


The Journey to Community Housing with Supports

A road map for individuals with intellectual and developmental disabilities and their families in Connecticut



This document is adapted from *The Journey to Community Housing with Supports: A road map for individuals and their families in New Jersey*, written by the Supportive Housing Association of New Jersey and Autism New Jersey.

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www.ct.gov/ctcdd

The Connecticut Council on Developmental Disabilities is a Governor-appointed volunteer Council comprised of twenty four members. Members of the Council include people with developmental disabilities, parents of children with developmental disabilities, representatives of non-profit organizations serving people with developmental disabilities, and state agencies serving this population. The Council promotes the full inclusion of people with disabilities in Connecticut through initiatives that promote systems change, advocacy, and capacity building.

www.shanj.org

The Supportive Housing Association of New Jersey (SHA) is a statewide, nonprofit membership organization, founded in 1998, whose mission is to promote and maintain a strong supportive housing industry in New Jersey serving people with special needs. SHA engages in education, advocacy and networking for and on behalf of its over 100 members.

www.autismnj.org

Autism New Jersey is a nonprofit agency committed to ensuring safe and fulfilling lives for individuals with autism, their families, and the professionals who support them. Through awareness, credible information, education, and public policy initiatives, Autism New Jersey leads the way to lifelong individualized services provided with skill and compassion. We recognize the autism community's many contributions to society and work to enhance their resilience, abilities, and quality of life.

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Dear Readers:

Welcome! *The Journey to Community Housing with Supports: A road map for individuals with intellectual and developmental disabilities and their families in Connecticut* was funded by the Connecticut Council on Developmental Disabilities and was adapted with permission from The New Jersey Council of Developmental Disabilities.

Connecticut does not offer a “road map” that details how individuals with intellectual and developmental disabilities and their families can navigate the complex service and support system, but we hope this document can serve as a place to start. This resource guide presents the obstacles associated with securing housing and supports separate of services while also highlighting available opportunities. Here you will discover what is or is not available now, what best practices are being considered here in Connecticut and throughout the country, and what we are calling “next practices”, which individuals and families could be practicing if given the opportunity.

This guide should be viewed as a journey toward establishing a home that enables you or your loved one to live as independently as possible. Written for the nonprofessional, the resource guide summarizes housing models through the experiences of individuals and families and offers suggestions for an individual's unique housing needs. There are many barriers to securing housing separated from services which necessitates creative thinking, planning, perseverance, and advocacy. While much of the information is specific to Connecticut and individuals with intellectual and developmental disabilities, the funding streams and opportunities described can benefit individuals with autism spectrum disorder and other disabilities. It could also benefit individuals with other housing needs as well as individuals from other states. The content also has value for providers, public officials, and advocates.

We are grateful to those who contributed to the development of this important resource. The Connecticut Council on Developmental Disabilities recognized the need for this guide, offered critical input, and generously provided grant funding for its development and dissemination; Project Director Melissa Marshall for her tireless attention to detail; Caresse Amenta at CLA design for making this document ready for publication; and Autism New Jersey and Supportive Housing Association of New Jersey who laid the ground work before us. Most importantly, thanks to the individuals and families who shared their personal journeys so that others could benefit from their experiences and who continue to inspire me every day to keep up the fight.

As part of your journey I encourage you to familiarize yourself with the many chapters of The Arc, the advocacy workshops and trainings The Arc offers, and to sign up for Arc Connecticut Advocacy E-Blasts to stay up to date on important issues facing individuals with I/DD and their families.

For more information, visit www.thearcct.org

This resource guide will continue to evolve in its content and presentation; therefore, I encourage you to contact us with feedback, recommendations, and additional ideas.

Good luck on your journey.

History of The Arc Movement

PARENT POWER

The Arc has a long, rich history of advocacy and is truly a parent-fueled civil rights movement. We continue today to carry out the mission and vision of people with intellectual and developmental disabilities (I/DD) and their families.

In the early 1950's, small groups of parents and other concerned individuals came together to act as voices for change. At the time, little was known about the condition of intellectual disability (at the time referred to as "mental retardation") or its causes. There were virtually no programs and activities in communities to assist in the development and care of children and adults with intellectual disability or to support families.

It was common at that time for doctors to tell parents that the best place for their child was in an institution. Emboldened by their collective desire to raise their children in the home and their stubborn refusal to accept that institutionalization was the only option, The Arc's founders fought even harder.

Like every parent of any child, they wanted more for their children. They wanted their children to lead fulfilling lives out in the community and not shuttered away in dark institutions. It was in that spirit that The Arc was born.

GROWING WITH THE TIMES

For over 60 years, The Arc Connecticut has grown and adapted to the changes that people with disabilities face across their life span. Through the decades,

The Arc has seen several name changes, advocated for the passage of state legislation on behalf of people with disabilities, assisted in the creation of and advocated for the private providers system of support, filed 4 class action lawsuits, advocated for the closure of institutions, and continued to advocate for individuals with I/DD and their families.

The Arc Connecticut is part of the oldest and largest charity federation in the nation that is dedicated to promoting and protecting the civil rights of people with I/DD and actively supporting their inclusion and participation in their communities.

PART OF A NATIONAL MOVEMENT

Nationwide, The Arc is the 8th largest charity federation in the U.S. with a total revenue of nearly \$4 billion dollars. There are 675 chapters in 49 states, with about 4,700 service locations. Across the country we have about 6,900 board members, 124,000 staff, more than 46,000 volunteers, and collectively we serve more than 1 million individuals with I/DD and their family members.

Here in Connecticut there are 17 chapters with total revenue of about \$103 million dollars, more than 195 board members, 3,729 staff, and 1,288 volunteers.

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Navigating the Systems

Systems of support for long-term care are changing. In the past, individuals' options were limited to placements in group homes or supervised apartments. While these residential settings continue to exist for those with more intensive support needs, options have and will continue to expand. Today, housing and services are being separated or "unbundled." Individuals with I/DD, working with individual budgets, select providers and direct the services that they choose. Increasingly, individuals with disabilities, by themselves or with supports, are controlling their own housing and services and living in more community-integrated settings. We call this independent housing.

There is a tremendous need for residential support, as well as housing that is affordable. It is likely that funding for these will come from multiple sources. We need to stop thinking of individuals with I/DD as people who need disability specific resources, and begin thinking of them as individuals who have low incomes and need resources. Given the limitations of government resources, individuals with disabilities need to access resources that are available to anyone with low income. These general resources, described in the guide, include such things as rental subsidies, food stamps, and utility assistance. Keep in mind that family income is not generally considered when determining eligibility for services for individuals who are over 18.

In most states, including Connecticut, there is no entitlement for services. States establish the number of individuals that they will serve based upon available state appropriations and available federal funding. Regulations define the means to access and maintain such benefits.

Independent housing requires that several factors be in place. There must be a readily available supply of affordable housing units. Funds, from several government sources, must be available to provide the individual with supports, based upon the person's level of need. The individual's personal income from social security and earnings pays for room and board, which may be supplemented by rental assistance or some form of housing subsidy.

Many housing models exist and some are described in this guide. Through person-centered planning, the individual designs where and with whom he/she wants to live. Working within the scope of an individual budget, it may be a challenge to use the available dollars to cover all of the expenses. The

individuals can select multiple providers or a single entity to address all of their needs. For some, technological advances can supplement assistance previously supplied by direct support personnel.

Note: *The authors did not vet the quality of service delivery in each of the models described. Most individual names and some details about their lives have been altered to protect their privacy. The authors made every effort to accurately and completely describe appropriate residential arrangements and services for individuals with a broad range of abilities and needs. We have strived to capture this range in the examples of models and description of individuals in their homes. The intensity of staff support can vary within each model.*

Multiple funding sources are also described. Each funding source has its own eligibility criteria and regulations. The systems of funding are in transition and corresponding regulations are changing. To obtain the most current information, check the internet links provided.

With an understanding of these requirements and some "out of the box" thinking, you can develop an individualized plan to fit within the funding structure. We hope that individuals use this guide to find models and elements of these models that may be a match for them or their loved one. We welcome feedback to improve future editions of this guide.

Sometimes traveling to a new place can be scary as well as enjoyable. We hope that this guide will help individuals and their families as they navigate the road to independent living and find their way.

Note: *This guide provides information best known at the time of publication. Much system change is in process and consequently regulations are changing. Refer to the websites for the most up-to-date information.*

A Brief History of Independent Housing

ALSO KNOWN AS SUPPORTIVE HOUSING IN OTHER STATES

For almost 40 years, residential services provided in the community have been the preferred residential option rather than living within institutional settings. The trends have increasingly supported smaller and more personalized settings while living as independently as possible with assistance. In 1999, the U.S. Supreme Court affirmed in the *Olmstead v. L.C.* decision that, under the Americans with Disabilities Act (ADA), people could not be required to live in institutional settings if a less restrictive alternative could meet their needs.



THE IMPACT OF THE 1999 OLMSTEAD SUPREME COURT DECISION

In a landmark interpretation of the Americans with Disabilities Act, the Supreme Court held that people with disabilities have a right to receive services in the most integrated setting appropriate. Unnecessary institutionalization violates the ADA. Every state is implementing plans to meet the mandate of the *Olmstead* decision. Individuals living in institutions who choose to leave are transitioning into community placements. Despite the *Olmstead* mandate, Connecticut still operates institutions for individuals with I/DD, including Southbury Training School and Regional Centers.



Innovative Housing Options

Housing models should be as unique as individuals. There is clearly no “one size fits all.” An individual’s dreams can be realized in various ways. The personally designed models depicted in this guide may or may not precisely meet an individual’s needs. The purpose of describing varied concepts in housing and supports is to inspire others to consider these ideas and redesign them to meet their own specific needs, desires, and circumstances. Connecticut is continuing on the journey to implement innovative models in housing and services. We need families and individuals with I/DD to work with The Arc Connecticut and like-minded organizations to advocate for systematic change and shifts in public policy to implement these new models.





YOUR DESTINATION: MANY ROADS CAN TAKE YOU THERE

Frequently used terminology

Independent (referred to as supportive in other states) **housing** is an approach to community living that is receiving much attention and implementation nationwide.

Group homes (known as Community Living Arrangements or CLAs) generally serve six or fewer individuals. The majority of the homes are receiving reimbursement through the Medicaid Waiver Program and are operated by public or private entities.

Agency-directed services is when the individual selects an agency that is responsible for supplying residential or vocational programs.

Self-directed services refer to services where individuals or family members hire and supervise staff.

In-home supports are delivered to the individual in their own home.

Continuous Residential Support (CRS) is a shared living arrangement for three or fewer individuals receiving DDS funding. It is not licensed as a CLA but can provide 24 hour staff support.

Community Companion Homes are licensed for up to three individuals to live in a family setting.

Shared Living is a residential option that facilitates the relationship between the individual with a Shared Living life sharer.

Integrated Housing refers to the opportunity to live in typical settings with opportunities to interact with individuals who do not have disabilities.

INDEPENDENT HOUSING MODELS

This guide provides an array of housing models and supports utilized by individuals with disabilities. Many of the models contain best practice elements of **independent housing**, a philosophy that calls for permanent, affordable housing for individuals with disabilities in communities of their choice. **Independent housing** advocates that everyone is entitled to a safe, decent place to live and should receive the services unique to their needs that will help them to live as independently and as self-sufficiently as possible. Housing should promote the development of relationships among individuals with and without disabilities.

There should also be a separation between the provision of housing and services. Individuals should be able to move and not lose their service provider. Similarly, an individual should be able to change his/her service provider and not be required to move. Also, the landlord should not be that individual's social worker. The individual has control of his/her housing through a landlord/tenant lease with the property owner. Skilled providers in various areas, including case management, care coordination, job coaching, crisis management, acquiring skills in daily living and much more, deliver these social services. The individual chooses the service provider to deliver supports flexibly and according to one's unique needs. Independent housing operates in a variety of settings, in different constellations and may include apartments, houses, townhouses, condominiums, shared housing as well as (more rarely) home ownership. Some independent housing exists in affordable housing complexes that are integrated with individuals without disabilities.

In Connecticut, funding for residential or day services provided by the Department of Developmental Services (DDS) is portable. Portability means that individuals have control over their supports and the money used to pay for the services they receive. Individuals can use their funds to purchase services from any qualified provider they choose, or they may use those funds to hire their own staff. Cost of services vary among providers.

For more information, visit www.ct.gov/dds/cwp/view.asp?q=382296.



INTEGRATED SUPPORTED HOUSING/REVERSE INTEGRATION

In this concept, the housing developer achieves integration by designating some of the rental units for individuals with disabilities and the majority of the units for those who do not have disabilities, or through reversing a congregate design by slowly integrating renters without disabilities into the complex.

Hope House Foundation and Hope House Residential Corporation: Integrated Supported Housing

“Hope House Foundation provides supported living services to adults with intellectual or developmental disabilities exclusively in their own homes or apartments—regardless of how complex their disabilities may be.” Hope House Foundation in Virginia converted all of their group homes and relocated everyone into apartments of their own. In some instances, individuals purchased condominiums or small homes of their own. Most tenants live in larger apartment complexes. Lynne Seagle, the executive director, believes that the 125 people that they support prefer living in their own place. “Having a roommate does not necessarily mean that a person is not lonely, especially if the person does not get to choose their roommate.” The essential ingredient of this organization involves “community connectors” or unpaid folks socializing with individuals who have disabilities. The agency assists the individual they are supporting to establish these relationships.

This organization found difficulty locating affordable housing in communities where people wanted to live. Not all property owners would accept rental assistance (vouchers). Hope House Foundation established Hope House Residential Corporation to develop housing and manage the properties. This corporation raises funds to purchase apartment complexes. They rent some of



After settling into his new home, Phil reports, “For the first time in my life, I have friends.”

the apartments to tenants with disabilities, but most of the people living there do not have disabilities. This ensures that everyone with supported services lives integrated lives within typical communities. The rental incomes received exceed the property owner’s expenses. These profits subsidize the living expenses of residents who need such assistance. Because the property owner and service provider are separate entities, the tenants can select a different service provider without having to move from their apartment. Conversely, they have the option to move to a different location and keep their supportive service provider. For more information, visit www.hope-house.org.



NATIONAL EXAMPLE: Individual-Directed Supports Model: Mary's Home

Mary lives in an affordable apartment complex in a barrier-free apartment. In this particular public housing complex, the residents must be 55 years of age or older. Mary financially qualifies for residency with income from Social Security. With a State Rental Assistance Program (SRAP) voucher, Mary contributes 30% of her income and the voucher subsidizes the balance of her fair market rent. With the remainder of her Social Security check, Mary pays for her food, utilities, clothes and recreation. She also is eligible for food stamps and energy assistance benefits that help to stretch her limited income.

A Medicaid waiver funds her supported services that consist mostly of staff supports. With the assistance of a Support Coordinator, Mary selected a provider agency. She interviewed and chose the direct support professionals referred by the agency. These workers provide needed services including physical assistance with transferring from her wheelchair, bathing, dressing, cooking, housekeeping, shopping, budgeting, taking her medications, and finding her way about town. Mary's staff supports her for several hours each day and are on-call in the event of an emergency.

Mary has her own one-bedroom apartment with a fully accessible bathroom, kitchen, dining area, and living room. She does not like to cook. She mostly uses the microwave. The local church delivers Meals on Wheels with a hot dinner, a sandwich and snacks each day. On Sunday mornings, Mary's neighbor drives her to church and then they go out for breakfast.

The county offers a transportation service to medical appointments, recreation, and shopping. A van from the complex also supplies transportation to the local shopping plaza twice a week. She enjoys swimming at the YMCA swimming pool, when she has free time. Mary attends the community Senior Center for recreation during the day. Within the apartment building, there is a fitness center, computers, and laundry. Some of the neighbors started a social club and asked Mary to join. This social group convenes twice a week to play cards or games in the community room. They also plan outings to the movies, shows, and community events.

When home alone, Mary wears a personal security system alert button. There is also an emergency call button in her bathroom. In the event of an emergency, Mary can access help quickly through these monitoring systems.

HOUSING SEPARATED FROM SUPPORTS

If an individual receives **SUPPORTIVE SERVICES FROM A PROVIDER AGENCY** and holds a lease from another entity, then that individual can change where he lives but keep his service provider. Conversely, that individual can change his service provider but continue to live in his home.

With **INDIVIDUAL-DIRECTED SUPPORTS**, individuals exercise more control to manage and direct the supports that they receive. They choose the desired services and who will provide them. Individuals who self-direct assume more responsibility for independently managing these services. Individuals select support to meet their needs, based upon a plan and individual budget. Most often, the individual has the ability to hire and discharge their direct support professionals. A fiscal intermediary manages the funds and may assume responsibility for paying salaries and administering benefits as the "employer of record."

SECTION 8 or FEDERAL HOUSING CHOICE VOUCHERS are government-subsidized programs that provide rental assistance. Typically, tenants pay 30% of their income towards the cost of the Fair Market Rent and the voucher supplements the difference. An annual certification of income is required to verify that the individual's annual income meets the threshold for rental assistance. Individuals obtain vouchers that are used to pay their rent (tenant-based rental assistance) while other vouchers are attached to the apartment unit (called project-based vouchers). Individuals can apply for rental assistance through local public housing authorities in cities, towns, or state offices. For more information, visit portal.hud.gov/hudportal/HUD?src=/states/connecticut.

Be aware that there is a significant wait time even to get on the waiting list. Families who may be interested should apply as early as possible. For information on Housing Choice Vouchers and the waiting list, visit www.cthcvp.org.

FAIR MARKET RATE (FMR) is the published rental rate established by the U.S. Department of Housing and Urban Development (HUD) and used for determining the monthly rent charged in an affordable housing unit. For more information, visit www.huduser.org/portal/datasets/fmr.html

In **SUPERVISED APARTMENTS** an individual lives alone or with a roommate in an apartment with staff available either on or off the premises for up to 24 hours a day.

Supervised Apartments within a Housing Complex: Gary's Home

With funds from the Low-Income Housing Tax Credit Program, a housing developer constructed 64 apartments. Within this building, four apartments adjoin with interior doors between the four living units. The state inspects and licenses each apartment as a community residence. Recently, Gary has been coping with medical issues related to his advancing age and cerebral palsy. His health is fragile and he needs staff present with him throughout the day and night. His individual budget from the waiver was not sufficient to fund all these staffing hours. Sharing the staff supports with his three friends has made this affordable. Gary loves having his own apartment with a kitchen, living room, bedroom, and bath. When he feels like it, Gary socializes with his three housemates watching movies or cooking meals together. Direct support professionals are available during the day and one staff overnight. The staff move freely between the four apartments attending to each person as needed.

Gary enjoys all of the amenities of living within a garden apartment complex, including having friends and neighbors who do not have disabilities. By sharing the expenses with three other people, Gary can live more independently and afford the services that he requires.

SMART HOMES + TECHNOLOGY

Depending upon the level of need, an individual may prefer receiving services on demand in the event of a medical need or emergency. Remote monitoring can identify when staff intervention is needed. In the event of an emergency, sensors identify a problem so that staff can respond to the need. This technology can be programmed so that the individual does not have to ask for help. Technology can support individuals with I/DD in living independently while reducing support costs.



Many low to high technological devices are readily available to assist individuals to live more independently. These assistive devices can break down barriers that deter individuals from living on their own. Simple apps on a smart phone possess unlimited possibilities for controlling the environment. Pre-programmed devices can automatically provide schedule information and prompts. Simple machines alert and dispense medications at designated intervals. If a dose is missed, these systems contact a designated individual by telephone to follow up. Monitors signal an alert when someone falls, has a seizure, is in the bathroom too long, or the front door opens. Emergency call buttons, computers or video cameras provide communication in the event of an urgent situation. Programs operate environmental controls such as lights or thermostats from computers or cell phones. Sensors detect when a stove is unattended and automatically shut it off. There are endless technological solutions that can be incorporated into a home to overcome barriers, reduce reliance upon personal aides, increase independence, and keep individuals safe.

Many simple assistive devices are purchased inexpensively. Systems that are more complex may be costly. If medically necessary, some items are paid by medical insurance. Technology that promotes independence may be funded through the Community First Choice Program. For those who are eligible, see page 35.

The Faison Residence in Richmond, Virginia, is an inclusive community of 45 apartments with 30% of the units designated for individuals with disabilities. Affiliated with The Faison Center for Excellence, the residence incorporated smart home technology into the construction to benefit all of the occupants. For more information, visit www.faisonresidence.net. At the renter's request, remote monitoring by staff is available. Homelink Technologies consulted on the state of the art design.

Night Owl Support Systems is utilized to maximize independent living for people with disabilities in Wisconsin and nationally. For more information, please visit nossllc.com.

Best Practices:

Technology supporting people with I/DD living independently in Connecticut

1

Abe, a man with intellectual disabilities in his 30's living in an apartment building, was having great difficulty managing his doctor's appointments and his health.

The state requested that he move into a group home setting where there would be 24/7 staffing and an increased oversight to assist him with his medical needs. The group home he moved into was located in a small, rural community about an hour away from the city where he had lived and where the majority of his friends and family resided. He was dissatisfied with losing his independence by having to move into a group home and he viewed this transition as a personal failure.

While living in the group home, his health significantly improved. His blood sugar levels had stabilized and all of his medical appointments were attended; however, he struggled to adapt to living in a group setting. The location of the group home had limited public transportation access and nothing was within walking distance. He relied on staff for transportation and he did not get along with one of his housemates. He despised staff being present all the time and felt that people were controlling all aspects of his life. He was not always able to verbalize his dissatisfaction and would instead express himself through maladaptive behaviors such as verbal aggression and property destruction.

After he made his discontent known to the Arc of Meriden-Wallingford, they collaborated with Assisted Living Technologies to identify alternative living arrangements based on his needs and preferences. Quick and easy access to emergency medical

services and compliance with medications were vital areas of concern that needed to be addressed.

A 2 bedroom condominium was located in a city near his hometown, where he would be able to live by himself, yet it allowed for the ability for him to have a roommate if he wanted one later. The technology incorporated into the apartment included a Medication Med-Minder, a BeClose Emergency Monitoring and Response System with motion and door sensors throughout the apartment, a cook stop for the stove, and Skype capability via his television set.

The Med-Minder is filled by him once a week with his medications and it reminds him when it is time to take his medications by utilizing a series of visual and auditory alerts as well as telephoning him and identified support staff in the event he does not take his medication within the predetermined time frame.

Through the use of wireless sensors placed throughout the apartment, the BeClose Emergency Monitoring System tracks his routines and activities, and informs identified support staff when issues of concern arise. The system is fully programmable and can send out alerts to identified support staff via text message, e-mail, and/or phone calls for the observance of motion at specified time frames from as little as every 5 minutes up to 24 hours. Staff is alerted if his front door opened during the time frames identified by his team and if there was an absence of movement in the apartment for more than a 2 hour time period. His team is not concerned with whom he may be inviting into his apartment, just that anyone entering his apartment was someone who was invited by him.

This system also has an emergency response function whereby he can elicit emergency assistance by pushing an emergency button located in his bathroom or a button on a pendant that he wears. Once activated, trained medical personnel announce themselves over the speaker located in base unit and he can communicate his need. The Be Close system can contact an identified support staff, family member or 911.

The cook stop is a safety device that connects directly to the stove and will automatically turn the stove/oven off if motion is not sensed within the programmable time frame.

Skype allows him to communicate with his contacts that also have Skype capability. Staff Skypes with him before he administers injections. Using the video camera, he holds the injection pen up to the television screen so staff can ensure he had dialed up the correct dosage. If there was any need for correction, they verbalize this to him and ask him to re-check it.

The technology identified and put into place was a huge success after a short learning curve.

The next year, he expressed a desire to move to a new apartment downtown so that he could be closer to additional shops and establishments that he liked to frequent. Such a move allows him to be in closer proximity to the city's bus routes and stops. Assisted Living Technologies was able to transfer all of the technology. He moved into his new apartment seamlessly. With this move, he has learned to utilize public transportation, taking the bus daily to and from work and is learning how to go from the city he lives now to the nearby city he is from. He has also availed himself to the use of taxi cabs and Uber.

1

The upfront cost for the technology was \$1771.95 plus tax. Breakdown is as follows:

- Stove Stop \$429.95
- Medication Minder \$200.00
- BeClose System
base station \$345.00
- All sensors \$275.00
- Emergency button \$219.00
- Personal help button/
pendant \$63.00
- 4 hours of labor
for installation \$240.00

The cost per year for the monitoring of the equipment was \$2278.20.

(Med Minder is \$59.95 a month, Skype Device was \$39.95 a month and BeClose System is \$89.95 a month.)

2

Bob, a man in his 60's with intellectual disabilities, has lived in his family home with his mother his entire life. His mother had to move out of the home into an assisted living facility due to her declining health.

His mother has helped him in many aspects of his life because he has difficulty walking and requires assistance with dressing, bathing, and personal care. He has a sister, who lives out of state, and she travels frequently to and from Connecticut to help care for her brother.

DDS is unable to support him around the clock with one-to-one support and his sister doesn't want him to move into a group home. The family has worked diligently to fill the staffing gaps and another family member began staying at the home.

In 2015, this family member became a live-in companion and provides 40 hours per week of support. Additionally, he attends a day program 30 hours a week, and receives 24 hours a week of Home Health Aid services and some personal supports for recreational opportunities. With the majority of the hours covered, there are still times that he is left alone for varying lengths of time and this was of great concern to his family.

The Arc of Meriden-Wallingford assisted the family in identifying technology that could be implemented in the home. They worked with Mule Security Systems to provide the family with a door lock system and home automation panel with smart phone control, remote video monitoring of the interior of the home and for the exterior front entry, 2 wireless photoelectric smoke detectors and 2 wireless carbon monoxide detectors with off premise monitoring (also known as Life Safety System).

The door lock system was installed on the 3 exterior entry doors and allows for system and smart phone control of the door locks. His sister and any other designated family member can lock or unlock any of the exterior doors from any location using their smart phone. This device also has a history log of door lock activity that can be viewed at any time.

The video monitoring converts video footage to an IP address for off-site storage and viewing. This allows designated family members to remotely monitor the home in real time from any location utilizing their smart phone, tablet or computer. The wireless photoelectric smoke detectors use a light beam to detect the presence of smoke. The detector aims a light source into a sensing chamber at an angle away from the sensor. Smoke enters the chamber, reflecting light onto the light sensor; triggering the alarm. These alarm types are more effective at sounding when a fire originates from a smoldering source, as smoldering fires can fill a home with dangerous gases before a fire ever erupts.

The technology implemented has exceeded the family's expectations and has given them the peace of mind knowing that they can monitor him and his environment at any time.

2

The upfront cost for the technology was \$1700.00. This included the equipment, all labor & materials for installation.

The cost per year for the monitoring of the equipment is \$720.00. This covers central station monitoring of life safety and intrusion devices (smoke and CO2 detectors), cellular link between life safety system and Mule Security Systems central station, smart phone control of front door lock and life safety system, history log of door lock activity, Emails and/or text messages of activity and recorded clips of video activity up to 50MB recorded off site.

3

Carl, a man with intellectual disabilities in his twenties, had been living in a nursing home for about 18 months as a result of a medical issue which had been particularly difficult to manage.

After leaving the nursing home, he moved in with a friend/mentor. He was informed that he would no longer be able to reside in his current home due to life changes with his friend.

Don, also a man with intellectual disabilities in his twenties, had been diagnosed with a terminal disease at the age of 18. When he was unsuccessful living in a residential care home, he was placed in a nursing home. With the help of people at DDS and the Arc of Meriden Wallingford he was able to move out of the nursing home into his own home.

The two men met and decided that they would like to live together in an apartment. There were multiple issues of concern for both men. The provider needed

to ensure that they both were accessing food/eating meals and maintaining/gaining weight as this was a struggle for both. The potential for low blood sugar and being able to access emergency services quickly as well if one of them were to lose consciousness before accessing emergency assistance was another concern that needed to be addressed. For one man, there was concern that he would leave the apartment and become confused about where he was and not be able to find his way home or access support staff for assistance. Medication compliance in the absence of support staff for both was something that staff needed to monitor. Combined, both men had 61 hours a week of direct on-site staffing supports. This left 107 hours a week without direct staffing that needed to be replaced in some fashion. The provider collaborated with Assisted Living Technologies to discuss the needs and concerns, and the technology incorporated into their apartment included 2 electronic locking medication minders, a BeClose

Emergency Monitoring and Response System with motion and door sensors throughout the apartment and on the refrigerator, freezer and microwave, a cook stop for the stove, A GPS locator watch, 2 bed sensors and a digital camera focused on the front door which would take a picture each time the door opened.

Both men had an electronic locking medication minder and both received VNA services. The nurse was responsible for overseeing their medications, including ensuring that they were packing them into the medication minder each week. The medication minder would remind each of them when it was time to take their medications utilizing a series of visual and auditory alerts, as well as telephoning them, and alerting identified support staff in the event either of them did not take their medication within the pre-determined time-frame.

Through the use of wireless sensors placed throughout the apartment, the BeClose Emergency Monitoring System tracks both of their routines and activities and informs identified support staff when issues of concern arise, such as inactivity for a set period of time. The system is fully programmable and can send alerts to identified support staff via text message, e-mail, and/or phone, reporting observance of or absence of motion at specified time frames, from as little as every 5 minutes up to 24 hours. This system also has an emergency response function whereby they can elicit emergency assistance by pushing a panic button located in their bathroom, a pendant that they can keep on their person, or a button located on the base station of the Be Close system. Once activated, trained medical personnel announce themselves over the speaker located in the base unit of the system. The Be Close system can contact an identified support staff, family member, or 911.

Sensors were placed on the refrigerator, freezer, and microwave to alert support staff if these appliances had not been opened within a set amount of time. For these two men, it was set to send an alert out after 2 hours of inactivity to ensure that they were accessing and eating food on a regular basis. A GPS locator watch was obtained for one of the men should he go out on his own and become disoriented or lost.

Additionally, a perimeter field can be programmed so that if he were to leave the established perimeter field, an alert would be sent out to support staff. The cook stop is a safety device that connects directly to the stove and will automatically turn the stove/oven off if motion is not sensed within the programmable time frame. Bed sensors are used to track when either of them got out of bed. This information is used to determine if there was excessive disruption in sleep or excessive use of the

bathroom. Mats were placed between the mattress and box spring and send out an alert to support staff when body weight has been removed from the mattress. A digital camera focused on the front door was put in place for the man vulnerable to becoming disoriented. Whenever the front door opened, a picture would be taken of the individual entering or leaving the apartment. The purpose of this is that, if he were to leave the apartment and support staff are unable to get in contact with him after a predetermined amount of time, they would have a photo of him with the clothing he was last wearing, a time stamp of when he left the apartment, and whether he was leaving by himself.

The incorporation of the technology worked for both men and the support staff. The two men lived together utilizing the technology until one of them made the decision to find another apartment for himself and his girlfriend. He continues to utilize the BeClose Emergency Monitoring and Response System with motion and door sensors in his new apartment.

3

The upfront cost for the technology for both men was \$2672.90 plus tax. Breakdown is as follows:

- Stove Stop \$429.95
- Medication Minder \$200.00
- BeClose System
 - base station \$345.00
- All sensors \$275.00
- Emergency button \$219.00
- (2) Personal help button/
 - pendants \$63.00 each
- 2 Bed Sensor pads \$219.00 each
- GPS Watch \$399.95
- 4 hours of labor
 - for installation \$240.00

4

Elaine, a 42 year old woman with intellectual disabilities who recently separated from her husband, is raising her 3 year old child who also has disabilities. She separated from her husband 2 years ago and both are committed to raising their child.

Elaine lives in an apartment by herself and receives 30 hours a week of staffing support. At this time, she must have staff supports or family present when she is caring for her child. Her main focus is on developing and enhancing her parenting skills and organizing/scheduling her responsibilities in efforts to obtain unsupervised visits with her child. She has worked diligently over the past 2 years with a team of nurses and support staff to learn such tasks as G-tube feedings, medication administration, re-positioning, recognizing signs and symptoms regarding the child's diagnosed medical conditions, and intervening accordingly with the developed emergency procedures.

Since she moved out on her own she has relied on support staff, her family, and her ex-husband for transportation. Through a provider she has learned how to access public transportation. She has a smart phone and a GPS app was downloaded so that she can input her destination and get step-by-step directions if traveling by car, bus, or walking. This was a helpful tool on one particular occasion when she had transferred onto the wrong bus and ended up traveling several towns away. With the help of the GPS app and guidance from her support staff over the phone, she was able to navigate safely back home.

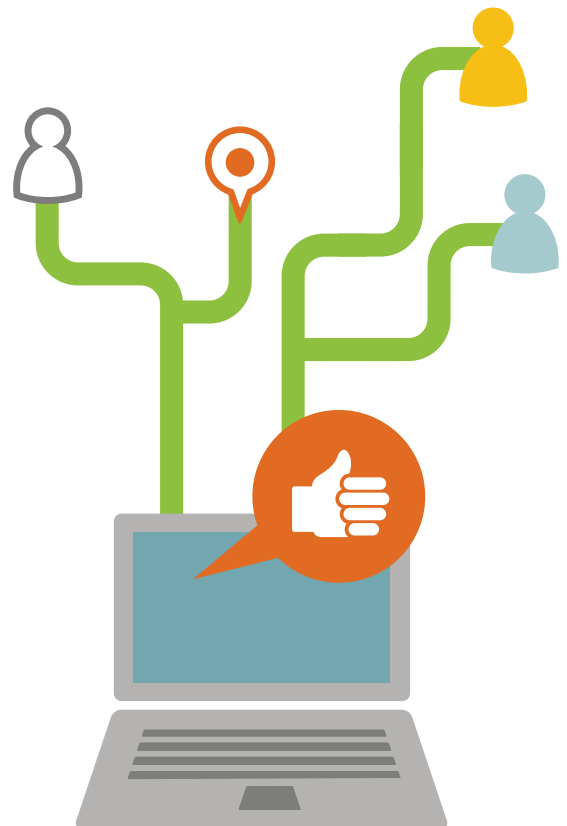
The Arc of Meriden-Wallingford has consulted with Assisted Living Technologies and identified a device that would both assist her with organization and connect to her support system quickly so that she can move closer to her goal of having unsupervised visits with her child. Claris Companion is a simplified tablet that is completely customizable. Unlike other communication devices, Claris Companion is always on so that reminders, messages, and notifications are displayed on time and alerts are always generated. The device is simplified so the home screen only has the icons and applications needed for the individual. Claris Companion was designed to accommodate many of the physical effects of aging (i.e., for individuals with visual disabilities, it displays information in large on-screen text).

4

The upfront cost for the technology will be \$180.00 for 3 hours of labor for activation, installation, customization and training.

The cost per year for the monitoring of the equipment will be \$1799.40.

(\$149.95 a month which includes 2 GBs of data per month, technical support, rental of the tablet and subscription to the application.)



CIRCLES OF SUPPORT

Circles of Support is a group of people chosen by an individual to help achieve valued outcomes. This group meets regularly and assists the individual in making decisions and taking charge of his/her own life.

NATIONAL EXAMPLE: Dan's Home

Dan enjoys structure and a consistent routine. Adjusting to change makes him uncomfortable. For many years, Dan lived in a group home with six other men with disabilities. Some of the behaviors of the other residents upset Dan. There were many disruptions including a continuous rotation of new staff members. Dan's parents dreamed of a better life for Dan. They researched an alternative arrangement for Dan called "shared living."

Dan and his family began meeting and planning with a Circle of Support which included his brother, family members and friends. They engaged a provider agency with experience in administering shared living to join the discussions. With the help of the agency, they found a compatible housemate. This person, Todd, receives hourly wages and a portion goes to his share of the rent for the home that he now shares with Dan. With his parents' assistance, Dan leased an apartment with two bedrooms and two bathrooms for himself and Todd. Todd assists Dan weekdays from 3pm-7am. Dan typically sleeps through the night but Todd is there if he needs help. Dan and Todd share some finances to purchase groceries, utilities and such. Todd helps Dan with his spending and medications. Weekdays from 7am-3pm, another staff person supports him. She assists while Dan volunteers at the local food pantry, attends the gym and enjoys a busy social life.

Two other people spend alternating weekends with Dan and sleep over, so Todd has most weekends free. Before any of the staff began working with Dan, each spent significant time with him at his family home getting to know his daily routine, likes and dislikes.

Dan's parents and sibling are very involved with Dan and his new lifestyle. Initially, they met as a Circle of Support every two weeks until everyone adjusted to the new living arrangements. Now meetings are once a month. Dan and his parents interviewed the potential housemate and staff to ensure that they were the right fit for Dan. The provider agency employs the staff but Dan hires and fires them.

Dan enjoys having four people who know him well caring for him. They understand his ways of communicating. They minimize disruptions and respond to changes in his moods. Dan's preferences are important to them. He likes not having to compete with anyone for his staff's attention. Dan keeps a lively social life that involves his housemates, family, and friends. They enjoy many activities together. Since Todd does not have family living close by, he spends holidays with Dan and his family. These two young men are becoming very close friends. It is hopeful that Todd will be a part of Dan's life for many years to come.





SHARED LIVING

This service is provided through DDS and may be self-directed or purchased from a qualified provider agency. Shared Living offers waiver participants the opportunity to invite a family or an individual (with whom they have an existing relationship or have developed a relationship) to share their lives. It is a residential option that facilitates the relationship between the participant with a Shared Living life sharer.

Shared living is about the relationship. Shared Living is an individually-tailored supportive service that was developed based on individual support needs. Ideally no more than two DDS participants live with a shared living provider. Shared Living requires the life sharer to live in the home and is not a rotating shift schedule. It is available to participants who need daily structure and supervision.

It includes supportive services that assist with the acquisition, retention, or improvement of skills related to living in the community.

Shared Living integrates the participant into the usual activities of family and community life.

The service should be provided in the participant's own home or the life sharer's residence.

The Shared Living residential support model cannot be used in combination with CLA, CCH, CRS, or live-in companion/caregiver.

For more information, visit www.ct.gov/dds/lib/dds/waiver/service_definition_shared_living.pdf.

To help you find roommates & staff

ROOMMATE MATCHING WEBSITE

In November 2016 The Arc Connecticut was pleased to launch a new roommate matching website for individuals with I/DD. This website is a safe, secure portal that is able to generate potential roommate matches. These matches are formulated from algorithms once individuals and family members have entered pertinent information into the website. We hope this new service will not only assist families in finding potential roommates, but will also generate networking and other valuable opportunities for families to share their experience, strength, and hope.

REWARDING WORK

Finding and hiring the right person to provide support to families and individuals with disabilities can be challenging. The Rewarding Work website provides the only comprehensive and current list of people in Connecticut who are ready to provide direct care in your home.

For individuals who receive services from the Connecticut Department of Developmental Services (DDS) and are considering hiring and managing their own support, they are eligible for a free long-term subscription. Contact a case manager or support broker for an access code and more information.

If individuals do not receive services from DDS, they may still access the list of Direct Support Professionals after they pay a small fee. The fee will allow them unlimited access to the names and information of all available care providers for a period as short as one month, or as long as one year.

www.rewardingwork.org/State-Resources/Connecticut

Housing Models & Practices

THROUGHOUT THIS DOCUMENT YOU WILL FIND NATIONAL EXAMPLES FOUND IN OTHER STATES. CONNECTICUT HAS NOT IMPLEMENTED ALL OF THESE PRACTICES, BUT FAMILIES AND ADVOCATES COULD RECOMMEND VARIATIONS OF THESE EXAMPLES AS NEXT PRACTICES.

Home Sharing Model: Tracy's Home

For seven years, Tracy has been living in her own home. She rents her house from her parents. Her mom and dad renovated a lovely ranch-style home just for her. Tracy's parents are responsible for maintenance, upkeep of the property, insurance and property taxes. Tracy's dad is a contractor so he knew how to handle all of the construction and repairs. The barrier-free design of the floor plan anticipated that Tracy was becoming less mobile and relying more upon using a wheelchair. Tracy lives in her hometown in the same neighborhood as her sisters and parents.

Prior to living in her own home, Tracy lived in a group home. Due to her increased medical care needs, her parents decided it would be best to purchase a home and have Tracy as the tenant. Her DDD support budget is now used to provide services to her in her own home. Her mom says, "All the stars and the planets were aligned for us." Mom's vision and determination were largely responsible for making this dream become a reality. Tracy's parents called upon key family members, a pro bono consultant, the executive director of the service provider agency, state workers and even the local senator for advice and support. It took two years of planning and negotiating, but their perseverance paid off.

Tracy, with her parents' assistance, selected a housemate to share this home. It took a few tries before the right match was made. For the past four years, her housemate, Stacy, has also been her best friend. They chose a service provider who had

experience supporting people who wanted to make their own decisions. This agency provides the staff to help these two women live as independently as they can. Tracy and Stacy, along with their parents and the provider agency, discuss any matters that arise that directly affect the ongoing care and happiness of these women. These decisions are always made in the best interest of Tracy and Stacy. Tracy is a person of few words. However, she is very capable of communicating what she likes or dislikes without conversation. Her parents serve as her spokesperson.

Tracy's mom says that this model and the way in which it operates may not be for everyone. Tracy's parents and sisters are very involved in her life. They oversee the supportive services that she is receiving and advocate on her behalf whenever needed. They help with support. Tracy's dad has the building expertise to maintain the property. Not everyone can do this, but some pieces of this type of self-determined housing may work for others just the same.

To ensure continuity, the family has made provisions for a succession plan. When Tracy's parents can no longer contribute their time and resources, Tracy's sisters have agreed to take charge. Legal documents have been prepared so that the home will continue to be a home for those with special housing needs, whenever Tracy no longer needs this home.



COMMUNITY COMPANION HOMES

When circumstances make it impractical for an adult with I/DD to live in their family home, living in a licensed Community Companion Home (CCH) can be an option. The CCH model offers a family setting to individuals with intellectual disabilities. Families of diverse cultures, backgrounds, and composition are sought for the best possible match.

CCH regulations provide the authority for homes to be licensed for up to three (3) individuals. However, to assure initial success, homes are initially licensed for only one individual. After a successful one year period with an individual living in the home, the region would consider requests for increased capacity based on strict guidelines to assure the best outcomes for individuals already living in the home. All regional recommendations for increases in capacity are reviewed and must be approved by Central Office Quality Management Services unit.

CCH licensees provide the individual with support and the ability to join with others in order to create and promote meaningful opportunities to fully participate as valued members of their communities. They also assist the individual in maintaining contact with people important in their lives and to ensure a safe environment. Licensed CCHs must meet strict standards set by the Department of Developmental Services.

For more information, visit www.ct.gov/dds/cwp/view.asp?a=3&q=527308.

Community Companion Home Model: Dennis' Home Next Practice

Before her passing, Dennis' mom made plans with her best friend, Mary, to look after Dennis. Dennis knew Mary and her husband well for many years. He now lives within their home and shares in all family activities. He participates in all the extended family holidays and events. A special needs trust left by his mom supplies money to support Dennis while preserving his eligibility for SSI benefits, Medicaid and other public entitlements. An agency provides supervision, training, and support so that Mary can best care for Dennis.

Parents often ask,
"What happens when
I can no longer care
for my adult child?"



"HOUSING FIRST" CONCEPT

The independent housing movement had its roots in addressing the needs of individuals with significant mental health conditions and chronically homeless individuals by recognizing lease-based housing and supportive services as separate, but of equal importance. An individual's basic needs must be met so that someone living in vulnerable circumstances can find stability while living in the community. The Housing First model was adopted for those who are chronically homeless. Implementation of the concept provides permanent housing as quickly as possible, rather than requiring individuals to successfully advance through various levels of care.

The continuation in housing is not contingent upon participation in rehabilitation. Service providers offer but do not require enrollment in services to assist the individual. Because individuals living without housing for many years have multiple challenges, they are often afraid of commitment and difficult to engage. The model does not restrict eligibility due to behavior challenges and allows individuals to move into housing regardless of active addictions and other behavioral impediments. Slowly over time, with the stability in their housing, these individuals are enrolled in a variety of behavioral and health care services that are rehabilitative and promote wellness.

Data compiled over the years has demonstrated the success of Housing First in various communities. Not only have a majority of chronically homeless adults become stable in their housing, states employing this model have saved significant public dollars formerly spent on emergency care, institutionalization, homeless shelters, and prisons. Food for thought: The I/DD community can learn from the mental health and other communities.



For additional information about Housing First, go to:

www.endhomelessness.org/pages/housing_first

www.csh.org/toolkit/supportive-housing-quality-toolkit/housing-and-property-management/housing-first-model



COLLEGE CAMPUS – LIVING IN THE DORMS

Some young adults with intellectual and developmental disabilities, mental illness, and other special needs are attending colleges and living on campus. According to research studies, adults with intellectual disabilities have the lowest rate of post-secondary education, career preparation, and employment of all other disability groups (Newman et al., 2011).

Opportunities exist for individuals with disabilities, including those with intellectual disabilities, to attend flexible college programs with supports. Peer mentors are available to assist students in their adjustment to college life. Readily available apps on smart phones and tablets can help a student to record lectures, dictate essays, take notes, complete assignments, and organize coursework. Colleges offer classes for credit and not-for-credit. Numerous colleges provide on-campus living experiences as well. Besides the educational benefits, the value of a college experience includes preparation for employment, inclusion with peers, and independent living experiences. Only 23% of students with I/DD, however, go on to post-secondary education (Grigal, Hart, & Migliore, 2011).

Most programs educate students between the ages of 18 and 25 during or after their graduation from high school. Fees for these educational studies vary. Students can apply for scholarships, grants, and work/study. In some instances, tuition can be waived for students of low-income. Funding for supports, including transportation, books, technology, and individual supports, might be supplied through Medicaid waiver services. In some instances, the Division of Vocational Rehabilitation may fund a college education. Similarly, a school district might approve postsecondary education through a teenager's educational entitlement.

For more information, visit www.thinkcollege.net.

Best Practice: College Campus Experience for Nicky

Nicky walked with her high school class for graduation but continued her educational entitlement in the local college. She lived on campus, learned, and adjusted to college life with supports. She made friends and enjoyed all the social and academic aspects of attending college. A fellow college student served as a mentor. Tutors helped with academics. She took courses in public speaking, drama, writing and math. In a drama class, Nicky role-played and learned how to interact in various interpersonal situations. Nicky used her smart phone to record classes so she could listen to them later and have someone assist her in taking notes. Tutoring was also available when course work was difficult. She dictated into her computer to write essays. Nicky enjoyed the experience of living away from home while attending classes in college.

Advocates in Connecticut are currently working to develop situations where adults with I/DD can live in college dorms while attending college in Connecticut.

For more information, visit [The Arc Connecticut at thearcct.org](http://TheArcConnecticut.org).

IN-HOME SUPPORTS

In-Home Supports means that a person with I/DD receives supportive services delivered within his or her own home or while living with family members. Services can include such things as personal care assistance, respite, and positive behavioral supports.

Living with Family and Receiving In-Home Supports Model: Nick's Home

Nick is young man who has Down syndrome and lives with his parents. Nick and his parents decided that it would be best for him to focus on developing his employment opportunities before he went out to live on his own. Nick plans to move out and live in his own apartment, perhaps with a roommate, as soon as he can afford it. For now, living with family is economical as he expands his potential for employment.

At age 28, Nick works between eight and sixteen hours each week as a clerk at a local supermarket. He started that job under his Individualized Education Program (IEP) during his transition program at his local school system before he reached the age of 21. When he finished school, the supermarket hired him.

During his school years, Nick was fully included in regular classes where he learned reading, writing and basic arithmetic. Most importantly, Nick learned the social skills that are essential for employment and community life. Nick was a manager on the high school baseball, football and hockey teams for which he earned seven varsity letters. He sang in the school chorus.

Nick receives Individualized Supported Employment (ISE) services from his state Department of Developmental Services. This support is funded through a state



It is not what you do
for your children,
but what you have
taught them to do for
themselves, that will
make them successful
human beings.



Medicaid Waiver and Nick's services are classified as Medicaid for the Employed Disabled (S05), which raises his income and asset limits to enable him to work and retain his benefits. He has been working since the age of 21, so Nick also receives SSDI and Medicare benefits.

Nick still needs some supports in his life. He is safe at home alone but he needs reminders for many activities and he needs assistance with his finances. Nick doesn't drive a car so he needs someone to drive him to work and social activities. He relies on family and friends for transportation because there are not public transportation routes to many of the places he goes. In a pinch he will take a taxi.

Nick's ISE staff help him to develop his income potential. Nick does not require 1:1 support at his supermarket job so his staff only occasionally observe him there and check in with his supervisor. Mostly they are helping Nick to pursue his dream of owning his own restaurant – beginning with a hot dog vendor cart. His staff helped him study to earn

his ServSafe Food Protection Manager Certification. They took him to meet with local restaurant owners and public officials. They helped him to create a business plan. They took him to apply for permits to operate in local towns. They helped him to raise money to purchase a food vendor cart and they are helping him to learn how to operate the cart.

Outside of work Nick enjoys karaoke, bowling and time with his nieces and his nephew. He plays video games, listens to music and uses a computer proficiently. Nick is also an active advocate for individuals who live with intellectual disabilities – attending meetings of self advocacy groups and frequently testifying to the state legislature.

Nick is preparing for a life on his own. He is developing an income that will provide for his own apartment with a roommate and, with some additional funding from the Community First Choice (CFC) program, he will be able to hire someone to help him with tasks at his home without his parents.

ACCESSORY APARTMENTS

Accessory Apartments are living units that are added or created within a single-family home. They are sometimes referred to as in-law apartments.

TINY HOUSE MOVEMENT: NEXT PRACTICE

The concept of tiny houses is growing nationally and internationally. As shown on HGTV and A&E Network's *Tiny House Nation*, individuals interested in a simpler lifestyle without financial burdens are downsizing. Small communities are being established internationally. **For more information, visit www.smallhousesociety.net.**

Such compact housing can be developed more cost effectively than traditional housing. The living space of 100 to 300 square feet is comparable to the size of a shed up to a single car garage. It can be built on wheels for portability. Similarly, small houses are between 400 and 1700 square feet.

In some instances, shipping containers have been re-purposed into small housing units. The durable material of these containers lends themselves to modular construction. These units interlock so more than one container can be connected into a larger living space. The internet supplies many creative interior and exterior designs for this cost effective re-purposing. **For more information, visit www.offgridworld.com.** This micro house idea is applicable for an individual seeking inexpensive housing.

Numerous floor plan designs are readily available on the internet. Construction is efficient and sustainable while being attentive to the environment by using natural, health conscious materials. Some units are self-sufficient using propane gas and holding tanks. Optional solar roof panels provide low cost energy. Local utilities' hookup connections can also be made when available.

Zoning ordinances may not specifically apply to small house dwellings and will have to be addressed on a local level.

Note: *Tiny homes are not for everyone. They are typically not accessible to or visitable by individuals who use wheelchairs.*

Accessory Apartment Model: William's Home

William lived with his parents but wanted more freedom. His family converted their two car garage into an efficiency apartment with a barrier-free bathroom for him. He obtains 30 hours per week of personal care attendant services from a state plan service called the Personal Preference Program to assist him with some activities of daily living like dressing and bathing. During the daytime hours, he has day habilitation services from the state service provider for people with I/DD. His family is steps away from him, if he needs additional help, especially during the overnight hours. On overnights and weekends, family and friends provide him with support.



PAST PRACTICE: HOUSING COOPERATIVES

During the 1990's a number of individuals with disabilities, including some with intellectual disabilities, lived in housing cooperatives developed by non-profit developers and the state of Connecticut. The co-ops still exist and individuals with disabilities remain there, though they are no longer developed or financed by the State. Co-ops of the '90's were inclusive—no more than 25% of families had members with disabilities and they were mixed income. Co-ops give individuals with disabilities the natural support that could come from living in a community. Families interested in co-ops will have to advocate to begin using that model again.



PERSON CENTERED PLANNING

In recent years, person centered planning has taken on a negative connotation for some individuals with I/DD, their families, and advocates. It has become conflated with bureaucratic solutions. We invite you to consider the original intent of person centered planning. This simply involves asking individuals where they want to live, how they want to spend their time, and who they want to spend it with. Person centered planning in housing means that individuals choose where they live, with whom they live, and who visits their home. Individuals with I/DD may have to compromise and set priorities as do individuals without disabilities. It is important to continue to evaluate the options that exist.

Someone can get lonely even with many people around them. They need to develop real friendships and become active members of their community.

Funding Sources



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

(DDS waiver services ... continued from p.29)

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.

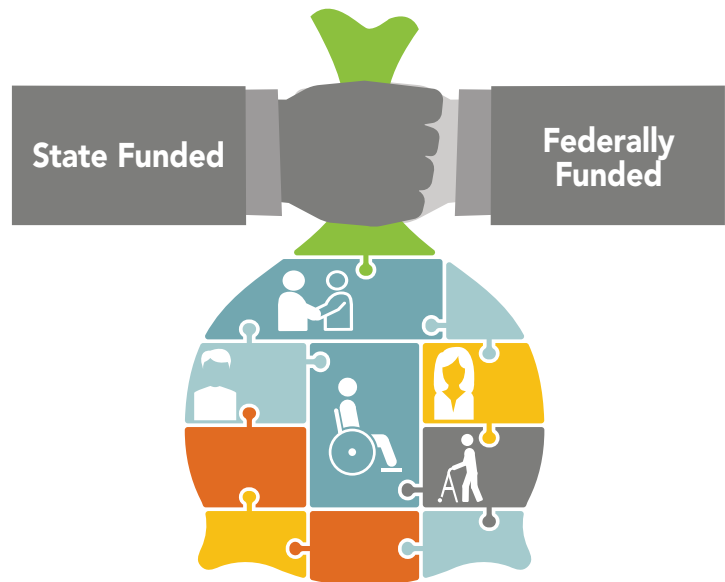
- **Qualified Enrolled Vendors.** Many agencies across the state are enrolled with DDS to offer waiver services. Each region has a listing of all those agencies and can help individuals with arranging services. Individuals have the choice of using any agency on the list that offers the service(s) they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

(DDS waiver service delivery options ... continued from p.30)

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.

It is so essential that your family member maintains eligibility for their Social Security and Medicaid benefits if they want to obtain state-funded services.



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.

For more information, visit www.medicaid.gov/federal-policy-guidance/downloads/cib-06-26-2015.pdf.

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

Build networks of support for yourself and your family member. You can learn so much from others. Many are willing to help if you invite them in.

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.

**IT IS WORTH THE EFFORT TO
APPEAL AN UNFAVORABLE DECISION.**

REMEMBER, THIS IS YOUR ONLY OPPORTUNITY TO APPEAL.

Individuals are encouraged to seek legal resources through the assistance of advocacy organizations or an attorney.



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

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.



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

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 (DDS). 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.

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:

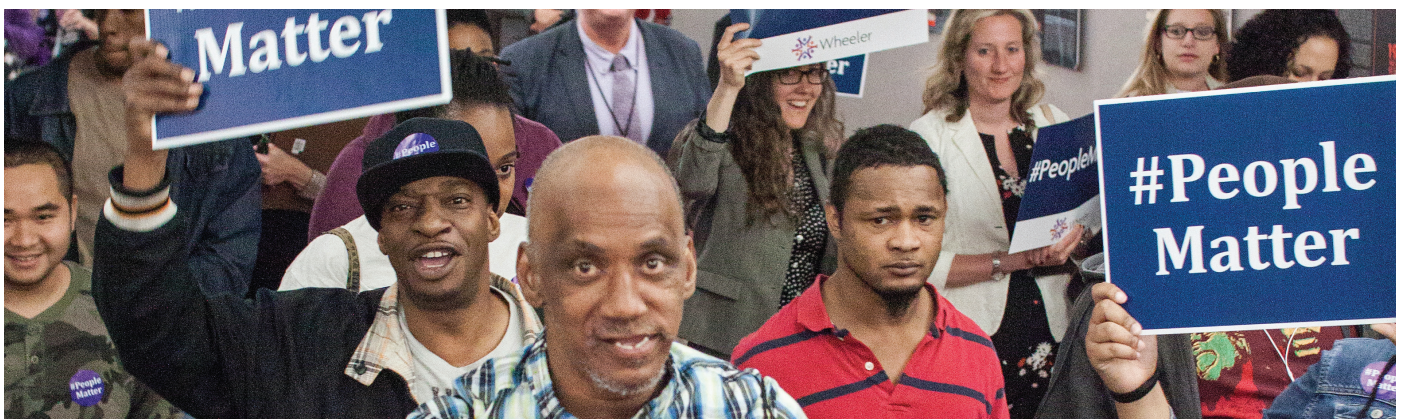
- Provides implementing regulations for section 1915(i) State Plan HCBS, including new flexibilities enacted under the Affordable Care Act to offer expanded HCBS and to target services to specific populations
- Defines and describes the requirements for home and community-based settings appropriate for 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/HCBS%20Settings%20Rules_What%20You%20Should%20Know!%20Final%201%202022%202016.pdf

www.aucd.org/docs/policy/HCBS%20Waiver/HCBS_Settings_Regulation_Issue_Brief.pdf



CMS FINAL SETTINGS RULE AND CT STATEWIDE TRANSITION PLAN

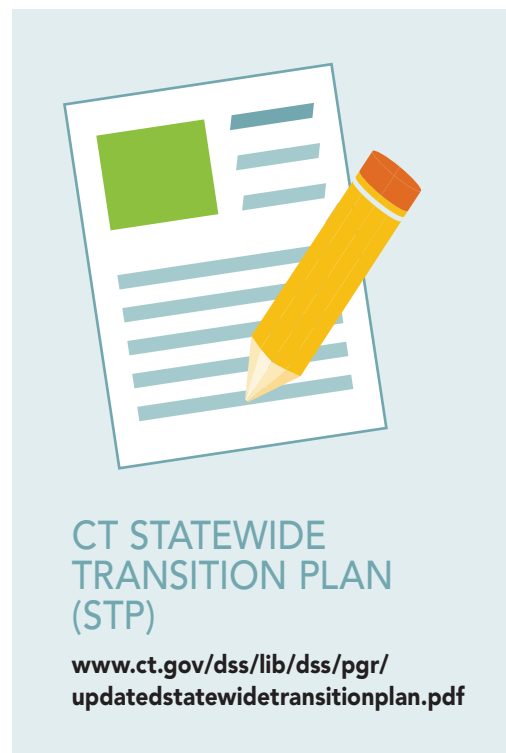
What does the CMS Final Settings Rule say about integration?

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).
- 4.** Bolsters disability services in some 3,000 one-stop career centers nationwide. **www.cpacinc.org/2014/07/workforce-innovation-and-opportunity-act-wioa**.

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**.

- **The State of Connecticut Department of Labor** posts information, events and resources for jobseekers with disabilities. Visit **www.ctdol.state.ct.us/gendocs/pwd-jobseekers.htm**.

- **The State of Connecticut Department of Rehabilitation Services** helps people with disabilities prepare for, find and keep jobs. Visit **www.ct.gov/dors/site/default.asp**.

- **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**.

- The Office of Disability Employment (ODEP) Integrated Employment, **www.dol.gov/odep/i toolkit/policymakers.htm**.

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.

health.usnews.com/health-news/family-health/brain-and-behavior/articles/2009/04/02/how-1-autistic-young-man-runs-a-business





Finding Housing that is Affordable

MANY ROADS CAN TAKE YOU THERE...

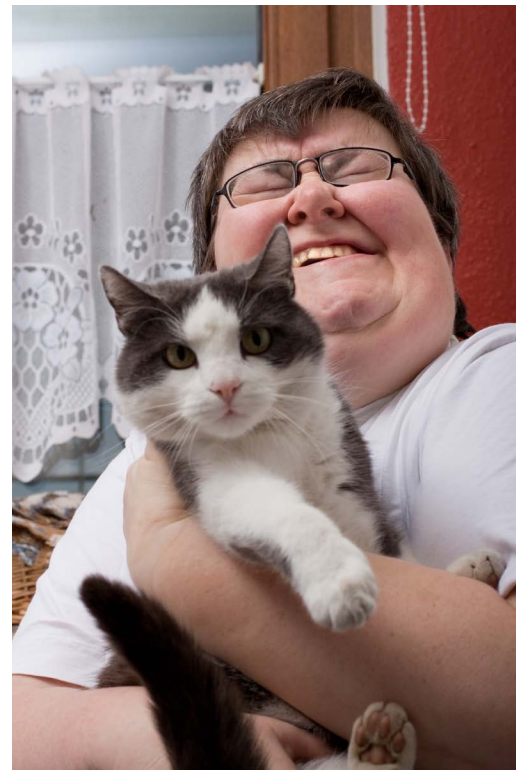
Affordable housing represents public and private sector efforts to assist individuals with low and moderate-income to lease or purchase housing. As a guide, individuals should not spend more than 30% of their income for housing. Affordable rental housing generally charges low cost rents at or below the HUD's published Fair Market Rents.

Fair Market Rent (FMR) is an amount determined by the U.S. Department of Housing and Urban Development (HUD) to be the cost of modest, non-luxury rental units in a specific market area. Generally, an "affordable" rent is considered to be at or below the Fair Market Rent.

Public housing refers to housing units constructed for individuals with disabilities, of low-income, and older adults. Generally, local public housing authorities administer these rental units. The purpose is to provide decent and safe rental housing for financially eligible tenants. Public housing comes in all sizes and types, from scattered single-family houses to high-rise apartments. **For more information, visit portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/ph.**

Subsidized housing means housing that has supplemental funding from federal, state, county or local government to assist individuals of low and moderate incomes. The rent paid by the tenant is often based on a percentage of the person's income and the subsidy pays the balance. Connecticut has several rental assistance programs.

It was hard work
but it is worth it.
I love living on
my own!



RENTAL SUBSIDIES

Many programs exist to help individuals with limited income secure affordable housing. Housing vouchers, for instance, provide a supplement so that the individual does not spend more than 30% of his/her income on rent. The U.S. Department of Housing and Urban Development (HUD) publishes Fair Market Rents for each county. Tenants pay a portion of their income (typically 30% to 40% of the household's adjusted monthly income) and the voucher pays the balance of the rent directly to the property owner. The following rental assistance programs are available with federal and state funds often called HUD's federal Housing Choice Voucher (Section 8):

- **The Housing Choice Voucher program** is the federal government's major program for assisting very low income families to afford decent, safe, and sanitary housing in the private market. Participants are able to find their own housing, including apartments, townhouses, and single-family homes. The participant is free to choose any private rental housing that meets the requirements of the program. Housing Choice Vouchers are funded through the federal Department of Housing and Urban Development (HUD) and are administered in Connecticut by over 40 public housing agencies (PHAs) and statewide by the Connecticut Department of Housing (DOH) and its agent, J. D'Amelia & Associates, LLC. (JDA). JDA subcontracts operation of the DOH HCV program to six local PHAs and one Community Action Agency in the state. Vacancies and opportunities fill quickly; households can only apply for housing assistance when there is an open waiting list.

www.ct.gov/doh/cwp/view.asp?A=4513&Q=530586

- **The Rental Assistance Program (RAP)** is the major state-supported program for assisting very-low-income families to afford decent, safe, and sanitary housing in the private market. Participants find their own housing, including apartments, townhouses, and single-family homes. The participant is free to choose any private rental housing that meets the requirements of the program, as described below. RAP certificates are funded through the Department of Housing (DOH) and are administered statewide by DOH and its agent, J. D'Amelia & Associates (JDA). JDA subcontracts operation of RAP to six local Public Housing Authorities (PHAs) and one Community Action Agency in the state.

www.ct.gov/doh/cwp/view.asp?a=4513&Q=530584&PM=1

211 HOUSING RESOURCES

The 211 website contains links to:

- Open Housing Choice Voucher waiting lists throughout Connecticut
- 211's Community Resources Database of low-cost housing options
- e-Library Papers on a wide range of housing topics, such as avoiding foreclosure and landlord/tenant rights and responsibilities

Following is the link to the United Way Housing Choice Voucher Program (also known as Section 8) waiting list www.cthcvp.org. Use this link to locate open Housing Choice Voucher waiting lists throughout Connecticut.

The rentals of new subsidized housing units and the process to apply are advertised in the local newspapers. Such complexes offer affordable rental rates and may have some project-based subsidies available. Applications are accepted, and then waiting lists are created. An applicant must submit income verification to document that everyone living in the household meets the financial eligibility guidelines.

The application asks if the individual has a disability. This includes individuals with mental illness and intellectual and developmental disabilities. Frequently, preference is given to individuals with special needs such as veterans, older adults, or someone with a disability. An individual can be on several waiting lists simultaneously.

Some affordable housing projects have vouchers assigned to the apartment called "project-based rental assistance." When the individual moves, he/she will lose the subsidy. Alternatively, "tenant-based vouchers" are assigned to the tenant and can move with the individual to any place with a Fair Market Rent that he/she chooses to rent. Vouchers may be time limited. Most are renewable.



FEDERAL HOUSING CHOICE VOUCHERS AND RENTAL ASSISTANCE PROGRAM (SECTION 8)

Individuals with disabilities may also receive a preference or priority consideration in obtaining a housing voucher based upon their disability. Contact the local public housing authority about rental assistance, and also ask about “set-aside” opportunities. These are vouchers reserved for individuals with disabilities. It is advantageous for an individual to apply and have his/her name placed on multiple waiting lists for low-income housing and rental subsidies.

Periodically contact the local Housing Authority to see if any waiting lists are open. Public Housing Authorities, also referred to as Public Housing Agencies, are designated entities that manage public housing units in a certain geographic area. Go to the Public Housing Agency to locate low-income housing options in each municipality. For a list of Connecticut’s housing authorities, visit portal.hud.gov/hudportal/HUD?src=/states/connecticut/renting/hawebsites.

HUD publishes a Fact Sheet on Housing Choice Vouchers at www.portal.hud.gov/hudportal.

To locate HUD Housing Choice Voucher (Section 8) housing inventory, visit www.portal.hud.gov/hudportal.

Obtaining a rental assistance voucher can be a significant step toward achieving affordable housing and independent living. Securing a voucher is a complicated, time-consuming process but worth the effort. Eligibility is determined by the public housing authority based upon the number of individuals in the household, the annual gross income, available assets, citizenship status, and criminal background.



If a voucher is not readily available, the individual/family is placed on a waiting list. When the waiting list becomes too long, the PHA can decide to close the waiting list until additional vouchers become available. The PHA can also determine local preferences favoring certain groups of people to receive vouchers. For instance, the PHA could decide to give preference to individuals who are homeless, displaced or currently paying more than 50% of their income toward rent. These eligible individuals could be determined to receive priority to receive available vouchers ahead of others on the waiting list. It is not unusual to be on a waiting list for several years.

Housing Choice Voucher Fact Sheet: portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/about/fact_sheet.



Once a name is added to a waiting list, it is important to notify the PHA of any changes in address and household composition. When the individual's name gets to the top of the waiting list, it is imperative to complete all of the paperwork in a timely manner.

AFFORDABLE HOUSING FUNDED BY TAX CREDITS

The Federal Low-Income Housing Tax Credit program provides tax incentives to housing developers to establish affordable rental units for individuals who meet established income criteria. Subsidized or affordable housing is available within these complexes. New tax credit funded housing projects publicize their application process in local newspapers. Existing housing complexes maintain waiting lists to fill vacancies. HUD maintains an inventory of tax credit housing at portal.hud.gov/hudportal/HUD?src=/program_offices/fair_housing_equal_opp/lihtcmou. Individuals interested in obtaining affordable housing within one of these complexes can locate such housing in the towns where they want to live and apply. In addition, further opportunities to find rental housing are listed under Rental Resources.



RENTAL RESOURCES

There are a variety of rental resources. The ones listed below are from the Connecticut Housing Coalition resource guide.

The Connecticut Housing Coalition works to expand housing opportunity and to increase the quantity and quality of affordable housing available to individuals with low and moderate incomes in Connecticut through advocacy, education, and collaboration. Visit the Connecticut Housing Coalition resource guide at ct-housing.org/resources/housing-help.

- **CTHousingSearch**, a housing locator service funded by the Connecticut Department of Economic and Community Development. **To utilize the service, visit www.cthousingsearch.org.**
- **HUD Subsidized Apartment Search** to find apartments that have received funds to provide lower rents for low-income tenants. You can find apartments for senior citizens and individuals with disabilities, as well as for families and individuals. **For more information, visit www.hud.gov/apps/section8.**
- **Public Housing Agency Websites (HUD)** for a listing of housing authorities that own and manage subsidized housing and administer Housing Choice Voucher (Section 8) programs. **For more information, visit portal.hud.gov/hudportal/HUD?src=/states/connecticut/renting/hawebsites.**
- **Housing Choice Voucher Waiting List website** to locate open Housing Choice Voucher Program waiting lists throughout Connecticut, and register to receive automatic notice of the opening of waiting lists whenever they occur. **For more information, visit www.cthcvp.org.**

It takes hands to build
a house, but only hearts
can build a home.

Ownership Resources for Individuals with Disabilities

Programs exist to help individuals with disabilities buy and maintain their own homes. There are national, state and local programs that offer mortgage assistance and other types of housing aid to help better serve individuals with disabilities. Local banks and housing counseling organizations can provide guidance and information about buying a home. In some instances, families purchase a home for their adult child with a disability to operate as a group home or home sharing. Cooperative arrangements have also been made for a few families to own the group home.

Home ownership can be costly and include unexpected expenditures for repairs. The advantages and disadvantages must be weighed carefully before making a decision to buy a home. Freddie Mac publishes a fact sheet on home ownership vs. renting. They suggest that if someone intends to build equity, stays in the home at least four years and has funds for ongoing maintenance/home improvements, home ownership has financial advantages. The buyer must have a source of steady income, a favorable credit rating and a down payment in order to finance a mortgage on the property. For more information, visit www.freddiemac.com/homeownership/rent_or_buy/right_for_you.html.

There are several programs to assist individuals with low incomes to purchase, renovate or refinance a home of their own with minimum down payments, subsidies, and/or low interest mortgages. The Housing Mortgage Finance Agency or your local bank may have special mortgage rates for first-time home buyers. With home ownership comes additional responsibilities and financial expenses. These factors must be considered carefully when contemplating the purchase of a home.

PROGRAMS FOR HOME BUYERS – CONNECTICUT HOUSING FINANCE AUTHORITY (CHFA)

www.chfa.org/homeownership/default.aspx

The Connecticut Housing Finance Authority (CHFA) is committed to assisting Connecticut individuals and families achieve and sustain their dream of homeownership for a lifetime. To that end, they offer a variety of competitive mortgage programs, designed especially for first-time home buyers, as well as loan programs designed for homeowners facing financial hardship. In partnership with HUD-approved housing counseling agencies throughout the state, they provide free education and counseling services for homeowners in crisis as well. Below are some of CHFA's homeownership programs:

Section 8 Housing Choice Voucher

Homeownership Program. This program offers home loans at below-market interest rates to Section 8 tenants who wish to purchase their own homes. This program allows eligible borrowers to use their Section 8 Housing Choice Vouchers towards a monthly mortgage payment.

CHFA is committed to helping Connecticut residents achieve their dream of homeownership and values its partnership with local Public Housing Authorities (PHAs) across Connecticut as well as the qualified lender for this program. Applicants interested in the Section 8 Housing Choice Voucher Homeownership Program should contact their PHA directly. They may also contact the McCue Mortgage Company directly.

Homeownership Program. The Homeownership Program offers mortgages at below-market interest rates to tenants of publicly assisted housing who wish to transition from renting to homeownership. Though the program primarily is designed to support first-time home buyers, renters who were homeowners may still be eligible for a loan under this program if the property they intend to buy is located in a federally targeted area that would benefit from increased home ownership.

Down payment Assistance Program.

Program Overview. The Downpayment Assistance Program (DAP) offers supplementary loans at below-market interest rates to eligible borrowers of home loans who are unable to raise sufficient funds to pay the upfront expenses associated with purchasing a home.

Note: A DAP loan is not intended to finance the purchase of a home. Because CHFA recognizes that the foremost obstacle to homeownership is a potential home buyer's inability to cover the down payment and closing costs of a home purchase, DAP loans can be used in conjunction with CHFA home loans. An eligible borrower must show his or her ability to repay the primary mortgage and the DAP loan in order to qualify for assistance under this program.

HFA Preferred™ Loan Program. The HFA Preferred™ Loan Program offers home loans at below-market interest rates to first-time home buyers with low mortgage insurance costs. Individuals who have owned homes before may also qualify for a loan under this program if they plan to purchase a home located in a targeted area. There are no exceptions for CHFA Income Limits in Targeted Areas with this Program. This Program cannot be combined with any other program offered by CHFA.

Financial Qualifications and Leasing. A principle of Independent Housing contends that the person with a disability or his/her guardian must have control over their housing. This is achieved most effectively through the signing of a lease. With control comes responsibility. The lease is a legal agreement that must be read and understood before signing. Residents should anticipate and plan contingencies when their roommates must change.

Landlords may require that tenants demonstrate their financial ability with a positive credit and rental history. In affordable housing, these standards may be waived. Agencies and services exist to assist tenants with these issues.

Housing Counseling Agencies. The U.S. Department of Housing and Urban Development (HUD) approves local agencies that can provide housing and financial counseling for those seeking affordable housing. These organizations supply various services such as money management counseling, financial literacy training, credit counseling, foreclosure avoidance and assistance locating affordable rental properties. For more information, visit www.hud.gov/offices/hsg/sfh/hcc/fc/index.cfm?&webListAction=search&searchstate=NJ&filterSvc=dfc.

Credit Information / Credit Repair. More information on credit and credit repair can be found on the Connecticut Department of Banking website at www.ct.gov/dob/cwp/view.asp?a=2235&q=297916.



Using Private Resources

INDIVIDUAL DEVELOPMENT ACCOUNTS (DDA)

In order to save money that may be used to support housing, the Individual Development Accounts Program may help. Individual Development Accounts (IDAs) are matched savings accounts designed to help families of low income and low wealth to accumulate assets of a few thousand dollars to fund investments in their education, homeownership, and small business ownership. Go to www.crtct.org/en/need-help/money/ida-savings-program for more information.

SPECIAL NEEDS TRUSTS

Special Needs Trusts allow funds to be saved for the individual with a disability without jeopardizing government means-tested benefits and in some instances providing additional options for an individual with a disability to secure housing.

Regardless of the type of special needs trusts established, the funds must be used for the sole benefit of the individual with a disability and in a way which does not jeopardize benefits. Therefore, if the individual is receiving SSI and/or Medicaid, then funds in a Special Needs Trust cannot be used for food, clothing or shelter because any funds used for these purposes are deemed to be "income" and could potentially jeopardize SSI and Medicaid eligibility.

Regulations and laws change, so legal advice must be obtained at the time of establishing trusts and reviewed periodically thereafter.

ACHIEVING A BETTER LIFE EXPERIENCE (ABLE) ACT

The ABLE Act establishes an additional way to save funds for an individual with a disability without jeopardizing some government means-tested benefits. The ABLE Act was passed by Congress in late 2014. In addition to the federal passage of the bill, each state must pass legislation to authorize its guidelines for ABLE Act provisions to be effective in that state. Connecticut has passed such legislation. At this writing Connecticut is in the process of exploring ways to create its own program. In the meantime Connecticut residents can open ABLE accounts in other states that have established programs. Visit www.ablenc.org for the most current information on ABLE in Connecticut and nationally.

An ABLE account must be established for the benefit of an individual with a disability that manifests itself before age 26. The funds must belong to the individual or their parents, family, or friends. Funds in an ABLE account grow tax-free and funds used from an ABLE account are not taxed so long as they are used for qualified expenses including housing, education, transportation, healthcare, employment supports, therapies, and other similar expenses.

It is imperative that families create a comprehensive plan to prepare for the future of an individual with a disability. When establishing an estate plan for a person with a disability, it is advisable to seek the advice of an attorney or financial advisor who has specific expertise in this area of the law.

For more information about The ABLE Act, visit www.realeconomicimpact.org/news/?id=460.

Involve your child in the community.
Do not shield them because they might not
fit in. My son has autism and cannot modulate
his volume when he speaks.

I took him to the library as a youngster
and explained to the librarians that he is loud.
They took him under their wings. He loves
to go to the library. Years later, they still
look out for him.



Other Resources

CT CENTERS FOR INDEPENDENT LIVING (CILs)

There are five CILs located in Hartford, Norwich, West Haven, Naugatuck and Stratford. CILs are community based, non-residential, consumer-controlled and cross-disability. Each CIL follows the independent living philosophy of self-help, self-reliance, and self-determination. Together, the 5 CILs cover the entire state. Typically, a CIL serves 25-30 cities and towns. CILs serve individuals of all ages, with all types of disabilities.

CILs provide 5 Core Services:

- **Advocacy:** Advocacy takes many different forms: Advocates serve to assist individuals to secure their rights, remove barriers, and support legislative changes which will ensure equal access for all members of our community.
- **Information & Referral:** With the availability of so many service providers, organizations, adaptive devices and equipment, it is often difficult to identify an appropriate resource. Through Information & Referral, Centers assist individuals in locating necessary information and providing appropriate referrals.
- **Peer Counseling:** Through Peer Counseling or Networking, individuals connect with other people with disabilities who may have shared similar experiences. This can provide a strong support system for consumers.
- **Independent Living Skills Training:** Independent Living Skills are those skills which enable a person to become more independent. Independent Living Skills may be addressed through referrals to existing resources, advocacy to ensure that these resources are accessible, or through direct instruction, either one on one or in small groups.
- **Transition:** Staff facilitate transition from nursing homes and other institutions to the community, provide assistance to those at risk of entering institutions and facilitate transition of youth to postsecondary life.

CILs support consumers with:

- Advocating for themselves and others, in order to control one's life
- Developing life-long independent living skills
- Connecting to appropriate technology to support living independently
- Providing benefits counseling
- Accessing health care, community supports, recreation, transportation, and other resources and services that promote independence
- Developing job readiness skills and accessing employment
- Finding housing in their community

CILs provide:

- A single point of access to services for all people regardless of the nature or type of disability and are leaders in the movement to consolidate services and streamline bureaucracy
- A place where people with disabilities can turn to establish independent living goals and to achieve them

Center for Disability Rights (CDR)

764 A Campbell Avenue | West Haven, CT 06516
(203) 934-7077 | www.cdr-ct.org

Disability Network of Eastern CT (DNEC)

18 Ohio Avenue | Norwich, CT 06360
(860) 823-1898 | (860) 237-4515 (Videophone)
www.dnec.org

Access Independence (Formerly DRCFC)

80 Ferry Boulevard | Stratford, CT 06615
(203) 378-6977 | www.accessinct.org

Independence Northwest (IN)

1183 New Haven Rd, Ste. 200 | Naugatuck, CT 06770
(203) 729-3299 | (203)490-0358 (Videophone)
www.independencenorthwest.org

Independence Unlimited (IU)

151 New Park Avenue | Hartford, CT 06106
(860) 523-5021 Voice/TTY
www.independenceunlimited.org

Resources that support individuals with disabilities, older adults, or those of low income, may be of assistance. Research is required to identify the eligibility criteria for each service. Here is a brief description and contacts for governmental agencies. Non-profit organizations, The Arc of Connecticut, United Way through 211, and others can assist with information and referral.

Municipal (Cities and Towns)

Cities and towns offer assistance to people who are elderly or have a disability regarding transportation, money management, income tax preparation, telephone reassurance calls, meals on wheels, food pantries, recreational activities, accessibility, home modifications, and more. To find out what your city or town offers visit portal.ct.gov/cities_and_towns.

The local Public Housing Authorities manage the rental of affordable housing units and rental assistance within their local communities.

Some programs designed for individuals of low income can also provide assistance for the individual with a disability to live independently and stretch a limited budget. Generally, when individuals with a disability reach the age of 18, their personal income, not the family income, is considered when applying for financial assistance. Eligibility for these programs requires research but may be well worth the effort. This section includes some options to consider. Visit portal.hud.gov/hudportal/HUD?src=/states/connecticut/renting/hawebsites.

FUNDING FOR LIVING EXPENSES

Social Security Administration

800.772.1213 | 800.325.0778 TTY | www.socialsecurity.gov
www.ct.gov/agingservices/lib/agingservices/manual/financialassistance/socialsecurityfinal.pdf

The Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs pay benefits to adults with disabilities (after their 18th birthday) who have limited income and resources. Maintaining Medicaid eligibility is essential for individuals with intellectual or developmental disabilities to secure waiver-funded services.

PRESCRIPTION ASSISTANCE

There are several programs that are available to help clients, with or without insurance, save money on their costs for medications:

For general info ... www.getcheapermeds.com/pdf/pharmacy_card_eng.pdf | 800.918.2177

For detailed info ... webtools.agelity.com/index.aspx?sGUI=bfc034cd-7c2c-4a6d-af30-badaaf41ae0d

Prescription Assistance Program (PAP)

www.ctdrugcard.com/index.php

As a resident of Connecticut, you and your family have access to a statewide Prescription Assistance Program (PAP).

SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM (SNAP)

Formerly known as Food Stamps Program | 800.687.9512

The Connecticut Supplemental Nutrition Assistance Program (SNAP), formerly known as the Food Stamps Program, issues monthly benefits that can be redeemed at local food stores to purchase groceries. An individual can apply through the Department of Social Services DSS) or by completing an application online at www.connect.ct.gov, under 'Apply for Benefits.'

Eligibility is determined based upon several factors such as income, household size, resources, etc. There is an online tool to assist in determining eligibility at www.snap-step1.usda.gov/fns.

SNAP Publications:

- EBT Handbook - How to Get Your SNAP and/or Cash Benefits
- Help for People in Need Brochure
- Help for People in Need Brochure - Spanish

The following resources are taken from the Housing Coalition Resource Guide:

UTILITY ASSISTANCE

Connecticut Department of Social Services Energy Assistance offers programs to help households with their heating bills and in conserving energy. Contact your local community action agency, or call the winter heating aid hotline at 1-800-842-1132.

Visit the **EnergizeCT Energy Assistance** website for links to assistance programs, a benefits calculator, and contacts for resolving utility problems to help consumers navigate the state's energy-related resources. Call state-wide toll-free Energy Information Line, 1-877-WISE USE (947-3873).

Weatherization Assistance Program

The U.S. Department of Energy (DOE) Weatherization Assistance Program (WAP) provides grants to states, territories, and some Indian tribes to improve the energy efficiency of the homes of low-income families. These governments, in turn, contract with local governments and nonprofit agencies to provide weatherization services to those in need using the latest technologies for home energy upgrades.

General Program Requirements

In order to qualify for this program, you must be a resident of the state of Connecticut. Preference may be given to:

- Individuals over 60 years of age
- Families with one or more members with a disability
- Families with children (in most states)

In Connecticut, the program is administered by the State Department of Energy and Environmental protection (DEEP). The statewide Community Action Agency (CAA) network operates the Weatherization Assistance Program. Applications are taken at the same time as the Connecticut Energy Assistance Program as part of a joint application process. Make sure to ask the staff person for a Weatherization Card or Referral Form if you are interested in the program. For the Energy Assistance intake site near you, call 211. **For more info on the Weatherization Assistance Program, visit DEEP at www.ct.gov/deep/cwp/view.asp?a=4405&q=509366&deepNav_GID=2121.**



For those that do not qualify for the Weatherization Assistance Program there are other programs available, including a utility ratepayer-funded low-cost energy audit. Contact your utility company for information:

Eversource

1 800 286 2000

Hartford/Meriden areas:

860 947 2000

United Illuminating Company

1.800.442.5004

Lifeline and Linkup America

www.phone-bill-assistance.com/lifeline/CT

Lifeline is a program that allows low income households to receive discounted telephone services, in order to help them make ends meet each month.

TRANSPORTATION

Individuals with intellectual or developmental disabilities must have access to both public and private transportation in order to lead full, independent lives.

In Connecticut, there is a lack of sufficient access to mass transit, paratransit, trains, ferries, airplanes, and other modes of transportation to perform everyday activities. Even where accessible public transportation exists, adults with disabilities consider transportation inadequate.

In the U.S., 24 million individuals with disabilities use public transit to maintain their independence and participate fully in society. For many, it is their only transit option.

Although federal and state legislation encourages more people with all types of disabilities to go to work, getting to work requires transportation. Inadequate transportation inhibits community involvement. Those living in rural areas often face the greatest challenge of all due to total lack of public transportation and long distances between destinations.

TRANSITNET

www.transitnet.info

The Arc Connecticut received a federal grant to create a coordinated website to bring all of the options for transportation into one site. We call this TransitNet.

The Arc realized that transportation agencies were not providing the necessary information in one, easy to use site that was accessible, available in a timely manner, and equipped to suit the physical, sensory, and/or cognitive needs of all individuals, including elders.

TransitNet is a website for individuals with disabilities, older adults, caregivers, and providers who want to learn more about what transportation options are available for them in Connecticut. The site is designed to be accessible and informative—providing transportation links, instructions on how to use those links, and contact information leading directly to individuals who can offer further assistance.

There is a video to inform the public about the website and brochure for people with disabilities, older adults, caregivers, and providers who want to learn more about what transportation options are available for them in Connecticut. The brochure is available by contacting The Arc office.

TransitNet is a project of Arc Connecticut and made possible through a Federal grant, Inclusive Transportation Partnerships to Promote Community Living, funded by the U.S. Administration for Community Living (ACL) and managed cooperatively with the Federal Transit Administration (FTA). Inclusive Transportation Partnerships is administered by the Community Transportation Association of America (CTAA) in partnership with Easter Seals, the National Association of Area Agencies on Aging (N4A), and Westat.



EMERGENCY PREPAREDNESS

For CT residents who want to prepare for the possibility of an emergency or a disaster in their community, these agencies offer information and guidance on how to prepare:

- American Red Cross Preparedness Information
www.redcross.org
- FEMA: Are You Ready? A Guide to Citizen Preparedness
www.ready.gov

Connecticut cities and towns Emergency Management Office's handle "Special Needs Registries", which maintain information about residents who may require assistance in the event of a disaster. Individuals with disabilities, people who cannot drive, and individuals who do not have access to transportation are included. Participation in the Special Needs Registry is voluntary. Visit 211 for a list of cities/towns who have Special Needs Registries.

LEGAL SERVICES AND ADVOCACY

The Office of Protection and Advocacy for Persons with Disabilities (P&A) is an independent State agency created to safeguard and advance the civil and human rights of individuals with disabilities in Connecticut. Part of a nationwide network of protection and advocacy systems, the Office operates under both State and federal legislative mandates to:

- provide information, referral, and advocacy services
- pursue legal and administrative remedies on behalf of individuals with disabilities who experience disability-related discrimination
- investigate allegations of abuse and neglect that arise in specific service settings or that affect individuals with particular disabilities
- provide education, information and training on disability rights to policy makers, advocacy groups and members of the public

Note: As of June 30th, 2017, P&A will no longer be a state agency. A non-profit, not designated as of this writing will be designated with many of its responsibilities. The Abuse Investigation Division will move to the State Department of Rehabilitation Services.



NATURAL SUPPORTS

Natural supports means personal relationships developed that enhance the quality of life for people. Natural supports include, but are not limited to, family relationships, friendships, and associations with fellow students or employees in regular classrooms and work places, as well as associations developed through participation in clubs, organizations, and other civic activities.

Individuals with disabilities should develop relationships with the people and places around them that define their community. When creating a housing plan, the individual with a disability should include participation within his or her natural supports environment. Professional staffing and assistance, while necessary in many areas, should not be the sole experience for consumers on a day-to-day basis.

www.dds.ca.gov/Publications/docs/Natural_Supports.pdf

Employment

Employment is also a part of the natural support system and an important way for an individual to achieve self-sufficiency.

For more information, go to
www.dol.gov/odep.

CONNECTICUT FAIR HOUSING CENTER

Connecticut Fair Housing Center, which can investigate complaints, offer information and advice, and provide legal assistance to victims of housing discrimination.

Call toll-free: 1-888-247-4401

www.ctfairhousing.org

State of Connecticut Commission on Human Rights and Opportunities (CHRO)

www.ct.gov/chro/site/default.asp

The mission of the Connecticut Commission on Human Rights and Opportunities is to eliminate discrimination through civil and human rights law enforcement and to establish equal opportunity and justice for all individuals within the state through advocacy and education. CHRO files disability and other types of discrimination legal complaints as well as providing training and other resources. The following resources are taken from the Housing Coalition Resource Guide (ct-housing.org/resources/housing-help):

Statewide Legal Services of Connecticut, a free legal aid telephone hotline for very low income people with noncriminal legal problems. Some of the problems they can talk to you about include family, employment, benefits (like social security, welfare and medical), and housing. To apply for assistance, call the Hotline at 1-800-453-3320 or from Middletown and Hartford areas, call (860) 344-0380.

Legal Assistance Resource Center of Connecticut has a library of Self-Help Materials that address a variety of legal areas including family, public benefits, housing, consumer, elder, children, education, energy and utilities.

American Bar Association. To locate an attorney or for more information about American Bar Association go to www.americanbar.org/aba.html.

Council of Parent Attorneys and advocate COPPA. To locate an attorney or a parent advocate go to www.copaa.org.

HOUSING DISCRIMINATION

For information on the rights of individuals with disabilities in housing go to **portal.hud.gov/hudportal/HUD?src=/program_offices/fair_housing_equal_opp/ReasonableAccommodations15**.



Housing Development

An adequate supply of safe, decent, accessible housing for individuals with disabilities is a critical part of the whole. This section describes the many resources that are utilized by housing developers to acquire, construct and/or rehabilitate housing for individuals of low income.

Funding is available to develop affordable housing for individuals with disabilities. Some families join together informally to support and formally to sponsor housing projects. For housing development, there are multiple sources for low-cost loans and grants. Federal, state, county, and municipal governmental agencies administer several programs. Private foundations, investors, banks

and lending institutions support the development of bricks and mortar projects as well. Each source has its own set of rigorous regulations.

Most often, funding is awarded competitively after the review of various project documents submitted with the funding application. The project sponsor assumes the risk that development fees advanced may not be reimbursed. The housing development process is complicated, time consuming and not for the faint of heart. Teaming with an experienced consultant and/or developer is highly recommended. The following is a very brief description of funding sources and programs for housing development.

The development costs include all expenses incurred prior to construction such as architectural, engineering and legal fees. Carrying charges comprise building permits, insurances, property taxes, and expenses incurred prior to and during construction. A contract for sale or similar legal document constitutes evidence of site control indicating that the developer has possession of the property once the project is funded.

A budget, referred to as a Pro-Forma, delineates the costs and sources of funding for the capital expenses to acquire, construct or renovate the housing. Funders require a credible description of income and expenses to justify that the rents can support the facility's operations. A social services plan explains what services will be available and how they will be funded.



FEDERAL FUNDING

Federal Department of Housing and Urban Development (HUD)

The Federal Department of Housing and Urban Development (HUD) is the primary federal agency promoting housing opportunities for individuals of low and moderate incomes. HUD administers several programs directly to not-for-profit and for-profit housing developers, and indirectly throughout the State, local public housing authorities, and counties, as well as Housing and Mortgage Finance Agencies, to support the creation of affordable housing for individuals with disabilities.

With federal dollars, HUD funds various initiatives such as the Community Development Block Grants, and HOME funds. They publish a Notice of Funding Availability (NOFA) to announce the regulations and application processes. Further information about HUD programs can be located at www.hud.gov.

HOME Program

Under the HOME Program, HUD allocates funds to eligible state, county and municipal governments to expand the supply of affordable rental housing for families with low-income. HOME funds can only be matched with non-federal funding resources. Participating jurisdictions award HOME funds to meet the community needs as described in their consolidated plans. Generally, funds are utilized for rental assistance or acquisition, rehabilitation and new construction of housing.

Community Development Block Grants

(CDBG) provide federal funding to municipalities to help with economic development, housing rehabilitation and neighborhood revitalization. Some municipalities pool their resources and administer the funding through a county consortium.

HUD Section 811 Program

HUD Section 811 Program for individuals with disabilities provides rental assistance to subsidize the difference between the Fair Market Rent and the amount the residents can afford.

Federal Low Income Housing Tax Credit Program (LIHTC Program)

The Housing and Mortgage Finance Agency (HMFA) administers the federal Low Income Housing Tax Credit Program (LIHTC) on behalf of the state. The program provides a dollar-for-dollar reduction in federal tax liability and acts as a catalyst to attract private investment into the affordable housing market.

This program has long been considered one of the most successful and efficient federal housing programs ever created to provide the private market with an incentive to invest in the creation or rehabilitation of quality affordable rental housing that enhances the character of our neighborhoods.

Just as I saved money for college for my other kids, I started when my son was young to save for his future. I bought life insurance when I was young, and it was affordable. I also set up a special needs trust in my will.

(Federal Funding ... continued from p.55)

Federal Home Loan Bank (FHLB)

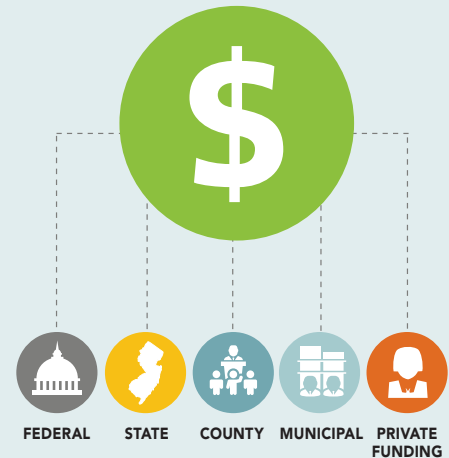
The FHLB funds the Affordable Housing Program (AHP) that directs member banks to collaborate with developers to utilize this funding in conjunction with other programs such as the LIHTC and CDBG to develop housing for low-income populations. In addition, the Community Investment Program (CIP) provides funding to member banks to be used for long-term projects that create low-income housing.

Community Reinvestment Act (CRA)

Federal law requires that commercial banks have a continuing obligation to assist the credit needs of the local communities that they serve. This law requires evaluation of these financial institutions in meeting the community needs including low- and moderate-income neighborhoods. Often local banks assist housing development through grants or loans.



FUNDING FOR THE CREATION OF SUPPORTIVE HOUSING



Given the high cost of housing, funding to support the creation of supportive housing generally comes from multiple sources. These sources may include a mix of federal, state, county, municipal, and private funding sources. Individuals and parents have joined in large and small groups to establish their own non-profit organizations to sponsor the development of housing units for people with disabilities.

Understanding the intricacies of government funding to creating housing involves a great deal of research. This brief review does not depict the whole range of opportunities. New funding sources are introduced and the regulations are frequently revised. There is much to learn before embarking on housing development. A good place to start is by joining a trade organization such as the Supportive Housing Association (SHA) and collaborating with experienced housing developers.

Advocacy

Advocacy is vital in improving and sustaining quality of life for individuals with intellectual and/or developmental disabilities. To be effective, advocacy must take place at both the individual and system levels. Advocacy can be aimed at public officials, support systems, media, and the general public.

Advocacy on the individual, family, or systems level is acting with or on behalf of an individual or group to resolve an issue, obtain a needed support or service or promote a change in the practices, policies and/or behaviors of third parties. Advocacy is essential for promoting and protecting the civil and human rights of individuals with intellectual and/or developmental disabilities and for establishing, maintaining or improving their quality of life, and The Arc Connecticut has been doing this for over 60 years.

Without strong advocacy at all levels, individuals with intellectual and/or developmental disabilities may not have access to needed supports as well as opportunities to exercise inherent civil and human rights. Additionally, strong advocacy may be required to prevent and/or address abuse, neglect, and exploitation that individuals with intellectual and/or developmental disabilities may experience. Individuals with intellectual and/or developmental disabilities may need the support of advocates to become effective self-advocates.

Systems change advocacy can provide tremendous benefit for individuals with intellectual and/or developmental disabilities.

The goal of systems advocacy is to enhance public awareness of the rights, strengths, needs, and interests of individuals with intellectual and/or developmental disabilities and influence law and policy to improve public and private systems of support and services. Family members and self-advocates should play a meaningful role in systems change. Agencies providing supports to individuals should also advocate for system change that will improve the quality of life for all individuals, whether supported by the agency or not.

For more information about how you can get involved with our Arc advocacy efforts, visit thearcct.org.

The surest way to expand opportunities in housing and services for individuals with disabilities is through good old-fashioned advocacy.



Self-Advocacy

For years professionals and families thought “they knew best”, and that individuals with disabilities need to be taken care of rather than supported. Now we know that individuals with disabilities are able to self-determine their own lives and should have control over their finances, be able to make choices about where they live, who they live with, and where they work. The self-advocacy movement came out of the institutional closure movement back in the 80’s when individuals with disabilities locked in institutions started speaking up and saying, “Get me out!”

To individuals with disabilities, self-advocacy means speaking or acting for yourself. It means deciding what is best for you and taking charge of getting what you want. It means standing up for your rights as an individual.

In 1983, People First of Connecticut was formed on the grounds of Southbury Training School and is a 501(c)3 whose mission is to close institutions, promote self-advocacy across Connecticut and it is still a vibrant organization today with 16 chapters across the state. For more information, visit www.peoplefirstct.org.

The Department of Developmental Services (DDS) believes that all of the individuals they provide services to can benefit from learning and using self-advocacy skills. In 2004, nine DDS Self-Advocate Coordinator positions were created to help expand and enhance self-advocacy throughout Connecticut. The Self-Advocate Coordinators are responsible for providing leadership, coordination, role modeling, and mentoring of self-advocacy to individuals in their assigned geographic area. They do this by supporting existing self-advocacy groups and helping start new self-advocacy groups. You can find out more about DDS’s Self-Advocate Coordinators at www.ct.gov/dds/cwp/view.asp?a=2050&q=332652.



Individuals should have access to Protection and Advocacy systems and other entities mandated by state and federal laws that:

- Have the flexibility to respond to issues raised at any time during an individual’s life
- Are independent of conflicts of interest, undue influence and government control
- Are adequately funded and staffed
- Provide advocacy on their behalf even though a formal complaint has not been filed
- Have appropriate government or other oversight of quality, cost effectiveness, efficiency, and high standards to ensure the health, safety and well-being of individuals being served
- Use multiple advocacy strategies, such as information and referral, mediation, legal action, and legislative and regulatory solutions
- Provide means for appealing unfavorable decisions

Conclusion

We hope this Resource Guide encourages creative thoughts about how individuals with intellectual and developmental disabilities can live more independently despite low incomes, lack of traditional services and public entitlements. Resources, both housing and services, exist; finding them and using them productively is challenging. We hope you now have the tools to begin to navigate the complicated maze and achieve, now and in the future, the life you envision for your family member.

In many ways, securing supported housing for your loved one with I/DD is like blazing the trails of the Wild West where maps were unavailable: resources are scarce, rules and regulations are abundant and cumbersome, but the outcome will ultimately be worth the effort.

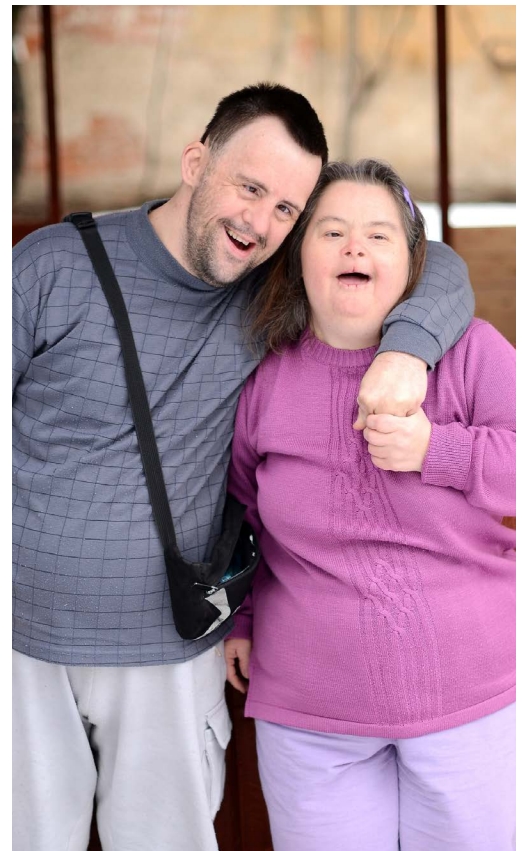
We are grateful for all who have shared their experiences, and hope that this Housing Resource Guide helps you identify and secure critical resources to find a place that you or your loved one can call home.



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Look out for
and help those
who don't have
the time, money
and resources
to manage for
themselves.



Toolkit Resources & Checklist Readiness Guides

- **Neighbors:** International publishes several helpful booklets for individuals on independence entitled *You and Your Budgets*, *You and Your Home*, *Living Your Own Life*, *You and Your Personal Assistants*. www.neighbours-international.com/our-books.html
- **The Boggs Center on Developmental Disabilities:** *Getting the Community Life You Want* www.rwjms.rutgers.edu/boggscenter/products/GettingtheCommunityLifeYouWant.html
- **Autism Speaks** publishes the *Housing and Residential Supports Tool Kit* www.autismspeaks.org/sites/default/files/housing_tool_kit_web2.pdf
- **The Minnesota Governor's Council on Developmental Disabilities** publishes a booklet with housing checklists for individuals at www.mn.gov/mnddc/extra/publications/choice/Its_My_Choice.pdf.
- **The Florida Developmental Disabilities Council** publishes a curriculum assisting people with disabilities who want to find a home of their own at www.fddc.org/sites/default/files/file/publications/APlaceCurriculum.pdf
- **The Florida Developmental Disabilities Council** publishes a guide to *Practical Information About Buying or Renting a Home* at www.fddc.org/sites/default/files/file/publications/FindingAHome.pdf

The websites included in the Appendix are shared for informational purposes only. Endorsement should not be implied.



Stop and Ask for Directions

1. Gather information

- Learn the rules and regulations of the services delivery and housing systems
- Join advocacy and/or support groups to network and obtain information

2. Apply for services from a variety of sources

- Apply and maintain eligibility for Social Security and Medicaid benefits
- Apply for waiver services with the state agency to which you are eligible (such as Division of Developmental Disabilities)
- Locate and apply for Supportive Services and other resources from generic and mainstream sources. For example, apply for food stamps, energy assistance, PADD, meals on wheels and such that can supplement your budget
- Apply for housing subsidies like Section 8 vouchers and vouchers through the State Rental Assistance Program (SRAP) by contacting public housing authorities and provider agencies. While often these are in short supply, there are multiple places to obtain vouchers or be on a waiting list to obtain one

3. Explore various housing options

- Research housing and supportive service options and plan for the best models to suit your needs
- Are there people with whom you can share resources?
- Determine what supports are needed and where to access them. Assess how many supports are available from friends and family. Seek additional supports from relatives, neighbors, and community connections
- Decide where and with whom you would like to live based upon access to family/ friends, job/daytime activities, transportation, and needed services

4. Develop independent living skills

- Learn how to deal with safety and emergency responses such as using the telephone, calling 911, basic first aid responses and how to respond in a fire
- Use technology like cell phones, GPS, iPods, computers, Skype, Face Time and emergency call buttons
- Develop independent living skills like meal preparation, taking medications, being independent for hygiene and grooming and/or other ways to meet these needs such as meals on wheels, microwave cooking and electronic reminders for medication administration



"What you do makes a difference,
and you have to decide what kind
of difference you want to make."

~Jane Goodall



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