

The Journey to **Community Housing** with Supports



*A Road Map for
Individuals and
Their Families
in New Jersey*

Acknowledgements



Supportive Housing Association
of New Jersey

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.



The Power of Connection

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.



The Supportive Housing Association of New Jersey expresses its deepest gratitude to the New Jersey Council on Developmental Disabilities for the grant funding to develop *The Journey to Community Housing with Supports: A Road Map for Individuals and Their Families in New Jersey*.

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March 2016; First Edition | October 2016; First Edition, Second Printing

April 2017; Second Edition | July 2019; Second Edition, Second Printing



Dear Readers:

Welcome! This housing guide, entitled *The Journey to Community Housing with Support: A Road Map for Individuals and Their Families In New Jersey*, has been designed specifically for individuals with disabilities and their families, providing information, advice and guidance about community housing and supports. Funded by the New Jersey Council on Developmental Disabilities, it is written to inspire individuals with intellectual/developmental disabilities and their families about the possibilities. Navigating the many complex systems, each with detailed regulations, is challenging. This document can assist you or your loved one in finding your way. This guide recognizes the obstacles associated with securing housing and supports. There is a need for additional affordable housing units, rental subsidies, mainstream resources and funding for supportive services.

This housing guide should be read in keeping with its title, as a journey toward establishing a home that enables you or your loved one to live as independently as possible. Written for the layperson, the guide summarizes housing models through the experiences of individuals and families, providing suggestions for your unique housing needs. We must be candid: there are many barriers, and creative thinking, planning, perseverance and advocacy are required.

While much of the information is specific to New Jersey and individuals with developmental disabilities, housing with supportive services encompasses many common features. The funding streams, opportunities and obstacles described can benefit people with other special housing needs and those from other states. The content also has value for providers, public officials and advocates.

We are grateful to many people who contributed to the development of this important resource. The New Jersey Council on Developmental Disabilities recognized the need for this guide, offered critical input, and generously provided grant funding for its development and dissemination. Grant partner, Autism New Jersey, offered substantial conceptual and practical contributions to the text based on their publication entitled, *New Jersey Housing Resource Guide for Adults with Autism Spectrum Disorders* (2009) and their community's experiences to date. Many professionals and state officials provided their expertise, and we are grateful for their input. Deborah Wehrlen, consultant to this project, invested countless hours researching and writing this guide. She translated complex subject matter into understandable prose. Most importantly, we appreciate the individuals and their families who candidly shared their personal journeys so that others could benefit from their experiences.

As part of your journey I encourage you to familiarize yourself with the many SHA members - developers and supportive services providers - who offer community housing with supports. For more information visit <https://www.shanj.org/member-directory/>.

On behalf of the Supportive Housing Association of NJ, I wish you a successful journey. This booklet will continue to evolve in its content and presentation; therefore, I encourage you to contact us with feedback, recommendations and additional ideas.

There is no place like home!

Gail Levinson, Executive Director (2016)
Supportive Housing Association of NJ (SHA)

www.shanj.org

Please refer to online companion file for *The Journey to Community Housing with Supports: A Road Map for Individuals and Their Families in New Jersey* to easily access live links and additional resources.

www.autismnj.org/Housing/SHAGuide



What is Supportive Housing?

Supportive housing is permanent, affordable, lease-based housing for people of low income with access to flexible supportive services. Supportive housing is designed for people with special needs including those with mental, physical and developmental disabilities as well as people who are homeless. Supportive housing provides a safe, affordable home with access to support services so that individuals can live as independently as possible in communities of their choice.

Supportive housing can be found in a variety of settings, in different constellations, and may include scattered site apartments, individual apartments, shared apartments as well as (more rarely) home ownership. Some supportive housing exists in affordable housing complexes that are often integrated with non-disabled individuals/families.

Supportive services can vary but often include case management, care coordination, job and education coaching, assistance with daily living skills, transportation assistance, access to public entitlements and crisis intervention.

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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, working with individual budgets, select providers and direct the services that they choose. Increasingly individuals with disabilities, by themselves or through their guardians, are controlling their own housing options and services and living in more community-integrated settings. This is called supportive housing.

There is a tremendous need for residential support as well as housing that is affordable. It is likely that funding for these expenses will come from multiple sources. Given the limitations of government resources, individuals with disabilities need to access mainstream resources that are available to anyone with low income in order to live within their budgets. These mainstream resources, described in the guide, include such things as rental subsidies, food stamps and utility assistance.

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

Supportive housing involves interconnected elements. There must be a readily available supply of affordable housing units. Funds, usually from several government sources, provide the individual with the supports necessary, 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 person designs where and with whom he or 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 person can select multiple providers or a single entity to address all of one's needs. For some, technological advances can supplement for assistance previously supplied by direct support personnel. Note: The authors did not vet the quality of service delivery in each of the models described. All individual names and some details about their lives have been altered to protect their

privacy. The authors of this guide 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. However, services in some models described may not be eligible for public funding, if determined by the state to be congregate in nature or at variance with state or federal 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 you use this guide to find models and elements of these models that may be a match for you or your loved one. We welcome your feedback to improve future editions of this guide.

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

Note: The authors of this guide 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. The authors did not vet the quality of service delivery in each of the models described. All individual names and some details about their lives have been altered to protect their privacy. 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 Supportive Housing

For almost 40 years, residential services provided in the community have been the preferred residential option rather than living within large 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 as established in 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.

According to the University of Colorado's State of the States in Developmental Disabilities Project, New Jersey was one of six states in the country operating the largest number of state-run institutions (Braddock, 2013). The Research and Training Center of Community Living at the University of Minnesota has several publications that review the research studies regarding individuals with intellectual/developmental disabilities (I/DD) living meaningful lives in their communities. In New Jersey, educational efforts prepare individuals leaving institutional settings for community living by talking with peers who have successfully completed such transitions. New Jersey has made progress to increase opportunities to live in communities and reduce the number of people living in state-operated developmental centers and psychiatric hospitals.

This is a welcome trend from both quality of life and financial perspectives. A research brief on costs and outcomes of community services for individuals with intellectual and developmental disabilities revealed that the cost of institutional care far exceeds that of supplying similar supports within community settings (Stancliffe & Lakin, 2004). States typically spend significantly more money supporting institutions and community residences than they provide to family support services. Yet, most individuals receiving services live in their family home. Fortunately, a shift is underway across the country to provide families with more funding and the flexibility to utilize resources as they see fit. Individuals and their families, given more control through individual-directed services with individual budgets, are better satisfied with the services that they receive (Lakin et al., 2003).

THE IMPACT OF THE 1999 OLMSTEAD SUPREME COURT DECISION

In a landmark interpretation of the Americans with Disabilities Act (ADA), the Supreme Court decided that people with disabilities have a right to receive care in the most integrated setting. Unnecessary institutionalization violates the ADA. Every state is implementing plans to meet the mandates of this *Olmstead* decision. People living in developmental centers who choose to leave are transitioning into community placements.

A lawsuit settlement between Disability Rights New Jersey and the NJ Department of Human Services mandates that anyone who meets the *Olmstead* criteria (initially estimated to be 600 residents) must move from the state's (then) seven institutional facilities into integrated settings by 2017 to comply with the Supreme Court's decision. For more information visit www.nj.gov/humanservices/ddd/programs/olmstead/oipac.html. The Centers for Medicaid and Medicare Services (CMS) permit states to re-direct funding for institutional care to serve people in the most integrated settings in the community through the process of a "waiver." To date, the state has transitioned individuals from developmental centers each year into homes in the community thereby meeting the state's legal obligation. For more information visit www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/DRNJ%20v.%20Velez%20II%20-%20Settlement%20Agreement.pdf.

Housing Options with Innovative Elements

When asked about residential models, one progressive state official said, “We have 568 people and 568 models.” This statement articulates the obvious fact that each person is unique. “No one size fits all.” An individual’s dreams are realized in various ways. The personally designed models depicted in this guide may or may not precisely meet someone else’s needs. The purpose of describing these varied concepts in housing and supports is to inspire others to consider these ideas and redesign them to meet their own specific desires and circumstances. New Jersey is continuing on its journey to implement innovative models in housing and services.



YOUR DESTINATION/ MANY ROADS CAN TAKE YOU THERE

The map key: terminology

Agency-directed services -

The individual selects an agency that is responsible for supplying residential or vocational programs, such as a group home placement.

Congregate housing refers to living situations where a group of unrelated individuals with disabilities live together, such as in a group home.

Integrated housing refers to the opportunity to live in typical mainstream settings with opportunities to interact with people who do not have disabilities.

Bundled and unbundled services refer to how services are delivered. With bundled services a package of supports are provided by one service provider usually through a program such as a group home. With unbundled services, a person obtains individually selected supports and services from one or more service providers. For example, one provider may supply individual supports while another agency delivers transportation. As systems are changing, most services will be unbundled and paid for through a fee for that service.

Support Coordination is a funded service that assists individuals in gaining access to needed program and state plan services, as well as needed medical, social, educational and other services. All individuals who are eligible and wish to access Division-funded services must either select or be assigned to a **Support Coordination Agency (SCA)**.

For more information visit www.state.nj.us/humanservices/ddd/services/support_coordination.html.

Supportive Living Models



This guide provides an array of housing models and supports utilized by people with disabilities. Many of the models contain best practice elements of **supportive housing**, a philosophy that calls for permanent, affordable housing for people with disabilities in communities of their choice. **Supportive 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 people with and without disabilities.

There should also be a separation between the provision of housing and services. People should be able to move and not lose their service provider. Similarly, someone should be able to change his or her service provider and not be required to move. The landlord should not also be someone'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. Supportive 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 supportive housing exists in affordable housing projects that are integrated with non-disabled individuals and families.

Supportive housing is an approach to community living that is receiving much attention and implementation nationwide, including in New Jersey. Other housing models are also delineated in this guide as part of the continuum of housing options. These settings generally provide more congregate housing or housing intentionally created exclusively for people with disabilities. While these models are not considered supportive housing, they continue to be used by persons with disabilities, and are described herein.

Group homes serving more than four individuals and campus style housing that offers apartment/condos exclusively for individuals with disabilities may be considered institutional in nature and individuals may not be able to use their Medicaid budgets for services in these types of settings. To ensure residential settings allow individuals access to and participation in community living and pending CMS approval of the Statewide Transition Plan, all new residential settings will be subject to a "Community Integration Review" conducted by DDD. For general information visit www.shanj.org/about/about-supportive-housing.



INTEGRATED SUPPORTED HOUSING/REVERSE INTEGRATION

In this concept, the housing developer achieves integration by designating some of the rental units for people with disabilities and the majority of the units for those who do not have disabilities, or through reversing a congregate design by slowly integrating non-disabled households 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 person 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 the apartments to tenants with disabilities but most of the people living there do not have special needs. 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.



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



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 holds a membership and 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

Ideally, a person receives supportive services from a provider agency and holds a lease from another entity. This concept ensures that the person can change where he lives but keep his service provider or conversely, can change his service provider but continue to live in his home.

FAIR MARKET RENT (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.

STATE RENTAL ASSISTANCE PROGRAM (SRAP) or federal SECTION 8 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 person's annual income meets the threshold for rental assistance. People 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). You can apply for rental assistance through local public housing authorities in towns, county or state offices. For more information visit www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/pha/contacts/nj.

With **INDIVIDUAL-DIRECTED SUPPORTS**, a person exercises more control to manage and direct the supports that they receive. He or she chooses the desired services and who will provide them. A support coordinator assists in planning and securing services. People who self-direct assume more responsibility for independently managing these services. The individual selects one or more providers to serve their needs, based upon a plan and individual budget. Most often, the person 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.

In SUPERVISED APARTMENTS,

an individual lives alone or with a roommate in an apartment with staff available to them on the premises for up to 24 hours a day.



Clustered Supervised Apartments within a Housing Complex Model: 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 AND TECHNOLOGY

Depending upon the level of need, a person may prefer receiving services on demand in the event of a medical need or emergency. Remote monitoring can identify when staff intervention is needed. The resident can push a button to call for help. 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 person does not have to ask for help.



A person may have difficulties performing certain tasks. Many low to high technological devices are readily available to assist a person to live more independently. These assistive devices can overcome barriers that deter a person 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 person 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 people 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 NJ Comprehensive Medicaid Waiver. Lending libraries exist so the person can test the equipment before purchasing.

The Faison Residence in Richmond, Virginia, is an inclusive community of 45 apartments with 30% of the units designated for those with special needs. 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.

Go to www.disabilities.temple.edu/tech or www.homelinktechnologies.com for sources for technological or adaptive devices that assist independence. The Assistive Technology Center in New Jersey has a lending library that can be accessed at www.assistivetechcenter.org.

Shared Living

SHARED LIVING means that a few unrelated people, with or without disabilities, share their resources to live in one home. This model works best when the person with special needs holds the lease and chooses who the housemates will be. Housemates might receive remuneration in exchange for providing supportive services. Often, long-term relationships develop among the people who share their home and their lives.

Agencies such as HomeSharing Inc. provide services to screen and match people interested in sharing responsibilities and expenses of a home. For more information visit www.HomeSharing.org.

These matching services are available in some but not all counties in New Jersey. In this model, social workers reach out to home providers (home owners with extra room and a willingness to share common space in return for payment toward household expenses), and home seekers (persons of very low income who are in need of a place to live and cannot afford independent housing), to provide match making opportunities.

CIRCLES OF SUPPORT

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



Shared Living Model: 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. Dan 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 with Technological Supports Model: Lenora's Home

Lenora shares her condominium with two women who also are deaf. They assist Lenora to live as independently as possible despite her multiple disabilities and intensive support needs. Although not everyone with a disability prefers to live with others who do, Lenora enjoys sharing her home with housemates who can communicate with her in sign language. To accommodate hearing impairments, they installed additional equipment such as smoke alarms with flashing lights. Lenora's bed shakes if smoke triggers the alarm. The phone and television display the words being spoken. 🏠



Shared Living with Live-in Supports Model: Eve's Home

Eve sustained a traumatic brain injury as the result of an automobile accident. She lived for three years in a nursing home where she received therapy as well as total physical and nursing care. Her dream was to return to live in her own home. With determination, she worked through intensive physical, occupational and speech therapy to regain some of the abilities that she lost because of her head injury. A team helped Eve plan for the services needed to live in her own home and funded her transition through the I Choose Home NJ program. For more information visit www.ichoosehome.nj.gov.

Through this program and with Medicaid waiver funding, Eve could live more independently in the community. To accommodate her motorized wheelchair, adaptations were made including ramps and bathroom modifications. Because of memory deficits and physical disabilities, Eve could not live alone. Eve hired Olga to live with her. Olga attends to Eve's care needs and household responsibilities. Eve and Olga share companionship with each other and they have developed a close bond. 🏠



SHARED LIVING ALSO KNOWN AS HOME SHARING

As more people find managing the finances of home ownership a challenge, home sharing has gained popularity. Some homeowners have a spare room to rent. An owner may struggle to afford the costs of taxes and property maintenance. Others find it difficult to manage the responsibilities to upkeep a home. They may need assistance with household maintenance tasks. They may be looking for companionship. Those seeking home sharing opportunities may be looking for an affordable place to live and have much to offer as a housemate. Shared living matches these people and their needs.

Agencies exist to match seekers with home providers who are interested in sharing their home or apartment as well as the expenses and responsibilities. These agencies conduct screening and background checks of the occupants. For more information visit www.homesharing.org. On their own or with the assistance of an agency, the home sharers can sign formal agreements delineating the responsibilities of each party. A model contract for shared living is available at www.ancor.org/resources/best-practices.

Potentially, this housing option meets many needs through these matches. For example, a person with I/DD may lease an apartment and want to share expenses with someone who can assist with supports. An elderly homeowner might welcome an able-bodied person with I/DD to assist with household duties. There are endless possibilities. With the assistance of an agency, a more formal prescribed process facilitates this match. For more information visit www.nationalsharedhousing.org.

A Guide for Shared Living specifically for people with disabilities is available at: www.nasddd.org/publications/nasddd-titles-for-purchase/shared-living-guide. Check local requirements because some towns may have ordinances that restrict unrelated persons from sharing/subletting their home.



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. 🏠



Support Families, Teaching Family Homes or Host Homes

A **SUPPORT FAMILY** is a family who is recruited, trained, monitored by a provider agency, and paid to supply long-term care in their home for a person with a disability. Sometimes extended family members provide a support family through kinship care. In other instances, people are recruited who are willing to integrate the person with a disability into their family.

Distinguished from traditional foster care, a Support Family can share parental responsibilities with relatives. The person and their family interview and choose their Support Family. Most often, the person's relatives maintain a strong role in their family member's life. The concept promotes the development of a strong bond between the individual with a disability and the family they join. Support families tend to be long-term in duration.

The Support Family receives training, supervision, respite and assistance from a social services agency that supervises the services. The Mentor Network supplies professional staff in their teaching family homes. In some states like Texas, Support Homes can be funded by a Medicaid waiver to supply wrap-around supports to individuals with intensive medical and behavioral care needs. Pennsylvania calls this model Lifesharing. In New Hampshire, Enhanced Family Care is their most commonly used model. Literature supports that individuals with disabilities, particularly children, respond well in family rather than institutional care. Relatives, birth families and adoptive families can share responsibilities through this family-based alternative. For more information visit www.everychildtexas.org.

In New Jersey, a licensed

- **COMMUNITY CARE RESIDENCE,**
- **TEACHING FAMILY HOME,**
- **HOST HOME OR**
- **FOSTER FAMILY HOME**

is where an individual lives as part of the family of a caregiver who provides training and assistance for that person.



Support Family Model: Dennis' Home

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. 🏠

“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.”

Group Homes

Group homes or community residences are homes shared by residents who receive services from an agency that provides on-site staff 24 hours a day. A provider agency operates a licensed group home, typically serving four to six residents with disabilities. As is the case with many housing options, the makeup of the residents in the group home model may change over time requiring individuals to adjust to housemates leaving and moving into their home.



Group Home Model for John

John loves the group home where he has lived for 10 years.

Three other men in the home have become his friends. John likes the camaraderie. He also likes having peers with whom he can socialize.

They share household responsibilities, take turns cooking, and enjoy eating several meals together each week. Sometimes they quarrel about things but most of the time John likes their companionship. When John prefers time to himself, his own bedroom offers the privacy that he wants. John has many interests. He bowls on a team each week with friends from work.

John grew up in the town where the group home is located. He stops by the local firehouse on Saturday mornings. He knows many neighbors and shopkeepers. John visits the library frequently to learn about local history. He is conversant about the U.S Presidents who summered at the Jersey shore. John's reading ability is limited so a library volunteer reads the reference books to him.

John has intensive support needs and requires assistance with everyday activities. For example, staff are available throughout the day and night to assist him with basic skills of daily living like toileting, bathing and dressing. Frequently, his medical needs become more acute. A nurse visits him on a daily basis. In extreme wintery weather or when ill, John's mobility is limited. In these instances, he particularly appreciates the staff support that he receives and enjoys the company of his housemates. 🏠

Intensive Specialized Group Homes

Individuals with significant medical, intellectual, behavioral or psychiatric needs may require intensive staff supports throughout their day. One model to meet these needs could be an intensive treatment group home with professional supports such as nursing, applied behavior analysis, counseling and therapeutic ancillary services. The primary goal of the intensive specialized group home is to provide needed clinical supports and prepare the individual for a less restrictive living model.



Intensive Specialized Group Home Model: Walter's Home

Walter lived in an apartment with supportive services. He was reclusive, angry and isolated. When support staff arrived, Walter demonstrated aggression towards them. He became aggressive by throwing rocks. Since the program was not equipped for these types of challenges, the staff would respond by leaving without an in-person visit. As a result of being left on his own and without the appropriate support structure, his life consisted of microwave foods and non-stop television. His inconsistent personal care created a serious health concern. He barely slept and paced the house throughout the night. He stopped taking his psychotropic medications and began to decompensate. His family felt helpless as a result of his disruptive behaviors. Because of this, they also were not able to visit him for several years. They located an agency that specialized in serving individuals with complex medical and behavioral challenges. Walter visited their group home and agreed to move there.

The agency prepared for Walter's needs by providing structure and consistency. The agency developed a program with additional clinical support to assist with his transition. They anticipated this to be an extremely challenging transition, since Walter was not accustomed to having this type of structure in his daily routine. Walter adjusted quickly and responded well beyond anyone's expectations. The successful transition led to a very quick, but systematic fading of the enhanced supports and allowing him to generalize into the existing program. With healthy meals and meaningful vocational and recreational activities, Walter felt better. His sleep patterns returned to normal. Walter became close friends with one of his housemates. They both enjoy NBA basketball and attend some of the 76er's home games.

The agency operates three homes serving individuals with similar support needs. They cluster their homes within a five-mile radius so that supportive medical, clinical and supervisory personnel can be shared among the residents. Utilizing Applied Behavior Analysis (ABA), all staff receive extensive training on the principles and practices of ethical and effective behavior support. To figure out why Walter acted this way, staff carefully defined and recorded the frequency, intensity, and duration of his challenging behavior as well as what occurred right before and after the behavior under the direct supervision of a Board Certified Behavior Analyst (BCBA). Then the team generated hypothesis statements regarding the purposes the behavior served for Walter and the likelihood of the behavior occurring or not occurring during various situations. These hypotheses served as the basis of the behavior intervention plan that outlined skills to teach Walter how to meet his own needs and get along with others in more adaptive ways. Staff were trained on the plan's implementation and consistently followed it to prevent and minimize challenging behaviors. Staff's adherence to the behavior plan kept everyone safe and taught Walter more adaptive behavior.

As the behavior program proved to be effective, the agency nurse communicated with his physician to review and adjust his medications with the goal of reducing them as much as possible. A medical practitioner and a psychiatrist consulted with a team of professionals regarding a comprehensive treatment plan maximizing the effectiveness of the behavior program while minimizing the use of medications that could result in more long-term detrimental effects.



Technology in a home permits the clinical staff to observe the person as they interact with staff and residents. When a resident engages in a challenging behavior, the behavior analyst can support the individual and staff during the incident through a remote monitoring system from any location, while not providing undue attention to the episode.

Walter continued to make progress as a result of ongoing behavioral assessment and the use of technology during transitions. Previously, staff noted Walter engaged in aggressive behavior during changes in his routine, especially when they intervened. Following direct observation, the behavior analysts taught the staff how to use antecedent-based interventions such as structuring Walter's daily activities, teaching him how to handle transitions appropriately, and teaching him how to use a watch to signal upcoming changes. These interventions have drastically reduced his aggression and increased his independence in maintaining his own schedule. Walter is eating healthy meals and participating in his daily hygiene routines. He has more opportunities for recreation and socializing with family and friends. 🏠

To learn more about Applied Behavior Analysis as a treatment visit www.autismnj.org or www.asatonline.org.



“Housing First” Concept

The supportive housing movement had its roots in addressing the needs of the seriously mentally ill, chronically homeless population by recognizing lease-based housing and supportive services as separate but of equal importance. A person’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 pertaining to 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 person. Because those 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.

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

www.endhomelessness.org/blog/entry/data-points-housing-first-decreases-re-offending-among-homeless-individuals#.VQTLmmTF90w



“Housing First” Model: Doug’s Home

Doug suffers with post-traumatic stress disorder and dulls his pain through alcohol. Over the years, he has frequently been homeless. A mental health agency reached out to Doug and connected him to much needed services. With a housing voucher, Doug now can afford to rent a small apartment. He attends a medical clinic for health care. Food stamps and the local food pantry supply him with groceries. Members of the local church provide warm clothes and household necessities. He formed a deep attachment to a rescued dog that now shares his apartment. They look after each other. Doug still has a dependence upon alcohol. He finds comfort, however, that he will not be evicted from his home because of his lack of sobriety. Having a stable home is a big first step toward recovery for Doug. 🏠

Supportive Housing Model



Supportive Housing Model: Cynthia's Home

Cynthia spent many years in unstable living circumstances and high cost treatment centers including the state psychiatric hospital and shelter services. She has been homeless and lived with her parents intermittently during difficult times. Cynthia was diagnosed with serious mental illness and addictions since her late twenties. Due to her illness, Cynthia spent years in unstable housing and lived on the streets.

Cynthia received a rental voucher from the Department of Human Services and promptly leased a one-bedroom apartment. She has resided there since 2008. Once her housing situation became stable, Cynthia discovered her talent and passion for art. She supplements her income modestly as an artist. Her income consists primarily of SSI benefits. Cynthia pays 30% of her income towards her rent and the voucher subsidizes the balance of the fair market rent.

Cynthia attends Alcoholics Anonymous meetings to keep sober and avoid drugs. She has reestablished her relationship with her mom and stepdad, who provide ongoing emotional support and guidance. She maintains contact with a therapist and utilizes services in the mental health system. Although she continues to experience symptoms of mental illness, her stable housing, participation in therapeutic mental health services and strong natural support system have assisted Cynthia to lead a happy life. 🏠

BOARD AND CARE HOMES OR SINGLE ROOM OCCUPANCY LIVING ARRANGEMENTS

are licensed in New Jersey by the Department of Community Affairs. A facility rents individual rooms and supplies three meals per day. Some facilities, Residential Healthcare Facilities, provide additional supportive services and physical care. For more information visit www.nj.gov/dca/divisions/codes/offices/roomingboarding.html.

While concern has been expressed by the substandard conditions in many rooming (room only, no meals provided) and boarding homes, families and individuals can research homes that are smaller and provide a nurturing environment. The Montclair Inn, for example, is a 21 bedroom boarding home with common space for tenants, owned and operated by a non-profit organization. The home is located within walking distance of the local town with access to transportation, shopping, jobs and socialization. Seniors and some individuals with disabilities live in the home. For more information visit www.themontclairinn.org.

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 people 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 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 post-secondary education through a teenager's educational entitlement. For more information visit www.thinkcollege.net.



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. 🏠

Living with Family and Receiving In-Home Supports

Living with Family and Receiving In-Home Supports means that a person with a disability receives supportive services delivered within his or her own home while living with family members. Services can include such things as personal care assistance, respite, applied behavior analysis, crisis intervention and tutoring.



Living with Family and In-Home Supports Model: Adam and Dave's Home

Adam and Dave are brothers who live with their parents. With diagnoses on the autism spectrum, these young men are unable to verbalize their preferences. Adam responds to pain by inflicting injury to himself. Dave cries uncontrollably but cannot vocalize what makes him sad. Often, they are unable to find relief from frustrations without others intervening on their behalf. Because of the difficulties that they experience, their parents believe that the best life for their two children is to continue living within the family home. Judging by their demeanors, it appears that Adam and Dave are very happy with their lives, as well.

There have been many challenging events over the years. Dave seeks harmony by his own definition. With a keen sense of hearing, certain words or loud noises provoke Dave. If a situation occurs, Dave wants to resolve it expeditiously. In such instances, Dave paces and shows agitation. If unchecked, he can be aggressive toward other people. He just wants them to stop the behavior that he finds disruptive. Failure to sustain this structured environment quickly disintegrates into a commotion that can escalate into a crisis. Following a traumatic event, both Adam and Dave regress from the progress that they have achieved.



At six feet tall, Adam does not comprehend his own strength. He likes his routine and hates interruptions of his favorite activities. Adam experiences grand mal seizures that can be life threatening. Adam cannot communicate where he feels pain. When in discomfort, Adam injures himself. Adam required hospitalization for several months when his self-injurious behavior threatened his own health and safety. Understanding what Adam communicates through his actions is a key to keeping him safe.

Adam and Dave's parents have wondered, at times, how long they can continue to care for their sons in their family home. Their children do well at home with a structured routine and a consistent approach to their behavioral challenges. They utilize funding from the Community Care Waiver to pay for in-home staff support and therapeutic services. Five staff people supply eight hours of support every day for each of the brothers. Adam has some significant medical conditions and qualifies for additional personal care assistance through the Personal Preference Program (PPP), a state plan service (see page 31.) All caregivers are chosen for their compatibility with Adam and Dave. Being close in age to their staff companions, they share common interests. Dave and Adam have grown to trust these new people in their lives.

Their parents and caregivers receive intensive training in applied behavior analysis. A Board Certified Behavior Analyst (BCBA) developed individualized behavioral support plans for each brother. After careful observation, the plans identify the antecedents that trigger maladaptive behaviors, the target behavior and the consequences that reinforce these behaviors. These plans describe how their caregivers can minimize the likelihood of the target behavior occurring and how to respond instead of react should the target behavior occur. As often as possible, their

parents and caregivers write down how often and under what conditions the target behavior occurs. Then, the BCBA continuously analyzes the data and updates the plans to increase their effectiveness. The implementation of these systematic and dynamic plans minimizes dangerous behavior and helps Adam and Dave maintain existing skills while learning new appropriate skills.

Staff must be very attentive. When Dave encounters someone who does not understand his ways, it can trigger an aggressive response. Caregivers must immediately respond by diverting Dave's attention and using a calming phrase to prevent an altercation. When needed, staff members know how to de-escalate the situation as well as utilize crisis intervention measures.

With the success of these methods, Dave enjoys daily outings in the local neighborhood. With his support worker, he goes each day to the gym to exercise. They shop for groceries and his companion assists him in preparing his own meal daily. Dave goes to the park, the library, the petting zoo, and local events. He loves dining out once a week. Dave works a few hours at a local business to complete clerical tasks by stuffing envelopes and making copies. He also volunteers at the animal shelter. Dave leads a very active life within his community.

Adam loves technology. He plays video games, listens to music and uses a computer tablet proficiently. Being more introverted, Adam struggles to stop using his electronics and engage in integrated activities. His worker uses effective strategies that promote Adam's cooperation when he needs to change his routine. He has a well-prepared plan that identifies the triggers and the interventions to promote Adam's continued safety. For instance, staff makes certain that Adam's hands are busy at all times. When he is holding something, he is less likely to bite his hands. Adam likes to walk through his neighborhood while listening to music. He visits the park and enjoys the activities that it offers.

Their home has many safeguards designed for their protection. Adam and Dave do not recognize danger or know how to respond. Since Dave only sleeps about 4 to 6 hours per night, the family has devices on their exterior doors to alert his parents when he leaves the house. The experience of glass breaking intrigues Dave. Consequently, nothing in the house is made of glass. Even the windows contain plexi-glass. Adam elopes and attempts to jump out of the car while it is running. The car is equipped with childproof locks, and

Adam is transported with two people in the car to ensure that he remains in his seat while the car is in motion.

Living within their family home with supports, Adam and Dave have achieved a high quality of life with fewer disruptions. Their family attributes this success to the great stability accomplished by only a few well-trained people giving support. They have the security of living with their loving parents in the comfort of their family home. For as long as they are able and their children continue to thrive, their parents have made a commitment to keep their sons at home with them. 🏠



Accessory Apartments and Tiny House Movement

ACCESSORY APARTMENTS are living units that are added or created within a single-family home. Sometimes called a “mother/daughter home,” relatives live in close proximity yet have their own private space.

Available in some states, **ELDER COTTAGE HOUSING OPPORTUNITIES (ECHO)** units are small modular cottages. These accessory units can be installed adjacent to a caregiver’s house for people who are elderly or have disabilities. This type of housing is best located on larger parcels of land and may require local zoning approvals.



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 DDD. 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. 🏠

TINY HOUSE MOVEMENT

The concept of tiny houses is growing nationally and internationally. As shown on HGTV and A&E Network’s Tiny House Nation, people 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.homedsgn.com/2014/04/14/22-modern-shipping-container-homes-around-the-world. This micro house idea is applicable for someone 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.





International and American Intentional Community Models



Intentional Communities are founded upon shared values. People with disabilities live together with families or caregivers in homes, campuses or villages in a community setting.

L'Arche Model

Jean Vanier founded the L'Arche Movement in Paris as an alternative to institutions by inviting two people with intellectual disabilities to live in his home in 1964. Today, there is an international federation of over 140 communities in 40 countries subscribing to common values. These faith-based communities adhere to the same founding principle that everyone has equal value. Communal life involves sharing experiences within a "stable, life-giving home environment." Members within L'Arche homes include people with and without disabilities who develop long-term mutually interdependent relationships. Everyone contributes to the home by sharing responsibilities. This worldwide movement received the 2014 Notre Dame Award for International Human Development and Solidarity. For more information visit www.larcheusa.org.

Camphill Village Model

Camphill Village was established more than 50 years ago in Europe based upon the insights of anthroposophy, the spiritual scientific understanding of human beings. Family homes include individuals with developmental disabilities and co-workers who "eat, pray, sing, work, and celebrate together." Co-workers receive no salary demonstrating that everyone exists on an equal plane. All community members care for each other and the earth. Work involves artistic endeavors, farming and crafts as well as household responsibilities. Since 1961, Camphill Village has operated more than eleven communities within the United States and Canada. For more information visit www.camphillvillage.org. Recently, Camphill established a similar assisted living concept for elder care.

Note: As of this writing, the New Jersey Department of Human Services will not permit individuals to use Medicaid Home and Community-Based Services (HCBS) Waiver funding while living in congregate settings such as intentional communities, farmsteads or gated communities.



Community Cooperatives

Community Cooperatives include people living and working together in a community setting such as a farm or ranch.



Community Cooperatives Model: Phil's Home

Phil loves nature and the outdoors. He lives on a seven-acre farm. Students from the local community college, as well as five other young adults with abilities similar to Phil, live together.

They all share responsibilities within the home such as cooking and cleaning and supporting one another. People without disabilities live in the huge farmhouse, as well.

Collectively, they cultivate a large organic garden and raise chickens and goats. They eat healthy whole foods from their crops. With hard work and fresh air, they sleep well at night. When not farming, they create soap from the goat's milk. Birdhouses and picture frames are constructed from repurposed wood. Some people enjoy weaving and make beautiful scarves. On weekends, they sell these products at the local farmer's market. The income generated from the sales helps Phil to pay his living expenses.

The farmhouse is a place of much activity. A local instructor teaches yoga classes. A masseuse provides free massages once a week. On Sunday afternoons, the residents host "high tea" for anyone from the community. They serve an elegant tea with finger sandwiches to the guests in their formal living room. Donations help to offset household expenses.

Interacting with strangers is sometimes difficult for Phil. These public events supply opportunities to become more comfortable in social settings. People are available to Phil when he is faced with a challenge. If it is not a good day for Phil, his housemates can help him through it or cover his responsibilities when necessary.

Phil leads an active social life. He attends classes at the local community college and participates in campus activities. Each week, he volunteers at a local restaurant where everyone pays for their food based upon what they can afford. High school seniors come over to the farmhouse on Friday evenings for pizza, ping-pong and camaraderie.

Phil's mom obtained grants to purchase, renovate and establish housing on the farm. Rent is charged and paid from each person's Social Security income. Phil chooses to work on the farm and earns additional income. 🏠

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

Secure Communities

The term Gated or Secure Communities could be used to describe large complexes with security features designed exclusively for people with disabilities. For example, one project describes itself as a "Unique Residential Lifestyle" featuring 97 affordable "apartment-style" rentals only for individuals with developmental disabilities. The complex offers one or two-bedroom accessible units with amenities such as a swimming pool and community center. Security features include on-call emergency assistance, community security cameras and on site security patrols.

In one such community, some tenants obtain rental assistance vouchers that subsidize the rent of \$550 per month. A projected budget of \$1,200 per month includes rent, utilities, food, clothing and personal spending money. The tenant can purchase supportive services including live-in staff, personal assistance, emergency support, employment and recreational services.

For more information visit www.arcjacksonville.org/village-on-hodges-planned-community.

While there may be cost efficiencies in larger settings, the Centers for Medicaid and Medicare Services resist approval of funding for group living if it secludes tenants with disabilities. When considering a congregate model, opportunities for the integration of people into the non-disabled community must be incorporated into the design.



Funding Sources

Medicaid's Home and Community Based Services (HCBS) Waivers

The **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. In New Jersey for instance, a Community Care Waiver (CCW) could pay for individual supports and supported employment/day habilitation as well as other services. Sometimes these are provided in a program like a group home or an adult day program. For others, an individual may select specific services and contract with providers to receive them.

In New Jersey's CCW as well as the Supports Program through the NJ Comprehensive Medicaid Waiver, individuals must be eligible for DDD services, be assessed to need a certain level of care as well as secure and maintain Medicaid eligibility.

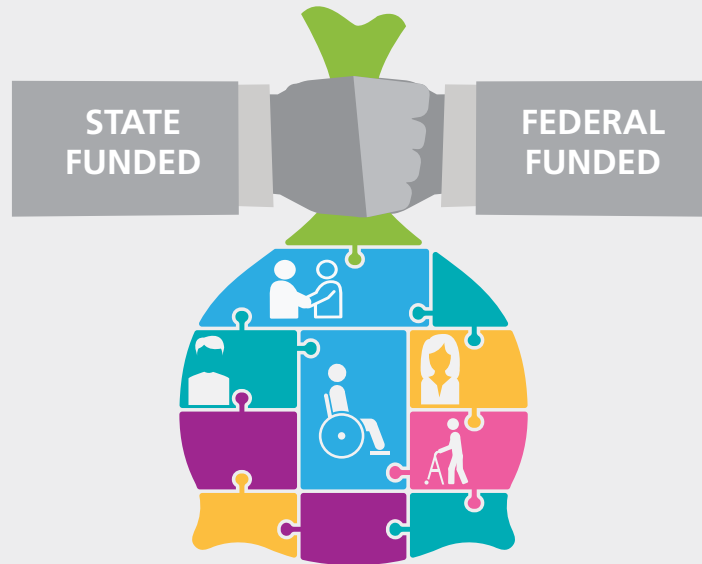
For example, persons eligible for the CCW in New Jersey live with significant intellectual and developmental disabilities as determined by functional assessments and meet the need for an institutional level of care. Individuals not receiving the CCW but eligible for DDD services may be provided a budget that can be used to purchase individualized supportive services as well as day habilitation/employment services. This Supports Program is not intended to fund extensive support needs.

Governmental agencies administer services appropriated by the state. In addition, state dollars combined with federal Medicaid funding supply supports and services through Home and Community Based Services (HCBS) Waivers.

For more information on **ACCESSING SERVICES**, see the flow chart on page 32.

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 support a person who is re-entering the community after a period of institutionalization. Medicaid regulations require that a person can be enrolled in only one waiver program. Someone 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 people of low income living with disabilities, including I/DD. Eligibility for Medicaid can be obtained through several doors. Perhaps most common is through Social Security's Supplemental Security Income (SSI) program, which provides cash and Medicaid benefits to eligible seniors and people 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 New Jersey Department of Human Services

NJ Department of Human Services (DHS) Division of Developmental Disabilities (DDD)

WHAT IS THE NJ DIVISION OF DEVELOPMENTAL DISABILITIES (DDD)?

The Division of Developmental Disabilities (DDD), within the NJ Department of Human Services, is a leading governmental agency supplying of community services for individuals with I/DD. DDD funds all residential services and supports for adults with I/DD within New Jersey through Medicaid funded services. The majority of those served by DDD live at home with their families, may receive supports in their own homes or in unlicensed settings, and may receive supportive services including day habilitation or employment. A smaller number of individuals receive funding to live within licensed community residences, independent and supportive living apartments.

There are limited resources for community-based residential supports for eligible individuals in emergent need of housing or incapable of living with family. The law requires that DDD services be designed to maximize developmental potential and shall be provided in a manner which is least restrictive of each person's personal liberty (N.J.S.A. 30:6D-9). DDD can assign people to waiting lists for the waiver when services are not immediately available.

For Medicaid and DDD eligible recipients who have been assessed to be in need, DDD has regulations to serve a person more quickly in an emergency. Service options depend upon the available resources. It is important that individuals have an understanding of DDD's most current regulations particularly those related to an emergency. For more information, go to www.nj.gov/humanservices/ddd/news/publications/divisioncirculares.html.

Circumstances may change where individuals urgently need residential services before reaching the top of the Community Care Waiver waiting list. If an emergency exists, it is up to the family to bring the situation to the attention of DDD. This state agency will determine, if an individual's circumstances meet their criteria of an emergency. If it does, the person will be moved to the top of the list to receive services. If there is disagreement about whether an emergency exists, whether services offered meets the emergency standard, or whether the long-term supports are adequate, the consumer can appeal DDD's determination.

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

WHO IS ELIGIBLE TO APPLY FOR DDD SERVICES?

Adults age 21 and older can be eligible to receive services under DDD when they meet the functional criteria of developmental disabilities, are legal residents of the US and NJ, and are eligible for Medicaid. The definition of I/DD is as follows:

- Diagnosis of a physical or mental impairment including but not limited to autism, intellectual disability, cerebral palsy, epilepsy, spina bifida or neurological impairment;
- A severe and chronic disability must manifest before the person reached age 22 and is expected to be lifelong; and
- Difficulties in at least three areas of life activities including self-care, learning, mobility, decision-making, and communication including receptive and expressive language, economic self-sufficiency, and independent living.



SUPPLEMENTAL SECURITY INCOME (SSI)

SSI is a federal program that provides monthly cash payments to eligible children and adults in need. In New Jersey, 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, a person must be eligible and maintain eligibility for Medicaid benefits. There are four common ways for a person with a disability to obtain Medicaid. The most common is through receiving Supplemental Security Income or SSI, which includes Medicaid benefits. The other three ways are 1) Disabled Adult Child (DAC) Status, 2) Community Medicaid, and 3) New Jersey Workability.

For more information about applying for Social Security and Medicaid, go to www.state.nj.us/humanservices/ddd/services/medicaideligibility.html.

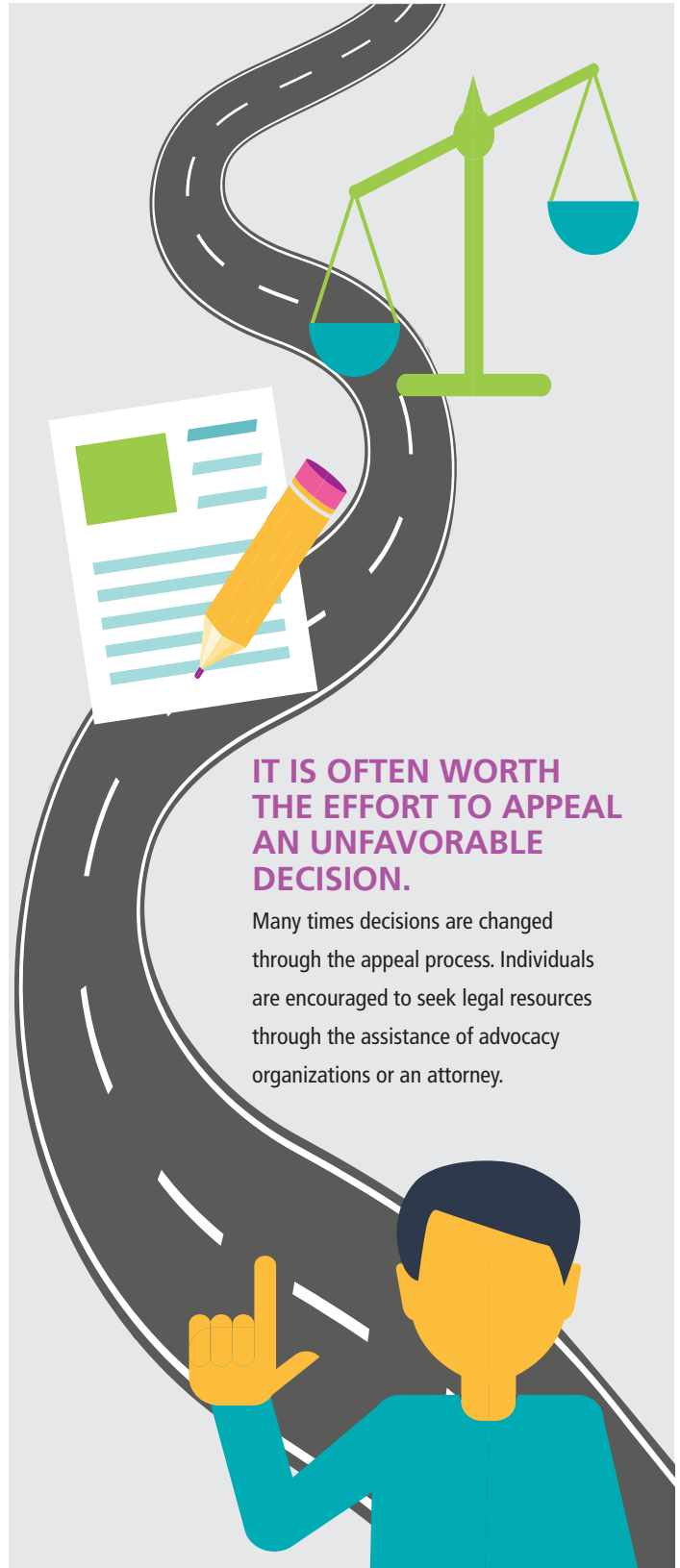
HOW DOES SOMEONE APPLY FOR DDD ELIGIBILITY?

To begin the process, a person can file an application for services at the local DDD office. For the DDD Intake Package Application go to www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/Intake%20Package%201-30-14.pdf.

An intake worker will interview the person and his/her family and gather the information needed to determine eligibility for DDD services. Necessary documentation includes information about the person's functional abilities, Social Security card, Medicaid eligibility and diagnosis of a disability. In addition, DDD 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, DDD 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?

In most instances, when a government agency makes a decision to deny a service, the person affected is entitled to appeal the denial of that decision. The notice of denial should include information about how to file an appeal. In DDD, the person will have the opportunity to attempt to resolve the dispute at a settlement conference. If the settlement conference is unsuccessful, the appeal will be referred to the Office of Administrative Law for a hearing before a judge.



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

Many times decisions are changed through the appeal process. Individuals are encouraged to seek legal resources through the assistance of advocacy organizations or an attorney.



What services can be funded through Medicaid waivers?

A wide variety of services and supports can be funded through a Medicaid waiver through hiring of staff from approved provider agencies or self-hires (self directed employees). Each waiver has its own regulations and service definitions. For a full explanation, these waivers can be found on the internet.

Go to www.nj.gov/humanservices/ddd/programs/supports_program.html for information about the Supports Program and the related policy manual.

Go to www.nj.gov/humanservices/ddd/services/ccw/index.html for information about the Community Care Waiver (CCW).

WHAT ARE THE MEDICAID WAIVERS IN NEW JERSEY?

There are a few waivers administered by different entities of state government. Each has different eligibility criteria and a menu of supports. An individual can only enroll in one waiver at a time.

COMMUNITY CARE WAIVER (CCW) ADMINISTERED BY DDD

New Jersey's Division of Developmental Disabilities administers the Medicaid **Community Care Waiver (CCW)** to pay for specific services that are needed so individuals with I/DD can live in the community. The CCW is reserved for people who require the most intensive levels of support. This Medicaid waiver funds most licensed residential programs and supported living services to those with I/DD. For more information visit www.nj.gov/humanservices/ddd/home/. These services can be obtained through one or more service providers selected by the individual.

For a fact sheet on CCW go to www.nj.gov/humanservices/ddd/documents/Documents%20for%20Web/CCW%20Renewal%20FAQs.

SUPPORTS PROGRAM ADMINISTERED BY DDD

Through the Supports Program adults with I/DD, who live with their families or in a non-licensed setting, can access Division-funded supports from a list of eligible services. For more information visit www.state.nj.us/humanservices/ddd/programs/supports_program.html. Such services are generally individual-directed with a menu of options accessed through the assistance of a Support Coordinator.

IS THERE A WAITING LIST FOR WAIVER SERVICES?

Yes, most waivers have a waiting list. For instance, a waiting list exists to receive more comprehensive services through DDD's Community Care Waiver (CCW). A person may also be eligible for other waivers that exist such as the Managed Long Term Services and Supports (MLTSS) described below. After an assessment is completed, a person may qualify for these intensive supports. If services are not available, a person may be assigned to a waiting list for waiver services. Services are distributed based upon funding initiatives, available resources and/or the assessment of a person's level of care needs.

DDD's Community Care Waiver is the most comprehensive source of funding for residential supports or services, and there is a lengthy wait for these services.

The Supports Program is another means of obtaining limited supports while living at home with family or in your own home. Previously, many people placed their name on the waiting list as soon as they were eligible and waited for a group home or supervised apartment placement. Today, eligibility for Medicaid is a pre-requisite for obtaining any services from DDD. Individuals must have Medicaid and meet an institutional level of care to qualify for these intensive long-term supports. Individuals wait for waiver funding to obtain individual support services in their own home, in their family home or in a licensed community residence. In circumstances where DDD determines that a Medicaid recipient's circumstances meet the criteria of an emergency, the individual may receive services regardless of their position on the waiting list. For more information go to www.state.nj.us/humanservices/ddd/services/ccw/ccwwl.html.

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



THE NEW JERSEY COMPREHENSIVE ASSESSMENT TOOL (NJCAT) is the assessment tool used by the New Jersey Division of Developmental Disabilities (DDD) to determine the abilities and needs of a person with I/DD in many areas including medical, behavioral and self-care needs. States use such instruments to document a person's level of service need, determine the individual budget to fund supports and promote fairness in the funding process. The assessment is an important document measuring a person's abilities at a particular moment in time. It substantiates the individual's need for assistance and supports. The assessment determines the commensurate funding that may be available for services and supports. Inconsistency among reporters' descriptions of a person's abilities can affect the accuracy of the assessment. Consequently, the assessment should be completed by those who know the person well. Ideally, the assessment should be done collaboratively involving the individual, if able, the family, and the service provider(s). If the results of the assessment do not seem to match with the individual's level of need or if the level of need has changed, re-assessment can be requested through the Intake Director in DDD's Community Services Office serving the region in which the individual resides. For a short video describing the assessment process, go to www.youtube.com/watch?v=nluCS05kFWk&feature=youtu.be.

INDIVIDUAL BUDGET - a sum of funding that may be available for a person with I/DD based upon an assessment of their needs and abilities.

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.



MANAGED LONG TERM SERVICES AND SUPPORTS (MLTSS) PROGRAM ADMINISTERED BY DMAHS

New Jersey residents with Medicaid, who are living in institutions or nursing homes for more than 90 days, may qualify for this program under the Managed Long Term Services and Supports (MLTSS) program within the NJ Comprehensive Medicaid Waiver. The person must meet financial criteria and be assessed to require a “nursing home level of care.” Services are planned so that the person has a smooth and successful transition moving back into a home of their own. A person requiring too little or conversely too much support may not qualify for the program.

An interdisciplinary team works with the person to develop an individualized plan of care based upon his/her needs. Funding for in-home services might include home health aides, adult day care, transportation, behavioral health care and meal delivery. Personal income such as Social Security benefits must pay for living expenses and housing.

Go to www.nj.gov/humanservices/dmahs/home/mltss.html for information regarding the MLTSS Waiver.

NJ Department of Human Services Division of Medical Assistance and Health Services (NJDMAHS)

The Division of Medical Assistance and Health Services (DMAHS) administers the state- and federally-funded Medicaid and NJ FamilyCare programs for certain groups of low-to-moderate income adults and children.

MLTSS or Managed Long Term Services and Supports refers to the coordination of the waivers for people with higher levels of medical care needs administered through the Division of Medical Assistance and Health Services. The **NJ Comprehensive Medicaid Waiver** encompasses four previous waivers called Global Options for Long-Term Care (GO); AIDS Community Care Alternatives Program (ACCAP); Community Resources for People with Disabilities (CRPD); and, Traumatic Brain Injury (TBI) Waiver that now operate within one managed care system.

These Medicaid funded long-term care and home and community-based services are overseen by Managed Care Organizations (MCO). An MCO is also known as Health Management Organization (HMO). They approve and coordinate all community-based services as well as acute and primary health care. People who qualify for a nursing home level of care must meet the clinical and financial guidelines for MLTSS. Funding is determined based upon an assessment and person-centered planning.

These comprehensive supports could be provided in-home, in an assisted living facility, in community residential services, or in a nursing home as long as the person meets the standard of care for this waiver. A person cannot receive MLTSS and DDD services at same time.



State Plan Services

WHAT ARE THE “STATE PLAN SERVICES” IN NEW JERSEY?

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 and such. No waiting lists exist for state plan services. The MCO/HMO however must assess and approve that there is a medical necessity for the services and they will determine the number of hours that an individual can receive.



NJ Department of Human Services Division of Disability Services (DDS)

The Division of Disability Services (DDS) serves as a single point of entry for people seeking disabilities related information and referral. DDS administers services that support people with different types of disabilities to live more independently in the community.

PERSONAL PREFERENCE PROGRAM (PPP)

Personal Preference Program (PPP), a State Plan Service is administered under the auspices of the NJ Division of Disability Services, PPP is a state plan service that can be utilized separately or in combination with waiver services. The PPP permits Medicaid recipients more choice in obtaining Personal Care Assistance (PCA) services. Personal Care Assistants perform non-emergency, health related tasks to assist with activities of daily living (ADLs) such as bathing, dressing, meal preparation, and light housekeeping. These tasks must be essential to maintain a person's health and comfort. Individuals can contact their MCO to start the enrollment process. For more information go to www.nj.gov/humanservices/dds/services/ppp/index.html.

Given a monthly cash allowance, individuals work within a budget to hire Personal Care Assistants directly or through an agency. Individuals with intellectual disabilities can identify a representative to assist with making decisions to implement

the plan. PPP also includes Fiscal Management (FM) services to help individuals with the financial aspects of the program. The Fiscal Management handles all payroll responsibilities for participants and acts as a bookkeeping service.

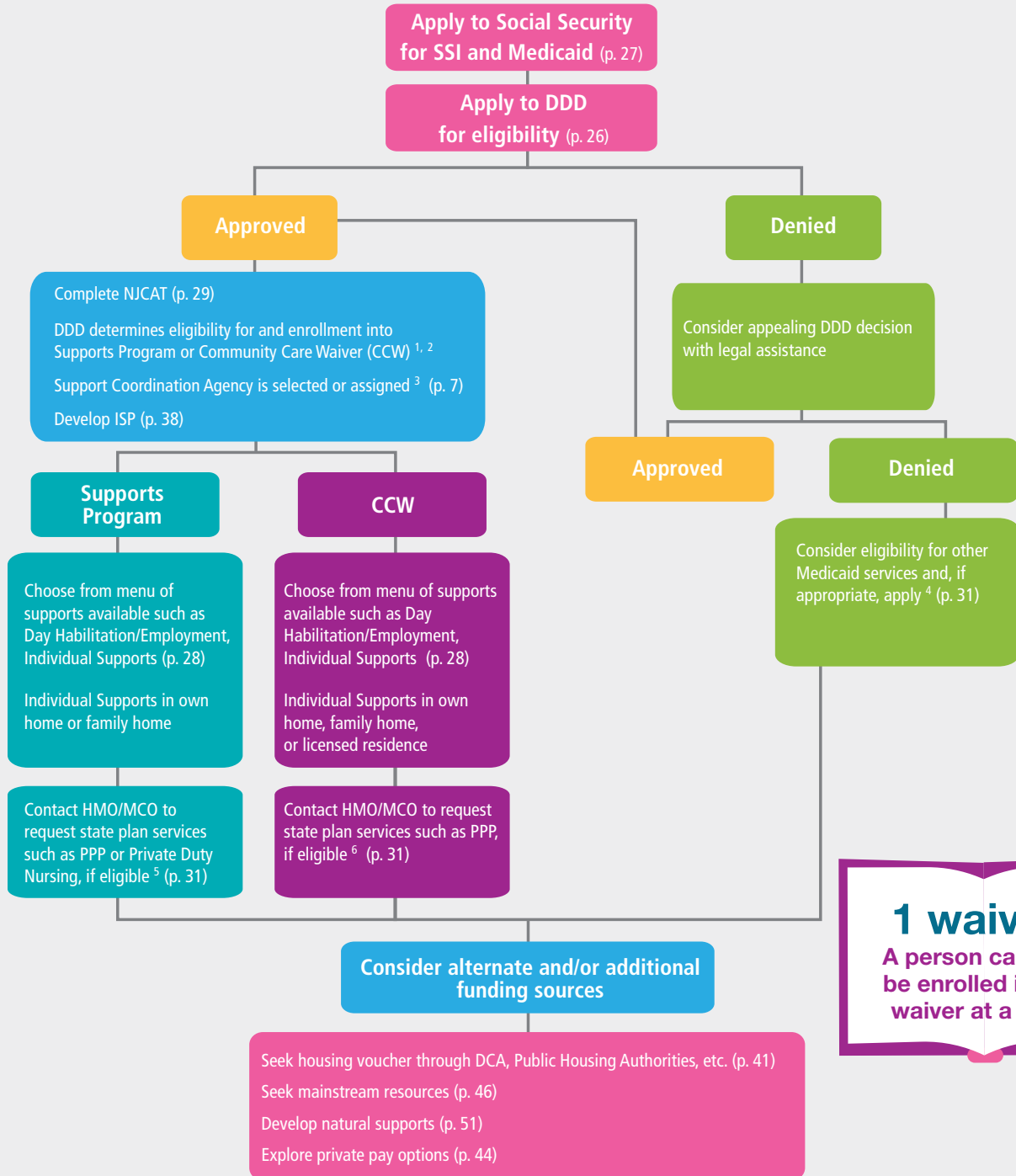
The PPP requires greater individual responsibility while providing more control, flexibility and choice over the services received. PPP also pays for environmental modifications, equipment, appliances or technology that enhance independence.

Regarding eligibility, a person must have Medicaid, qualify for needing Personal Care Assistant Services (PCA) for at least six months and be able to self-direct services or choose a representative who can act on their behalf.

PERSONAL ASSISTANCE SERVICE PROGRAM (PASP)

Personal Assistance Service Program (PASP) is another state plan service that supplies up to 40 hours per calendar week of personal care assistant services to support adults with disabilities going to work or school. Additional hours of services may be approved on a case-by-case basis, based upon exceptional circumstances. Individuals are responsible for directing their own services that can include assistance with activities of daily living like bathing and dressing as well as housekeeping, cooking, shopping and using transportation. For more information visit www.nj.gov/humanservices/dds/projects/pasp/.

FUNDING FOR LONG-TERM CARE



¹ Currently, the demand for CCW enrollment exceeds capacity. Unless there is an emergency, there may be a multi-year wait before accessing services through the CCW.

² Individuals who are eligible for the CCW may access the Supports Program while waiting for CCW services (p. 31).

³ Some individuals may still be working with case managers. Going forward, virtually all individuals will eventually transition to Support Coordination Agencies.

⁴ If a nursing home level of care is met, Managed Long-term Services and Supports (MLTSS) waiver or state plan services may be an option. For more information (p. 30 and 31).

⁵ No state plan service(s) can be used that are duplicative of services received on the Supports Program.

⁶ No state plan service(s) can be used that are duplicative of services received on the CCW.

MEDICALLY ORIENTED SUPPORTS

HEALTH HOME



Health Home refers to how medical, behavioral and mental health issues are all interconnected when implementing a robust plan of care. A health home addresses all issues concurrently in the context of health and wellness. The various medical practitioners work in coordination with all interdisciplinary team members to develop a comprehensive treatment plan for the person with special needs. Health Homes are Medicaid reimbursable and have been piloted in New Jersey in several counties. For more information visit www.npaonline.org/website/article.asp?id=12.

SKILLED NURSING



Skilled Nursing Care or Nursing Homes are licensed facilities regulated by the state's Department of Health. They provide skilled nursing for those who require intense medical care. Such facilities provide 24 hour per day nursing care to frail or medically complex residents on a long or short-term basis. Individuals with disabilities require a Pre-Admission Screening and Resident Review (PASRR) prior to entering a Medicaid certified nursing facility to determine the appropriateness and identify any in-home or community placement alternatives. MLTSS must be approved for long-term care by the MCO/HMO.

ASSISTED LIVING



Assisted living serves adults who are elderly or have disabilities and do not require skilled nursing care. These facilities provide a combination of personal supports, assistance with activities of daily living and health care. Residents are encouraged to maintain as much independence as possible, pursue personal interests and sustain relationships with family, neighbors and friends. The individual must be approved for MLTSS and can only receive services from one waiver at a time.

Supports vary depending upon a person's needs, desires and the amenities offered at each location.

Typically, services include **staff assistance, meals, transportation, housekeeping, medication administration, nursing and medical care as well as social and recreational activities.**

Costs and insurance reimbursements vary according to the facilities. The New Jersey Department of Health licenses and inspects assisted living facilities.

Note: Assisted Living cannot be funded through a New Jersey Department of Human Services Home and Community Based Services Waiver.

NJ Statewide Transition Plan (STP)

CMS “FINAL RULE” AND NJ STATEWIDE TRANSITION PLAN

What does the CMS “Final 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 also be provided in the most integrated settings appropriate to the needs of the person. Settings that tend to isolate people 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-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/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 people 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.

NJ Statewide Transition Plan (STP)

New Jersey's plan declares that, “HCBS settings must provide opportunities for individuals to: seek employment and work in a competitive and integrated environment; engage in community life and control personal resources with the same

access to the community as people not receiving Medicaid HCBS. The setting must promote individual initiative, autonomy, and independence in making life choices.”

For more information visit www.state.nj.us/humanservices/dmahs/info/hcbs_trans.html.

All individuals receiving HCBS waiver services must have full access to the benefits of community living like others without disabilities and have the opportunity for choice, privacy, community integration, landlord tenant protections and the ability to select supportive services based on individual needs.

What are some of the implications of the STP for housing?

DDD has made a tangible commitment to diversify housing options for individuals with developmental disabilities and expand community-based options. The STP submitted - but not yet approved - includes a “Community Integration Review” process to gather relevant information for all new settings. The STP limits the number of individuals with disabilities who can live together and discourages certain settings.

- Community residences for individuals with intellectual and/or developmental disabilities will typically have a level of service of no more than four. However, this can be expanded to more than four for programmatic reasons with prior approval by DDD.
- Each individual served in any setting, regardless of size, shall be integrated into the community to the maximum level possible, based on their individual abilities, preferences and needs.
- Multiple programs cannot be co-located (a waiver of this prohibition may be granted based on clinical need).
- Gated or secure communities as well as residential schools are discouraged from consideration as home and community based and must be subject to a heightened scrutiny process to secure CMS approval for individuals using HCBS funds.

All settings, existing and new, must comply with the HCBS Final Rule. The site-specific assessments to be conducted by DDD will determine whether each existing setting complies with the State's Transition Plan. For existing sites, the size of the site, in and of itself, will not be the sole determinant of compliance with the regulations.

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

What is the status of the STP?

When the NJ Department of Human Services (DHS) requested public comment on the first draft of the STP, more than 1,000 stakeholders commented. Hundreds of families requested more flexibility for individuals with special needs to choose settings they needed or wanted. DHS revised the STP to assess existing settings for compliance. The State Density Review was eliminated and replaced with a Community Integration Review which will look at a variety of factors, including individual experiences, in determining whether a setting is truly home and community based. As of this writing, CMS approval is pending.

The state has until 2019 to bring all HBCS waiver funded services such as CCW, MLTSS and the Supports Program into full compliance, and DHS has taken substantial measures to implement the policies in the STP as submitted in preparation for this deadline.

The DHS will likely adopt regulations incorporating these policies as requirements. Thus, when considering housing and vocational options to be funded by Medicaid waivers, one should be well informed of the current state requirements and any changes that may have occurred since the writing of this publication.

To learn more about the New Jersey Statewide Transition Plan go to www.state.nj.us/humanservices/dmahs/info/hcbs_trans.html.



MORE ABOUT THE CMS "FINAL RULE:" MANDATE ON INTEGRATION

Beth Miller of The News Journal reported that some people see a group home "as a sequestered environment, exactly the kind of thing the nation is trying to leave behind as it promotes community-based life for all. Others see such options as a welcome, sustainable alternative for those who may need support but still want a place of their own." The Centers for Medicare and Medicaid Services (CMS) released guidance regarding its final rule concerning isolation in institutional settings and describing what federal funds will support in the future. Each state receiving HCBS waiver funding must submit and implement a transition plan by 2019 that identifies how the state will bring all of its waiver-funded services into

compliance. Miller states that CMS is "steering everything toward independence, choice, and community integration. Anything that looks or functions similar to an institution will have to prove it is no such thing to be eligible for future home and community-based funding. The new rules reflect the mandates of the Americans with Disabilities Act (1990) and the subsequent 1999 U.S. Supreme Court ruling known as Olmstead, which said that people with disabilities have the right to full access to the benefits of community living and the opportunity to receive services in the most integrated setting appropriate." For more information visit www.delawareonline.com/story/news/local/2014/10/31/conference-focus-innovative-neighborhoods/18234271.



Other Governmental Agencies

Other governmental agencies **within the New Jersey Department of Human Services (DHS)** may have resources that a person with a disability may access. If a person has a developmental disability with a secondary condition such as blindness, deafness, mental illness, are aging or have a physical or medical disability, other agencies may have services from which the individual can benefit.

NJ Commission for the Blind and Visually Impaired (CBVI)

CBVI provides a wide range of educational services, vocational rehabilitation services as well as independent living services for New Jersey residents of all ages who live with blindness or visual impairment. CBVI also offers a number of special programs that address specific needs of people with this disability. Depending on family income, some people who apply are required to pay a share of the cost of programs or services.

NJ Division of Deaf and Hard of Hearing (DDHH)

DDHH serves New Jersey residents who are deaf or hard of hearing by providing advocacy, employment and vocational opportunities and by assisting with a wide variety of social, legal, medical, educational and recreational issues. DDHH administers New Jersey's primary sign language interpreter referral service, provides assistance through an information

and referral hotline and publishes a monthly newsletter. DDHH distributes text telephone equipment and voice carryover phones to assist individuals in their daily activities.

NJ Division of Aging Services Program of All-Inclusive Care for the Elderly (PACE)

is a Medicare funded program for frail individuals ages 55 and older that supplies comprehensive medical and social services in a community-based center and in the person's home to avoid the need for nursing home care. The PACE® model is based upon the belief that elderly individuals with chronic health conditions are better served in the community whenever possible. An interdisciplinary team of professionals meets regularly with each participant to plan to address his/her needs. Services may include primary medical, dental, and nursing care; prescription medications; adult day health care; in-home personal care services; nutrition services; transportation; and in-patient and nursing home care if needed.

There are limited geographic areas where PACE is available. Participants must reside in the service area of a PACE organization to be enrolled in this service. The elderly person attends the PACE Center a few times each week where they can receive medical care, rehabilitation, social activities and dining. Medicaid, Medicare or private payment can pay for these services.

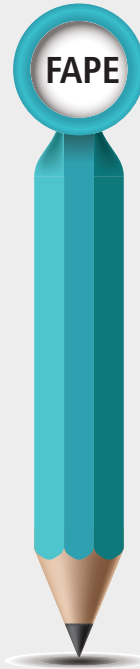


NJ Division of Mental Health and Addiction Services (DMHAS)

DMHAS provides public mental health services to individuals with serious mental illness and addictions through provider agencies statewide. As part of a settlement agreement with Disability Rights New Jersey, this Division has been developing more supportive housing arrangements generally with a combination of housing vouchers and access to supportive services. Individuals with greater needs may be discharged from state psychiatric hospitals into supervised apartments and group homes referred to as “legacy homes.” Services will be funded through the Community Support Services Rehabilitation Program delivered by community provider agencies statewide. Rental assistance vouchers will be administered and managed by the Supported Housing Connection for eligible individuals.

Many other social service organizations recognize that having the security of a safe place to live is crucial to a person recovering from a mental illness. Individuals with mental health conditions need a full array of supports in order to seek recovery. In addition to locating affordable housing and supportive services, people need employment, education, health and wellness, transportation and medication supervision. Periodically, individuals experiencing de-compensation may need additional supports such as food preparation, medication administration, and housekeeping. The intensity of a person’s needs dictates the level of supports that they require at any given time. DMHAS serves people with serious mental illness and addictions; however, there are programs and services addressing co-occurring diagnosis for persons with both developmental disabilities and mental illness.

Self-help and family support groups such as the National Alliance on Mental Illness supply information, education and advocacy www.naminc.org.



WHAT SERVICES ARE AVAILABLE FOR CHILDREN?

All children, including children with a disability, are entitled by law to a Free Appropriate Public Education that is designed to meet their individual needs. In some instances when a child’s educational needs cannot be met within a local school setting, the local educational agency funds a placement within a residential school to meet the child’s educational needs. Educational entitlement ends after the school year following the person’s 21st birthday.

For the New Jersey Department of Education’s *Parental Rights in Special Education* booklet go to www.state.nj.us/education/specialed/form/prise/prise.pdf.

At the age of 18, an individual or guardian can apply to DDD to be determined eligible for DDD services as an adult. The Department of Children and Families is responsible to provide all direct services (residential, in-home, behavioral, family support, etc.) until age 21 and has their own requirements for eligibility and service delivery.



Assuring Quality

The purpose of this housing guide is to describe traditional and innovative ways in which to receive housing and residential supports. Individuals and guardians make many more choices and decisions regarding how they or their loved ones receive services. It is important to know the options that exist and continuously evaluate service delivery quality.

The size and location of the home can affect isolation. It is important to consider elements that influence the quality of life. Do I feel safe and have access to the services I need? Do I have caring people nearby? How many will be living together? Who signs the lease? Is the service provider also the property owner? What happens if I am not happy with a staff member? Who hires/fires the staff? What opportunities exist to interact with people who do not have disabilities? These components are important in deciding what model works best.

These factors alone are not sufficient to determine satisfaction. There are elements of quality that must be evaluated by each person and extend beyond these individual features. For some, living in their own scattered site apartment is an ideal situation. For others, it might be lonely, if there are not enough opportunities to have meaningful interactions with friends. For others, living with friends in a small communal setting can be very satisfying, particularly if they can choose their housemates. If choices are available, the individual and his family or advocates should research the options to decide which types of supports and settings best suit him/her.

Having a stable service provider that respects self-direction and choice is very important. The CMS Final Rule on Home and Community-Based Services (HCBS) listed factors that could lead to isolation. This list intentionally consists of

settings that include more individuals with disabilities than the population as a whole. The intention behind this position is so that "HCBS programs provide full access to the benefits of community living and offer services in the most integrated settings." For more information visit www.state.nj.us/humanservices/dmahs/info/hcbs_trans.html. CMS and the NJ Department of Human Services will not fund services that do not comply with these requirements. Choice and community integration are values held dear by people within the disability community and one essential means of measuring quality. Ultimately, each person must decide what he/she prefers and evaluate the quality based upon his/her own criteria. Resources are available to assist individuals and their families to identify quality indicators in residential services. For example, you can contact Autism New Jersey's Helpline 800.4.AUTISM or information@autismnj.org for a list of quality indicators in residential settings. Several toolkits and resources are also available and referenced in the Appendix.

Not all residential settings require a license. There are advantages and disadvantages of licensing. In a provider operated setting, the oversight by a state license offers some basic assurance of quality as well as recourse, if dissatisfied. Some individuals feel it is an imposition to meet the many tedious requirements of having a licensing inspection of their living quarters. To assess quality, individuals and their families must determine what factors are important to them, assess what they are receiving and advocate for improvements that are needed. Each person measures quality of life objectively and subjectively based upon one's own perspective. What factors/questions/services are important to you and your loved one? Through a Person Centered Planning process, each person develops an Individualized Service Plan (ISP) that identifies his or her goals and objectives. This document can serve as a basis upon which to evaluate quality of life.

"Recharge your batteries by taking care of yourself. Don't be too proud to ask others for help."

Finding Affordable Housing

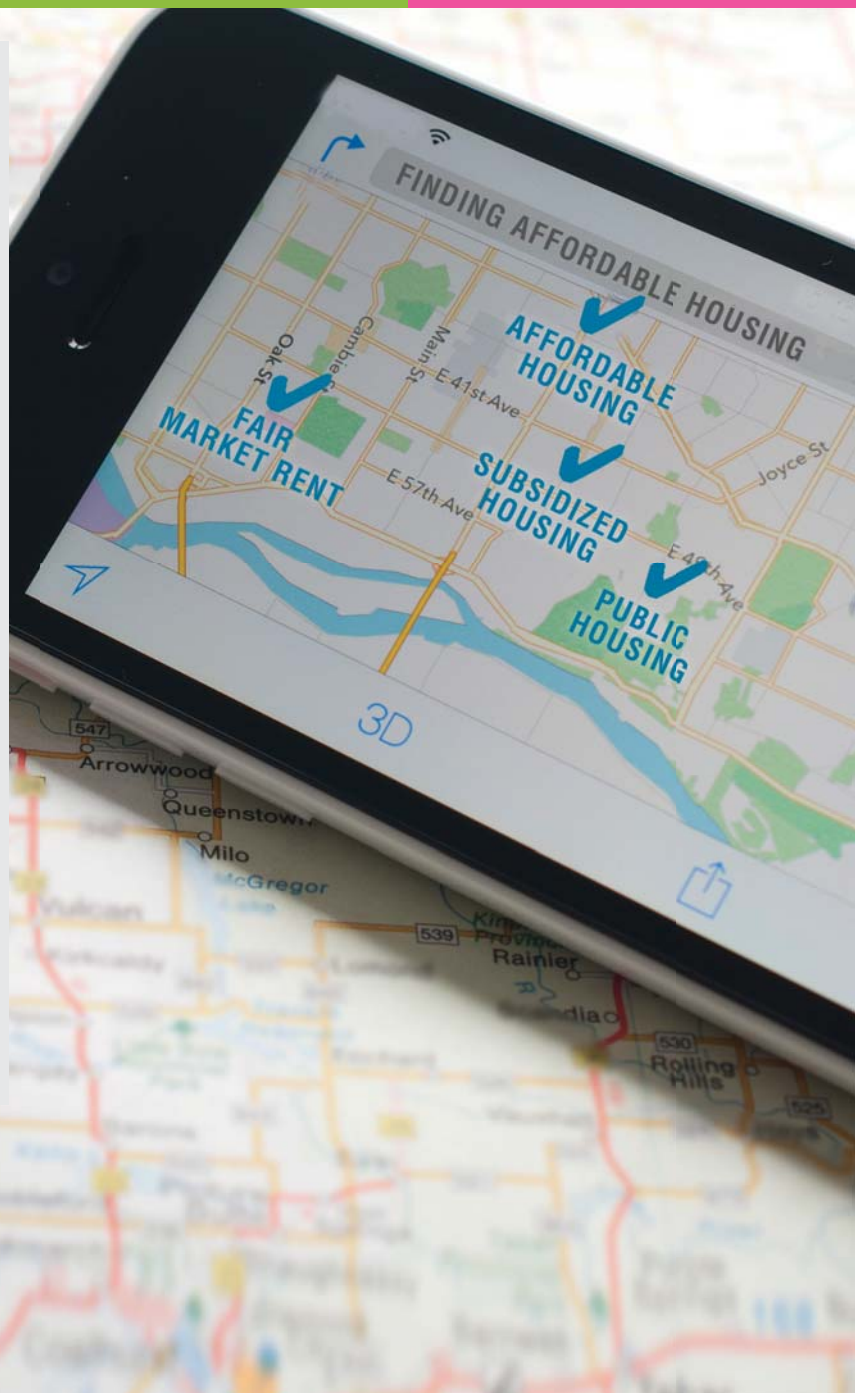
MANY ROADS CAN TAKE YOU THERE....

Affordable housing represents public and private sector efforts to assist people with low and moderate-income to lease or purchase housing. As a guide, a person 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 people with disabilities, of low-income, and the elderly. 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 www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/pha/contacts/nj.

Subsidized housing means housing that has supplemental funding from federal, state, county or local government to assist people 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. New Jersey has several rental assistance programs.



Rental Subsidies

Many programs exist to help people with limited income secure affordable housing. Housing vouchers, for instance, provide a supplement so that the person 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.

These rental assistance programs are available with federal and state funds often called HUD's federal **Housing Choice Voucher** (Section 8) or **State Rental Assistance Program** (SRAP). The state's Department of Community Affairs, county social services offices and local housing authorities administer these vouchers. Vacancies and opportunities fill quickly; households can only apply for housing assistance when there is an open waiting list.

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 person has a disability. This includes people with mental illness and intellectual and developmental disabilities. Frequently, preference is given to people with special needs such as veterans, the elderly or someone with a disability. A person can be on several waiting lists simultaneously.

The Department of Human Services also offers "Sponsor-based rental assistance" to eligible individuals managed through the Supportive Housing Connection. www.nj.gov/humanservices/ddd/documents/houing_assistance_policy.pdf.

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

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 people in the household, the annual gross income, available assets, citizenship status and criminal background. Federal tenant-based vouchers are portable across state lines.

TENANT-BASED RENTAL ASSISTANCE



SEARCH

People use tenant-based rental assistance to secure affordable, decent, safe, and sanitary housing in single-family homes, condominiums, townhouses or apartments. The recipients of this subsidy locate their own rental housing and sign a lease with the property owner. Both parties are required to meet the terms of that lease. The landlord must also sign an agreement accepting the terms of the voucher program. The rents must be determined reasonable as compared to rental rates in that community.



AGREE

The landlord must agree to the terms of the program that includes meeting basic health and safety standards and submitting to an inspection of the property. The Public Housing Authority (PHA) pays the rental subsidy directly to the property owner. Tenants pay their share of the rent directly to the landlord.



ELIGIBILITY

The PHA determines eligibility for a voucher based upon the family size, annual household gross income, assets and citizenship status. The tenant must also report changes to income and household membership. If determined no longer eligible, the family could lose its subsidy.

Federal Housing Choice Vouchers and NJ State Rental Assistance Program (NJ SRAP)

People with disabilities may also receive a preference or priority consideration in obtaining a housing voucher based upon their disability. When contacting the NJ Department of Community Affairs, the county, or the local public housing authority about rental assistance, also ask about “set-aside” opportunities. These are vouchers reserved for people with disabilities. It is advantageous for a person to apply and have their name placed on multiple waiting lists for low-income housing and rental subsidies.

How to Locate Rental Assistance Vouchers

Periodically contact the **NJ Department of Community Affairs (DCA) Customer Services at 609.292.4080** to see if any waiting lists are open.

To locate the agency in each county, usually called the **Board of Social Services**, go to www.nj.gov/humanservices/dfd/programs/njsnap/cwa/.

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 **Public Housing Agency** to locate low-income housing options in each county or municipality. For a list of New Jersey's public housing entities go to www.hud.gov/offices/pih/pha/contacts/states/nj.cfm.

HUD publishes a **Fact Sheet on Housing Choice Vouchers** at www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/about/fact_sheet.

To locate HUD **Housing Choice Voucher** (Section 8) housing inventory go to www.portal.hud.gov/hudportal/HUD?src=/states/new_jersey.

For more information on The New Jersey Housing and Mortgage Finance Agency's (HMFA) Supportive Housing Programs, contact: 609.278.7521 or visit www.NJhousing.gov.



VOUCHER

If a voucher is not readily available, the person/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 people who are homeless, displaced or currently paying more than 50% of their income toward rent. These eligible people 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 [www.portal.hud.gov/hudportal/ HUD?src=/program_offices/public_indian_housing/programs/hcv/about/fact_sheet](http://www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/about/fact_sheet).



LIST

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 person'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 people 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 www.huduser.org/DATASETS/lihtc.html. People 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 described as follows.



Rental Resources

HOUSING RESOURCE CENTER (HRC)

The New Jersey Housing Resource Center (HRC), located on the web at www.NJHRC.gov is a free service for people searching for affordable housing and property owners looking to lease housing. The HRC website, created by the NJ Housing and Mortgage Finance Agency (HMFA), provides a central location for people to search for accessible and affordable housing that is for rent or sale in New Jersey. People without Internet access may call the bilingual toll-free number 877.428.8844 for help in using this service.

SUPPORTIVE HOUSING CONNECTION (SHC)

The **Supportive Housing Connection** is a partnership between the New Jersey Housing and Mortgage Finance Agency (HMFA) and the New Jersey Department of Human Services (DHS), formed to administer DHS rental subsidies to individuals served by DHS. This entity provides unit referrals, administers DHS rental subsidies, inspects rental units and responds to inquiries regarding disputes with property owners. For more information visit www.njhousing.gov/dca/hmfa/rentals/shc/index.html or www.state.nj.us/humanservices/providers/housing.

The Supportive Housing Connection will provide:

- Landlord outreach and training
- Rental and other housing assistance
- Unit referrals and inspections
- Resident inquiry resolution services

Ownership Resources for Individuals with Disabilities

Programs exist to help people 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 people 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 people 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 homebuyers. With home ownership come additional responsibilities and financial expenses. These factors must be considered carefully when contemplating the purchase of a home.

PROGRAMS FOR HOME BUYERS - NEW JERSEY HOUSING AND MORTGAGE FINANCE AGENCY (HMFA)

Buying a house is a big step with a rewarding outcome – a home to call your own. **The New Jersey Housing and Mortgage Finance Agency** (HMFA) promotes affordable homeownership and housing opportunities for New Jersey residents.

The Homeward Bound Program provides for a 30-year loan at a fixed interest rate and no points. The program is open to first-time homebuyers, trade up and trade down borrowers. The home must be the borrower's primary residence or a two-to-four unit dwelling in which one unit will be the borrower's primary residence and the remaining unit(s) may be rented.

The Smart Start Program provides down payment and closing cost loans of up to 4% of the first mortgage amount to qualified First-Time Homebuyer Program borrowers and certain Homeward Bound Program borrowers.

- Further information on purchasing a home through one of HMFA's homebuyer programs and brochures on the home buying process also can be requested by calling 1.800.NJ.HOUSE (1.800.654.6873) or visit www.njhousing.gov.

Refinancing For Home Owners through New Jersey Housing and Mortgage Finance Agency

The Stay At Home Program provides for the refinancing on an existing single family home that has been and will continue to be used as the borrower's primary residence or a two-to-four unit dwelling in which one unit has been and will continue to be the borrower's primary residence and the remaining unit(s) may be rented. The loan will be for a term of 30-years, at a fixed interest rate.

- Further information on purchasing a home through one of HMFA's homeownership programs can be requested by calling 800.NJ.HOUSE (654.6873) or visit www.njhousing.gov.

HMFA publishes a guide to buying a home at www.state.nj.us/dca/hmfa/homeownership/owners/refinance.

Financial Qualifications and Leasing

A principle of Supportive Housing contends that the person with a special need 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

For more information on credit and credit repair contact New Jersey Division of Individual Affairs at www.njconsumeraffairs.gov/News/Consumer%20Briefs/credit-reports-and-credit-repair.pdf or call toll free 888.656.6225.

Using Private Resources

EMPLOYMENT

Employment is another important way to increase income and afford independent housing. In April of 2012, Governor Christie announced that New Jersey would be the 14th state to adopt the “Employment First” initiative. The Employment First initiative requires state government to eliminate barriers or practices that prevent persons with physical, developmental, and mental disabilities from being employed and is intended to increase the employment opportunities available to persons with disabilities. Both the New Jersey Department of Labor and Workforce Development and the Department of Human Services are tasked with implementing the goals of the Employment First initiative and encouraging private sector employers to improve their efforts to hire persons with disabilities.

Competitive employment after high school is the first and preferred activity for everyone, including people with disabilities. Vocational services such as career counseling, job training and losing their benefits, New Jersey’s Medicaid Buy-in Program, NJ WorkAbility, and the Social Security Administration’s Work Incentive programs allow individuals with disabilities to earn more income and still keep their Medicaid benefits. For an overview of the Social Security Administration’s Work Incentives, as they pertain to both SSI and SSDI cash and healthcare benefits go to www.nj.gov/humanservices/ddd/documents/section_1619b_factsheet.pdf.

For information about the NJ Division of Vocational Rehabilitation Services, go to: www.careerconnections.nj.gov/careerconnections/plan/foryou/disable/vocational_rehabilitation_services.shtml The Division of Vocational Rehabilitation (DVRS) publishes a Case Services Manual. This guide describes the policies and procedures involved with access vocational services from DVRS. www.careerconnections.nj.gov/careerconnections/document/plan/DVR_CSPM_2016.pdf

INDIVIDUAL DEVELOPMENT ACCOUNTS (IDA)

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.

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 (NJ approved 1/11/2016 P.L.2015,c.185), each state must pass legislation to authorize its guidelines for ABLE Act provisions to be effective in that state. These regulations will more clearly define the benefits and limitation of ABLE accounts.

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. Deposits into an ABLE account are limited to \$14,000 per year. If the account exceeds \$100,000, Supplemental Security Income (SSI) benefits will be suspended until the account balance is below \$100,000. Funds in ABLE account are subject to a payback to the State for any amount paid for medical benefits after the funding of the ABLE account.



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 special needs, it is advisable to seek the advice of an attorney or financial advisor who has specific expertise in this area of the law.

National Disability Institute: For more information about The ABLE Act visit autismnj.org or www.realeconomicimpact.org/news/?id=460.

ABLE National Resource Center: www.ablenrc.org
www.ablenrc.org

SPECIAL NEEDS TRUSTS

Special Needs Trusts allow funds to be saved for the individual with a disability without jeopardizing government means-tested Benefits. Special Needs Trusts may provide additional options for an individual with a disability to secure and maintain housing.

For individuals who receive SSI and/or Medicaid, the use of funds in a Special Needs Trust for food and shelter may be restricted, or disallowed. Funds used for these purposes are deemed to be "income", defined as In-kind Support and Maintenance (ISM) and could potentially jeopardize eligibility for these programs. First Party (or Self-Settled) Trusts are funded with assets belonging to the person with the disability. These trusts must be used for the sole benefit of the individual. Parents may also establish a Third Party Supplemental Benefits Trust to hold an inheritance for a loved one who has a disability and who is receiving means tested benefits. Third Party trusts, although more flexible in nature, are still subject to ISM rules. Federal and State laws, as well as public benefits regulations change, so legal advice must be obtained at the time of establishing trusts and reviewed periodically thereafter.

Special Needs Alliance Handbook for Trustees:
www.specialneedsalliance.org/free-trustee-handbook/
www.specialneedsalliance.org/free-trustee-handbook/
Planned Lifetime Assistance Network of NJ (PLAN/NJ):
www.plannj.org www.plannj.org

"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."

Quality Monitoring of Housing

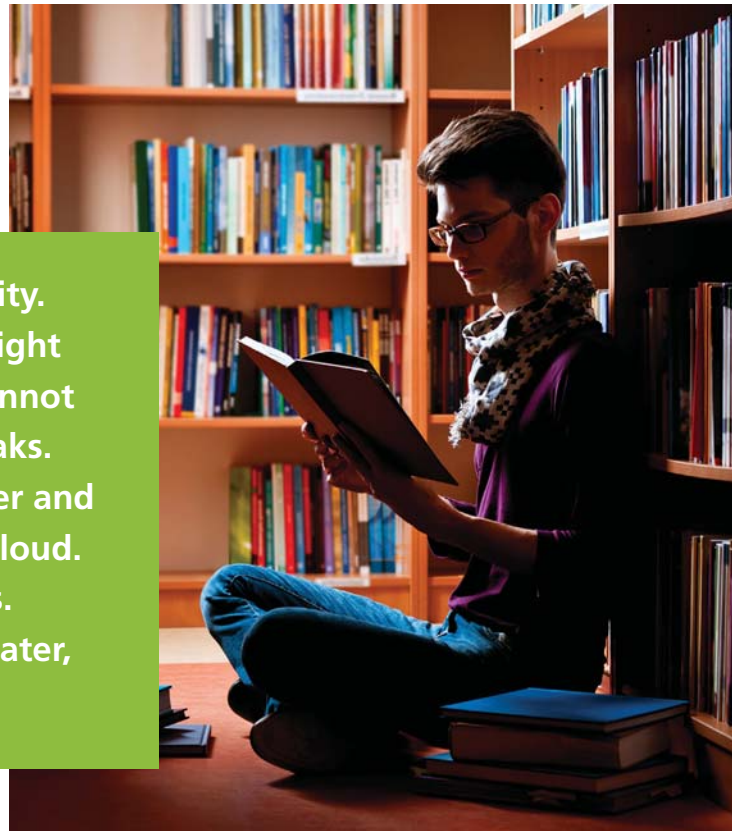
Quality Monitoring

The U.S. Department of Housing and Urban Development (HUD) has identified "13 key aspects of housing quality, performance requirements, and acceptability criteria" when evaluating the quality of housing that they use during an inspection. A checklist is available online. HUD or their designee performs such inspections to ensure basic housing quality standards (HQS) are met.

The Supportive Housing Connection is responsible for making these inspections in DDD and DMHAS funded housing that are not licensed. Licensed housing units will be inspected through the Office of Licensing under the guidelines set forth in NJAC 10:44A. For more information visit www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/hqs.

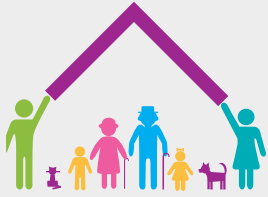
HOUSING DISCRIMINATION

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





Mainstream Resources



MAINSTREAM RESOURCES,

such as those that support individuals with disabilities, the elderly 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,

such as Autism New Jersey, The Arc of New Jersey, United Way and others can assist with information and referral. See the Appendix for contact information.

Local Municipal and County Services

Most counties and some 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. Contact the County Board of Social Services, the Office on Aging and Disability Services and your local municipality. The county offices will be aware of other programs or services that can be of assistance. Some towns and counties have funds to assist in getting started in a

new home by funding a security deposit, purchasing food or household supplies, etc. The local Public Housing Authorities manage the rental of affordable housing units and rental assistance within their local communities.

Some programs designed for people of low income can also provide assistance for the person with a disability to live independently and stretch a limited budget. Generally, when people 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.



FUNDING FOR LIVING EXPENSES

Social Security Administration

- 800.772.1213
- 800.325.0778 TTY
- www.socialsecurity.gov
- www.state.nj.us/humanservices/ddd/services/medicaideligibility.html

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. In New Jersey, a person with SSI automatically receives NJ Medicaid benefits. Maintaining Medicaid eligibility is essential for individuals with intellectual or developmental disabilities to secure waiver-funded services.

PRESCRIPTION ASSISTANCE

Pharmaceutical Assistance for the Aged and Disabled (PAAD)

- 800.792.9745
- www.state.nj.us/humanservices/doas/services/paad

PAAD is a program that assists eligible New Jersey residents to pay for their prescription medicines with a co-pay of \$5.00 for each covered prescription. Enrollment in this program provides access to additional benefits. (Note: Medicaid provides for prescription drug coverage, consequently individuals on Medicaid cannot also receive PAAD assistance.)

Senior Gold Prescription Discount Program (Senior Gold)

- 800.792.9745
- www.state.nj.us/humanservices/doas/home/seniorgolddetail.html

Senior Gold is a New Jersey funded prescription program for people over age 65 or receiving Social Security Disability Insurance (SSDI) who meet income eligibility requirements. Medicaid provides for prescription drug coverage. Consequently, individuals on Medicaid cannot also receive PAAD assistance.

SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM (SNAP)

Formerly known as Food Stamps Program

- 800.687.9512

The **NJ 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. A person can apply through the county's Board of Social Services or by completing an application online at www.nj.gov/humanservices/dfd/programs/njsnap/apply.

Eligibility is determined based upon several factors such as income, household size, resources, etc. There is an online tool to assist in determining eligibility. For more information about SNAP and other local benefits, contact your County Welfare Agency or Board of Social Services who determine eligibility for Food Stamps. See www.nj.gov/humanservices/dfd/programs/njsnap/cwa for the phone numbers of the county offices.

“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.”

UTILITY ASSISTANCE

- www.bpu.state.nj.us/bpu/assistance/programs
- www.nj211.org

Weatherization Assistance Program

- **609.292.6140**

This program works with community-based agencies to help seniors, residents with disabilities and low-income households to weatherize their homes to improve heating system efficiency, conserve energy and decrease utility bills. The program also provides funds to pay heating bills under emergency circumstances.

Home Energy Assistance (HEA) Program

- **800.510.3102**

- www.nj.gov/dca

Home Energy Assistance helps pay home energy bills for households with limited income. This program provides heating, cooling and emergency energy assistance to eligible applicants.

LIHEAP Energy Assistance Program

- www.acf.hhs.gov/programs/liheap

LIHEAP is a federally funded program to help eligible residents of low-income in New Jersey meet their home heating and/or cooling needs.

“There are no entitlements after my kid graduates from high school. I cannot rely entirely upon DDD funded programs being available to meet all of his needs. I have become an expert on the rules of the government programs and knowledgeable about the community resources that are available.”



New Jersey Statewide Heating Assistance and Referral for Energy Services (NJSHARES)

- **866.657.4273**

- www.njshares.org

NJSHARES is a nonprofit corporation organized to assist New Jersey residents who are in need of temporary help in paying their energy, water and telephone bills. NJSHARES administers assistance programs for several companies including NJ Natural Gas, JCP&L, American Water Company, United Water and Verizon.

New Jersey Natural Gas Gift of Warmth

- **800.221.0051**

- www.customerservice@njng.com

Funded through NJ Natural Gas, **Gift of Warmth** assists customers who are unable to afford their natural gas heating bills.

Verizon Telephone Company Verizon's Communications Lifeline and Linkup America

- 866.452.4623
- www.njshares.org/otherPrograms/communications-lifeline.asp

Discounted telephone service is available from Verizon Telephone Company through its **Linkup America Program** for seniors and people receiving Social Security benefits. Verizon Communications makes residential telephone service more affordable in its service area in New Jersey by offering

Communications Lifeline and Linkup America services for qualified customers of low- income. If a person receives SSI benefits or qualifies for PADD, he/she meets the qualifications for this program as well.

Communications Lifeline provides a credit toward your monthly telephone bill including a full credit for Touch-Tone service. Communication Lifeline allows someone of fixed income to receive the discount by choosing Flat Rate Service, Moderate Use Message Rate Service or Low Use Message Rate Service Plans.



Mainstream resources, such as those that support individuals with disabilities, the elderly or those of low income, may be of assistance. Research is required to identify the eligibility criteria for each service. Non-profit organizations, such as Autism New Jersey, The Arc of New Jersey, United Way and others can assist with information and referral. See the Appendix for contact information.

TRANSPORTATION

Accessible public transportation and demand-response para-transit are two of the most pressing problems facing individuals with disabilities. Public transportation provides greater access to employment, education, medical care and a host of other services and activities to help people who do not drive to be active and productive members of their communities. Therefore, many individuals with disabilities need to be able to access public transportation. It is important to identify transportation mechanisms that are in place on a municipal, county and statewide level that will support individuals with disabilities to lead independent and full lives.

Medicaid funded medical transportation is currently contracted through LogistiCare, New Jersey's current designated Medicaid transportation broker.

- **For transportation reservations, call 1.866.527.9933**
- www.state.nj.us/humanservices/dmahs/home/logisticare.html

NJ TRANSIT Accessible Services

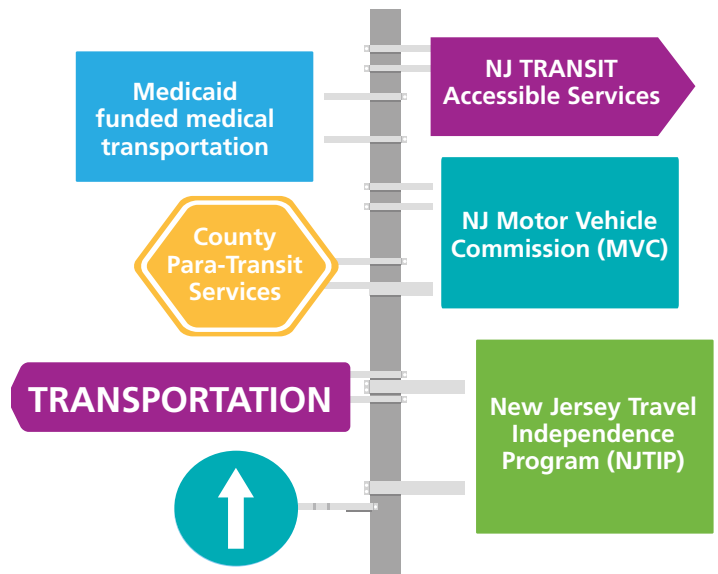
NJ TRANSIT is responsible for making public transportation in New Jersey accessible to people with disabilities. NJ TRANSIT also administers the **Reduced Fare Program** for seniors and individuals with disabilities who use NJ TRANSIT buses or trains. Access Link is NJ TRANSIT's para-transit service. This curb-to-curb service is designed for individuals with disabilities who cannot use the local fixed route bus service.

- **Transit Information Center, for service and trip planning questions call 1.973.275.5555**
- www.njtransit.com/tm/tm_servelet.srv?hdnPage=AccessibleServiceToAction

New Jersey Travel Independence Program (NJTIP)

The mission of the New Jersey Travel Independence Program (NJTIP) is to increase the independence and self-sufficiency of people with disabilities, older adults and others by empowering them to use the public transit system safely and independently.

- **848.932.4499**
- www.njtip.rutgers.edu



Access Link ADA Paratransit

- **800.955.2321 (TTY 800.955.2321)**
between the hours of 8:30 a.m. and 5:00 p.m., Monday through Friday
- www.njtransit.com/tm/tm_servelet.srv?hdnPageAction=ParaTransitTo

Each county operates a **para-transit system** to serve seniors and residents with disabilities. Services vary by county and may be door to door or link the person to public transportation. These specialized transportation services charge a minimal fee. To utilize each county's para-transit bus system, individuals must complete an application process and provide advance notice to arrange for these transportation services.

NJ Motor Vehicle Commission (MVC)

- **888.486.3339 toll-free in NJ**
- **609.292.6500 (TTY 609.292.5120)**
- www.state.nj.us/mvc/About/Contact.htm

The New Jersey Motor Vehicle Commission (MVC)

issues license plates and placards that are required to legally park in a designated parking space for a person with a handicap. These license plates and placards are issued free of charge and are useful for drivers or passengers with disabilities. Applications may be obtained by visiting any MVC location or calling the customer service number. For persons with temporary physical disabilities, temporary placards (valid for up to six months) are available through local police departments for a small fee.

The Motor Vehicle Commission also issues Non-Driver Photo ID cards to individuals who need a valid photo ID for the purpose of identification, but who are unable to drive. An applicant must appear in person at a MVC office with the required identification documents to obtain this card.

- www.state.nj.us/mvc/Licenses/NonDriverID.htm

EMERGENCY PREPAREDNESS

New Jersey Register Ready

- www13.state.nj.us/SpecialNeeds/Signin?ReturnUrl=/SpecialNeeds

REGISTER READY – Call 211 (toll free) is

New Jersey's Special Needs Registry for disasters or other emergencies. NJ residents with special needs can call to register their special medical needs and/or functional needs information, so that emergency responders can better plan to serve them in a disaster or other emergency.

LEGAL SERVICES

Disability Rights New Jersey (DRNJ)

- www.drnj.org

Disability Rights New Jersey is a private, non-profit, individual-directed organization established to advocate for citizens of New Jersey with disabilities, promote public awareness, advise and assist in obtaining and protecting the rights of individuals with disabilities, and provide education, training and technical assistance.

Community Health Law Project (CHLP)

- www.chlp.org

CHLP is a legal services organization with regional offices in NJ providing civil legal representation to people of low income with disabilities.

Legal Services of New Jersey (LSNJ)

- www.lsnjlaw.org

LSNJ is a statewide legal services system which provides free legal assistance to low-income New Jerseyans for their civil legal problems.

American Bar Association To locate an attorney or for more information about American Bar Association go to:

- www.americanbar.org/aba.html

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.

People with disabilities should develop relationships with the people and places around them that define their community. When creating a housing plan, the person 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 Policy

Employment is also a part of the natural support system and an important way for a person to achieve self-sufficiency. For more information go to

- www.dol.gov/odep

Housing Development

An adequate supply of safe, decent, accessible housing for people 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 people 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. Funding is available to for-profit and non-profit developers. 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 and guidelines.

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 **Pre-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)

Region II
Jacob K. Javits Federal Building
26 Federal Plaza
New York, NY 10278

212.264.8000

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

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 Project Rental Assistance

(PRA) for people with disabilities provides rental assistance to subsidize the difference between the Fair Market Rent and the amount the residents can afford.

Money Follows the Person Housing

Partnership Program (MFPHPP) is a partnership between the HMFA and the New Jersey Department of Human Services (DHS) Division of Aging Services (DoAS). The program provides capital subsidy in the amount of \$75,000 per unit to eligible non-profit and for-profit developers to set aside housing units for qualified disabled individuals aged 18 and over, currently living in nursing homes and assessed as being capable of living in the community with supportive services transitioning from nursing facilities to community settings.

STATE FUNDING

NJ Department of Community Affairs (DCA) Division of Housing and Community Resources

609.633.6302

Within the NJ Department of Community Affairs, the **Division of Housing and Community Resources'** mission is to strengthen and revitalize communities through the delivery of affordable housing, supportive services and the provision of financial and technical assistance to communities, local government and community-based organizations. The Department of Community Affairs oversees several federal and state funded programs that promote affordable housing for families with low income, persons with disabilities. Through its Division of Housing and Community Resources, DCA administers programs for rental assistance, housing rehabilitation, relocation assistance, family self-sufficiency, emergency shelter grants and homelessness prevention, Community Services Block Grant and weatherization programs. The Division assists local groups to sponsor housing through programs that preserve, rehabilitate and expand the housing supply for families of low and moderate income.

New Jersey Housing and Mortgage Finance Agency-Division of Special Needs

The **New Jersey Housing and Mortgage Finance Agency (HMFA)** administers financing programs for service-enriched permanent, affordable housing development for people with special needs. They also provide technical assistance and coordination with developers and other state agencies. The agency works to improve housing opportunities for some of New Jersey's most vulnerable residents, including people with developmental disabilities, mental health concerns, the homeless, elderly, people with HIV/AIDS and other under-served communities.



Special Needs Housing Partnership Loan Program (SNHPLP)

is collaboration between HMFA, DCA, and DHS/DDD and municipalities to provide financing to create permanent supportive housing and community residences for individuals with developmental disabilities.

Loan funds may be used for the acquisition, construction and rehabilitation of existing three to four-bedroom homes. The program matches with a municipality's commitment of funds from its Affordable Housing Trust Funds (AHTF). This allows municipalities to leverage their trust funds with the SNHPLP to create much needed affordable housing for special needs populations.

One of the fundamental reasons the SNHPLP was developed was to meet the demands of the state's Olmstead Settlement Agreement. The SNHPLP specifically targets affordable housing opportunities for individuals with developmental disabilities who are leaving state developmental centers, returning home from out-of-state placements, and who need independent housing in the community.

The **Special Needs Housing Trust Fund (SNHTF)** was signed into law in New Jersey in 2005 (P.L. 2005, c. 163) to provide capital financing to create permanent supportive housing and community residences for individuals with special needs. The Trust Fund provides capital financing in the form of loans, grants, and other financial vehicles and investments to eligible non-profit and for-profit developers. Project costs include the acquisition of property, rehabilitation, new construction, or conversion of building(s) into rental apartments/units as well as community residences for people with special needs. Funding for rent, operating subsidies and supportive services must be financed by other sources and is not available from the Trust Fund. The Trust Fund, established as a revolving loan program, has been fully utilized. As loans are repaid, funds will become available again for new projects. Advocates are working to urging public officials to replenish the Trust Fund for additional housing development.

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. Since its inception in 1986, the federal Low Income Housing Tax Credit (LIHTC) program has helped produce more than 40,000 affordable housing opportunities in New Jersey.

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.

HMFA is continuously working to adapt the program's rules in New Jersey to reflect the state's current housing policies and priorities through its Qualified Allocation Plan (QAP). The QAP details the selection criteria and application requirements for both the 9% and the 4% tax credits. Revisions have been made to the QAP in 2013 including prioritizing the need to provide permanent supportive housing to the homeless and individuals with developmental disabilities following the Olmstead Settlement Agreement. During each tax credit round, a specific allocation is set-aside for special needs housing as well. The QAP includes special needs set aside (points for 5% or 5 units – whichever is greater) and a Supportive Housing Cycle, which is an amount of tax credit allocation reserved for special needs projects only –minimum of 25% of the project's units must be special needs.

For additional information about HMFA's Programs, contact NJHMFA at 609.278.7400 or www.NJhousing.gov.

“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.”

OTHER SOURCES OF FUNDING

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 www.federalreserve.gov/communitydev/cra_about.htm.

Affordable Housing Trust Funds, Council on Affordable Housing (COAH) and the Mount Laurel Decision

- The *Mount Laurel Doctrine* prohibits housing discrimination against the poor by the state and municipalities. In 1975, New Jersey's litigation was one of the first court cases of its type in the nation. It is widely regarded as one of the most significant civil rights cases in the United States. In direct response to this litigation, the New Jersey Legislature enacted the Fair Housing Act in 1985. This created the Council on Affordable Housing (COAH) to assess the statewide need for affordable housing, allocate that need on a municipal fair share basis, and to review and approve municipal housing plans that develop housing for people of low and moderate income. After a series of legal challenges by the NJ Fair Share Housing Center (www.fairsharehousing.org) the courts determined that COAH was not properly executing its responsibilities and that towns must use the trial courts to get their housing plans approved. In addition, it was determined that **municipal affordable housing trust funds** are to be spent on affordable housing development. These funds are accumulated at the municipal level through an assessment of a developer's fee when building permits are issued. Families should reach out to their mayors and local housing officials to ask about the municipal housing plans and encourage municipalities to use trust fund dollars now and in the future, along with their zoning powers, to provide affordable housing for people with special needs.



Advocacy

There are many challenges associated with securing supportive housing. New Jersey needs additional resources. The numbers speak for themselves. According to 2013 data, in New Jersey there are approximately 120,000 adults or adult households receiving Social Security's Supplemental Security Income (SSI) benefits for disabilities and receiving less than \$800 per month. Of that total, approximately 40,000 receive housing assistance from the federal or state government in the form of housing units or housing vouchers. Furthermore, these numbers do not reflect people in institutions, prisons and homeless shelters, as well as those living with aging parents, and are a sobering reminder of the many thousands of New Jerseyans living with disabilities on very low incomes in need of independent, safe, decent housing with supports.

The surest way to expand opportunities in housing and services for people with disabilities is through good old fashioned advocacy. Families, individuals and providers should regularly communicate with lawmakers to request that resources for support services, affordable housing development, rental vouchers or other subsidies be available for people on very low incomes. Please use the SHA or other disability advocacy organizations' websites to become aware of federal and state advocacy initiatives. Feel free to contact these organizations to learn more about the most urgent initiatives. You can sign on to help support petition drives, contact public officials and write letters to the editor of local media publications on these issues. Your voice in Trenton and Washington DC is essential to a effective supportive housing industry. The Supportive Housing Association calls for assertiveness, networking and advocacy to achieve these objectives. Our collective and coordinated efforts can create change.

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

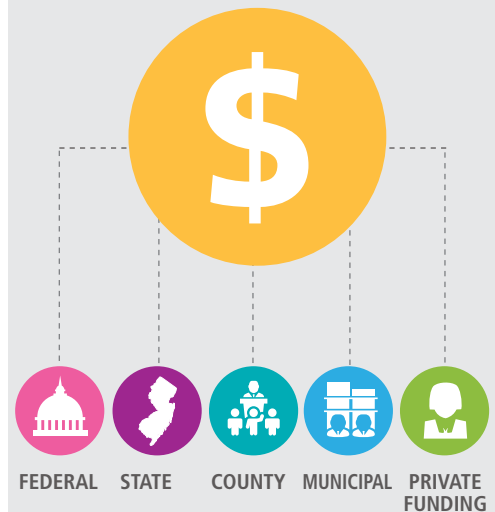
Conclusion

We hope the guide encourages creative thoughts about how people can live more independently despite low incomes, how families can contribute without jeopardizing a loved one's public entitlements, and the importance of full or part-time employment for those able to work so they can better afford a more robust lifestyle. Resources, both housing and services, exist; finding them and using them productively is what we hope you will achieve, now and in the future, as you use the information compiled for you in these chapters.

To secure supported housing for her daughter, one mom describing her journey said, "It is like traveling to the Wild, Wild West." In many ways, she has been blazing the trails where maps were unavailable. Resources are scarce. Rules and regulations are abundant and cumbersome. The outcome for her daughter 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 these critical resources to find a place you or your loved one can call home.

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.

About the Author

DEBORAH WEHRLLEN

While there were many contributing writers for the Housing Resource Guide, Deborah Wehrlen served as the primary author. Deborah Wehrlen has over forty years of experience in establishing innovative residential supports and developing affordable housing in New Jersey. Prior to establishing her consulting business in 2002, Deborah Wehrlen was the director of the New Jersey Division of Developmental Disabilities (DDD). In this policy-making position, she advanced efforts to develop in home supports, fund deinstitutionalization and downsize the state operated developmental centers.

Deborah Wehrlen was also employed as the residential director and then the executive director with The Arc of Monmouth, establishing housing for over 85 people. Currently as a consultant in DTW Consulting Group LLC, Deborah Wehrlen has worked with several organizations to obtain funding, implement supported housing and residential supports for persons with disabilities needing permanent supported housing. She has secured millions of dollars of capital and operating funds from various governmental funding sources, grants, capital campaigns and private foundations. During her entire career, Deborah Wehrlen has strongly advocated for quality services and best practices to support individuals with developmental disabilities and their families.

Further Acknowledgements

The following individuals providing ongoing advice and management to the development and finalization of this guide:

- Gail Levinson, Executive Director, SHA
- Ed Murphy, Director of Operations, SHA
- Suzanne Buchanan, Psy.D., BCBA-D, Executive Director, Autism New Jersey
- Jessica Barkosky, Manager of Communications & Marketing, Autism New Jersey
- Deborah Charette, Coordinator of Public Policy, Autism New Jersey
- Amy Smith, Director of Information Services, Autism New Jersey

We would like to thank the many stakeholders including the NJ Council on Developmental Disabilities, The Arc of New Jersey, Disability Rights New Jersey, the NJ Department of Human Services, the New Jersey Housing & Mortgage Finance Agency and several parents and consumers for their review and feedback on the guide before its final publication.

We also express appreciation to Maria Fischer, Esq., a partner in the firm of Hinkle, Fingles, Prior & Fischer, P.C., Attorneys at Law, who contributed considerable information regarding legal and regulatory issues within this guide.

Thank you to Joan Migton for her attention to detail by providing copy editing.

State Agencies, organizations and individuals reviewing the guide have provided much appreciated feedback but have not endorsed its content.

Finally, thanks are due to members of the SHA Family and Consumer Housing Workgroup whose voices gave rise to this publication.

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Appendix

ADDITIONAL RESOURCES

Affordable Housing Resources

- **NJ Housing and Mortgage Finance Agency (HMFA)** *(For help with mortgages and housing resources)*
800.NJ.HOUSE
609.278.7400
www.nj.gov/dca/hmfa
- **NJ Guide to Affordable Housing by County** www.state.nj.us/dca/divisions/codes/publications/developments
- **HUD: US Department of Housing & Urban Development** *(Rent Information)*
www.portal.hud.gov/hudportal/HUD?src=/states/new_jersey
- **NJ Public Housing Authorities for Section 8 and Public Housing**
www.hud.gov/offices/pih/pha/contacts/states/nj.cfm

Affordable Housing Subsidies and Resources

- **Housing Choice Vouchers**
www.state.nj.us/dca/divisions/codes/publications/developments.html
- **Housing Choice Voucher (Section 8) housing inventory** www.portal.hud.gov/hudportal/HUD?src=/states/new_jersey
- **HMFA's Housing Resource Center** www.NJHRC.gov
- **Supportive Housing Connection** www.njhousing.gov/dca/hmfa/rentals/shc/
- **Low Income Housing Tax Credit Locations** www.huduser.org/DATASETS/lihtc.html

Assistive Technology to Support Independence

Technology - Advances in technology offer many options for people to live with less dependence upon caregivers. Assistive Technology refers to any device to improve the functional capabilities of a person with a disability. These tools can be simple or complex.

- **Assistive Technology Advocacy Center (ATAC)** *Advancing Opportunities' Technology Lending Center (TLC) features a wide variety of assistive technology including computer access technology, communication devices, adapted toys and an impressive array of adaptive equipment used for daily living.*
888.322.1918
www.assistivetechcenter.org
- **Coleman Institute for Cognitive Disabilities** *University of Colorado*
3825 Iris Ave., Suite 200, Boulder, Colorado 80301
www.cu.edu/ColemanInstitute/agenda.html
- **RESNA**
The Technical Assistance Project is a sponsored project of the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). RESNA continues to operate the Technical Assistance Project under a grant from the Rehabilitation Services Administration, U.S. Department of Education. The RESNA Technical Assistance Project Resource Guide provides information about assistive technology and home modifications. The guide covers definitions, laws and guidelines, initiatives from the Assistive Technology Act grantees, advocacy, financing, modification, and research resources, accreditations, online courses, and a bibliography. www.resna.org
- **Temple University** www.disabilities.temple.edu/tech
- **Your ReSource** *is a not-for-profit organization, affiliated with Goodwill Industries of Southern Jersey and Philadelphia that collects durable medical equipment and redistributes it to people in need.*
8 Industry Court, Ewing, NJ 08638
609.530.1513
www.yourresourcenj.org
- **Home Link Technologies** *develop Smart home technology to promote independent living.*
www.homelinktechnologies.com

Building Design to Support Independence

- National Resource Center on Supportive Housing and Home Modification www.homemods.org
- Northeast ADA & IT Center www.northeastada.org
- TechConnections www.techconnections.org

Building Design Information to Support Specific Needs

- **Making Homes that Work A Resource Guide for Families Living with Autism Spectrum Disorder + Co-occurring Behaviors** *George Braddock & John Rowell*
- **Developing Housing for the MS Community - Partnering with Developers to Create Housing Opportunities** *Ken Regan & Candice Baldwin*
- **Moving Out: A Family Guide to Residential Planning for Adults with Disabilities** *Dafna Krouk-Gordon & Barbara D. Jackins*
- **Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders** *Urban Land Institute Arizona, Southwest Arizona Research and Resources Center & Arizona State University*
- **Renovating Dwellings for Basic Access: A Guide for Construction Professionals**
www.silcga.org/wordpress/wp-content/uploads/2015/01/Renov-Tool-revised.pdf
www.iacc.hhs.gov/events/2011/091511/homes_that_work_091511.pdf

Developmental Disability Agencies that are Federally Mandated

- Disability Rights New Jersey (DRNJ) www.drnj.org
- New Jersey Council on Developmental Disabilities www.njcdd.org
- The Elizabeth M. Boggs Center on Developmental Disabilities www.rvjms.rutgers.edu/boggscenter

Disability Specific Organizations

- Arc of New Jersey: www.arcnj.org
- Asperger Autism Spectrum Education Network (ASPEN): www.aspennj.org
- Autism New Jersey: www.autismnj.org
- Autism Speaks: www.autismspeaks.org
- Brain Injury Alliance of New Jersey: www.bianj.org
- Cerebral Palsy of North Jersey: www.cpnj.org
- Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD): www.chadd.org
- Cystic Fibrosis Foundation: www.cff.org
- Epilepsy Foundation of New Jersey: www.efnj.com
- Family Support Center of New Jersey: www.FSCNJ.org
- Learning Disability Association: www.ldanj.org/
- Mental Health Association in New Jersey: www.mhanj.org
- Muscular Dystrophy Association: www.mda.org
- National Multiple Sclerosis Society: www.nationalmssociety.org
- National Alliance on Mental Illness of New Jersey: www.naminj.org
- New Jersey Association of the Deaf: www.deafnjad.org
- Spina Bifida Resource Network: www.spinabifidaassociation.org

Employment

- New Jersey Department of Labor, Division of Vocational Rehabilitation (DVR)
www.jobs4jersey.com/jobs4jersey/jobseekers/disable/
- NJWINS - *The Family Resource Network's New Jersey Work Incentives Network Support (NJWINS) program assists Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries to start, continue or increase work efforts while maintaining benefits for as long as they are needed.* www.njwins.org
- Full Circle Employment Solutions LLC
www.fullcircledc.com/wipa.html
- NJ WorkAbility
www.state.nj.us/humanservices/dds/projects/discoverability/

Home Sharing

- www.nasddd.org/publications/nasddd-titles-for-purchase/shared-living-guide
- www.ancor.org/resources/best-practices
- www.nationalsharedhousing.org
- www.homesharing.org

Housing First

- www.endhomelessness.org/pages/housing_first
- www.csh.org/toolkit/supportive-housing-quality-toolkit/housing-and-property-management/housing-first-model
- www.endhomelessness.org/blog/entry/data-points-housing-first-decreases-re-offending-among-homeless-individuals#.VQTLmmTF90w

Information and Referral Sources

- **Autism New Jersey** is the largest statewide network of parents and professionals dedicated to improving lives of individuals with autism spectrum disorders. 800.4.AUTISM www.autismnj.org
- **NJ Department of Human Services
Division of Disability Services (DDS)**
888.285.3036
609.292.7800 TDD 609.292.1210
www.state.nj.us/humanservices/dds
- **The Division of Disability Services (DDS)** serves as a resource for all people seeking disability-related information in New Jersey. Information and Referral Specialists are available to confidentially discuss issues and provide information, assist with problem solving and refer to appropriate agencies or services. Annually, they publish *NJ Resources*, a guidebook on service delivery. www.nj.gov/humanservices/dds/documents/RD%2015.Web.pdf
- **New Jersey Aging and Disability Resource Connection** www.adrcnj.org/
ADRC provides information and assistance to older persons, adults with physical disabilities, caregivers and professionals looking for services or programs.
- **Centers for Independent Living** are community-based, individual-driven organizations that provide information and referral, peer counseling, skills training, advocacy and a variety of services based on individual needs.
www.state.nj.us/humanservices/dds/home/cntrindlivindex.html
- **211 for Information and Referral** www.211.org
877.652.1148
Spearheaded by The United Way, 211 is an easy-to-remember telephone number to connect people regarding community services and referral agencies in local communities nationally. 2-1-1 is a growing national model for information and referral. NJ 2-1-1 can help you find resources in the community for utility assistance, housing, social services, vocational training programs, senior services, medical insurance, and more.
- **Madison House Autism Foundation** A project of Madison House Autism Foundation, the AHN is the first interactive online community to provide free access to the best information and discussion on creating housing options for autistic adults and others with special needs. This innovative tool is reinventing the way project starters navigate today's supportive housing landscape.
[/www.madisonhouseautism.org/ahn_big_unveiling_launch_1/](http://www.madisonhouseautism.org/ahn_big_unveiling_launch_1/)
- **New Jersey Helps** Connects people to various forms of assistance, including housing, through the Department of Human Services and other NJ State partners:
www.njhelps.org

Information and Referral from County Resources

- **County Board of Social Services** www.nj.gov/humanservices/dfd/programs/njsnap/cwa/
- **County Office for People with Disabilities** www.state.nj.us/humanservices/dds/home/cntyofficeindex.html

Guardianship

- www.ganji.org/index.htm

Medicaid

- 800.356.1561 www.lwd.dol.state.nj.us/labor/roles/disable/ACDS_list.html

Medicare

- 800.MEDICARE
800.633.4227
www.nj.gov/humanservices/dmahs/clients/medicaid

Mental Health Supports

- **National Alliance on Mental Illness New Jersey (NAMI)** www.naminj.org
- **County Crisis Intervention** www.state.nj.us/humanservices/dmahs/resources/services/treatment/mh.html
- **NJ Mental Health Cares** www.njmentalhealthcares.org
NJ Mental Health Cares has mental health professionals who can link a person to mental health information and referral services at
866.202.HELP or TTY: 877.294.4356.
- **National Suicide prevention Lifeline** www.suicidepreventionlifeline.org
1.800.273.TALK (8255)
- www.after55.com

Plan NJ

- www.plannj.org/019D31EE-009863F9.0/SPONSOR%20DIRECTORY%20%204-25-2014.pdf

Protection of Rights and Advocacy

- **Disability Rights New Jersey (DRNJ)** www.drnj.org
210 South Broad Street, 3rd Floor, Trenton, NJ 08608
609.292.9742 or 800.922.7233 (NJ Only)
609.633.7106 TDD
- **Disability Law: A Legal Primer (Sixth Edition)** www.njsbf.org/images/content/1/1/11582/Disability%20Law%20Primer%206th%20Ed.pdf
A booklet to help explain laws concerning persons with disabilities.

Self-Advocacy

- **NJ Self-Advocacy Project:** www.arcnj.org

Senior Services

- **New Jersey Department of Human Services**
In 2013, senior supports and services transferred from the Department of Health to the Department of Human Services. The Division of Aging Services constitutes a single point of entry and coordination of care to support people to continue living at home.
- **Division of Aging Services**
12B Quakerbridge Plaza, P.O. Box 715, Mercerville, NJ 08625-0715 www.state.nj.us/humanservices/doas/home

Shared Living

- **A model contract for Shared Living is available at** www.ancor.org/resources/best-practices
- **A Guide for Shared Living is available at**
www.nasddd.org/publications/nasddd-titles-for-purchase/shared-living-guide
www.homesharing.org
www.nationalsharedhousing.org

Special Educational Resources

- **New Jersey Coalition for Inclusive Education:** www.njcie.net
- **New Jersey Department of Education:** www.state.nj.us/education
- **Statewide Parent Advocacy Network:** www.spannj.org
- **IDEAL Group - free Assistive Technology applications for students** www.onlineconferencingsystems.com/at.htm
- **NJ Department of Education's Parental Rights in Special Education booklet**
www.state.nj.us/education/specialed/form/prise/prise.pdf

Support Coordination

■ Support Coordination Agencies

www.irecord.dhs.state.nj.us/providersearch

To search for Support Coordination Agencies, go to the website above, and follow these four steps:

- (1) under Filter, select "Service" and check Support Coordination;
- (2) select "Medicaid Approved" and check the box;
- (3) select "County Served" and select the county in which the individual resides; and
- (4) click the magnifying glass

■ Supports Program

www.nj.gov/humanservices/ddd/documents/family_guide_to_supports_program_policy_manual.pdf

Supports Program Policies and Procedures Manual: A Quick Guide for Families can assist families in gaining a basic understanding of the Supports Program and its service benefits.

■ Supports Program Policies and Procedures

www.nj.gov/humanservices/ddd/documents/supports_program_policy_manual.pdf

Toolkit Resources and Checklists Readiness Guides

■ Ready? Get Set. Go! Guide to Independence

Health checklists developed as part of a framework for transition planning to help youth and their families begin preparations for adulthood at an early age by setting goals and making plans for all levels of development.

www.nhfv.org/wp-content/uploads/2014/11/Ready-Set-Go-Final-10-2014.pdf

■ 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

Selecting a Support Coordination Agency: Making choices, Becoming Empowered

www.rwjms.umdnj.edu/boggscenter/products/SelectingandEvaluatingSupportCoordinationAgency.html

Selecting a Service Provider: Making choices, Becoming Empowered

www.rwjms.umdnj.edu/boggscenter/SelectingaServiceProvider.html

■ Autism Speaks publishes the *Housing and Residential Supports Tool Kit*

www.autismspeaks.org/sites/default/files/housing_tool_kit_web2.pdf

■ CSH Toolkit on quality

www.csh.org/wp-content/uploads/2013/07/CSH_Dimensions_of_Quality_Supportive_Housing_guidebook.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

Statewide Agencies and Resources

NJ Department of Human Services

- Department of Human Services (DHS) www.state.nj.us/humanservices
- Division of Developmental Disabilities (DDD) 800.832.9173 www.state.nj.us/humanservices/ddd/home
- Commission for the Blind and Visually Impaired (CBVI) www.nj.gov/humanservices/cbvi/home
- Division of the Deaf and Hard of Hearing www.nj.gov/humanservices/ddhh/home
- Division of Mental Health and Addiction Services (DMHAS)
www.state.nj.us/humanservices/dmhas/resources/servicestreatment/mh.html
- Division of Family Development (DFD) www.state.nj.us/humanservices/dfd/home
- Division of Disability Services (DDS) 11A Quaker Bridge Plaza Mercerville NJ
Telephone: 888.285.3036
TDD: 609.631.4366
www.nj.gov/humanservices/dds/home/index.html

NJ Department of Community Affairs

- Department of Community Affairs www.state.nj.us/dca
- Division of Housing www.state.nj.us/dca/divisions/dhcr
- Division of Supported Housing and Special Needs 609-278-7603
- New Jersey Housing and Mortgage Finance Agency Main: 609-278-7400 www.njhousing.gov

NJ Waiver Programs and State Plan Services

- I Choose Home NJ (MLTSS)
www.nj.gov/humanservices/ddd/documents/Documents%20for%20Web/MFP_OP_FINAL8.8.2012.pdf
- Community Care Waiver
www.nj.gov/humanservices/ddd/documents/Documents%20for%20Web/CCW%20Renewal%20FAQs.pdf
- Personal Assistance Service Program (PASP) www.nj.gov/humanservices/dds/projects/pasp
- Personal Preference Program www.state.nj.us/humanservices/dds/services/ppp
- Supports Program www.state.nj.us/humanservices/ddd/programs/supports_program.html

Advocacy and Professional Organizations

- Alliance for the Betterment of Citizens with Disabilities (ABCD) www.abcdnj.org
- Autism New Jersey www.autismnj.org
- CSH (formerly the Corporation for Supportive Housing) *is a national nonprofit organization and community development financial institution that helps communities to create permanent housing with services to prevent and end homelessness.*
www.csh.org
- Fair Share Housing Center www.fairsharehousing.org/
- Housing and Community Development Network of NJ (HCDDNJ) www.hcdnj.org
- New Jersey Association of Community Providers, Inc. (NJACP) www.njacp.org
- Statewide Parent Advocacy Network (SPAN) www.spannj.org
- Supportive Housing Association (SHA) *a statewide non-profit organization working for the establishment of a strong supportive housing industry in New Jersey serving persons with disabilities* www.shanj.org
- The Arc of New Jersey www.arcnj.org



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.



Supportive Housing Association
of New Jersey

www.shanj.org

908.931.1131 • 185 Valley Street • South Orange, NJ 07079