



The Journey to Community Housing With Supports

A Companion Guide

Case Studies:
Stories shaping new housing opportunities





January, 2018

Dear Readers:

In 2016 through a generous grant from the New Jersey Council of Developmental Disabilities and along with partner Autism NJ, the Supportive Housing Association of NJ (SHA) published a housing guide entitled *The Journey to Community Housing with Support: A Road Map for Individuals and Their Families in New Jersey*. The guide has been a tremendous resource to individuals and families first by opening them to the possibilities of community housing that had been largely unknown and some that were recently emerging. And further by offering important guidance in navigating the complex systems that encompass securing housing and supports.

I am happy to say that the guide has been used by over 4,000 people! Yet even as it continues to help people every day to find and secure safe, affordable and accessible homes, in communities near to their loved ones, more resources are needed.

This booklet is a companion to our original housing guide. It offers candid stories of three case studies of people with different needs, opportunities, challenges and outcomes. Deb Wehrlen, consultant to this project, spent time interviewing those involved who generously shared their journeys. Each offer real insight into how the pieces of the puzzle fit together. Amid the practical advice, their hopes and dreams shine through showcasing not only how universal their quest is to live as independently as possible in neighborhoods of their choosing but also how much is possible with the right kind of supports.

Please note that the identity of the people in these cases have been altered to protect their privacy. This resource offers the best information available at the time of its writing and is meant to build upon the information in our original housing guide available at <http://www.shanj.org/resources/housing-guide>.

On behalf of SHA, I wish you all continued success.

A handwritten signature in cursive script that reads "Diane Riley".

Diane Riley, Executive Director
Supportive Housing Association of NJ

Acknowledgements:

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

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* and related resources.

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CO-HOUSING



Terms to Know

Co-Housing is an intentional community with a diverse population of residents who live in a planned neighborhood with shared spaces and activities to promote social interactions among residents of all ages and cultural backgrounds. Typically, residents in co-housing subscribe to a common philosophy about community living with a commitment to the value of caring for one another.

Resources and a directory of **Co-housing** are available at <http://www.directory.cohousing.org>

Plans for a Co-Housing Community

Jill, a parent of a disabled adult, is developing an intentional community where people with disabilities can live in the same location as their family, mentors/natural supporters and direct service staff who support them. This concept envisions shared living with supportive services for people with varying levels of disabilities. Extended family, mentors and caregivers can live and enjoy the amenities of this complex as well. All members of this community will share their skills and resources with one another. Small service industry businesses affiliated with the community will provide employment and vocational training opportunities.

In these apartments, people with disabilities may live in the same complex as their mentors or direct support worker. Residents with disabilities share their skills and may help their neighbors in need of such things as childcare, running errands, pet sitting or light housekeeping. Relatives, friends and advocates of those with disabilities can rent housing or work in the local small business enterprises. Everyone, including the public, can buy their groceries or prepared meals from the local store, grow produce in the common garden or join the complex's wellness center. Mentors assist with transportation, companionship, tutoring, or whatever may be needed. All who wish to participate can enjoy social and recreational activities together. These formal and informal activities are designed to promote the building of strong relationships among community members.

People with disabilities and their advocates will have access to barrier-free, affordable housing with readily available supportive services. Parents, who want their adult child to have independence yet want to live close by to support their development, can live on the same property. Advocates and mentors can live close and be involved in the lives of those to whom they provide natural supports. Many direct support caregivers also

need affordable housing options. This community would accommodate these needs and promote the development of strong relationships.

The founders of this community have formed a not-for-profit corporation to plan, develop and oversee the community. Family and close friends of the founder have agreed to support this project with their time, resources and expertise. They have recruited people with various professional backgrounds in finance, architecture, real estate and construction to serve as advisors. Currently, they are exploring models and designing elements of this complex. The board members are researching funding options including foundation grants to support the development of this innovative residential concept.

An architect is designing a cluster of small housing units around a common meeting spaces and storefronts. The housing units initially could accommodate 16 people with intellectual and developmental disabilities and 16 mentors, advocates or family members. Common areas include active and passive outdoor recreational amenities, gardens, a community room, and fitness and computer equipment. Storefronts adjacent to the housing will accommodate small business development.

This concept envisions shared living with supportive services for people with varying levels of disabilities

Employment opportunities will be designed into the plans. Ideas under consideration might include a food establishment, laundry service, childcare center, and a health and wellness center. Members of the housing complex could work within these service enterprises. These businesses would serve the public as well as community members.

The plans include collaborating with local community organizations to seek mentors and supporters to this neighborhood. Members of a local civic organizations or religious congregation, for example, might supply friendship and support to people with disabilities and assist them in various ways. These types of natural supports will become a strong component within the supportive housing available.

Foundation grants and philanthropy will support the project as well as capital development funds from government sources such as the Low-Income Housing Tax Credit (LIHTC), the Housing and Mortgage Finance Agency (HMFA), local and county affordable housing funds. Planning and development will take a few years to execute the vision of this intentional community.

Existing projects with similarities to this concept are:

Madison House Foundation and Autism Housing Network provide information regarding intentional communities that offer integrated lives for people with disabilities. For more information, go to <http://www.madisonhouseautism.org/housing-program/>

Visitation Homes is a faith-based intentional community providing homes for people with disabilities in Hamilton, New Jersey. For more information, go to <http://www.visitationhome.org/>.

The **L'Arche Community** is ecumenical and open to people of all lifestyles in 40 locations internationally. The mission involves people with and without disabilities living communally. For more information, go to <http://www.larcheusa.org>

Camphill Village's mission is based on the "active affirmation of the dignity, spiritual integrity and valued contribution of each individual <http://www.camphillvillage.org/>." Operating in several states, people live and work within small family-like homes located within the village. Multi-generational volunteers are recruited internationally to live and work within this campus setting.

The Centers for Medicare and Medicaid Services (CMS) Final Rule on Integration and the NJ Statewide Transition Plan

Funding for all settings must comply with the CMS Final Rule regarding Home and Community Based Services (HCBS). Based upon an assessment, the setting must assure full access to the benefits of community living such as choice, privacy, community integration, landlord/ tenant protections and the ability to select supportive services based upon individual needs.

SHARED LIVING



Terms to Know

Individual models are specialized programs tailored to individual needs and involving different types of residential settings.

Lifesharing or Shared Living is when an individual shares his/her home with others who provide care and supervision.

Fran's Home through "I Choose Home New Jersey"

Fran is a staunch advocate for herself and others. As a member of the Monday Morning Advocacy Group, she knows how to speak up. Initially, Fran shared a duplex home with her aunt. When her aunt passed away, it was devastating to Fran in multiple ways. She struggled with some serious medical issues including diabetes in addition to her developmental disability. She became very depressed. Her health declined. When she suffered a stroke, Fran moved into a nursing home to convalesce.

At age 55, Fran had little in common with most of the people in the nursing home who were quite elderly. She shared a room with two other women and had no privacy. Her opportunities to leave the nursing home for outings were extremely limited. She tended to use a wheelchair most of the time and had little exercise.

Fran's "circle of support" consisted of professional advocates and supportive staff who helped her plan for her return to the community after living in a nursing home for three years. A program called "I Choose Home NJ" provided Fran with

A program called "I Choose Home NJ" provided Fran with funding for staff to support her to live more independently within her own apartment

funding for staff to support her to live more independently within her own apartment. She relied upon a wheelchair but with physical therapy, Fran now uses a walker and can ambulate on her own for short distances. Fran explored options prior to moving from the nursing home. The idea of living in a group home

did not appeal to her. She prefers living alone but having friends close by. She likes having staff that are responsible only for her. Initially, she needed direct support staff to be with her around the clock. As she made progress, Fran has become capable of assuming more responsibility for herself and relies less upon continuous staffing support.

Fran moved into an affordable housing apartment complex. She rents a one-bedroom apartment that is barrier-free. She can use her walker and ambulate throughout the building. Her bathroom is equipped with grab bars and a walk-in shower. There are ramps throughout the facility and her apartment is located on the first floor. Staff are available to her whenever she needs them. She can also have time to herself without staff present. The service provider that employs her support staff also have a van available so Fran can go out to activities and shopping in her shore community. She has made a few friends in the apartment complex with whom she enjoys spending free time. She leads a very active social life. There are many things to do in her neighborhood.

Recently with persistence, Fran received a HUD Section 8 housing assistance voucher. This helps her limited budget considerably. With this rental assistance, Fran pays only 30% of her income and the voucher pays the balance of her rent. With the remainder of her income from Social Security, Fran pays for her food, utilities, clothes and recreational expenses. She also receives SNAP, formerly known as food stamps, to buy her groceries. The Department of Human Services provides for her staff supports through waiver funding.

Resources about **I Choose Home NJ** are available at <http://www.ichoosehome.nj.gov/>

INDIVIDUAL-DIRECTED SUPPORTS



Terms to Know

With **Self-Directed or Individual-Directed Supports**, a person exercises more control to manage and direct the supports that they receive. The individual selects one or more providers to serve their needs, based upon a plan and individual budget.

Tyler's Home through Self-Directed Services

Tyler is a bright young man with many interests. He spends much of his free time using the computer and loves to shop online. Tyler and his family share many interests and love spending time together. Certain situations can cause Tyler to become very distressed however. When experiencing such anxiety, Tyler can behave in ways that are dangerous to himself and others. He started having some difficulties during his teenage years that necessitated Tyler to move to a specialized residential school in Pennsylvania.

Yet, overtime it became apparent that Tyler did not have the quality of life he deserved, and he was far away from family and friends. His family wanted Tyler to live closer so they could be a more active part of his daily life. Additionally, the cost of his care in an institutional school setting was very expensive and did not completely meet his needs. The setting was large with many caregivers. To remedy these concerns, his family sought Community Care Waiver funds from the NJ Division of Developmental Disabilities to develop a small residential setting tailored to Tyler's needs in his hometown. The state was willing to utilize Waiver funds to bring Tyler back to New Jersey to live in his own place with a small cadre of staff and supports that he needed.

In this self-directed model, Tyler and his family are very involved with directing his care

His parents found a small house for rent. With Tyler, they interviewed and hired staff people to support Tyler to live in his own place. One caregiver lives with Tyler and shares his home. They enjoy many common interests and activities. Another staff member has developed a very close relationship with

Tyler. She understands him well and can teach other direct support professionals in his care. Tyler's mom, dad and brother are very involved in his care. They spend a few nights each week with Tyler enjoying time with him and ensuring that the staff and Tyler are working well together.

In the residential school, Tyler often had incidents where a few male staff had to restrain him to prevent Tyler from self-injury. In the past six months living with well-trained caregivers, Tyler has had only two such events. With careful analysis of the circumstances that upset Tyler, his direct support caregivers know the signs that trigger Tyler's disruptive behaviors. For example, when Tyler does not feel well, he will repeatedly bang his head. There are cycles when he cannot tolerate the stress of demands being placed upon him. Any transitions from the routine can disrupt him. The small group of caregivers knows to prepare Tyler for all changes to avoid his becoming upset. They also give him space when he shows the precursors to an outburst. Tyler is so much happier in his own home.

In this self-directed model, Tyler and his family are very involved with directing his care. Tyler's mom says that this individual-directed model is not perfect. They are continuously evaluating and making changes to find the right supports to assist Tyler most effectively. They are improving ways to communicate and orient staff to Tyler's needs. If staff are not compatible and do not carefully follow direction, their employment with Tyler is discontinued. Fortunately, Tyler's mom, dad and brother are capable and willing to be very intensely involved in his care. This is crucial to establishing a successful individual-directed model.

Resources about **Individual or Self-Directed Options** are available at <http://nj.gov/humanservices/ddd/programs/selfdirected/>