Bureau of Vocational Rehabilitation (BVR) is a department within Opportunities for Ohioans with Disabilities (OOD). This is the program that provides individuals with disabilities the services and support necessary to help them attain and maintain employment. *See* OPPORTUNITIES FOR OHIOANS WITH DISABILITIES, HTTP://WWW.OOD.OHIO.GOV/CORE-SERVICES/BVR (last visited Feb. 13, 2015).

[154] Salary date provided by Gina LoPresti, M.Ed., CRC VocWorks Ohio.

[155] Although each state determines the salary limitations for Medicaid eligibility within the state, and the ACA expansion has shifted the income limits higher, there are no provisions currently in practice or discussion that would allow a person with income above 250% of the FPL to participate in Medicaid. With income at 400% of the FPL, Jane would not qualify for Medicaid.

[156] *See supra* Part II(C). The current best guess is that for Jane to live independently she would require approximately 40 hours per week of PCA assistance. If we assume that the cost for this care is $21/hour, the annual cost for Jane's PCA support is $44,000.

[157] *Giving Hardworking Americans With Disabilities A Chance At A Middle Class Life*, AAPD FACT SHEET, available at http://www.aapd.com/what-we-do/health/aapd-pilot-program-fact-sheet.pdf (last visited Feb. 15, 2015).

threshold could be set that would suggest that once income exceeded 500% of the FPL ($58,350 for an individual) participants would make contributions on a sliding scale.

A reasonable plan might be to have participants begin to pay 5% of the cost of their annual LTSS once they exceed 500% of the FPL and to have this increase to a maximum of 10% of the annual LTSS costs as income continues to grow.[158] In Jane's scenario the net result is a cost savings to the government and a better life for Jane.

D. How Many Americans would be Eligible for the New Program?

Much work needs to be done to understand fully what the cost of this new federal Program would be. The advantage of focusing on just the group of working age disabled Americans is that it allows the government to create and prove feasibility of the Program on a manageable sized population. To understand exactly what the size of the population is we revisit data presented in section II (B) of this Note.[159] Of the 12 million Americans who currently require some level of LTSS, approximately 47% (5.64 million) are working age adults. However, using the current criteria that in order to be eligible for LTSS benefits a person needs to require assistance with 2 or more ADLs, the eligible population is much smaller. If we apply the same percentage of 47% to the 3.2 million people currently eligible for LTSS benefits under Medicaid, we can estimate that about 1.5 million people would fall into the category of working age and eligible for LTSS benefits.

Of this 1.5 million, not all will have the ability to earn income that would preclude them from continuing with Medicaid. In reality, we may be looking at as few as half of these individuals – about 750,000 who would participate in the new federal program.

E. What Would the New Program Cost and can we afford it?

If we estimate that the average amount of LTSS support per year that each person needed was $65,000, the cost to the federal government for this program would be ~49 billion per year. The true cost to the federal government would actually be less than this since these individuals would no longer require Medicaid.

Medicaid is currently spending 140 billion per year on LTSS.[160] Approximately 47% (65.8 billion) of this total is spent on LTSS for working age disabled Americans. If we assume that half of this population could earn income that would qualify them for the Pilot Program, ~ 33 billion dollars currently spent on Medicaid would be eliminated. Since the average federal contribution to Medicaid funding is 58%, the federal government would reduce its Medicaid spending by about 19 billion. This means that the net cost add for this Program to the federal government is about 30 billion per year.[161] This figure could be even less, because as participants began to

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[158] This is simply a proposal by the author of this note on how the sliding scale contributions could work and not actually part of the AAPD Pilot Program. The AAPD Pilot Program calls for a sliding scale cost sharing, but does not offer details of what that would look like.

[159] *Supra* Part II (B).

[160] *Supra* part II (C).

[161] The estimated total cost of the new program of 49 billion minus the Medicaid cost savings of 19 billion leaves a net cost of 30 billion.

earn substantially more income they would make contributions to their own LTSS expenses which could range from 5 – 10% of their annual LTSS costs.[162]

To give some perspective, a review of other items currently funded by the federal government is useful. The United States has been engaged in the "war on drugs" for the past 25 years, currently spending ~ 50 billion per year trying to eradicate drugs from the United States.[163] Despite this commitment of resources, the DEA estimates that we only capture about 10% of all illicit drugs.[164] The federal government also spends significant money every year on aid to foreign governments. In 2013, the US spent 55 billion on foreign aid to more than 180 countries.[165] The federal government spends about 100 billion per year on direct subsidies and grants to Companies – also known as Corporate welfare[166] In addition to some of these large annual expenditures which are controversial, there are many smaller equally controversial expenditures that are funded every year through various federal programs. A Heritage Foundation study of government waste in 2009 identified several areas of seemingly inefficient spending. Some examples include: (1) the government spent at least 72 billion in 2008 on improper payments;[167] (2) Washington spends 25 billion annually maintaining unused or vacant federal properties;[168] (3) a five-year government audit of all federal programs showed that 22% of them costing 122 billion annually, failed to show any positive benefit on the populations they serve;[169] and (4) the government planned in 2010 to spend 2.6 million teaching Chinese prostitutes to drink more responsibly. [170]

The government could elect to fund this new federal LTSS program for the working aged disabled as a cost neutral program by eliminating or trimming some other current spending (such as the examples provided above). The alternative is that the federal government can simply decide that providing the opportunity for disabled Americans to be able to work up to their potential and live independently is the right thing to do even if it means something as unpopular as a new tax. While 30 billion is not a trivial sum of money, funding it translates to an annual cost per taxpayer of ~

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[162] *Supra* Part II (B).

[163] Jim Telesmanich, Dorean Kass, and Matt Wright , *The United States War on Drugs*, STANFORD UNIVERSITY, available at https://web.stanford.edu/class/e297c/poverty_prejudice/paradox/htele.html (last visited Jan. 20, 2015).

[164] *Id.*

[165] *Good Question: How Much Foreign Aid does the US Give?*, CBS MINNESOTA (August 20, 2013), available at http://minnesota.cbslocal.com/2013/08/20/good-question-how-much-foreign-aid-does-the-u-s-give/ (last visited Feb. 10, 2015).

[166] Scott Lincicome, *Calculating the real cost of Corporate Welfare*, THE FEDERALIST (Sep. 30, 2013), available at http://thefederalist.com/2013/09/30/calculating-the-real-cost-of-corporate-welfare/ (last visited Feb. 15, 2015).

[167] Brian Reidl, *50 Examples of Government Waste*, HERITAGE FOUNDATION REPORT (Oct. 6, 2009), available at http://www.heritage.org/research/reports/2009/10/50-examples-of-government-waste (last visited Feb. 10, 2015).

[168] *Id.*

[169] *Id.*

[170] *Id.*

$125. [171] The United States is a nation of generous people and $125 per taxpayer per year is a very reasonable sacrifice to ask people to make to guarantee the rights of some of our most deserving fellow Americans. As the 25th anniversary of the enactment of the ADA approaches, it is appropriate to pause and remember the important words that President George H.W. Bush spoke when he signed the ADA into law:

> With today's signing of the landmark Americans for Disabilities Act, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom. As I look around at all these joyous faces, I remember clearly how many years of dedicated commitment have gone into making this historic new civil rights act a reality. It's been the work of a true coalition, a strong and inspiring coalition of people who have shared both a dream and a passionate determination to make that dream come true. It's been a coalition in the finest spirit -- a joining of Democrats and Republicans, of the legislative and the executive branches, of Federal and State agencies, of public officials and private citizens, of people with disabilities and without.
> This historic act is the world's first comprehensive declaration of equality for people with disabilities -- the first. Its passage has made the United States the international leader on this human rights issue. Already, leaders of several other countries, including Sweden, Japan, the Soviet Union, and all 12 members of the EEC, have announced that they hope to enact now similar legislation.
>
> Our success with this act proves that we are keeping faith with the spirit of our courageous forefathers who wrote in the Declaration of Independence: ``We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable rights.'' These words have been our guide for more than two centuries as we've labored to form our more perfect union. But tragically, for too many Americans, the blessings of liberty have been limited or even denied. The Civil Rights Act of '64 took a bold step towards righting that wrong. But the stark fact remained that people with disabilities were still victims of segregation and discrimination, and this was intolerable. Today's legislation brings us closer to that day when no Americans will ever again be deprived of their basic guarantee of life, liberty, and the pursuit of happiness.
>
> This act does something important for American business…You've called for new sources of workers. Well many of our fellow citizens with disabilities are unemployed. They want to work, and they can work, and this is a tremendous pool of people. And remember this is a tremendous pool of people who will bring to jobs diversity, loyalty and proven low turnover rate, and only one request: the chance to prove themselves. And

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[171] Internal Revenue Service Data Book, 2013, Publication 55B, 4 table 2, Washington, D.C. (Mar. 2014), available at http://www.irs.gov/pub/irs-soi/13databk.pdf (last visited Feb. 10, 2015). This report shows that there were 240 million tax returns filed in the United States in 2013. Based on this data, the cost per tax return to fund the proposed LTSS program would be $125.

> when you add together Federal, State, local and private funds, it costs almost $200 billion annually to support Americans with disabilities – in effect, to keep them dependent. Well, when given the opportunity to be independent, they will move proudly into the economic mainstream of American life, and that's what this legislation is all about.
>
> Our problems are large, but our unified heart is larger. Our challenges are great, but our will is greater. And in our America, the most generous, optimistic nation on the face of the Earth, we must not and will not rest until every man and woman with a dream has the means to achieve it.
> And today, America welcomes into the mainstream of life all of our fellow citizens with disabilities. We embrace you for your abilities and for your disabilities, for our similarities and indeed for our differences, for your past courage and your future dreams. Last year, we celebrated a victory of international freedom. Even the strongest person couldn't scale the Berlin Wall to gain the elusive promise of independence that lay just beyond. And so, together we rejoiced when that barrier fell.
>
> And now I sign legislation which takes a sledgehammer to another wall, one which has for too many generations separated Americans with disabilities from the freedom they could glimpse, but not grasp. Once again, we rejoice as this barrier falls for claiming together we will not accept, we will not excuse, we will not tolerate discrimination in America. [172]

Whether this new federal LTSS Program is funded by a new tax or by correctly prioritizing it ahead of other less urgent programs, the time is right to initiate the program now and the federal government must move beyond the mode of constantly studying the problem and focus on actually implementing a very viable solution.

IV. CONCLUSION

While in its entirety the problem of how to provide LTSS for all Americans who need them is daunting and seemingly unsolvable, the Federal government must takes steps now to solve the problem for a small subset of the people who need LTSS – significantly disabled people who are able to work, support themselves and live independent lives. The AAPD Proposed Pilot Program is an innovative and workable solution for the working aged disabled and the Federal government must implement this program to allow those Americans the rights promised to them by the ADA. By determining that a single solution for LTSS funding is not required, it may finally be possible to implement a solution for at least this one small group. The real question is not can we afford to do this but rather can we afford not to?

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[172] Remarks of President Bush at the Signing of the Americans with Disabilities Act, Jul. 26, 1990, available at http://www.eeoc.gov/eeoc/history/35th/videos/ada_signing_text.html (last visited Jan. 17, 2015). The ADA is considered to be the Emancipation Proclamation for the disabled community. *Id.*