



# Lessons Learned from a Year's Alternative Housing Series

Awarded a generous grant by the John E. Fogarty Foundation in 2020 and supplementary funding by the Developmental Disabilities Council and the Carpiato Group in 2021, Personal Lifetime Advocacy Networks of RI (PLAN RI) conducted an extensive review of North American housing options that focused on the inclusion of individuals with disabilities. Each month, we would offer a Zoom session by families or service providers in the United States or Canada who had established alternative housing options. Over the year, almost 200 Rhode Islanders with disabilities, their family members, service providers and members of state agencies participated in those informational and interactive webinars. In addition to answering questions, many of our presenters made their power points, handouts and innovative principles available to people who attended online.

The following week, we would hold an in-state discussion online about what we had learned, what we might want to consider or avoid ourselves and what steps or help we might need to proceed toward a person-centered version that would provide greater self-direction and community membership here. As our body of knowledge expanded and participants reached out to agencies and state decision-makers, alliances were formed, and a third session was added each month. Representatives of the Department of Behavioral Health, Developmental Disabilities and Hospitals (BHDDH) and PLAN RI held "Office Hours," answering questions and overcoming barriers for individuals and their families who were looking toward greater independence and community participation from a secure residential site.

This document highlights some of the most valuable information we gleaned from more than 30 online meetings in our grant-sponsored project in order to help increase the number and varieties of housing options in Rhode Island. Some may find such innovation jarring, but we point to the progressive philosophy spoken more than a century and a half ago to inspire action to a new birth of liberty for all: "Object whatsoever is possible, still the question recurs, 'Can we do better?' The dogmas of the quiet past are inadequate to the stormy present. The occasion is piled high with difficulty, and we must rise with the occasion. As our cause is new, so we must think anew, and act anew." *Abraham Lincoln, 2<sup>nd</sup> Inaugural Address, 1865.*

Applying this past message to our current thinking about housing alternatives for individuals with disabilities, we might summarize our situation in a few words: **In the past**, the goal was described as permanent out-of-home placement. The orientation was to locations where caregiving arrangements were available. The quality outcome was viewed as competent care. The system task was to secure placements and coordinate staffing patterns. The system was optimized to resolve crisis. The guiding principles were case coordination,

adherence to regulations, and securing funding streams

**In the present**, the goals are to promote a sense of belonging, along with family and individual orientation to personal experience and growth. The focus is on relationships. The quality outcome is viewed as lifelong connection. The system tasks are to secure relationships and connect people in life-sharing patterns. The focus on the future – and the reference point -- is the lifespan. The guiding principles are that everyone has a gift that can be shared and that the community has room for all its members. Living with dignity, flexibility and relationships make a home. It is **far more** than being taken care of.

Based on what we have learned from this series, we offer the following advice to individuals and families preparing for a move to a new setting:

## Person-Centered and Person-Directed:

**One unique person at a time:** We found in David Wetherow a kindred spirit in values and, beyond that, in a wealth of experience in bringing those values to life. Thus, we invited him to participate in our journey of residential discovery by communicating with us at least weekly and providing logistical assistance. That collaboration proved to be valuable indeed.

In a 2003 post on his website, “Community Works,” Wetherow maintained that the foundation of a home lies not in cement and rebar, but rather in the way we customize it for an individual. “First, last and always,” he said, “think about who [the person] is

- His or her interests
- Experience
- What makes him/her ‘come alive’
- What creates peace, connection and engagement
- What would s/he love to be doing long-term
- The relationships that are the most important, soul -satisfying and creative
- The kind of understanding, acceptance, skill and energy s/he needs in surrounding people. . .

“Then,” Wetherow added, “follow a logical sequence of development:”

1. Find a few good people so the home will be about relationships.
2. Together find a house or apartment that would create comfort, happiness and connection.
3. Talk with the government or whoever is providing funds
4. Collaborate to move the money into the hands of the individual or family or authorized circle of supportive decision-makers.
5. Find ways for the new resident to settle into the surrounding community and to contribute his/her gifts to it.

As we listened to other presenters, we learned many strategies that worked well, such as the group where parents did much of the arduous legwork themselves in securing property and funding. But to access part of the funding, they made the mistake of abandoning their principle of natural proportions and created a segregated wing where dwelt 25% of the total population of the apartment complex – all with the same developmental disability. Other presenters taught us many positive strategies.

**Start planning early.** Thinking about where your son or daughter will live long before they move out of your home will increase the number and kinds of options you and s/he could consider. Formerly, most people waited until there was an urgent need, but they often discovered they were left with a very limited number of options. Remember that your vision influences where you and your child will end up. A vision of customized living in the community can guide educational choices and life experiences.

**Individuals and their families have much more control when their residential and day supports are separate.** Joe Wykowski suggested we imagine how we might react if there were a serious problem with the agency that provides activities during the day. Would we press more or less strongly for change if that same agency also ran the residential supports? Could we be sufficiently proactive if we knew that conflict might spill over to all the parts of our loved one's life?

**Self-direction is a flexible option to adults on Medicaid.** The successful use of person-directed planning and customized employment supports have enabled greater decision-making in recent years. Now, individuals are also extending these personal controls into other areas of their lives. Some select where to live and who provides their chosen supports. When people rent or own their own place, they can stay “at home,” even if they choose to change the support-providing organization. The old provider leaves, and the new one initiates the next contract. This new paradigm is making it possible for some families and individuals to focus on relationships that improve quality of life in the community.

When you are offered a place in a congregate setting, ask, “How does the presence of others with a similar level of support needs help me (him or her) reach my personal best life?” Teach your child to ask those questions at every meeting where a plan is being developed for him or her which starts with the word “individual”!

## Community Inclusion and Natural Supports:

**The best predictor of a safe and secure future** for a person with a disability is the number of caring, committed friends, family members, acquaintances and supporters actively involved in his or her life. Families from all over North America have been working on operationalizing this principle as they have developed new and creative ways to help individuals with disabilities live more fulfilling lives.

As more children experience inclusive educational opportunities, they are coming to be known to their community and to know their community. Relationships started in childhood have a greater possibility of extending into adulthood. The possibility of their employment within their own community increases. Because individuals are familiar with the people and places of their neighborhood, the opportunity for greater independence is provided. For these obvious reasons families and individuals are thinking “local,” especially when looking for housing.

Currently, the settings most providers offer are located in large to medium sized cities or towns, requiring people who were raised in rural areas or who prefer more quiet and privacy to settle for what is available and not for what would create the ideal setting to continue existing friendships or to seek a peaceful setting in keeping with personal preferences.

As individuals with disabilities live in increasingly inclusive housing environments their **opportunities to develop supportive relationships** with neighbors are also increasing. These relationships span the gamut of potential support from casual acquaintances to helpful neighbors, to protective neighbors and advocates, to close personal relationships. These neighborhoods could potentially become more structured in community development models such as “The Village” organizations that may provide natural support commonly needed by aging adults. That kind of support could temporarily augment the paraprofessional support individuals sometimes lose during natural disasters and pandemics.

**Isolation and loneliness are a threat to individuals’ physical and emotional health.** Even before Covid savaged many of our opportunities for life-affirming socialization, families and policy makers were looking for solutions to isolation and loneliness. They recognized that being surrounded by paid care takers is not enough. For this reason, the movement toward customized residential support is spurring on the development of personal support networks for individuals living in the community. Such committed family members, friends, neighbors, co-workers, and interest-sharing citizens find ways to encourage and engage them regularly. The growth and operation of personal support networks provide quality of life for the person at the center of that circle and peace of mind for their parents and siblings.

People with IDD living in congregate settings are much less likely to be engaged by their typical neighbors than an individual living in their midst with appropriate supports. Ask yourself, “Who could be more helpful as a natural supporter? Another person with my loved one’s disability or a neighbor with resources, contacts and skills with whom s/he might be willing to champion their friend’s good life periodically?”

## Variety:

**Housing decisions, like all decisions, can be altered.** Families and individuals are no longer thinking of the first housing choice as the last housing choice. We have seen

numerous examples of adults with disabilities choosing to move because they want to be closer to family, friends, or work. Conversely, they may prefer try out new communities and lifestyles. These desires are the same as those of their non-disabled peers. In many states, now that individuals are receiving customized support in their own homes (rented or owned), they are less geographically tied to their support provider's area of operation. No one should feel obliged to accept the first or only option offered.

## Technology:

**The use of safe home and smart technology devices may assist individuals** with disabilities to live more independently. It is increasingly being used as a vital support that can reduce reliance on human support. The cost of acquisition and ongoing support should be anticipated and built into budgeting mechanisms that are used to provide customized residential support. The workforce demands for individuals with the necessary skills to use this technology also need to be anticipated and educational programs provided to keep these personnel abreast of a rapidly changing technology environment.

The most serious and life-limiting problems confronting individuals with disabilities are isolation and loneliness. Over reliance and improper use of technology supports may exacerbate these problems. Families and supporters must develop new ways of reducing isolation and loneliness. If individuals are living in inclusive environments, the creation of relationships with friends and neighbors will become an important and necessary part of any customized living plan.

## Financing:

**Adults with IDD are eligible for subsidized housing through several different programs:** Housing Choice Vouchers, Project Based Vouchers, Public Housing, and Privately Owned Subsidized Housing. Because there is a significant shortage of affordable housing in RI, people need to plan on waiting lists that may be several years long. Application for housing choice vouchers can be made through Rhode Island Housing; application for public housing is made through city or town housing authorities. Application to privately owned subsidized units needs to be done with each owner. Although this process may often be time consuming, the subsequent monthly rental is approximately one-third of that individual's monthly income and well worth the wait. If an individual gets to the top of the waiting list and they are not ready to move into a customized living option, they may pass on that apartment until a more convenient time.

**Medicaid funds were created to meet medical necessities.** This includes Medicare and self-directed supports as well. While regulations have been broadened in recent years to include such things as transportation, gym memberships, recreational and social activities, these federal programs do not pay housing costs. Advocating for a higher tier of funding will

not make it easier to pay rent or mortgage costs. However, Social Security Income (SSI) or Social Security Disability Income (SSDI) may be used for such expenses.

**Special Needs Trusts and other financial investments may help individuals access alternative and inclusive housing options.** The amounts that most people receive from SSI and SSDI, however, maintain people at a poverty level of support. Planning ahead with a tax-sheltered account such as Achieving Better Life Experiences (ABLE) allows the individual and/or their family members to save up to \$15,000 per year in an investment account. These funds may be accessed for a broad array of goods and services, including housing costs. For more information on ABLE, you may contact the state treasurer's office.

**It may make more sense to rent than to buy,** especially as the person is moving out of the family home or an agency setting for the first time. That makes it much more likely that you can walk away as you make new discoveries.

## Collaboration:

Because housing decisions are made locally, **acting locally** often yields the quickest and best results. Thus, it is important that local housing decision makers and policy makers become aware of the existence of individuals with disabilities in their community and the desire of these individuals to remain close to family and friends where they grew up

Given the **common needs of individuals with disabilities and elders for physical accessibility**, advocates in the respective populations need to work together to promote the development of universal design principles in the construction of new housing units ranging from individual homes to various kinds of rental units. This will resolve the problems of accessibility, which become more important as individuals age. More importantly, it will resolve the problems of visit-ability, which will help individuals become more included in their local communities.

In some areas collaboration goes beyond the administrative level to include home sharing between an elder and an able-bodied individual with IDD. For seniors who want to continue to age in place in their own homes, having a companion who not only pays less than market value on rent, but also handles some physical challenges can provide comfortable levels of interdependence for both generations. For example, the younger person can carry laundry up and down the stairs or haul the trash bins out to the curb for his/her older housemate.

## What is next?

PLAN RI has just hired three part-time housing information and referral specialists to help individuals and proactive family members learn what they can do to help progress toward more of these ends over time. You may access their contact information on our web site or Facebook page.

All states have some version of shared living. Most have flexible regulations and laws that **make it easier for the individual to share their own place with paid caregivers**. PLAN RI is currently working with state officials to identify and overcome barriers to “reverse shared living.” Currently, shared living takes place when an individual with a disability moves into the home of another(s). However, finances, in-kind benefits, laws protecting renters, etc. all look different when the paid supporter moves into the home of the individual seeking support. Such barriers need to be addressed so that the person whose home welcomes a paid provider is not at a legal or financial disadvantage if the agreements are not followed.

Training can help spread the knowledge we gained from this year’s review. We will train PLAN RI’s information and referral specialists, our members and their families, the facilitators of our personal support networks and our board of directors. In addition to this “internal training,” we have committed to train staff at the RI Parent Information Network (RIPIN) and members of Advocates in Action for self-advocacy in this new arena.

In return, Advocates in Action will establish and populate a PLAN RI You Tube channel with the on-line sessions that provided us with these insights. Each session will also be translated into Spanish to reach another group who may benefit from what has already been made available in English.

## Conclusion:

Many families, advocates and policy makers across North America are thinking anew and have demonstrated that the need of housing for individuals with disabilities is the same as that of their non-disabled peers. There is a common recognition that we need more affordable housing, more inclusive housing, and more supportive housing. Support, both formal and informal, for those who are seeking the promise of citizenship is possible and available, as we have seen in our year-long look at creative solutions throughout North America.

We conclude with advice from The Reverend Dr. Martin Luther King, Jr., given a century after Abraham Lincoln’s Inaugural Address. “Through education we seek to change attitudes; through legislation and court orders we seek to regulate behavior. Through education we seek to change internal feelings (prejudice, hate, etc.). Through legislation and court orders we seek to control the external effects of those feelings. Through education we seek to break down the spiritual barriers to integration. Through legislation and court orders we seek to break down the physical barriers to integration. One method is not a substitute for the other, but a meaningful and necessary supplement. Anyone who starts out with the conviction that the road to racial [or any] justice is only one lane wide will inevitably create a traffic jam and make the journey infinitely longer.”

We at PLAN RI want to increase the opportunities for all Rhode Island residents to live in inclusive, supportive, and affordable housing. We are seeking to partner with other like-minded Rhode Islanders to speed our travel to that destination.