For all of the questions below, please see The Arc’s website pages entitled: [Funding for Federal Disability-Related Programs](http://www.thearc.org/what-we-do/public-policy/funding) and [Public Policy and Legal Advocacy: Know Your Rights](http://www.thearc.org/what-we-do/public-policy/know-your-rights). These pages provides an overview of funding sources for social protection programs for persons with disabilities in the United States as well as key laws affecting individuals with disabilities in the U.S.

1. **Please provide information in relation to the existence of legislation and policies concerning mainstream and/or specific social protection programmes with regard to persons with disabilities, including:**
   1. **Institutional framework in charge of its implementation;**
   2. **Legislative, administrative, judiciary and/or other measures aiming to ensure access of persons with disabilities to mainstream social protection programmes (e.g., poverty reduction, social insurance, health care, public work, housing);**
   3. **Creation of disability-specific programmes (such as disability pensions, mobility grants or others);**
   4. **Fiscal adjustments or other similar measures.**

**Social Security and Supplemental Security Income**

For information on Social Security, see:

[U.S. House of Representatives Green Book: Background Material and Data on the Programs within the Jurisdiction of the Committee on Ways and Means - Chapter 1: Social Security](http://greenbook.waysandmeans.house.gov/2014-green-book/chapter-1-social-security).

For information on Supplemental Security Income, see:

[U.S. House of Representatives Green Book: Background Material and Data on the Programs within the Jurisdiction of the Committee on Ways and Means - Chapter 3: Supplemental Security Income](http://greenbook.waysandmeans.house.gov/2014-green-book/chapter-3-supplemental-security-income).

**Health Care**

There are many approaches taken to ensure access to health care for all Americans including:

* Medicaid is a federal/state partnership to provide health insurance coverage for low income Americans including children and adults with disabilities. States have flexibility about who is served and what services they provide. Medicaid also provides comprehensive benefits to children through the Early and Periodic Screening, Diagnosis and Treatment coverage requirements. For more information, see: [Medicaid: Individuals with Disabilities](http://medicaid.gov/medicaid-chip-program-information/by-population/people-with-disabilities/individuals-with-disabilities.html).
* Medicare is a federally administered health insurance program that provides insurance to approximately 8 million younger adults with disabilities. For more information, see: [Medicare: I Have a Disability](http://www.medicare.gov/people-like-me/disability/disability.html).
* The Affordable Care Act has numerous provisions important to people with disabilities including expanding access to affordable private health insurance, expanding long term supports and services options, health insurance reform to remove discriminatory health insurance practices, penalizing large employers (under limited circumstances) who do not provide affordable health insurance to their workers. For more information, see: [www.healthcare.gov](http://www.healthcare.gov)

Inaccessible facilities and services remain a problem when accessing health care services. The ACA included provisions to promote the physical accessibility of medical diagnostic equipment and the federal Access Board is working on standards. The work of [The Access Board](The%20Access%20Board) is applicable in other areas beside health care. The issue of medical providers not being properly reimbursed for taking the extra time that it might require to provide health care services to some individuals with I/DD is not addressed.

**Medicaid Health Services**

Amendments to the Social Security Act in 1965 created Medicaid through Title XIX. <http://medicaid.gov/>. Each state has the authority to determine the type, amount, duration, and scope of services through its state Medicaid program (Centers for Medicare and Medicaid Services, 2007). Federal Medicaid law, however, mandates that certain service categories are covered.

Mandatory health care services to be covered are: physician services; laboratory and x-ray services; in/outpatient hospital services; early and Periodic Screening, Diagnosis, and Treatment (EPSDT) for individuals <21; family planning services and supplies; health center services; rural health clinic services; nurse midwife services; vaccinations for children; certified pediatric and family nurse practitioner services. Optional health care services are: medical or remedial care provided by state licensed practitioners; prescription drugs; diagnostic, screening, preventative, and rehabilitative services; primary care case management services; dental services; physical therapy and related services; prosthetics and eyeglasses; TB related services; transportation services; and targeted case management services.

**Medicaid Long Term Supports and Services (LTSS)**

Mandatory LTSS are: Skilled Nursing facility (SNF) services for people >21 and home health care services for those entitled to nursing facility services. Optional LTSS are: Inpatient hospital and NF services for individuals 65+ in an Institute for Mental Disease (IMD); ICF/ID services; inpatient psychiatric hospital services for individuals 21+; home health care; case management; respiratory Care services for ventilator-dependent; personal care services; private duty nursing; hospice; services under Program of All-Inclusive Care for the Elderly (PACE); and HCBS Waiver.

**HCBS Waiver Program**[[1]](#footnote-1)

Congress authorized the Home and Community Based Services (HCBS) Waiver in 1981 as an alternative to the ICF/ID program (Braddock et al., 2005). Under the HCBS Waiver, three main provisions of the Social Security Act were ‘waived,’ thus allowing services to be delivered in community-based settings (DHHS, 2000). The three waived provisions are: 1) ‘statewideness,’ requiring the program to be offered state-wide and therefore allowing states to target waiver programs in particular areas; 2) comparability of services, which requires availability of services for all Medicaid eligible persons therefore allowing states to make waiver services available to those at risk of being institutionalized; and 3) income and resource rules allowing states to provide Medicaid services to those who would otherwise be eligible for an institutional setting (Centers for Medicare and Medicaid Services, 2008).

Services covered under the HCBS Waiver include: case management (i.e., service coordination), personal assistance (i.e., homemaker, home health aide, and personal care attendant), adult day health services, habilitation (both day and residential), and respite care. Additionally, states can propose "other" types of services that may assist in maintaining individuals in their community homes and rather than divert them to institutional settings (CMS, 2014). For inclusion in the HCBS waiver program, the state must assure the following: 1) waiver services cost less, on average, than institutional care; 2) protection of the health and welfare of individuals served; 3) standards meet the needs of the population served; and 4) services are provided in accordance with a plan of care (Centers for Medicare and Medicaid Services, 2008). While the Centers for Medicare and Medicaid Services (CMS) is the federal agency responsible for Medicaid oversight, HCBS Waivers are administered by the state in which they are housed, and thus allow states flexibility in the management of them. The Secretary of the U.S. Department of Health and Human Services has the legal authority to waive these Medicaid requirements and approve state waiver program applications (Crowley & Elias, 2003).

Each state is required by federal law to designate a single state Medicaid agency to provide oversight of its Medicaid activities (Kaiser Commission on Medicaid and the Uninsured, 2013). That single state Medicaid agency has the option of overseeing Medicaid programs itself, and/or entering into agreements with other state agencies to administer specific services. Participating states must submit an application for approval of each waiver program to CMS and renew as required (CMS, 2008). There is no limit on the number of waiver programs or services provided by a state, and states have the choice of the number of individuals they intend to serve in their HCBS Waivers. As such, state Medicaid programs vary greatly from state to state.

The provision of the HCBS Waiver allows states to provide persons with disabilities the option of receiving community-integrated services rather than segregated institutional care. The number of Waiver programs available as well as the scope of and spending on such programs indicate a trend toward provision of services in the community. In fact, since the early 1980’s, amendments to federal laws and policies have been chipping away at Medicaid’s institutional bias and making way for funding options for home and community based long-term care alternatives. The HCBS Waiver “…has been an essential part of community services expansion in the states…” (Braddock et al., 2005, p. 28). Incorporation of the federal match under the Medicaid program has allowed states to offer an array of Medicaid funded community-based services to individuals with IDD who would otherwise require institutional admission to skilled nursing, intermediate, or ICF/ID facilities.

The Secretary of the U.S. Department of Health and Human Services has the legal authority to waive these Medicaid requirements and approve state waiver program applications (Crowley & Elias, 2003). Participating states must submit an application for approval of each waiver program to CMS and renew as required (CMS, 2008a). As of 1999, HCBS Waiver programs were available in every state (DHHS, 2000a), however, not all states choose to finance all waiver options (Braddock et al., 2005). HCBS Waiver expenditures surpassed that of the ICF/MR program in 2001 (Braddock et al., 2005).

System Rebalancing

Since peaking in 1967 (U.S. Department of Health, Education, and Welfare, 1972) census reduction of institutions has occurred at an average rate of 5% nation-wide annually, resulting in the closure or in process closure of 168 public institutions in 42 states. There were still, however, 84,433 individuals living in institutional settings in the U.S. in 2011 (Braddock et al., 2013). Much of the rebalancing completed in the U.S. has been the result of advocacy, class action litigation, including *Olmstead* cases, waiting list cases, and access to Medicaid benefits cases (Braddock et al., 2013).

Litigation

The Olmstead Decision of 1999 was issued by the United States Supreme Court (Olmstead v. L.C., 1999) in response to a lawsuit brought by Lois Curtis and Elaine Wilson in 1995 (Bazelon Center for Mental Health Law, 2009). Both women had a dual diagnosis (developmental disability and mental illness) and were voluntarily admitted to Georgia Regional Hospital’s psychiatric unit (Olmstead, 1999). After receiving clearance from treating professionals, neither woman was granted their desired community placement (Bazelon, 2009). The court rejected the state’s claim of inadequate funding for community placement and ruled this was a violation of the women’s rights under Title II of the Americans with Disabilities Act (ADA) of 1990 (Olmstead, 1999). Title II states, “A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities” [28 CFR § 35.130(d)]. Olmstead found states are to comply with Title II of the ADA in order to avoid discriminatory practices of institutionalization when community-based alternatives would be an appropriate setting (Ng, Wong, & Harrington, 2012).

*Olmstead* has had a significant impact on litigation related to institutionalization. As of May of 2013, Ng, Wong, and Harrington (2013) reported a total of 193 *Olmstead*-related cases in all but five states (Iowa, Idaho, North Dakota, South Dakota, and Vermont) and the District of Columbia. Despite the number of lawsuits, progress on moving people from segregated institutions into community based living situations has been slow. The Civil Rights Division of the U.S. Department of Justice (DOJ) has the authority to enforce Title II of the ADA (National Disability Rights Network, 2009). On June 22, 2010, then Assistant Attorney General Thomas E. Perez testified before the Senate Committee on Health, Education, Labor and Pensions on the role of the DOJ in relation to Title II of the ADA and the *Olmstead* decision. He stated that the Disability Rights Section of the Civil Rights Division of the DOJ had made the enforcement of *Olmstead* a “top priority.” This reprioritization signaled what Assistant Attorney General Perez called a “paradigm shift” from previous work done primarily under the authority of Civil Rights of Institutionalized Persons Act of 1997 (CRIPA). Under CRIPA authority, the DOJ primarily focuses on the safety of institutions and the protection of Constitutional rights of the persons living in them. Under the renewed focus of *Olmstead* enforcement, the DOJ will be questioning the appropriateness of institutional as compared to community-based settings (DOJ, 2010). In fact, Assistant Attorney General Perez stated that “… the *Olmstead* decision makes it clear that states have an obligation to provide services to individuals with disabilities in the most integrated setting appropriate to their needs” and that the DOJ is “…committed to aggressive enforcement of *Olmstead*” (DOJ, 2010).

Policy

Money Follows the Person (MFP) was first authorized by the Deficit Reduction Act of 2005 with the intent to provide states with assistance in balancing long term services and supports (LTSS) spending with HCBS waiver spending by assisting Medicaid recipients with the transition to communities from institutions (CMS, 2014). Federal MFP funds were not to exceed $1.75 billion through fiscal year 2011, however were extended through the Patient Protection and Affordable Care Act of 2010. The extension included $2.25 billion from fiscal year 2012 through 2016. As of December 2012, nearly 30,000 individuals (15% with IDD in 2012) were enrolled in MFP and had received assistance to transition to a community placement from an institutional setting (Mathematica Policy Research, 2013). MFP is significant in that it acknowledges the institutional bias of Medicaid and allows for money that was intended to be spent on institutional services to ‘follow’ the person into a community-based option. In addition, it allows for assistance with the costs associated with an individual’s transition to a community-based setting.

The American Recovery and Reinvestment Act of 2009 (ARRA), signed into law in February of 2009, provided an economic stimulus including a temporary increase in state FMAPs to provide relief from increased medical expenditures during the recessionary period (Association of University Centers on Disabilities, 2010a). The FMAP increase was retroactively effective October 1, 2008 and intended to last for nine quarters, ending December 31, 2010. In August of 2010, due to the continued economic recession, however, the FMAP increase was extended an additional six months through June of 2011 (AUCD, 2010a). The increased FMAP extension was critical to Medicaid service provision, particularly during the Great Recession, as Medicaid utilization has an inverse relationship with the economy. The Great Recession, which occurred in 2007-2009, saw an increase in unemployment and an increase in Medicaid beneficiaries coupled by a decrease in state revenues (Holahan & Chen, 2011) which created a gap between revenues and spending (Kaiser Commission on Medicaid and the Uninsured, 2011).

The Patient Protection and Affordable Care Act of 2010, which was signed into law on March 23, 2010 by President Obama, contains provisions which will provide individuals with disabilities opportunities for community-based living (AUCD, 2010b). One provision in particular, the Community First Choice Option (CFC), should have a significant impact on people with IDD. The CFC is available to states as a waiver option, however, participation in the program requires that home and community-based attendant services and supports are made available to all eligible individuals for assistance with activities of daily living. In addition, states participating in this option are not allowed to cap the number of people served or maintain waiting lists for services. All eligible persons, those individuals that would otherwise require an institutional level of care and meet income requirements, must receive benefits under this option should they require them. States are not mandated to provide this option, however, an additional 6% will be added to the FMAP of states that have an approved plan (AUCD, 2010b; Caldwell, 2010). As of 2013, eight states were offering this option (Kaiser Family Foundation, 2014).

The CFC is significant for people with IDD in that it allows states greater flexibility in their Medicaid Waiver programs (Caldwell, 2010) and provides a more comprehensive home and community-based program (AUCD, 2010b). It is also expected that the CFC will support *Olmstead* implementation by offering services in the least restrictive setting appropriate to an individual’s needs. Finally, due to the restriction on waiting lists and limits on the numbers of individuals served, it is hoped that more people with IDD will be removed from waiting lists and receive the services necessary to lead to a fulfilling and integrated life in the community.

[End quote.]

**Housing**

For information on housing programs, see:

[National Council on Disability: The State of Housing in America in the 21st Century: A Disability Perspective](http://www.ncd.gov/publications/2010/Jan192010).

1. **Please provide information on how persons with disabilities are consulted and actively involved in the design, implementation and monitoring of social protection programmes.**

Through the involvement of non-governmental organizations in the political process, like The Arc, through appointment to committees and commissions like the Presidents’ Committee for People with Intellectual Disabilities, and through family members of people with disabilities who work in the federal government.

1. **Please provide information in relation to difficulties and good practices on the design, implementation and monitoring of mainstream and/or specific social protection programmes with regard to persons with disabilities, including:**
   1. **Conditions of accessibility and the provision of reasonable accommodation;**
   2. **Consideration of the specific needs of persons with disabilities within the services and/or benefits of existing programmes;**
   3. **Difficulties experienced by persons with disabilities and their families in fulfilling requirements and/or conditions for accessing social protection programmes;**
   4. **Consideration to age, gender and race or ethnic-based differences and possible barriers;**
   5. **Conflicts between the requirements and/or benefits of existing programmes, and the exercise by persons with disabilities of rights such as the enjoyment of legal capacity, living independently and being included in the community, or work;**
   6. **Allocation of grants to personal budgets;**
   7. **Disability-sensitive training and awareness-raising for civil servants and/or external partners;**
   8. **Existence of complaint or appeal mechanisms.**

**Social Security and Supplemental Security Income**

For information on Social Security and Supplemental Security Income, see:

[Consortium for Citizens with Disabilities: Fact Sheets on Social Security and Supplemental Security Income (SSI)](http://www.c-c-d.org/rubriques.php?rub=factsheet.php)

**Housing:**

For information on housing programs, see:

[National Council on Disability: The State of Housing in America in the 21st Century: A Disability Perspective](http://www.ncd.gov/publications/2010/Jan192010)

[U.S. Department of Housing and Urban Development: Annual Report on Fair Housing](http://portal.hud.gov/hudportal/documents/huddoc?id=2012-13annreport.pdf)

1. **Please provide any information or data available, disaggregated by impairment, sex, age or ethnic origin if possible, in relation to:**
   1. **Coverage of social protection programmes by persons with disabilities;**
   2. **Rates of poverty among persons with disabilities;**
   3. **Additional costs or expenses related to disability.**

**Employment**[[2]](#footnote-2)

Workforce exclusion of people with disabilities continues to be a significant issue today. Yamaki and Fujiura (2002) conducted a national study of the employment and income status of adults with I/DD receiving community based services. They reported a 27.6% employment rate among persons with I/DD as compared to 75.1% of the general population. Despite the intentions of the Americans with Disabilities Act (1990) to reduce barriers to employment of persons with disabilities (Nibert, 1995), the advances in technology and the export of manual labor jobs overseas have resulted in even fewer opportunities for people with IDD to join the labor force. Due to these high levels of unemployment, people with IDD are disproportionately reliant on publicly financed health insurance (Hill, Livermore, & Houtenville, 2003), like Medicaid, which provide them with supports and services necessary to their well-being. Medicaid, however, due to income limits for eligibility, requires that people are in poverty in order to qualify. This presents a Catch-22 in which a person must be in poverty to receive necessary services, but due to income caps for eligibility, is unable to work due to making too much money and disqualifying themselves from the services they need. Participation in the Medicaid program precludes participation in the market economy, or at least limits it significantly.

Frequently, individual insurance policies for persons with sub-optimal health are expensive and/or unavailable due to pre-existing conditions, for example (Hill, Livermore, & Houtenville, 2003). Should an individual be able to afford and obtain private health insurance coverage, it typically does not meet all of his/her disability related needs (Crowley & Elias, 2003). It is for these reasons that a large number of persons with I/DD rely on publicly financed health insurance, such as Medicaid, to meet their healthcare needs (Hill, Livermore, & Houtenville, 2003). As such, publicly financed health insurance bears the responsibility of managing health issues for Americans with disabilities no other sector of the health care system address (U.S. Public Health Service, 2001; Weil, 2003).

[End quote.]

**Social Security and Supplemental Security Income**

For information on Social Security and Supplemental Security Income, see:

[Social Security Administration: Characteristics of Noninstitutionalized DI and SSI Program Participants](http://www.ssa.gov/policy/docs/rsnotes/rsn2014-02.html).

**Housing**

For information on housing programs, see:

[National Council on Disability: The State of Housing in America in the 21st Century: A Disability Perspective](http://www.ncd.gov/publications/2010/Jan192010)

[Technical Assistance Collaborative: Priced Out](http://www.tacinc.org/knowledge-resources/priced-out-findings/)

[U.S. Department of Housing and Urban Development: Worst Case Housing Needs: 2015 Report to Congress](http://www.huduser.org/portal/publications/affhsg/wc_HsgNeeds15.html)

[University of Minnesota: In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities](https://risp.umn.edu/)

**Rates of Poverty**

For information on rates of poverty among individuals with disabilities, see: [U.S. Census Bureau: How Disability Data are Collected](https://www.census.gov/people/disability/methodology/).

1. **Please provide information in relation to the eligibility criteria used for accessing mainstream and/or specific social protection programmes with regard to persons with disabilities, including: Definition of disability and disability assessments used for eligibility determination;**
   1. **Consistency of the eligibility criteria among different social protection programmes;**
   2. **Use of income and/or poverty thresholds;**
   3. **Consideration of disability-related extra costs in means-tested thresholds.**

**Housing**

For information on housing programs, see:

[National Council on Disability: The State of Housing in America in the 21st Century: A Disability Perspective](http://www.ncd.gov/publications/2010/Jan192010)

**Social Security and Supplemental Security Income**

For information on Social Security, see:

[U.S. House of Representatives Green Book: Background Material and Data on the Programs within the Jurisdiction of the Committee on Ways and Means - Chapter 1: Social Security](http://greenbook.waysandmeans.house.gov/2014-green-book/chapter-1-social-security)

For information on Supplemental Security Income, see:

[U.S. House of Representatives Green Book: Background Material and Data on the Programs within the Jurisdiction of the Committee on Ways and Means - Chapter 3: Supplemental Security Income](http://greenbook.waysandmeans.house.gov/2014-green-book/chapter-3-supplemental-security-income)

**Medicaid**[[3]](#footnote-3)

Eligibility for Medicaid falls into two broad categories based on a mixture of financial and group membership standards. As a federal condition of participation in the Medicaid program, three basic groups of low-income Americans are covered: those 65 and older, those with disabilities, and children and some parents based on varying financial criteria (Crowley & Elias, 2003). The financial criteria for parents and children are: 1) pregnant women with an income under 133% of the Federal Poverty Level (FPL); 2) children under six with a family income below 133% of the FPL and children ages six to eight with a family income below 100% of the FPL for a family of four; and 3) parents with income and resources below the Aid to Families with Dependent Children standards (Crowley & Elias, 2003). Additional requirements for persons with disabilities include residence in a nursing home, or eligibility for nursing home services, as well as limited income and resources (Centers for Medicare and Medicaid Services, 2005). Eligibility requirements may vary from state to state.

[End quote.]

1. The following paragraphs are excerpts from: Lulinski, A. (2014). *Community Capacity to Provide Mental/Behavioral Health Services to People with Developmental Disabilities*. Unpublished dissertation. Chicago, IL: University of Illinois at Chicago. [↑](#footnote-ref-1)
2. The following paragraphs are excerpts from: Lulinski, *Community Capacity to Provide Mental/Behavioral Health Services to People with Developmental Disabilities*. *Ibid*. [↑](#footnote-ref-2)
3. The following paragraph is excerpted from: Lulinski, *Community Capacity to Provide Mental/Behavioral Health Services to People with Developmental Disabilities*. *Ibid*. [↑](#footnote-ref-3)