MEDICAID HOME AND COMMUNITY BASED SERVICES (HCBS) WAIVERS

Medicaid HCBS Waivers pay for services and supports necessary for eligible individuals with I/DD to live in the community and avoid institutional care. State appropriations, supplemented with federal Medicaid dollars, fund these waivers. The federal government’s Centers for Medicare and Medicaid Services (CMS) permit each state to create waivers that fund specific services.

What is a Medicaid Waiver?
Medicaid Waivers help provide services to individuals who would otherwise be in a nursing home or hospital so that they can receive long-term care in the community. Although there are waivers for many conditions, the focus for this document is towards waivers for individuals who have intellectual disabilities, developmental disabilities, and autism spectrum disorders (ASD).

The waiting period to get onto a waiver program can be many years, and varies by state. Unfortunately, waiver eligibility does not transfer from state to state. This is a huge problem for families who wish to move to another state. It also unfairly distributes the federally matched dollars among states because each state determines its own budget.

There are still individuals living in state institutions today, and it has been questioned as to whether states violate the Americans with Disabilities Act (ADA) when they limit the number of participants to home and community-based waiver programs. However, states chose to participate in these waiver programs. An individual’s best hope is to get statutes changed at the federal level, and The Arc of the United States, together with the state chapters like The Arc of Connecticut, continue to advocate for these policy changes.

The 1915(c) waiver is known as the “home and community-based services waiver” (HCBS) because it allows states to treat certain Medicaid populations in the home or other community-based settings rather than in institutional or long-term care facilities, such as hospitals or nursing homes.

Approximately 44 states and the District of Columbia have received waivers to provide home and community-based services to individuals with developmental disabilities. Depending on each state’s I/DD definition, these waivers may cover services to people with autism spectrum disorders. In Connecticut, the definition excludes individuals with IQ’s 70 or higher, so an autism-specific waiver had to be created separate of the I/DD waivers.

Connecticut’s Individual and Family Support Waiver (IFS) and The Comprehensive Support Waiver assist individuals with developmental disabilities. Both waivers further set specific dollar limits of services and supports that can be offered based on an individual’s assessed level of support need. Also, the CT Home and Community Supports Waiver for Persons with Autism was approved on 12/31/2012.

There is a set number of slots for the IFS Waiver of 3,115 individuals. The Comprehensive Support Waiver has been approved for a total of 5,117 individuals. CT Home and Community Supports Waiver for Persons with Autism has 136 slots (www.cms.gov, kkf.org).

For more information, visit the DDS Waiver Page at www.ct.gov/dds/cwp/view.asp?q=332294.
What services are provided through the waivers?

In Connecticut, DDS waiver services are used in combination with other Medicaid and generic services to provide a level of support that enables individuals to remain in the community and meet their health and safety needs. The following lists the variety of services offered in Connecticut for each DDS waiver (www.cms.gov, www.kff.org).

### Comprehensive Support Waiver:
- ** Licensed Residential Services  
  - Community Living Arrangements (CLA)  
  - Community Training Homes (CCH)  
  - Assisted Living
- **Residential and Family Support Services**  
  - Continuous Residential Services (CRS)  
  - Shared Living  
  - Individualized Home Supports (IHS)  
  - Personal Support  
  - Adult Companion  
  - Respite  
  - Live in Caregiver  
  - Personal Emergency & Response Systems (PERS)  
  - Environmental and Vehicle Modifications
- **Vocational and Day Services**  
  - Adult Day  
  - Individual & Group Supported Employment  
  - Group Day Supports  
  - Prevocational  
  - Individualized Day  
  - Senior Supports
- **Specialized and Support Services**  
  - Healthcare Coordination  
  - Behavior Consultation  
  - Nutritional Consultation  
  - Specialized Medical Equipment & Supplies  
  - Interpreters  
  - Transportation  
  - Individual Goods & Services  
  - Independent Support Broker  
  - Parenting Support  
  - Assistive Technology  
  - Peer Support  
  - Training & Counseling for unpaid caregivers

### Individual and Family Support Waiver:
- ** Licensed Residential Services  
  - Community Living Arrangements (CLA)
- **Residential and Family Support Services**  
  - Continuous Residential Services (CRS)  
  - Shared Living  
  - Individualized Home Supports (IHS)  
  - Live-in Companion (same as live-in caregiver)  
  - Personal Support  
  - Adult Companion  
  - Respite  
  - Personal Emergency & Response Systems (PERS)  
  - Environmental and Vehicle Modifications
- **Vocational and Day Services**  
  - Adult Day Health: Individual and Group Supported Employment  
  - Group Day Supports  
  - Prevocational Services  
  - Individualized Day  
  - Senior Supports
- **Specialized and Support Services**  
  - Health Care Coordination  
  - Behavior Support Services  
  - Nutritional Consultation  
  - Specialized Equipment & Supplies  
  - Interpreter  
  - Transportation  
  - Individually Directed Goods & Services  
  - Independent Support Broker  
  - Parenting Support  
  - Assistive Technology  
  - Peer Support  
  - Training & Counseling for Unpaid Caregivers
Employment and Day Support Waiver:

- **Family Support Services**
  - Respite

- **Vocational and Day Services**
  - Adult Day Health
  - Individual & Group Supported Employment
  - Community-Based Day Support Options
  - Individualized Day

- **Specialized and Support Services**
  - Behavior Support Services
  - Specialized Medical Equipment & Supplies
  - Interpreters
  - Transportation
  - Independent Support Broker
  - Individual Goods & Services Assistive Technology
  - Peer Support

What DDS waiver service delivery options do individuals have?

Depending on the DDS waiver, individuals will have different service delivery options. How much service and support they are eligible for is decided based on their Level of Need Assessment and the budget allocation the individual is awarded.

- **Qualified Enrolled Vendors.** Many agencies across the state are enrolled with DDS to offer waiver services. Each region has a listing of all those agencies and can help individuals with arranging services. Individuals have the choice of using any agency on the list that offers the service(s) they want.

- **Agency with Choice.** Some agencies will work with individuals to let them decide who is hired to work with them, how much to pay, and provide help to supervise and train their staff, but the agency will be the employer of their staff.

- **Self-directed.** Individuals can choose to directly hire the staff who work with them and be the employer themselves. If they do this, those individuals decide who to hire, who to fire, how much to pay, schedules, benefits, and job duties. Self-directing services requires that individuals use a Fiscal Intermediary to handle the transfer of funds, payroll, tax filing, and reporting duties. They also might need a DDS Broker, or they can hire their own Family and Individual Consultation and Support person to help them manage their staff and individual budget.

Don’t pamper them because they have a disability. We think we are protecting them but we are not. We need to teach them what they need to know to be on their own.
Each waiver has specific eligibility requirements for the finite number of beneficiaries to be served with the state’s appropriated funding. Some waivers are available for pre-determined, renewable periods while others are ongoing in their duration. The intent of a waiver is to prevent the need for placement in an institutional setting, or to support an individual who is re-entering the community after a period of institutionalization. Medicaid regulations require that an individual can be enrolled in only one waiver program. An individual may, however, be enrolled in one waiver while on a waiting list for another.

MEDICAID IS A SOCIAL HEALTH CARE PROGRAM FOR FAMILIES AND INDIVIDUALS WITH LOW INCOME AND LIMITED RESOURCES

It is jointly funded by the state and federal governments and managed by the states. Medicaid is a key entitlement that will provide both physical health care and supports to individuals of low income living with disabilities, including I/DD. Eligibility for Medicaid can be determined through several sources. Perhaps most common is through Social Security’s Supplemental Security Income (SSI) program, which provides cash and Medicaid benefits to eligible seniors and individuals with disabilities. Community Medicaid and the Disabled Adult Child Social Security benefit (DAC) also provide Medicaid options.

For more information on Social Security, go to www.ssa.gov. Medicaid also funds state plan benefits and long-term care.

The Centers for Medicaid and Medicare Services (CMS) issued an information bulletin (June 2015) regarding Coverage of Housing-Related Activities and Services for Individuals with Disabilities. While Medicaid cannot be used to fund rent or utilities, the bulletin does describe some flexible options including one-time only needs such as security deposits and furniture purchase, as well as transition services to assist individuals with housing stability.

THE CONNECTICUT DEPARTMENT OF DEVELOPMENTAL SERVICES (DDS)

The Connecticut Department of Developmental Services is a state department in the executive branch of the Connecticut General Assembly, headed by a Commissioner appointed by the Governor. Connecticut is one of the last states in the country that utilizes outdated eligibility criteria—requiring an IQ of 69 or lower—in order to allow an individual to be eligible for services. DDS chooses to operate both public and private facilities while the national trend is moving away from this dual service system.

According to the DDS Management Information Report as of June 2016, DDS supports 16,724 individuals statewide residing in family homes, independently, in state-operated facilities, in licensed community training homes, and in over 830 licensed/certified community living arrangements. Since 1987, most services and supports provided by DDS have been subject to federal reimbursement under Home and Community Based Waivers (Medicaid) which are approved by the Center for Medicaid and Medicare Services (CMS).

As of FY13 there were 39,585 people with I/DD living with family caregivers. Of these caregivers and estimated 10,645 are over 60 and an estimated 13,886 were between the age of 41-59 (Braddock et al., 2014, State of the States). As of June 2016, DDS placed 1,784 people on the DDS Residential Waiting and Planning lists and approximately 100 people on the Day and Employment Waiting list.

DDS has no plan for this growing crisis, not to mention the crisis in the Autism Spectrum Disorder community. The Arc Connecticut will continue to advocate for increased resources to invest in future supports and services.

Autism Gap

Individuals with autism spectrum disorder with IQ’s of 70 and over are not served by DDS and yet they face the same services and housing challenges as individuals with I/DD. There is a small waiver program that serves people with IQ’s of 70 and over which has been moved to the Department of Social Services. For more information, visit www.ct.gov/dds/cwp/view.asp?q=442840.

WHO IS ELIGIBLE TO APPLY FOR DDS SERVICES?

In order to be eligible for supports or services from the Department of Developmental Services (DDS), an individual must be a resident of the State of Connecticut and have an intellectual disability as defined in Connecticut state law or have a medical diagnosis of Prader-Willi Syndrome (PWS), which is a neurobehavioral genetic disorder that must be diagnosed by a physician.

What is an intellectual disability?

An intellectual disability is defined under state law as a significant limitation in intellectual functioning and existing concurrently with deficits in adaptive behavior that originated during the developmental period before eighteen years of age. Intellectual disability was formerly referred to as mental retardation in Connecticut Statutes and many psychological and clinical evaluations.

To be regarded as having an intellectual disability, an individual must have a valid Full Scale IQ score of 69 or below as indicated on intelligence/cognitive tests, and significant limitations in adaptive functioning, that began during the developmental period from before the age of 18. Visit www.ct.gov/dds/cwp/view.asp?q=382310 to review the Intellectual Disability Eligibility Fact Sheet.
SUPPLEMENTAL SECURITY INCOME (SSI)

SSI is a federal program that provides monthly cash payments to eligible children and adults in need. In Connecticut, individuals who are determined eligible for SSI are also eligible for Medicaid.

If Medicaid is required to obtain services, how does someone apply for these benefits?

To receive Medicaid funded waiver services, an individual must be eligible and maintain eligibility for Medicaid benefits. For more information about applying for Social Security and Medicaid, go to www.connect.ct.gov/access/jsp/access/Home.jsp, under Apply for Benefits.

How does someone apply for DDS eligibility in Connecticut?

To begin the process, an individual can visit the DDS website at www.ct.gov/dds/cwp/view.asp?a=2039&q=533014 and click on an application form or view an eligibility video. Individuals without internet access can call 1-866-433-8192.

Necessary documentation includes information about the individual's functional abilities, Social Security card, proof of residency eligibility, and diagnosis of a disability. In addition, DDS will request written permission to obtain school records, psychological test reports, and medical records that assist in determining eligibility. Once all of the necessary information is assembled, DDS will review and send a decision in writing about eligibility. Receiving services depends upon the availability of waiver funding and is not an entitlement. If denied eligibility, the decision can be appealed.

What is the process to appeal a decision, if denied eligibility?

If a decision of ineligibility is made, the reasons for this decision will be explained in the notification letter. Also included will be a form for individuals to submit to request a hearing on the finding of ineligibility. Individuals may submit this form within 60 days of receiving the eligibility determination. This is a one-time only opportunity to appeal.
INDIVIDUAL BUDGET
A sum of funding that may be allocated to an individual with I/DD based upon an assessment of his or her needs contingent on available funding.

FEE FOR SERVICE
The state is adopting a change in the way services are paid to providers. Rather than annual contracts from the state, providers bill Medicaid directly after services have been delivered to individuals. This is called fee-for-service.

CT LEVEL OF NEED ASSESSMENT TOOL
Level of Need Assessment Tool (LON) is the assessment tool used by the Connecticut Department of Developmental Disabilities to determine the level of support an individual with intellectual and developmental disabilities will require. States use these instruments to document an individual’s level of support needs to determine the individual budget to fund supports and promote fairness in the funding process. It is quite possibly the most important assessment individuals with I/DD and their families will undergo as adults in the DDS system. The assessment determines the commensurate funding that may be available for supports and services. Inconsistency among reporters’ descriptions of an individual’s abilities can affect the accuracy of the assessment, allocating less funding than deserved for the individual’s abilities. The assessment should ONLY be completed by those who know the individual well. Ideally the assessment should be done collaboratively involving the individual, the family, and other professionals that know the individual. LON questions should be answered about the individual’s abilities—if no one were there to assist them, could they complete the task questioned.

For more information about the LON including the screening tool, the manual and the instructions, visit the DDS website www.ct.gov/dds/cwp/view.asp?q=394074.

Individuals can appeal the results of the LON if they disagree with the score. They also can have a family member reassessed if the level of need changes for any reason. The appeal process starts with an individual’s case manager. If an individual is just entering the system and has not yet been assigned a case manager, the appeal process starts with the DDS Help Line.

North Region Help Line: 1-877-437-4577
email: dds.nr.ifshelpline@ct.gov
South Region Help Line: 1-877-437-4567
email: dds.sr.ifshelpline@ct.gov
West Region Help Line: 1-877-491-2720
email: dds.wr.ifshelpline@ct.gov
COMMUNITY FIRST CHOICE

The Community First Choice Program (CFC) comes from the Affordable Care Act (ACA) and is an amendment to the State Plan. It is administered by the Connecticut Department of Developmental Services (DSS). To qualify, an individual must be on Medicaid and be at risk of institutionalization without this service.

It enables qualified individuals to receive a maximum of $5,818 per month or $69,816 per year for services such as dressing and personal assistance or making meals. It requires that individuals with disabilities self-direct services. Under certain circumstances family members may be paid under CFC.

CFC is an entitlement. This means that funding availability is not subject to state budget constraints and must be given to all who qualify. When determining the amount of funding an individual may receive, all services provided from DDS will be deducted from the amount of funding for which the individual is qualified.

For more information or to apply for CFC visit ctmfp.com or call 211.

STATE PLAN SERVICES

What are the State Plan services in Connecticut? State Plan services are those services that the state supplies to its beneficiaries. Any Medicaid recipient who meets the specific eligibility criteria for a State Plan service is entitled to receive it. Such services may include dental services, various therapies, personal care assistance, etc. No waiting lists exist for State Plan services.

SELF-DIRECTED SERVICES

Self-directed services are those that an individual and/or their family can direct. To utilize the Community First Choice Medicaid option, an individual will need to self-direct services.

Self-direction allows an individual or family member to direct the services they receive by becoming the employer of the staff that provides supports to them. This option gives the individual the most control over their supports but also the most responsibility. They are able to choose their own staff and have control over who works with them, their schedules, and their routines. Under certain circumstances, when they are not a spouse, guardian, or have any legal liability for the individual, they may hire family members.

If an individual hires staff, they will be required to use a Fiscal Intermediary (FI). This service helps both the individual and DDS, in the case of Community First Choice, manage CFC budgets. It also helps individuals who hire their own staff to manage the financial responsibilities of being an employer.

DDS has been offering self-direction options to families for many years and has resources available to offer families exploring self-direction for CFC or for DDS services. Visit www.ct.gov/dds/cwp/view.asp?a=2050&q=391098.

Look for the following resources:

- HCBS guidebook
- An understanding to your hiring choices
- Making good choices about your DMR Supports & Services
- Rewarding work
**WHAT IS THE HCBS FINAL SETTINGS RULE AND WHY IS IT IMPORTANT TO FAMILIES AND INDIVIDUALS WITH I/DD?**

Medicaid is overwhelmingly the largest provider of health care and long term services and supports for individuals with disabilities. Currently, 57% of Medicaid’s long term care funding goes to institutional care. Individuals are entitled (guaranteed) to nursing facility care under Medicaid; however, individuals who want to receive their long term services and supports in community settings are not entitled to home and community based services (HCBS).

In January 2014 the centers for Medicaid and Medicare issued the “The Final Settings Rule” which addresses several sections of Medicaid law under which states may use federal Medicaid funds to pay for home and community-based services (HCBS). The rule supports enhanced quality in HCBS programs and adds protections for individuals receiving services. In addition, this rule reflects CMS’ intent to ensure that individuals receiving services and supports through Medicaid’s HCBS programs have full access to the benefits of community living and are able to receive services in the most integrated setting. Highlights of this final rule include:

- Provides implementing regulations for section 1915(i) State Plan HCBS, including new flexibilities enacted under the Affordable Care Act to offer expanded HCBS and to target services to specific populations
- Defines and describes the requirements for home and community-based settings appropriate for the provision of HCBS under section 1915(c) HCBS waivers, section 1915(i) State Plan HCBS and section 1915(k) (Community First Choice) authorities
- Defines person centered planning requirements across the section 1915(c) and 1915(i) HCBS authorities
- Provides states with the option to combine coverage for multiple target populations into one waiver under section 1915(c), to facilitate streamlined administration of HCBS waivers and to facilitate use of waiver design that focuses on functional needs
- Allows states to use a five-year renewal cycle to align concurrent waivers and state plan amendments that serve individuals eligible for both Medicaid and Medicare, such as 1915(b) and 1915(c)
- Provides CMS with additional compliance options beyond waiver termination for 1915(c) HCBS waiver programs

For more information on the HCBS Final Settings Rule:

- [www.aucd.org/docs/policy/HCBS%20Waiver/HCBS_Settings_Regulation_Issue_Brief.pdf](http://www.aucd.org/docs/policy/HCBS%20Waiver/HCBS_Settings_Regulation_Issue_Brief.pdf)
CMS FINAL SETTINGS RULE AND CT STATEWIDE TRANSITION PLAN

What does the CMS Final Settings Rule say about integration?
In January 2014, the Centers for Medicaid and Medicare Services (CMS) issued guidance to the states that administer Home and Community-Based Services (HCBS) Waivers. Funded community-based services must be provided in the most integrated settings appropriate to the needs of the individual. Settings that tend to isolate individuals from the broader community may not be eligible for federal funding, if they violate the ADA mandates. For more information, visit www.medicaid.gov/medicaid/hcbs/downloads/settings-that-isolate.pdf. The following are excluded settings for Medicaid Home and Community-Based Services:

- Nursing homes
- Intermediate Care Facilities (ICF)
- Institutes for Mental Diseases (IMD)
- Hospitals

According to CMS, large long-term care settings such as gated or secure communities, farmsteads, disability-specific or intentional communities, or residential schools might not be eligible for Medicaid funding. Even smaller group homes are subject to a higher level of scrutiny to demonstrate that individuals have autonomy as well as integration within these settings. The residents served in specialized housing must have opportunities to access the benefits of community living while living in the most integrated settings. Day habilitation programs must meet these requirements, as well. States must implement a transition plan indicating how such programs within the state will become compliant with these regulations.

Go to www.HCBSAdvocacy.org for state-specific information about this transition planning process.

CT Statewide Transition Plan (STP)
As of the printing of this guide, the Department of Developmental Services submitted its Statewide Transition Plan (STP) to comport with the CMS Final Rule Settings regarding Home and Community Based Settings (HCBS) and is awaiting approval.

What are some of the implications of the Final Settings Rule for CT housing?
The goal of the CMS Final Settings Rule is to give individuals more control over their living arrangements and to increase integration. All settings, existing and new, must comply with the HCBS Final Settings Rule.
EMPLOYMENT CAN BE AN IMPORTANT SOURCE OF FUNDING FOR HOUSING

In 2011, Connecticut became one of 32 states which has now formally adopted an Employment First policy. Employment First (EF) "[...]is the vision of making employment the first priority and preferred outcome of people with disabilities" (MN Employment First Coalition, 2007 p.4).

Employment is another important way to increase income and afford independent housing. We need to reconsider the concept of employable. Many adults with I/DD who were once deemed unemployable are now working.

The Employment First initiative requires state government to eliminate barriers or practices that prevent individuals with physical, developmental, and mental disabilities from being employed and is intended to increase the employment opportunities available to individuals with disabilities.

WORKFORCE INNOVATION AND OPPORTUNITY ACT

Under the Workforce Innovation and Opportunity Act (WIOA) signed by President Obama in 2016, programs for individuals with disabilities have been boosted. Four key provisions will impact individuals with disabilities:

1. Emphasis on competitive employment by providing career counseling services and information about alternatives to subminimum wage employment.
2. Expands access to pre-employment services including job exploration counseling, work-based learning experiences, counseling on post-secondary education programs, workplace readiness training and self-advocacy. States must use 15% of vocational rehabilitation services funding to support these services.
3. Strengthens transition-to-work for youth with disabilities by requiring states to coordinate pre-employment services with services provided by IDEA (see CEC’s FAQ on IDEA here).

EMPLOYMENT RESOURCES

- The Connecticut State Department of Developmental Services For more information about Employment First, visit www.ct.gov/dds/cwp/view.asp?q=492524.
- Centers for Independent Living offer advocacy, information and referral, peer support other services for people with all disabilities. Some Connecticut Centers offer prevocational training. For information about the center closest to you, visit www.cacil.net.
- Connecticut Business Leadership Network is a coalition of business committed to promoting employment opportunities for people with disabilities. In addition to training for employers CTBLN host career fairs targeting people with disabilities and other events. Visit ctbln.com.
- The LEAD Center is a collaborative of disability, workforce, and economic empowerment organizations dedicated to improving employment & economic advancement for people with disabilities. Visit employmentfirst.leadcenter.org/about.
Nancy Shute U.S. & World Report: Joe's Story

Joe's parents, Ray and Janet, of Louisburg, Kan., didn’t agree with the assessment of the school district in which they lived previously, which had said Joe would never be able to work or live independently. "I'm one who can easily get ticked off," says Ray. "That ticked me off. We saw more in Joe than that. We set out to prove to the school that he had capabilities." They came across kettle corn while on a trip to Alaska and realized that all that popping, scooping, and serving suited Joe’s love of work.

The path to Joe Steffy’s success was not an easy one; Ray Steffy worked closely with Dave Hammis, an advocate for self-employment for people with disabilities in Middletown, Ohio, who trains business owners, government employees, and parents on how to make use of state and federal programs. The Steffys wrote up a business plan and helped Joe secure $25,000 in grants from programs like Social Security Administration's Plan to Achieve Self-Support program (PASS).

In 2005, Poppin' Joe's Kettle Korn was born. Sales have grown from $16,000 in 2005 to $50,000 in 2008, both from selling at festivals and from delivering popcorn to local outlets. Joe has five part-time employees, and his parents help out with driving and other tasks. "Pop and everyone that works with him knows whatever Joe wants to do you let him do, because he’s the boss," Ray says. "If he wants to pop, he'll shove Dad out of the way and pop."

If the business stays on track, it should be grossing more than $100,000 in three years, and the Steffys are seeking a business partner who can work with Joe to manage the business. Joe is no longer on Social Security disability payments; instead, he pays state sales tax and state and federal income tax. He rents his own house and is helped by caregivers who are paid by a state program.

"It’s been hard work, from the standpoint of physical work," says Ray Steffy, who is 67. "But a parent with a child like Joe has a choice. You can either kick in and do this kind of thing, or you can sit and fret emotionally with the amount of energy, worrying about what’s going to happen to them."

The payoff for that effort, as far as the Steffys are concerned, has been priceless. They see their son make a local popcorn delivery, accept payment, fold it, and put it in his pocket. When he walks out, his dad says, Joe looks 3 inches taller than when he walked in.