

**Housing Options for People with
Intellectual and Developmental Disabilities**
Discovery Phase Report
An Integrated Supported Housing Model



Research for Practice and Policy

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June 2017

Produced in Partial Fulfillment for a Contract with a Group of Parents of Adult Children with
Intellectual and Developmental Disabilities

Acknowledgements

I wish to thank the families for their vision and thoughtful guidance of this work. I also wish to thank the government, social service agency, real estate and finance professionals and others that provided information, review and insights for this report.

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Executive Summary

Housing Options for People with Intellectual and Developmental Disabilities is a project for a small group of parents of transitioning youth with intellectual and developmental disabilities (IDD) who would like to develop quasi-independent living housing for their children and other families. This report describes findings from an initial discovery project to provide information on available options to develop housing that provides staff supported independent living in the community for a small group of young adults currently living with their families in New York City. The families were given these results to use in developing their own housing model that fit the conditions of their city, neighborhoods, and transitioning youth with disabilities. The discovery phase of the project identified:

1. Models for this kind of housing that meet Medicaid's Home and Community Based Settings (HCBS) criteria, including staff and organizational structures needed to maintain the housing model long term.
2. Information on the number of adults with disabilities that would be needed for an initiative like this to be cost effective, as well as the number and types of staff needed for this type of housing model.
3. Available sources of funds from government and private sources to buy housing, provide for ongoing staffing, and maintain housing over time.
4. The time line, process, and amount of time needed to obtain funding and acquire housing and staff. Different estimates are given for the various sources of funding identified in the report.
5. Organizational structures (non-profit status, other options) needed to develop and maintain housing if the families choose to form their own organization. The names of other NY based organizations providing similar programs these parents could join that would offer similar housing models.
6. New York and national resources that could provide additional support for the next phase of the project.

An initial assessment and discussion with the families revealed the following priorities for housing:

- Individual, family or program owned housing.
- Need for a range of independent living housing options.
- Housing located in a safe neighborhood with amenities within an hour of their families.
- 24-7 emergency staff support on site, with additional support for individuals as needed.
- Shared activities and connections to employment opportunities or programs.
- Shared meals.

The report describes the impact of the 2014 Home and Community Based Settings (HCBS) rule for the Medicaid waiver services that pay for most programs for people with IDD on housing choices for transitioning youth. The various programs and sources of funding available through New York's OPWDD system for individuals with disabilities and sources for funding for developing housing for people with disabilities in New York and issues specific to New York City are described next. Several existing housing programs are described that include elements similar to the model requested by these families. Based on this information, the report develops a model, *Resident Owned Community Integrated Supported Housing for People with Disabilities*, which includes the following elements:

Program size: 8-25 people with disabilities.

- **Property owned by the program or its residents.** The organization could buy apartments or houses either in a large complex under development or buy a series of houses or a small apartment building for use by the program. Alternatively, participating people with disabilities or their families could purchase housing that would be managed by the organization.
- **Property managed by the organization.**

- **Common space and housing for 24/7 staff support.** In addition to buying housing for program participants, the program would purchase a common space with a kitchen that could be used for shared meals and activities. Housing or other compensation would be provided for 24/7 emergency staff support.
- **Individualized supports for ADLs and other activities.** Individuals with disabilities participating in the program would be either on self-direction or contract with an OPWDD agency for Community Habilitation Services.
- **Shared services based on resident interests.** Activities would include training and support for independent living, also potentially offering employment and volunteer activities.
- **Community integrated shared meal plan.** Develop a shared meal and activity plan that people without disabilities in the complex or community can buy into in order to create an integrated program. The meal plan would consist of participation in between 5 and 7 shared evening meals per week. Food choices, meal times and other aspects of the program would be determined on an ongoing basis by participants and individuals could choose which days they want to eat with the group. Payment for the minimum number of meals would be a requirement for participation in the program for people with disabilities.
- **Integrated shared activities.** The group would regularly develop a roster of shared leisure activities open to others living in the community or complex. Participation in these events would be voluntary, with people signing up to participate.
- **Mentoring:** One on one mentoring with other people with disabilities and people engaged in careers or hobbies of interest.

The remainder of the report discusses development and management issues related to developing this model. A section outlines options for organizational and incorporation structures for the organization that would be responsible for developing and implementing the model, financing for housing acquisition, property management, and ongoing service provision. This includes strategies for each family to purchase housing independently that would be managed by the organization versus various ways that the organization could obtain properties that would be owned through shares like a co-op or lifetime leases. Various strategies for providing 24/7 emergency supports, staffing shared programming and activities, the meal program, and mentoring are also discussed. A final section outlines the step by step process to determine assets for participating families and develop the model.

Project Goals

Housing Options for People with Intellectual and Developmental Disabilities is a project for a small group of parents of transitioning youth with intellectual and developmental disabilities (IDD) who would like to develop quasi-independent living housing for their children and other families with similar needs by either buying a building and developing a system for staff supervision, payment, and program development/oversight or joining an already existing group established for this purpose. This report describes findings from an initial discovery project to provide information on available options to develop housing that offers staff supported independent living in the community for a small group of young adults currently living with their families in New York City. The families were given these results to use in developing their own housing model that fit the conditions of their city, neighborhoods, and transitioning youth with disabilities.¹

The model developed here is based on the new Federal Medicaid Home and Community Based Services waiver regulations (HCBS) and other federal housing programs. The HCBS regulations govern services for people with intellectual and developmental disabilities (IDD) nationally that receive services funded through Medicaid by CMS and reflect current standards for employment and community integration for people with IDD. These include encouraging people with IDD to live as independently as possible in the community and work or be engaged in productive activities in integrated settings with both people with disabilities and those without disabilities. The transitioning youth already identified for this initiative would require housing in the next 5-10 years.

The discovery phase of the project identified:

1. Models for this kind of housing that meet HCBS criteria, including staff and organizational structures needed to maintain the housing model long term.
2. Information on the number of adults with disabilities that would be needed for an initiative like this to be cost effective and the number and types of staff needed for this type of housing.
3. Available sources of funds from government and private sources to buy housing, provide for ongoing staffing, and maintain housing over time.
4. The time line, process, and amount of time needed to obtain funding and acquire housing and staff. Different estimates are given for the various sources of funding identified in the report.
5. Organizational structures (non-profit status, other options) needed to develop and maintain housing if the families choose to form their own organization. The names of other NY based organizations providing similar programs these parents could join that would offer similar housing models.
6. New York and national resources that could provide additional support for the next phase of the project.

The project began with an assessment of the transitioning youths' current abilities and support needs and their vision of abilities and the level of support they would need as adults. The assessment also discussed both youths and families' vision for their ideal future living situation. All of the transitioning youth would qualify for supports as adults through New York's Office for People with Developmental Disabilities (OPWDD) as adults. OPWDD has three systems to support adults with IDD, a certified support system where adults receive a range of services through agencies with programs or sites certified by OPWDD, services provided by OPWDD's qualified approved providers to people living in their own homes or with family, or self-directed services where individuals design their support system on their own, hiring staff or purchasing services from agencies. Most youth in this project ranged in age from 17-19, with one already an adult living in an apartment building with supports through self-direction funds. Most planned to be in school until they were 21, then transition to adult services. Overall, the core group of youth included individuals with mild to moderate IDD, some with physical disabilities as well.

While a few parents anticipated that their children would need some help with medications and other activities of daily living (ADL) as adults, most thought that individuals would be able to handle their personal care and medication on their own or with minor supervision. All felt that these individuals would require some assistance

¹ Produced in partial fulfillment for a contract with a group of parents of adult children with intellectual and developmental disabilities.
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or guidance on independent living skills (AIDL) such as cooking, cleaning, buying food or household items, getting to work or other activities, and managing money. While most parents felt that they would continue to play a role in their youth with disabilities lives into adulthood, some had already identified siblings as potential guardians for the future. Some had already established special needs trusts to support their adult children with disabilities.

Most envisioned these youth working and engaged in other activities in the community as adults. All were concerned about social isolation, even if living independently in apartments in their community. When asked about ideal living situations as adults, the youth and their parents described a range from living independently in an apartment, to sharing with roommates, to living in a home with a spouse and children. All identified the following elements as important:

- **Individual, family or program owned housing.** Due to concerns about redevelopment or rising rents in rent controlled buildings in New York City, these families wanted to own the buildings or apartments where their children resided to ensure that they would have housing throughout their lives. As an alternative to each individual or family owning their housing, the program developed by the families could buy housing for use by participants that would be owned by participants as a group or rented to program participants with a lifetime lease clause.
- **Range of independent living housing options.** While planning to own the properties, the youth and their families envisioned a range from efficiency apartments to houses for their individual needs. As the project developed, families envisioned apartments or condos in apartment complexes, a small apartment building, or located in houses within close proximity to each other. The model envisions a range of apartment sizes from efficiencies to two or three bedroom units to fit various needs.
- **Safe neighborhood with amenities within an hour of their families.** Neighborhoods envisioned would be comfortable for the people with IDD to walk unaccompanied and carry out their activities of daily living. The neighborhoods would have adequate shopping, recreational facilities (parks, etc.), and transportation to jobs and other activities. Most of the families in this project currently live in Brooklyn. While they would ideally like to develop the model in the five boroughs of New York City, they were amenable to their children living within an hour of their family homes. For this reason, connecting with programs in upstate New York or elsewhere was not explored.
- **24-7 emergency staff support with additional support for individuals as needed.** Given the range of disabilities and support needs of the adults potentially participating in this program, families felt that each youth would either obtain individualized staff support through self direction funds or contracting for supports. However, all also felt that they wanted someone either in the same building or nearby available to respond in case of emergencies. For this reason, the model includes a staff apartment or other mechanisms to provide this support.
- **Shared activities and connections to employment opportunities or programs.** The youth and families wanted to have a range of shared social activities for those engaged in the program and potentially their neighbors. Some talked about having businesses in a building owned by the project that could potentially employ program participants. Others envisioned contracting with agencies that offered employment opportunities.
- **Shared meals.** The unique aspect of the program envisioned by everyone discussing a future program was regularly sharing meals in a common space. As we discussed this further, we settled on a plan to have common dinners 5 to 7 days per week for participants as a mechanism to both build community and ensure appropriate nutrition. Options for this meal plan are outlined in the model and questions about shared meals were asked of all other models researched for this project.

The project involved researching existing policy, programs, and resources to determine if any currently available housing programs met the family's needs, resources needed to pay for participation or develop a new program, and federal and state policy. This involved interviews with 23 organizations involved in housing in New York, neighboring states, and nationally, coupled with review of online materials and reports from these programs. This included state and regional government staff at OPWDD, representatives from statewide

umbrella organizations providing services and technical assistance to people with disabilities like the New York State Association of Community and Residential Agencies (NYSACRA) and the local University Center for Excellence on Developmental Disabilities (UCEDD), representatives from New York City's mayor's office involved in housing for people with disabilities, representatives from organizations facilitating financing or managing housing for people with disabilities or similar populations, housing developers, disability services agencies offering housing in New York City or nearby, staff at programs offering similar models to that envisioned by these families, parents of people with disabilities, and direct support staff for those in self direction. An additional eight programs providing housing and other services identified by the families were researched online. Potential sources of funding for housing was researched through a combination of interviews, online research, and search of Foundation Center files.

This report outlines findings from this research and develops a model that fits the goals envisioned by these families. The model includes several options to structure and fund each aspect of the program. This report is a public document to share what was learned through this process. A separate memo to the families provides additional detailed information on options for next steps.

The Federal and New York Housing System for People with Disabilities

People with disabilities are eligible for a number of federal and state government programs, depending on their income and the nature of their disability. Those on social security (SSI) or social security disability (SSDI) are eligible for public housing or housing vouchers available through the local public housing office. As discussed in later sections of this report, individuals with disabilities are also eligible for federal low interest loans to purchase or renovate homes. Those with developmental disabilities may also be eligible for Medicaid and housing services offered through state developmental disability agencies. These agencies provide a wide array of services using Centers for Medicare and Medicaid Services (CMS) Medicaid funds to those whose disabilities are severe enough to qualify for services.

Federal HCBS Rules

Most services for people with disabilities in the community are funded through Medicaid waivers to each state. These waivers fund a broad array of services for housing, employment and other supports. Information on Medicaid Home and Community Based Settings (HCBS) program is available at <https://www.medicaid.gov/medicaid/hcbs/>.

In January 2014, CMS released new rules for the HCBS program that significantly strengthened efforts to ensure that people with disabilities served through this program can live in integrated settings in the community with life experiences like other community residents. These rules built on a gradual movement toward expectations that people with disabilities should have supports necessary to be fully involved citizens, working, participating in social activities, and having the same rights as others. In the past several decades, most of the large institutions that housed many people with IDD in previous generations have closed. While people with disabilities have always lived in a variety of settings, for many years group homes with staff became a common residential option. Group homes ranged in size from 3 or 4 people to 10 or more. In addition, from the 1950s on, alternative settings that segregated people with disabilities from the rest of society became another popular option. The farm settings like Camphill discussed later in this report are examples of these segregated intentional communities. More recently, advocates for people with IDD have stressed that people with disabilities should not live differently than anyone else. Like others in the U.S., they should be able to live in their own homes or apartments, with the same rights and responsibilities as others. If they live in group homes, those houses should have a small number of residents, like adults without disabilities sharing a house and apartment. The new HCBS rules codify this shift in thinking about the quality of life for people with disabilities. The full text of the new rules and other information is available at <https://www.medicaid.gov/medicaid/hcbs/guidance/index.html>. AUCD, the umbrella group for university centers for excellence for people with disabilities has a useful analysis and summary at http://www.aucd.org/docs/policy/HCBS/HCBS%20Settings%20Rules_What%20You%20Should%20Know!%20Final%201%202022%202016.pdf.

The HCBS rules give states five years to develop a plan that shifts their housing, employment and other programs toward community based services that enable productive lives for people with disabilities. On May 9th, 2017 CMS announced that all states had an extension to comply with the rules, giving them until March 17, 2022 to demonstrate compliance with the final rule (see <http://www.medicaid.gov/Federal-Policy-Guidance/Federal-Policy-Guidance.html>). New York's system will be discussed in the next section. For housing, the new rules discourage large group homes or segregated settings, encouraging people to live either in their own homes or small group settings in the community. People with disabilities are expected to have their own leases or occupancy agreements like others living in that community. While housing could be owned or managed by an OPWDD provider agency or other organization, the new HCBS rules require that people choose where and who they live with and that they have a lease or occupancy agreement that outlines the same protections from eviction/loss of housing as anyone else would have in that community.

Housing is meant to be integrated into the community, with any setting that isolates people with disabilities from others receiving heightened scrutiny. Settings can be isolating even if they are located in the community. For example, a group home for 10 people located in the midst of a city neighborhood could be isolating if the residents rarely go out or are transported to programs exclusively for people with disabilities with little opportunity to interact with others in their community. Settings like gated communities exclusively for people with disabilities or farm settings where people with disabilities live and work together would also receive heightened scrutiny. In order to be eligible for CMS funds, these settings would have to explain why they do not isolate people with disabilities from the community and measures the organization takes to ensure that their residents regularly interact with people without disabilities in their community.

The Home and Community Based Settings Rule (HCBS Final Rule for CMS) includes the following basic elements for Housing in the New York plan:

- **Integrated Settings Rule:** Under the amended rules, states will be encouraged to downsize large group homes by 2022 (unless the state gets an extension on this deadline). In New York, all new group homes developed after 2019 will house 4 people or less, unless they have special permission for a larger number. Any housing unit (apartment/house) that houses a majority of re disabled residents and/or receiving Medicaid waiver services, any campus like setting, or gated community with only people with disabilities and their staff will face heightened scrutiny to be considered an integrated setting. In New York, OPWDD uses a guideline for housing developed with public capital funds of the building/apartment or housing complex having no more than 25% of the residents as people with disabilities. However, projects can negotiate for a higher percentage of people with disabilities. **Any new nonintegrated setting may require heightened scrutiny to receive OPWDD capital funds for housing under the Multifamily Integrated Supportive Housing Program.**
- The HCBS rules intend for people with disabilities to live in the community in integrated settings and have housing options like people without disabilities.
- All residents in housing that is part of an OPWDD certified program (i.e., provider operated and managed housing) will need to have a lease and the setting must guarantee that the person has privacy and the right to choose their own activities. The person must have access to food at all times and be able to choose what they eat and their meal schedule. This means that they must have choices of what they eat and participate in scheduling meals.
- People with disabilities (with family support) must be able to choose their roommates and who provides their services.

Each state develops its own state plan that meets the general criteria of these rules. The rules for housing are part of a package of changes to systems for employment and other activities as well. Overall, these rules envision that as many people as possible will be employed in the community, with sheltered workshops and other nonintegrated forms of employment phased out. Rather than spend nonworking day time in day programs with other people with disabilities, people with IDD will receive social skills development, training, and other programming in the community along with others without disabilities. Participation in volunteer opportunities and community wide events are also encouraged. Housing is anticipated to facilitate becoming part of the community, with staff supports available to facilitate integrated community life.

OPWDD Housing Systems and Programs

The state of New York posted its HCBS final rule transition plan in January 2017, expecting to be in full compliance with the rule by March 2019.² The state plan is available at https://www.health.ny.gov/health_care/medicaid/redesign/hcbs/docs/2017-01-20-final_rule_statewide_transition_plan.pdf. According to this report, OPWDD serves more than 72,719 people, approximately 55 percent of whom reside in their own homes or the home of a family member, relative, or friend.

OPWDD's congregate housing system contains over 6,000 certified Individualized Residential Alternatives (IRAs) and Community Residences (CRs) serving over 30,000 people. Fifty-four percent of the group homes are currently designed to serve more than four unrelated individuals.³ Certified housing is offered by an OPWDD certified provider agency and meets all state regulations for staff and facilities for people with disabilities. Currently, 37 percent of the group homes are in compliance with the new HCBS rules.⁴ In New York, all new group homes developed after 2019 will house 4 people or less, unless they have special permission for a larger number. Guidance and tools to facilitate transition of group housing to meet the HCBS rules are available at https://opwdd.ny.gov/opwdd_services_supports/HCBS/hcbs-settings-toolkit. OPWDD anticipates developing guidance for new residential developments and templates for leases and other documents that ensure individualized living plans by the end of 2019.

Applicants to OPWDD's Residential Request List for certified housing through OPWDD are prioritized by individual need, with people coming out of institutions and those about to lose their housing have priority for placement. Youth currently housed with their families would be lower priority. Given both the institutional nature of much certified housing and the long waits for service, certified housing through OPWDD was not considered a viable option for the families that commissioned this report.

That said, the HCBS rules also impact on the nature of housing available to people living in uncertified settings in the community. Uncertified housing is any housing where people with disabilities live that is not certified by OPWDD. Uncertified housing could include housing found on the open market or public housing found independently by individuals or their family. It also includes staffed housing programs offered by providers that have not been certified to provide housing by OPWDD. Many of the intentional communities and other program models described later in this report are uncertified housing. While individuals with IDD may use their ISS grants to pay for uncertified housing, with OPWDD approval in some cases, any staff and programming at these facilities would not be automatically covered by state funds. For example, in several of the key ring program models described later in this report, the families of people with IDD found housing for their family members individually, sometimes paying for them with ISS housing funds received as part of their self-direction supports. However, the programs are not covered through OPWDD and families must pay for them out of pocket.

OPWDD plans to assess how well these residential options promote integrated, community based living in 2016-2017. Results of this assessment were not available at the time of this report.

OPWDD offers several alternatives to group homes for housing for people with IDD. Information on these programs is available at https://opwdd.ny.gov/opwdd_services_supports/residential_opportunities. These include:

- **Family Care:** Family care is like foster care for adults, with trained people providing certified residential housing in someone's home. If set up correctly, family care can be a form of shared housing that creates a long-term relationship between the family and the person with disabilities

² All deadlines in this report come from the January 2017 report. New York had not formally extended these deadlines when this report was published.

³ NY HCBS Settings Transition Plan, pages 99-100.

⁴ NY HCBS Settings Transition Plan, page 118.

living together. Information is available at

https://opwdd.ny.gov/opwdd_services_supports/residential_opportunities/family_care

- **OPWDD Certified Housing with Individualized Services:** OPWDD offers several forms of housing owned and operated by OPWDD agencies, licensed, and regularly inspected by the state. The two relevant for individuals who want to live in small residences or their own apartments are:
 - **Supported Individualized Residential Alternatives (IRA):** IRAs are certified and licensed like other OPWDD group homes, but provide individualized services along with room and board. OPWDD offers two alternatives in this program, supportive and supervised residential alternatives. Supportive Individualized Residential Alternatives (IRAs) have a maximum capacity of four individuals or fewer. Supportive IRAs enable individuals with intellectual and/or developmental disabilities to enjoy the benefits of community residential life with habilitation support staffing tailored to the times and circumstances that is most needed by residents to remain living independently. These settings could be apartments or homes. The provider agency would hold the lease to the setting.
 - **Supervised Individualized Residential Alternatives (IRA):** In contrast, supervised group homes are for individuals requiring staff on site at all times that individuals with disabilities are present in the home. While supervised residences could be apartments or homes, they can have up to 14 residents.
- **Community Habilitation Services:** For individuals with disabilities who want to live in their own homes or apartments but receive services from an OPWDD certified agency, the Community Habilitation program provides a middle ground between living in a group home and self direction. Community Habilitation is similar to residential habilitation supports offered in group homes or IRAs or day habilitation supports delivered in day habilitation facilities, however, services are delivered largely in the community (non-certified) settings. Community Habilitation offers a wide range of skill training and supports: adaptive skill development, assistance with activities of daily living, travel, health, adult educational supports, communication, social skills, leisure skills, money management, socially appropriate behaviors, life safety, hands-on-assistance provided by staff as necessary, professional oversight services as necessary, self-advocacy, informed choice, community inclusion, and relationship building. Community Habilitation may also include personal care, health care, protective oversight and supervision, and program-related transportation among other services. Information is available at https://opwdd.ny.gov/opwdd_services_supports/residential_opportunities/individualized_residential_alternative
- **Multi-family Integrated Supportive Housing (ISH) Program:** OPWDD sponsors the development and management of apartments within developments built with public funds that have services provided by OPWDD certified provider agencies. These services can be community habilitation or supportive IRA services. Individuals living in non-certified ISH apartments hold the lease for the apartment in their own name and control the setting and may receive an array of other OPWDD waiver services such as community habilitation and other non-waiver services. ISH apartments are expected to be non-certified unless the service provider can document a rationale why the apartment needs to be a certified IRA, based on the individualized needs of the person(s) who will reside there. Many of the Dunn Development apartments through AHRC's ISH Program mentioned later in this report are certified as Supportive IRAs.
- **Individual Support Services (ISS):** ISS is a housing subsidy that can be used to pay for rent or a mortgage, with the amount determined by the individual's income and where they live. ISS payments can be used for housing for people who are eligible for OPWDD services. People who self-direct their services can also receive an ISS subsidy to pay for their housing. Additional information on ISS in New York City is provided in the section on financing housing. General

information is available at

https://opwdd.ny.gov/opwdd_services_supports/supports_for_independent_and_family_living/individual_supports_and_services.

- **Self Directed Services Housing Supports:** Self direction allows people with disabilities and their families to design services that meet their individual needs. The service package is designed and managed with the help of a support broker and, once approved by OPWDD, funds are managed by a fiscal intermediary. People self-directing their services can hire their own personal support staff and design or purchase other programs or supports to meet their goals. Self direction supports include a housing subsidy through an ISS grant. Additional information on these housing supports are discussed in the housing finance section. Information on self-direction is available at <https://opwdd.ny.gov/selfdirection>.
- **Home of Your Own (HOYO):** HOYO is New York's version of a federal low interest loan program for home buyers with disabilities. This program will be discussed in more detail in the financing housing section. General information is available at https://opwdd.ny.gov/opwdd_community_connections/housing_initiative/home_of_your_own_hoya

The bulk of this report explores the impact of the HCBS rules as implemented by New York state on housing models and ways to finance them. The report will pay special attention to ISS and HOYO as ways that individuals can pay for housing. The housing options, financing systems, and eligibility rules for people with IDD in New York are complex. As a result, OPWDD and other organizations have sponsored guides such as the West Chester Institute for Human Development's [Housing Resource Guide](#) and YAI's [Roadmap to Housing](#) and training for housing navigators that help individuals and families explore their housing options. The housing navigator system is outlined next.

Housing Navigator Programs

Recognizing the complexity and confusion of finding appropriate housing options for people with disabilities, NYSACRA developed housing navigator training to create a pool of trained individuals that could help families navigate the housing system. Housing navigators are trained to work with individuals, not groups. Given their focus on helping families identify resources, develop plans, and locate housing, their services are an important resource even for families developing housing as part of a group.

Housing navigators first help families clarify their resources, potential income available to the person with a disability, and the impact of savings systems like special needs trusts and ABLE accounts on their ability to obtain housing supports from government or other sources. Special needs trusts and ABLE accounts are discussed in more detail later, but provide a way to save for housing and other special needs for people with disabilities. Housing navigators are familiar with the various housing options available through OPWDD and other sources, as well as assessing the support needs of individuals. Part of their activities involve developing an individualized housing plan for the person with a disability. Housing navigators can also help people find housing and negotiate with brokers to obtain it. In some cases, housing navigators actually locate housing for the individual. In other cases, they provide resources that families or individuals could use to find housing on their own.

Housing navigators can be found in several places. OPWDD and other resource organizations have housing navigators on staff that help people eligible for OPWDD services free of charge. Some agencies have NYSACRA trained housing navigators on staff. The agencies interviewed for this report said that at present their housing navigators help people contracted with that agency for services free of charge, but they had no mechanism to assist families not working with the agency. Other housing navigators are consultants working on a fee for service basis. NYSACRA can provide a list of housing navigators trained through their program.

Issues Unique to New York City

The New York City real estate market is one of the most expensive and tightest in the country, making it difficult for all low or moderate income people to find housing. People with disabilities face additional challenges for several reasons. In addition to accessibility issues, like many places in the U.S., many potential

landlords, condo, or co-op boards have negative stereotypes about people with IDD, in part because they are lumped in with people with mental illness. Landlords and residence boards fear that people with IDD will cause fires, be loud or violent, or fail to keep up the apartment. While many landlords are familiar with public housing vouchers, few understand the OPWDD housing subsidies. As a result, many landlords refuse to accept the ISS housing funds for rent payments. In order to address these challenges, the New York City mayor's office has developed a housing coalition designed to advocate for more housing for people with disabilities and educate landlords about the OPWDD payment systems. This coalition is primarily focused on rental housing.

People familiar with the New York City real estate market strongly encourage families and individuals with disabilities to work with a real estate broker to find housing. The broker identifies potential housing, negotiates with the landlord, helps finalize the contract and collects the initial rent and security deposit. Brokers charge a fee based on the rent, usually one and a half to two month's rent. People with disabilities and their families are encouraged to save for broker fees in advance.

Another strategy for developing housing programs like this one involves locating them in complexes that are naturally occurring retirement communities (NORC). Many NORC models have services for elderly residents in the building or nearby and would be familiar with the service systems envisioned for this model. These housing units are also more likely to be accessible for those facing physical challenges. The potential negative to pay attention to when partnering with NORCs is ensuring that the building has residents of a mix of ages. This is important to ensure that the people with disabilities can be part of a community with their peers and because of the different needs of the elderly and young adults.

Financing Housing Acquisition and Providing Services for Shared Housing

The housing model described below includes housing owned either by the individual participating people with disabilities or by the organization on behalf of its members. In each case, the individual is expected to be responsible for a monthly mortgage or rental payment and have a formal mortgage or lease contract. Financing the purchase of properties and services can be done in a number of ways. This section outlines government programs and other resources that can be used to pay for these services. These programs will be referenced in later sections describing the model and ways to finance it.

Housing Purchased by Each Individual/Family

One option for the model program involves each family purchasing housing separately, then joining the program for services and potentially property management. The similar existing models discussed in a later section all involve each family obtaining and maintaining housing independent of the program. Several forms of savings plans help people with disabilities and their families put money aside to purchase housing and other special needs. As outlined above, the HOYO program offers low interest mortgages for people with disabilities to buy their own homes. Once purchased, funds from several OPWDD programs can be used to pay rent or mortgages. Outlines of each program and current limits are outlined here.

ABLE Accounts

Achieving a Better Life Experience (ABLE) accounts were established at the federal level in 2014 (see <http://www.ablenrc.org/> for more information). Like 529 college savings accounts, they provide an opportunity for people with significant disabilities that occurred before the age of 26 to create a tax free savings account for college, housing, and other costs to enhance employment, health and functioning. While states can set a higher maximum for the accounts, only the first \$100,000 is exempt from social security asset calculations. If the person is receiving SSI or SSDI and the account goes above \$100,000, social security is suspended until the account falls below \$100,000. At present, up to \$14,000 can be contributed to the account each year. ABLE accounts are not counted as assets when determining eligibility for HOYO, ISS, or self-direction housing grants.

Individuals can only have one ABLE account, but it can be established in any state with the program that allows out of state accounts. The ABLE resource center offers a comparison of state programs at http://www.ablenrc.org/state_compare. New York has passed legislation for ABLE accounts and is in the

process of developing its program. The program will have an annual contribution limit of \$14,000 and a maximum of \$375,000.

Special Needs Trusts

Special needs and pooled trusts take a number of forms and are governed by state and federal laws. They provide resources to the beneficiary with disabilities for expenses like housing and other needs. Details and appropriate structures for each individual are best determined by a financial advisor who specializes in these kinds of trusts. According to OPWDD, a special needs trust does not count against asset limits for the Home of Your Own program, but if income payments from the trust puts the individual above the HOYO income limits, they may be disqualified.

Home of Your Own (HOYO)

New York's HOYO program is a partnership between OPWDD and the State of New York Mortgage Agency (SONYMA) to offer a 4 percent, 30 year fixed rate mortgage to eligible participants. The program also offers housing counseling and other assistance in finding apartments. At present, the income limit is \$82,840 for the household, which would mean that the person with a disability could not be a dependent in a family household with higher income levels. The HOYO program can be used for individuals to purchase housing, or two to three individuals could buy housing together.

The challenge of using the HOYO program in New York City is the limits on the cost of the housing. At present, the upper limit for the property is \$596,970 for New York City's 5 boroughs. There is also a mechanism to purchase a two family home with an upper limit of \$764,260.

Once purchased, mortgages could be paid through funds from a number of sources. These include ISS and self directed housing funds, as well as social security, employment, trust income, or family contributions. Rental income from roommates is another option.

ISS Housing Subsidies

ISS funds can be used to pay either for rent or mortgage payments. The current maximum for the programs is \$1324 for a one bedroom apartment, which can also include utilities. If two individuals with disabilities share an apartment, they would receive more but based on a complicated formula. The amount for two people would not be double the maximum for an individual. If a person with a disability has a roommate without disabilities, the maximum amount would be the maximum based on the two bedroom payment standards. Families and individuals can pay additional amounts above the subsidy maximum from a variety of sources, including social security, wages, trust income or direct family subsidies.

ISS pays the landlord or mortgage holder directly, but through different mechanisms depending on whether or not the person is self-directing services. ISS payments go directly from OPWDD to the landlord or mortgage holder. For people using self direction, funds are paid to the landlord or mortgage holder by the fiscal intermediary. In the version of the housing model outlined below where the program owns the housing, ISS funds could be paid to the program as rent to cover property costs.

Housing Purchased by Organization Developed by the Group

Another option for the envisioned housing program involves an organization created by the families purchasing a building, several houses, or apartments close to each other, or a number of apartments in a larger development for use by program participants. As discussed in the section on development and management issues for the proposed model, community-based specialized financial institutions (CDFI) and housing brokers may know of a variety of loan arrangement and other sources of funds for an organization to purchase housing for an independent living housing program. This section outlines some of the major programs and resources available to fund building acquisition costs.

Leased Housing through Tax Credit Development

The federal government and states offer several tax credit programs for developers to build new low income housing or renovate existing structures as low income housing. These are large, competitive tax credit

programs that fund low to moderate income housing for a variety of populations. Together with other state agencies, OPWDD offers annual RFPs for OPWDD capital funds for the Multi-Family Integrated Supportive Housing Program that works in partnership with tax credit programs offered through New York State Homes and Community Renewal (HCR) agency. Most programs require that the property provide low to moderate income housing for at least 30 years.

The programs for people with disabilities require that the developer team with a certified OPWDD agency which would provide services to the people with disabilities in tax credit subsidized units. These services would usually be offered in the building and would provide other supports to people with disabilities as needed. The people in the subsidized apartment would generally, but not always, be clients of the agency offering services. This housing would generally be offered at 30 percent of household income and would be paid for with ISS subsidies. In the past, developers generally signed a master lease with the service agency for 10 or 15 years, although this may change given the new HCBS rules. HCBS requires that each individual have their own lease.

One major concern of families involved in this project is that leased housing would be converted to condos or redeveloped with rental rates above what people with disabilities could afford. One major developer interviewed for this project said that this was unlikely to happen in tax credit projects like these. He commented that even when the agency providing services changed, the people with disabilities remained in their same apartments.

The major drawback of working with a developer and agency to create tax credit housing is that the transitioning youth already housed with their families are not likely to get these units. They are prioritized for individuals on the OPWDD and public housing waiting lists, and these young adults would be far lower on those lists. However, several agencies are developing groups of transitioning youth that may be recipients of tax credit housing currently in development. People currently in large group homes or institutions would receive priority, as would people who were either homeless or likely to become homeless in the near future. OPWDD is unclear how this may change in future as currently agencies play a large role in picking who receives this housing. However, OPWDD staff stated that their regional office should play a role in the selection process.

One potential option to benefit from tax credit developments would be to find a property that includes both rental and home ownership opportunities. In this case, the organization could negotiate with the developer to purchase some of the properties for sale for the group. As with other tax credit properties, this is best done in partnership with an OPWDD certified agency selected to provide services to the development.

Housing owned by the Organization

At present, the federal government does not offer a system for small organizations like this to obtain building acquisition, renovation, or building funds. Until 2011, the HUD 811 program provided loans of up to 40 years to develop and maintain housing for people with disabilities. Organizations needed to include a service plan for the people living in the housing. The loans were forgiven after the project had been in successful operation for 40 years. Organizations receiving 811 funding could also apply for annual maintenance funds. However, the program was reorganized and is now given to selected states for development of multi-unit housing for very low income individuals, usually those given priority on the state housing list. However, the original rules for the program remain and could be reinstated at a future date. Information on this program is available at https://portal.hud.gov/hudportal/HUD?src=/program_offices/housing/mfh/grants/section811ptl

Private sources of funding to purchase and renovate buildings are available through private financial institutions and foundation grants. Perhaps the best resource for a small special purpose organization to provide housing for people with disabilities is working with a CDFI, community-based specialized financial institutions that work with low income people and others who would have difficulty finding funding through traditional financial systems. CDFIs can help an organization find financing, provide bridge loans, and many provide support to develop project ideas, find properties, and otherwise support project development.

The CDFI targeted toward people with disabilities is the *Disability Opportunity Fund* (<http://www.thedof.org/>). This national organization is located in New York City and has been functioning since 2007. The staff team includes people who can help refine project ideas, develop funding models, help locate funds through private

and government sources, and otherwise facilitate project development. Another CDFI, CSH (<http://www.csh.org/>) focuses on providing supportive housing nationwide. This organization focuses more generally on housing coupled with supportive services for very low income people. The organization provides project development support and bridge loans. Staff from the regional office that includes New York were unclear if this project fit into their target population because the families were not low income.

Several foundations provide grants to nonprofits to support the development and operation of housing for people with disabilities. Description of foundations funding projects in New York are in appendix A. Some foundations target pre-development costs like plan development, property design, and related activities. Others fund the purchase and renovation of buildings. Others fund services once the project is underway. Several fund a combination of services and building acquisition.

Shared service options for Individuals: Paid Neighbor and other mechanisms

The families involved in this project envisioned that each of the young adults would have targeted support services to meet their personal ADL and IADL needs. In addition, the project would include shared services to develop activities, prepare common meals, learn how to live independently, and perhaps find work or participate in volunteer activities. Families were also concerned that someone be available 24/7 to respond in case of emergencies.

OPWDD offers several programs that individuals can use to provide staff supports through the self-direction program. As part of developing a self direction plan, the family works with a support broker to identify staff needs for activities of daily living, shopping, transportation and other needs. The self-direction plan can also support job coaches, training, participation in community recreation activities and a number of other services to meet the individual's goals. Families can also purchase individual services through self direction, for example using an employment provider to help find work and provide staff support as needed on the job.

The Paid Neighbor program is specifically designed to provide as needed occasional supports to a person with disabilities that lives independently. A paid neighbor lives near the person with a disability and is available on call to provide support. Paid neighbors receive a stipend up to \$800 which could be cash or a rent rebate. For example, an apartment in a building owned by the program could be rented to an individual without disabilities who provides 24/7 paid neighbor supports for emergencies with a rent reduction to provide the paid neighbor supports. In another scenario, someone already living in a building housing several people with disabilities in the program could be hired to serve as a paid neighbor.

Someone hired as a paid neighbor could also receive an hourly wage when they actually provide a community habilitation service (CH) to the person with a disability. OPWDD would allow one person to serve several people with disabilities. In a situation where several people are being served by one paid neighbor, the families sharing staff need to clarify when the paid neighbor is on call for each person, as they have to be able to respond when needed and they can't be in two places at once. If and when the paid neighbor is called to provide service, they would need to document that time as CH and would be paid a separate hourly wage. The paid neighbor stipend could be split among each person's self-direction budget. The budgets would also need to reflect some time to account for the CH hours generated when the paid neighbor is called in.

While these programs do not envision staff shared by several people with disabilities, OPWDD suggested some mechanisms that would allow sharing staff among several people self directing their services. The same mechanisms would be used if the person was renting housing through an OPWDD provider, but received services in their own home as opposed to an agency operated group home. OPWDD provided several scenarios for shared services that could be used through either self direction or a provider agency. OPWDD stressed that services are developed for each individual based on their own plan, but that these kinds of sharing scenarios are possible:

- **Shared staff in an apartment:** *Two people with I/DD live together in an apartment. They could decide to share a staff to provide them with Community Habilitation (CH) at the same time, in their apartment or out in the community, for the amount of hours per week that they want and need. As the staff person is providing services to both people at the same time, the provider agency can bill the group rate for both*

people. If the people self-direct with budget authority, the costs of the staff would be split between the two budgets.

- **Shared evening staff:** Three people with I/DD live together in a house. During the day, each spends time 1:1 with their own CH staff and attends to their own goals and interests. During evenings, everyone is home and there is 1 staff on duty to help with cooking and cleaning. At night, one staff is on duty in the house. The daytime staff are billed at the 1:1 rate for each person. If these people self-direct with budget authority, the costs for the staff is fully allocated towards the person they were with.

The evening staff is billed at the 1:group rate for all 3 people. The hours worked by the overnight staff are not directly billable if everyone is asleep, as face-to-face service cannot be delivered to a sleeping person. However, the costs driven by the overnight staff can be combined with the costs driven by the evening staff and billed for with the hours worked by the evening staff. If these people self-direct with budget authority the costs associated with the evening and nighttime staff would be distributed evenly across their budgets.

- **Shared staff in separate apartments:** Four people with I/DD live in separate apartments in the same apartment building. Each needs just a few hours of CH each day – though not necessarily at consistent times. They all choose the same CH staff. Community Habilitation has to be a face to face service so the CH staff needs to interact with each person directly within a continuous period when the service is provided. To make this work, the CH worker could go from apartment to apartment and document the time spent with each person on their habilitation goals—timesheets would then be used to support billing. There has to be face to face service provided in the documentation for each continuous time period for each person. For example, if the CH worker is with Person A for 20 min and provides a face to face, then goes to person B in a different apartment and provides face to face and then comes back to Person A, another face to face service for person A would need to be provided for the CH hours to be billable.

The provider agency would bill the 1:1 rate for each person actual amount of time that the CH staff spent with each person. If these people self-direct with budget authority the costs associated with the staff could start out as evenly distributed in their budgets, and be modified later if it is determined that distribution of the staff's time is not even across the four people.

These examples suggest that each individual in a housing program such as the one envisioned by these families could have individualized services to meet their needs. If several people needed limited services, it is possible to share staff. In addition, the emergency support that is a significant concern for these families could be provided economically through the paid neighbor program.

Services Provided by OPWDD Certified Programs

As an alternative to self direction, individuals can opt to receive individual support in their own apartments or homes through an agency through the OPWDD Community Habilitation Services program outlined earlier. This works in a similar way to self-direction staff, but the staff are hired, trained, and paid by the agency. The scenarios above describe the billing procedures for agency staff shared among several people.

In addition to individual supports, the model program calls for common activities, training in activities of daily living, and common meals. Families also expressed interest in support to help their young adult children find jobs. These shared services are best provided by an OPWDD certified agency with the experience and track record to develop tailored programs with groups of families or small organizations. OPWDD certification is also required to gain access to some program funding for housing and other services. Interviewing several agencies about developing the service plan for this program to find the best match would be a suggested strategy for this program.

Interviews for this report asked umbrella groups, government staff and others familiar with services for people with disabilities which agencies they would recommend as service providers for programs like this one. Several agencies were named, including FREE and Jobpath, but two were uniformly highly recommended as offering high quality programming and working with developers, families, and others to meet their unique needs. Both organizations are currently working with developer the Dunn Development Corporation to provide services in tax credit projects that provide housing for people with disabilities. For a full list of agencies partnering with this developer see <http://www.dunndev.com/L2/partnerships.html>.

- **AHRC New York** (<https://www.ahrcnyc.org/>): AHRC is a very large agency primarily serving people with IDD that operates in all five boroughs in New York City. The agency offers a wide array of programs from childhood to the elderly, including employment and day programs as well as residential. While most of their residential services are currently group homes, they also have a number of participants served through ISS grants or self direction in their own homes. They have worked with several families that bought apartments for their children or used foundation funds to purchase housing. They also currently have a group of transitioning youth like the families that sponsored this project that are working to identify housing options for their children. As a partner with Dunn Development Corporation, they have master leases for apartments in developments that are rented to people with disabilities served by the agency. In these projects, services are provided on site through an office located at the housing development.
- **The Center for Family Support (CFS)** (<https://www.cfsny.org/>): CFS is a middle sized agency serving people with IDD and autism in New York and New Jersey. The agency was founded by parents of people with IDD in the 1950s and started provided supported housing in the 1990s. Most of their work is with families that are self directed, and in addition to providing housing, they offer case management, respite, day habilitation without walls, and enhanced supported employment. The agency has worked with the Dunn Development Corporation for a number of years, providing 24/7 staff support and services in 10 Dunn projects. They have master leases for apartments in a complex that are rented to people with disabilities in their program. Like AHRC, they work with families to identify housing solutions.

These initial sections have outlined the policy environment for new programs, funding sources and services available to any family or organization for people with IDD in New York, and services available through certified agencies or self-direction. In addition to housing and individual support services offered through this system, a variety of ongoing programs offer housing and related services as a package to people with disabilities. These existing programs offer models for the housing options wanted by these families. Before describing the model and options to develop it, the next section outlines some existing model programs.

Existing Models for Housing for People with Disabilities

The next section outlines a housing and services model for people with IDD that meets the criteria outlined at the beginning of this report. The model draws on a number of existing housing programs, learning from their experience. The families expressed interest in a number of programs. Eight intentional communities and three key ring models were researched in detail. This report primarily includes programs that have been in operation for at least 10 years and are located in or near New York.

This section explores two forms of housing programs: Intentional Communities and Key Ring models. Intentional communities bring together people with disabilities to provide a combination of housing, meals, shared activities, and possibly work or training options. In key ring models individuals with disabilities have housing in the community near to each other, but not all in the same building or the same floor of a large complex, and some shared services and shared activities are provided through an agency or program. The model outlined in this report is a key ring model with some elements common in intentional communities.

Intentional Communities

Intentional communities can be residential campuses like a farm or housing and other community buildings located together, gated communities, or housing spread throughout the community with community members coming together for shared activities and meals. Depending on the level of segregation from the wider community, they may require heightened scrutiny and may not qualify for funding through OPWDD. These models share a strong sense of shared community among members and generally include shared meals as part of the program. They vary greatly in the forms of recreational activities and employment activities offered by each program. They appeal to families as a structured environment for adults with IDD that provide safety, a community, and programming.

In addition to the models described here, a movement is developing throughout the country to develop intentional communities that bring together seniors and people with disabilities. Both groups are anticipated to need similar services and seniors are expected to provide additional support to people with disabilities in the community. These communities are also envisioned as ways that families can stay together as both the

parents and adult children age. Most of these programs are in the early development stage and are not located in New York.

Based on the history of mixing people with disabilities and seniors in public housing and the goals of integrated housing in the community, this model is not recommended. Public housing combined seniors and people with disabilities in apartment complexes for many years, but moved toward senior only building because of the different lifestyles of the two groups. Segregating people with disabilities from people of their own age potentially defeats the purpose of integrating people with IDD into communities of their peers and people of all ages.

L'Arche and L'Arche Long Island

L'Arche, began in 1964 in France by Jean Vanier as a faith based intentional community. It is now an international federation of more than 130 communities in over 30 different countries. The L'Arche website states: *L'Arche enables people with and without disabilities to share their lives in communities of faith and friendship. Community members are transformed through relationships of mutuality, respect, and companionship as they live, work, pray, and play together.* The basic model involves people with disabilities living in shared housing with people without disabilities that provide supports. The people with disabilities become members of L'Arche for life while the people without disabilities may leave after some time working in the community. People without disabilities in the community function like staff in certified group homes.

The community involves regular prayer and shared meals. In Europe, some L'Arche communities function like key ring models with individuals with disabilities living in their own housing in the community. In the United States, most L'Arche communities are similar to group homes (see <https://www.larcheusa.org/who-we-are/communities/> for a full list of communities).

L'Arche Long Island (<http://www.friendsoflarcheli.org/>) is in the process of developing a program on Long Island that would not be a certified group home. The project director reports that L'Arche Long Island would not provide service in a classical sense, but develop community life for its members. Working with an OPWDD certified fiscal intermediary EEDA (East End Disability Associates), the program will provide housing and supports to people in self direction. Most of the funding for the housing and salaries for the non-disabled assistants would come from pooled self-direction funds.

The initial project would include six to eight people, plus their assistants in a property with a house that holds four people with disabilities and a community center on same lot. Two apartments would be located nearby for another two or three people with disabilities, plus live in assistants. Once this location is functioning, they plan to branch out and do same model elsewhere nearby. Participants with disabilities would be renting the housing for themselves and their caregiver. The community life consists of being friends with each other, praying together (nondenominational), taking five meals at night together, and doing activities together on weekend. In the group house, each person has their own bedroom, community center living room, house kitchen and living room. There is a large shared bathroom.

Camphill and Camphill Hudson

Camphill (<http://www.camphill.org>) is another international intentional community that brings together people with and without disabilities. Founded in 1939 in the UK by a pediatrician who had fled Nazi Germany, there are now 100 Camphill communities in 22 countries. The first community in the U.S. started in 1961. Camphill Village Copake (<http://camphillvillage.org/>) is the largest of the U.S. communities operating a collective farm and residential program with 250 people, 100 with disabilities. According to the Camphill website, *members of the house community share in the daily life and tasks of the house, and engage in work at school, on the land, in one of the craft workshops or providing some other service* in all of the Camphill communities. A full listing of the U.S. communities is available at <http://www.camphill.org/communities/>.

Camphill Village Copake and most of the other Camphill communities are farming programs. Camphill Hudson (<http://www.camphillhudson.org/>) is the exception, operating two shared living residences with five people with disabilities and a community center that creates crafts and offers other arts activities. People with disabilities live in homes with families working on the project, similar to OPWDD's family care. Solaris, the social arts center, is a conference center available to the wider community and a place where crafts and theatre projects

are developed. Program participants with disabilities work at the center doing maintenance and other chores, make crafts, and perform community service in the wider community. The program reaches out into the wider community, including offering a weekly dinner for anyone in the Hudson community at the center. While not clear in the organization's materials, interviews suggest that Camphill may also have a mechanism to include people with disabilities that are housed elsewhere in Hudson in their own homes.

Key Ring Models

King ring models differ from intentional communities in that participants are housed throughout the community in their own homes. Housing is generally located within walking or easy commuting distance of each other, with the agency office space nearby. For example, people may be housed in apartments throughout a large apartment complex, in homes or apartments within walking or easy public transit from the shared services, etc. Staff are provided either to the individual through self-directed services or through an agency (usually drop in services with someone to contact for emergency backup). In the U.S., agencies or programs generally provide some staff support (supported housing), activities that either teach independent living skills or are social activities, and may offer employment services in a variety of ways. Most also offer group social activities and may include weekly or monthly regular shared meal opportunities.

None of these models provides housing to participants: the people with disabilities or their families obtain, pay for, and maintain housing on their own. The one exception are the apartments operated by JChai, which are all in the same building. However, JChai does not own this complex and participants sign leases with the complex independently of the program.

JChai

JChai (<http://www.ichai.org/>) is a Philadelphia program founded in 1991 initially as a group home model. It still operates three group homes with six people each, but the model includes activities to integrate residents into the community and many work in the community. It started the apartment program in the mid 1990s and JChai at home, services to people in their own homes, about nine years ago. It also runs a program for transitioning youth (18-30) that combines classes on independent living skills, social activities, and volunteer activities. People in all of the JChai programs can participate in the transitioning youth activities. Social activities for all ages are also offered. JChai's volunteer activities include people with and without disabilities working together on projects. Many of the participants have jobs in the community, often found through connections with those affiliated with the agency. JChai is unique in that its case managers are MSWs and most of their direct support staff have worked with the agency for many years.

Program Costs: Program costs vary depending on the program and individual plan, with the staff setting program fees annually. They do have a sliding scale for some participants and receive some Pennsylvania Department of Human Services Office of Developmental Programs (ODP) funding for services. ODP is the Commonwealth's agency providing services for people with developmental disabilities. Staff estimate that about 20 percent of their funding comes from agency fundraising, with 1/3rd of the remainder coming from government. The rest comes from fees paid by participants and their families.

- **Apartment Program:** Residents are vetted for the apartment program through an assessment. Apartments are located in a large apartment building across from the JCHAI offices. About 20 people are currently in the program. There is no 24/7 overnight supervision at the apartment building. Depending on individual needs, participants receive a varying amount of staff support from 8 in the morning to 8 at night. The role of the staff is to foster independent living skills, teaching participants cooking, cleaning their apartments, personal care, socialization, transportation, and providing other supports as needed. The staff ratio is 1-5 and 1-6. The program meets regularly with the person with the disability and families, particularly at the beginning.

The apartment program offers shared evening meals throughout the week, although not everyone needs to go to every shared meal. Hosting the meal moves among apartments, with small groups of 5-7 people with staff in a meal group. The meals are generally planned in advance and food bought as group. Program staff in conjunction with consumers develop meals. The agency orders food, buying in bulk from grocery

stores and through a CSA community supported agriculture program. Some of the food is delivered, but in some cases staff go with participants to buy food.

- **JChai at Home:** The independent living program serves about 60 people living either independently in their own homes or with family throughout the Philadelphia area. Trained social workers provide supports to learn independent living skills, find employment, and fulfill other needs based on individual plans. Participants are also invited to participate in group social activities which would include people in the apartment, group home, and transition programs.
- **Transitions program:** The transitions program serves adults ages 18-30, some of whom may be candidates for the apartment or independent living programs. It offers a menu of classes such as cooking and computers, along with shared meals once a week and a variety of both small and large group social events.
- **Social programs.** The events in the transitions program are primarily targeted toward adults aged 18-30, but JChai at home does group outings for people of all ages. Some in the apartment program do transition programs. JChai offers at least 2 group outings a week, plus small group activities. On a smaller basis, the program encourages participants to make plans with friends in the community, with staff facilitating plans. Activities are based on client interests.

Philadelphia Independence Network (PIN)

PIN is a program of Philadelphia's Jewish Employment and Vocational Service (JEVS) human services. See https://jevshumanservices.org/static/media/uploads/program%20documents%20/PIN%20/at_a_glance_flyer_fa ll_2016.pdf. As such, the program is connected to a highly respected vocational and human services provider and participants are referred to employment and other programs at the parent agency as needed. Founded by a group of families that came to JEVS to develop the model, it has been fully operational for five years with a cap of 25 participants. PIN is located in Narberth, a suburb of Philadelphia with shopping, cultural amenities and good public transportation. Participants find their own apartments, within walking distance of the program office, which is an apartment. The program provides independent living supports on a one on one basis, some shared independent living activities, and a variety of social activities. They work to build a community among participants so that they can help each other as needed. Staff includes a director, two assistants and a career navigator. Staff are available on site six days a week and a staff person is on call 24/7 for emergencies.

Program Costs: Currently \$8,000 per year plus the costs of housing. While some government OPD support covers services, most is paid by the individual and their families through a combination of special needs trusts, employment, and family support.

- **Employment in a whole life environment.** The program emphasizes helping participants find and keep jobs in the community, but in the context of living in the community. The career navigator develops customized jobs and people are referred to other JEVS employment services as needed.
- **Individual plans and as needed support.** Participants may have some experience outside the family home before joining the program, but some may come directly from their family homes. Individual plans to develop and support independent living skills are developed for each individual with staff providing more support when people first join the program. Individuals who have additional personal support needs may have other personal staff.
- **Independent living and social activities developed and lead by participants.** The program includes regular social activities like shared meals, volunteer work, going to festivals, museums, and other events. These events are planned and lead by program participants, with staff facilitating. There are also independent living classes like cooking. Participants can choose which events they want to attend.

Pursuing Our Independence Together(POINT)

POINT (<http://www.wjcs.com/point-pursuing-our-independence-together-program/>) is a program of Westchester Jewish Community Services and JCCA New York located in White Plains, NY. Its founders included some of the families that started PIN and it has many features in common with the Philadelphia program. Families either buy or rent apartments for young adults with disabilities within walking distance or

easy public transportation of the POINT offices. The program provides a weekly visit from a staff person to address independent living needs. Group classes in independent living skills, particularly cooking, are offered, along with social activities, internships and volunteer activities. There is a regular meal and meeting once a month and some other joint social activities. Staff are available 24/7 by phone for emergencies.

Program costs: \$13,000 the first two years with tiered costs based on need after that, plus the cost of housing. This is an uncertified program. While self-direction funds can be used for some community habilitation training, most costs are paid by the families.

- **Intake process and previous living away from home experience required.** The director stressed that participants are 100 percent living independently, with training and case management support from staff. Joining the program includes an intake process that may involve visiting the program. Individuals are required to have lived away from their families with a roommate or through a post-high school experience program before joining this program.
- **Employment emphasis and internship opportunities:** Over half of the participants are employed in the community, with the remainder doing internships or other volunteer experiences through the program. The program can refer to services through its parent agency or other vocational services.
- **Activities include exercise, social events, theatre, and volunteering:** The program calendar includes several kinds of exercise classes and activities, along with a theatre program, cooking program, and several volunteer opportunities.

Proposed Model: Resident Owned Community Integrated Supported Housing for People with Disabilities

Based on the information on available resources and program models discussed above, this section outlines a proposed model for the families called *Resident Owned Community Integrated Supported Housing for People with Disabilities*. The model would be a key ring model based on the activities, supports, and shared meal systems of the JChai and PIN programs. The model would require incorporating an organization as a nonprofit, LLC, or LC3 to obtain and manage properties, develop and manage services, and select residents. The program organization could contract with property management companies and OPWDD certified service providers to offer some shared services. It would be an uncertified housing program, but could potentially partner with OPWDD certified agencies to carry out some of its activities.

It would differ from the key ring models outlined in the previous section in two ways. First, the organization formed to manage the program or individual people with disabilities would own their homes or apartments, with the organization responsible for housing maintenance. Second, in an effort to foster integration into the wider community, the meal plan and some shared activities would be open to others living in the apartment complex or community through fee for service plans. Drawing on best practices to foster independence and develop employment, the program would also include a mentoring component.

This section outlines the various aspects of the proposed model. The next section describes various options to develop and finance each aspect of the model. Additional information on contacts and potential partners is provided in a separate memo to sponsoring families.

Program size: 8-25 people with disabilities. These lower and upper bound numbers come from conversations with program providers, OPWDD staff, and others. Eight people is considered the minimum for economic viability of a program with shared staff and over 25 requires a higher level of staffing and management to maintain individual plans and quality. As discussed below, one option to raise participation and help fund shared activities and the meal plan involves allowing others to buy into these programs on a fee for service basis.

- **Property owned by the program or its residents.** The organization could buy apartments or houses either in a large complex under development or buy a series of houses or a small apartment building for use by the program. People with disabilities participating in the program could either own shares in the property like a co-op or have life time leases for their apartments. Alternatively, participating people with disabilities or their families could purchase housing that would be managed by the organization. People

would have the options to leave the program if they chose. This presumes that people could either sell their units or the corporation would own the units and participants rent them from the corporation. In all cases, the apartments owned by people with disabilities would be part of larger buildings, complexes, or communities to ensure integrated housing.

- **Property managed by the organization.** Regardless of how the apartments or housing is purchased, the program would be responsible for regular maintenance and upkeep. This could be done through a property management company or staff hired for this purpose.
- **Common space and housing for 24/7 staff support.** In addition to buying housing for program participants, the program would purchase a common space with a kitchen that could be used for shared meals and activities. This space could either be a common area in the complex or an apartment designed for this use. Another apartment could also be purchased as 24/7 emergency contact staff housing, or a resident without disabilities living in the complex could be hired to provide this support through the paid neighbor program or other payment systems.
- **Individualized supports for ADLs and other activities.** Individuals with disabilities participating in the program would be either on self-direction or contract with an OPWDD agency for community habilitation services. Each would have their own plan to address any supports for activities of daily living like dressing, bathing, preparing meals, and health needs. Each individual may also hire staff or contract with agencies for employment and other activities, or use their budget dollars to cover joint services offered through the program. Individuals could share staff as per OPWDD rules.
- **Shared services based on resident interests.** Activities would include training and support for independent living and potentially employment and volunteer activities. As in the PIN program, the various class topics would be identified by residents with disabilities, with residents co-leading classes. These staff would also meet individually with residents on a regular basis to address issues and provide individualized support. Staff would also facilitate the meal plan and, along with staff hired by individuals, help with purchasing food. Employment services could be provided through existing agency programs, connections with businesses located nearby, or a combination of strategies. Given the expertise of established agencies and the need to use OPWDD certified agencies to access some resources, either working with an OPWDD certified agency to provide shared services and meals or developing a system to purchase shared services from a certified agency using self-direction funds is recommended. In a program with less than 10 residents, the shared classes could be opened up to other people with IDD living nearby on a fee for service basis.
- **Community integrated shared meal plan.** Develop a shared meal and activity plan that people without disabilities in the complex or community can buy into in order to create an integrated program. The meal plan would consist of participation in between 5 and 7 shared evening meals per week. In order to fund the plan, individuals in the program must pay for the minimum number of meals, but there is nothing that says that an individual MUST go to those meals every day. The one meal per day requirement is similar to those for seniors living independently in continuing care retirement communities (CCRC). The meal plan would be available to people without disabilities in the apartment complex or community on a fee for service basis, with the number of people without disabilities capped at the number of disabled participants to maintain balance. This would help foster relationships with neighbors.

Like the JChai apartment meal plan, participants in the meal plan could be divided into smaller groups that would migrate from apartment to apartment, with selected participants responsible for cooking and clean up, with the support of their individual staff. In this option, the entire group would share a meal a few times a month to foster connections among members of the larger community. The larger group meals could be in the program community space. Menus would be developed by each group on a regular basis. Food could be purchased by residents shopping with the support of their staff or include some bulk purchases and delivery of food as in the JChai model. Alternatively, the meal plan could include all participants in the shared space, with responsibility for cooking and clean up rotating among participants.

The meal plan both meets the HCBS rules criteria for individual choices regarding meals and fosters relationships with others in the community. The meal plan only covers one evening meal for some days of

the week, for breakfast, lunch and days the plan group do not meet, each individual is on their own. Members of each small group chooses what they want to eat that week, shops for the food, determines who will cook and clean up, and when they want to eat, all individual choices. For example, if Mary lived in her own apartment and belonged to a program with 10 participants with disabilities, she might have a choice of two to four meal groups. While she might decide to join group A because she has a friend in that group, there is nothing that says she can't eat with another group if she wants, go out for dinner, or simply cook her own meal.

Similar types of meal groups have been a feature of shared housing for people without disabilities for years and meal plans similar to this one are beginning to appear in urban settings with large numbers of young professionals. While the format of these shared meal plans vary greatly, they all provide an opportunity for individuals living independently to share the burden of meal preparation among a group and to make connections with others living nearby. For people with developmental disabilities, they offer an opportunity for one meal several times a week with friends as well as an ability to develop their own cooking, shopping, and decision making skills naturally through working with others.

- **Integrated shared activities.** The group would regularly develop a roster of shared activities, anything from card or bingo nights, watching movies together with dinner, to trips or events, like going to museums, theatre, music or movies. Shared activities could also include volunteering in the community. Participation in these events would be voluntary, with people signing up to participate. An activity fee would be included in the costs of the program for people with disabilities, with possible additional charges for trips or events with high ticket charges. As with the meal plan, these activities would be open to others living in the community on a subscription or per-event fee basis, including both people with disabilities and people without disabilities in the complex or community.
- **Mentoring:** One on one mentoring with other people with disabilities and people engaged in careers or hobbies of interest is an important way to help young adults develop relationships with others, enhance independent living skills, and grow in their ability to carry out their interests. I would recommend that each participant be connected with two kinds of mentors. First, each new participant in the program would be partnered with an older person with similar disabilities who now lives independently. These buddies could help the individual learn skills and serve as role models. Mentors could be found through the local Center for Independent Living (CIL), through agencies, or through self-advocacy and social groups for people with disabilities. Once the program is established, more established program participants could mentor newcomers.

Career or hobby mentors would be drawn from among professionals or skilled hobbyists in a particular job or hobby (art, music, model trains, gardening, etc.) in the community. These individuals would be found through professional connections, professional organizations, or organizations for particular interests. The mentors would help the individual develop their skills, understand the career or hobby, connect to others involved in that interest, and potentially find work in the field.

Each element of this program model would need some further design and development to implement, but the general framework is outlined in this section. Taken together, the model offers the security of home ownership and 24/7 staff combined with mechanisms to create a community both among participants with disabilities and their neighbors. Staff support provides professional direction, independent living skills training, and potentially access to employment and other community activities. Staff are bolstered by mentors who offer specific expertise and a relationship based understanding of independent living and developing personal interests. The next section outlines a variety of options to develop and pay for elements of the model.

Development and Management Issues for the Housing Model

Development and initial implementation of the model is likely to take a minimum of three to five years. Once the properties are purchased, organizational structures and programming are in place, the organization can anticipate that the first one to three years will involve experimenting and trial and error to refine the design. Part of this time will involve developing long term funding mechanisms for staffing, programming, and maintenance as grants may be available to develop new programs with fewer resources available for ongoing programs.

Organizational and Incorporation Structures

Regardless of whether participants purchase housing independently or if it is purchased by the organization for the group, the program will need to incorporate as a non-profit or for-profit entity to obtain funding, contract for programming, and develop relationships with property management firms. Some people interviewed for this report suggested that properties should be put under an LLC structure to avoid liability to board members should there be a default in payments. This may mean potentially developing both a nonprofit for the program and property management and an LLC as the official owner of the properties. Another option for the properties is a condominium or co-op structure, with individuals either owning their units or shares in the cooperative. Whatever the organizational structure, I would encourage developing a board structure that include family members, residents with disabilities, and perhaps some others. Residents and family members both should have a clear role in governance of the organization.

Three organizational structures were recommended for this program: LLC, LC3, and 501c3 nonprofit status. The rules for each structure are established by each state, although nonprofit status is granted by the federal government IRS. The LC3 is a new organizational form that is a hybrid between and LLC and a nonprofit, and may be eligible for grant funds from some foundations. See [Wikipedia LC3 Structure](#) for more information on LC3s. Research on LC3s suggests that an LC3 structure may not be optimal because it is not generally recognized by a number of states and IRS recognition is unclear. Foundations can fund LLCs with charitable intent. This report suggests that any organization seek legal advice to determine the best organizational structure for their project.

Development and financing of housing

Purchasing properties for this project could be accomplished in two ways: each family purchases a property that is then managed by the organization or the organization buys a building or apartments for the group.

1: Individual property purchases

In this option, individuals with disabilities and their families could use a combination of Home of Your Own (HOYO), special needs trusts, or ABLE accounts to purchase properties in a designated complex or neighborhood that would become part of the program. There are several options for an individual purchase plan:

- **1.a: Condominium or Co-op purchases in a designated existing development.** The organization would develop a relationship with an existing complex that already has a naturally occurring retirement community (NORC), supported housing, or is amenable to such a program. Ideally this would be a complex with low to moderately priced units. As condominiums become available, families would buy individual apartments in the complex. The organization would then purchase shared space and/or a staff apartment. For example, the Parkchester complex (see <http://www.theparkchesternorthcondo.com/>) includes both low income rentals and two condominium buildings. Purchasing properties in these buildings or something similar would offer the advantage of existing property management and a supportive neighborhood with amenities.
- **1.b: Apartment purchases in a designated neighborhood:** Another alternative could involve each family purchasing apartments in houses or small apartment buildings in a designated neighborhood. The organization would then provide property management for these individual properties. The organizations would need to set parameters for these purchases, for instance within walking distance of communal staff space purchased by the organization. This would potentially have the advantage of allowing families to purchase a range of kinds properties. The disadvantage is that there would not be a pre-defined community for shared activities and property management could be more complex.
- **1.c: Families subdividing their own properties to create housing for their kids.** A variant of 1.b would involve families creating separate apartments in their existing houses or apartments for their adult children that would then become part of the program. This option has the advantage that the families have more control over the nature and maintenance of the housing, but this strategy could potentially limit independence for the people with disabilities.

2: Organization purchases properties

In this option, the organization purchases a building or block of apartments that would then either be leased to participants or participants would own shares in the corporation like a co-op. In either case, the best plan to identify financing and properties involves working with a CDFI, disabilities housing brokerage firm, or property management company to identify properties, obtain financing, renovate or modify the building and set up the management structures. Working with an existing community development corporation like Brooklyn's 5th Ave committee might also be a way to obtain a property that has already been renovated for low to moderate income residents (www.fifthave.org/). Several options could be explored to obtain property:

- **2.a: Buy small apartment building:** In this option, the incorporated organization developed by the families would buy an existing small apartment building with 10-20 units. In order to maintain the spirit of the HCBS rules, this report recommends limiting people with disabilities to 1/3rd of residents to ensure community integration. The organization would also purchase an apartment for staff or designate one apartment as a rebate for someone who agrees to be a paid neighbor. Community shared space for the program could be developed through a common space in the apartment building or designating one apartment for this purpose. In this scenario, other apartments in the building could be rented or sold to people without disabilities to cover some of the purchase and ongoing maintenance costs. An additional option to cover costs would be renting out retail space on the first floor that could potentially provide employment to people in the program.
- **2.b: Buy several houses in a neighborhood to form a community:** This option is similar to 2:a, except that instead of buying one building, the organization would buy several houses with 3-6 apartments each within walking distance of each other. As with 2a, up to 1/3rd of each house would be apartments for people with disabilities in the program. Staff housing, shared space, and paid neighbors would need to be obtained as well. This option has the advantage that the organization could start smaller and add buildings as it grows. The disadvantage is that the community is more diffuse and these spaces may be harder to renovate for shared uses.
- **2.c: Buy a block of apartments in an existing development.** This option is similar to 1a, but the organization purchases the properties which are then leased or co-owned to people with disabilities living in the complex. This option has the advantage of lower overall costs and the benefits of management from the existing complex, but means less control over the space. In this option, the organization would need to purchase space for shared activities and meals, as well as a staff apartment or identify a paid neighbor in the complex. It would need to negotiate with the complex to have the shared activities and advertise shared meal plans and programs for other complex residents.
- **2.d: Buy apartments in complex under development.** In this scenario, the organization could work with an OPWDD service provider connected to a developer to identify a development in the planning stages that includes both owned and rented units. The organization would then negotiate to purchase apartments in this development from the pool of home ownership units, as well as shared space. The organization would own the apartments, not the developer, ensuring that the housing would remain available to program participants as long as they participated in the program. This property would potentially be eligible for tax credits for low to moderate income residents. Alternatively, the group could work with a developer building market rate complexes to purchase apartments in the complex. Either way, the group may have some say in the structure of the housing and shared space. This would have the advantage of working with an existing service agency and developer from the start. That said, it may be hard to find a developer doing a mixed low income ownership/rental property.

3. Leased Housing in Tax Credit Development

A final option to obtain housing would be to work with an existing OPWDD service provider developing housing for transitioning youth to develop this model in a tax credit complex under development. Both AHRC and CFS have groups of transitioning youth that they are developing housing for and ongoing projects with Dunn Development Corporation. The developer commented that people in his complexes have not lost their housing even if the service provider changes. However, the families that commissioned this report remained concerned that after the period requiring that the housing be reserved for low income people is over, the property might be

sold, rent raised, or supports for people with disabilities disappear, requiring their children to find other housing. Joining these ongoing initiatives to develop the model would have the advantage of working in already existing structures with someone else obtaining the housing. As part of existing groups of youth, participants might have a chance of being chosen for this housing.

That said, the developer and OPWDD both noted that these youth may not be high on the list to receive housing. This plan also would involve buying into existing service structures and asking them to modify their programs to fit this model. Given the emphasis on home ownership for this group and the risks of not qualifying for housing through this system, this option is not recommended.

Ongoing Financing of Properties and Maintenance

Regardless of how the properties are purchased, payment of ongoing rental or mortgage fees for program participants could be covered through ISS or self-direction housing budgets. Paid neighbor stipends could cover part of the cost of housing for neighbors offering 24/7 emergency support. If these funds are not sufficient, participants could use social security, wages, proceeds from special needs trusts, ABLE accounts, or family support to cover the difference. In options 2a. or 2b. rental income or condo/coop fees from building residents without disabilities could cover some of the maintenance and general financing costs.

Property Management

In options 1a, 2c-d, property maintenance would be managed by the complex, potentially requiring the organization to cover condo, co-op or other management fees. However, maintenance within the apartments may be the responsibility of the organization. In the other options, the organization is responsible for maintenance, upgrading, and keeping the complex up to codes set for properties in general or those housing people with disabilities. While the organization could hire someone as a building manager to handle ongoing maintenance, the better option probably involves hiring a property management company.

CDFIs and housing brokers can recommend management companies with good records in the local area or nationally. I would recommend following the guidance of these entities in exploring property management companies. People involved in the New York City Mayor's Office housing coalition may also have recommendations.

Ongoing maintenance costs could be covered in a variety of ways. In buildings owned by the organization with residents who are not part of the program, condo or rental fees could include money to cover part of maintenance costs. Maintenance for participant's apartments and shared spaces could be covered through program fees or grant income.

Ongoing Service Provision Options

The model presumes that individual participant supports will be covered through self-direction or individuals signing up for services with a chosen agency. It also calls for several forms of shared services. This section outlines options to provide for these shared services.

1. 24/7 Emergency Support

- **1.a: Paid Neighbor.** The paid neighbor program is perhaps the easiest and most economical way to ensure 24/7 emergency support as needed. Paid neighbors could be people already living in the building or nearby or an apartment designated for this support.
- **1.b: Agency staff on call.** The agency providing other staff for the program could designate on-call staff that would either live in the building or nearby. The Point and PIN programs both use this model. Funding would be built into the contract for other supports.
- **1.c: Self-direction staff on call.** In this model, self-direction staff for the various participants could share overnight on call supports for everyone in the program. This would presume that these staff lived close enough to be available as needed. Budgeting could be shared as per suggestions by OPWDD.

2. Staffing Shared Programming and Activities

The program would need a minimum of a director (who may double as a case manager), trained case management staff, and people with expertise in various independent living skills. Teachers for independent living classes could be hired on a per course basis. Given the importance of having an OPWDD certified service agency involved in the program, I would strongly recommend working with a certified agency to offer any services specifically for people with disabilities. That said, self-direction staff could provide supports for shared meal programs and possibly shared activities as well.

- **2.a: OPWDD agency staffs all services:** In this option, the organization chooses one OPWDD service agency to develop the model and staff independent living programming, shared activity development, and the meal plan. This would involve discussion with several agencies to choose the one that could best work with the families to develop the model. Ideally, agency staff could develop independent living programs for participants as well as refer them to employment services offered by the agency or elsewhere. Some employment services may be developed in house. In all cases, I would recommend opening up the independent living programming and activities to other people with disabilities who are not part of the housing program on a fee for service basis. This would guarantee enough participants and help cover costs. Independent living and employment services may be covered through self-direction budgets, or could be covered through program fees or overall agency fundraising.
- **2.b: Self-direction staff responsible for shared meals and activities:** In this model, OPWDD certified agency staff are responsible for independent living programming and may participate in developing activities on a regular basis, but the meals and activities are staffed through participants' personal staff using self-direction dollars. In this option, participants' staff could take turns being responsible for support in shopping, cooking, and cleaning up meals and accompanying participants on activities.

3. Meal Program and Activities

Both the meal program and social activities call for integrated participation with people without disabilities living in the complex or neighborhood. These opportunities would be advertised through home owners associations, building management, and other community communication systems. The meal program would be limited to half of the participants without disabilities while the activities could be generally open with people paying for each activity individually.

For participants in the program, the meal plan (5-7 dinners per week) and activities would be covered by a program fee. This could be paid for through participants' regular sources of income (SSI, wages, etc.) or through fees paid by their families. Events with above average costs, for example theatre tickets or trips would have separate fees. Organization fundraising could also cover some of these costs. These programs could be partially subsidized by payments from participants not in the programs.

As with program participants, participants without disabilities would buy into the meal plan for a period of time, with regular renewal systems. Costs would include the cost for ingredients and additional fees to cover shopping and cooking. Nondisabled participants would participate with program participants in cooking and cleanup on a rotating basis.

Options for activities for community residents and other people with disabilities not in the program could include buying into a general plan for regular activities or paying individually for each event. They could opt in to various activities on a regular basis. As with participants, activities involving higher costs like theatre events or trips would have separate fees.

4. Mentoring

The program model calls for two kinds of mentoring: employment or personal interest mentoring and independent living mentoring. Mentoring programs are generally volunteer initiatives and no cost is projected for the mentors themselves. However, program staff will need to facilitate finding mentors, performing background checks, and otherwise managing the activity. These program staff could be found through the agency providing other services or by connecting with existing mentoring programs.

Employment mentoring or mentors for a particular interest like art or gardening are best developed by the staff responsible for employment or day services. This may involve reaching out to professional organizations or established professionals to find mentors. Mentoring should be developed separately for each individual.

As discussed above, the best mentors for learning to live independently and integrate into the community are successful people with disabilities. One key resource to find these mentors is the local Center for Independent Living (CIL). Another are individuals served by the agency offering services who are now living independently. Once the program is established, established participants could mentor new ones.

Steps to Develop the Model

Developing this model will require a number of steps, both for families that want to participate in the program and for the organization as a whole. This section outlines the primary steps in this process. Details on each step are covered earlier in the report.

Determining each family's assets

The first step for each family individually is to clarify the income and assets that will be available to cover housing costs for the person with disabilities. This is best done by working with a housing navigator. As discussed above, free housing navigator services are available through the regional OPWDD office. Those working with agencies may also have free services available. There are also housing navigators that provide these services as a consultant on a fee for service basis.

Developing organization structures and incorporation

Once each family has determined their assets, the group will need to identify a minimum of eight families to sign on to developing the model. These families will need to commit to purchasing housing either to include in the program or through its organizations, as well as initial participation in developing its structures and serving on the board of organization formed to run this program. Each family should fill out the assessment form used initially for this project or a similar instrument to clarify the needs and wishes of the people with disabilities and families in the initial program.

Once the initial group to move the project forward has been identified, the organization will need to clarify their mission, program model and incorporation structures they plan to use for the program. This may be done with the help of a CDFI or another organization familiar with housing for people with disabilities in New York City. Further conversations with the JCHAI and PIN programs may also prove beneficial. Determining the organizational structures that make the most sense for the project will need to take into account how the group plans to purchase property, funding resources (grants, loans, revenue from leases, etc.) they plan to use, and mechanisms they plan to use to carry out the program. Alternatively, the group may decide to work with an existing agency and become a program of that agency. In that case, they will want to form an advisory committee to oversee the program.

Based on findings from this report and other advice, the organization will need to decide if it wishes to incorporate as a 501c3 nonprofit, LLC or use both organizational structures, reserving the LLC structure for property bought for the program. The incorporation process will take some time and will require identifying initial board structures, officers and members. I would highly recommend including both program participants with disabilities and their family members on the board.

Working with CDFI or Broker to Obtain Housing and Financing

Expertise in developing a program of this nature and its financing is best sought early in the process, perhaps before incorporating the organization. Once the group is ready to move forward to purchase property, working with a CDFI or other organization with similar resources is highly recommended as these organizations have expertise, connections to funders, and connections to OPWDD to identify properties, identify property management companies, evaluate service providers, and generally develop the project. These agencies should remain involved into the initial start up phase of the project.

Developing the Services Plan

The service plan should be developed simultaneously with purchasing property. If the group plans to work with an existing OPWDD service provider to approach developers, identifying this agency may need to happen first. In either case, the group will need to interview potential service providers about their willingness to work with the families to develop the model that fits their needs and manage it either under contract or as part of a portfolio of programs.

Developing the services plan will also involve refining and fleshing out each of the various aspects of the model discussed earlier. This includes service plans, participant recruitment plans, and costs. Methods to fund the program would also be addressed and initial grants or other fundraising developed at this time. Since the integrated services model is a key component of the model that is new to most agencies, clarifying methods to enroll people without disabilities in the service plan and activities, as well as ensure that the programs primarily reflect the wishes of disabled participants, will need to be developed.

Start up

Model programs like this one should anticipate a minimum of two years of trial and error to fully develop the program and ensure that it operates smoothly. Especially in programs developed by people deeply invested in the program and with little previous experience, it is important to remember that initial experimentation and problems are part of any development process. The best way to use this initial start up time productively and quickly move toward success is to have an evaluation and feedback process with a continued quality improvement model in place at the beginning. Continued quality improvement involves having short cycles of trying out program plans, evaluating them, modifying elements that need improvement, then continuing the development and evaluation cycle. This evaluation system should include record keeping systems that regularly provide appropriate data and an outside evaluator skilled in this kind of process evaluation.

Before the program starts, while building or renovation is being completed, the program will need to recruit additional participants, hire staff, and otherwise develop the systems the program will need to operate. This should be done with active participation by program participants, families, and staff of agencies involved in the program. Part of this will be finalizing contracts for services and setting up the initial program service plans. This start up phase will likely continue for at least a year, and it may be best to start with a small number of participants and add more as the program is refined.

Appendix A: Foundations Supporting Housing Development for People with Disabilities

These foundations provide support for projects involving housing for people with disabilities in New York. Some only provide one kind of support, while others will offer a combination of capital, ongoing, and or predevelopment support. Funders that fund projects in multiple categories are listed under each category.

Predevelopment Support

MUFG Union Bank Foundation:

(formerly Union Bank Foundation)

P.O. Box 45174

San Francisco, CA United States 94145-0174

Telephone: (619) 230-3105

Contact: J.R. Raines, Asst. V.P.

E-mail: charitablegiving@unionbank.com

URL: <https://www.unionbank.com/global/about/corporate-social-responsibility/foundation/foundation-grants.jsp>

The foundation supports nonprofit organizations involved with affordable housing, community economic development, education, and the environment. Special emphasis is directed toward programs designed to benefit low-to-moderate income populations and toward pre-development funding; housing for targeted populations including seniors, youth, farmworkers, and others with special needs; and emergency and transitional housing. Does not fund capital campaigns.

The New York Community Trust

(also known as NYCT)

909 3rd Ave., 22nd Fl.

New York City, NY United States 10022-4752

Telephone: (212) 686-0010

Contact: Mary Gentile, Exec. Asst., Grants and Special Projects

Fax: (212) 532-8528

E-mail: aw@nyct-cfi.org

URL: www.nycommunitytrust.org

The trust does not support capital campaigns, building funds or operating expenses, but it may provide funding to develop the services and meal plan model. Priority under health and special populations are: Children and Youth Disabilities - goal is to stimulate policymakers and service providers to improve existing services for children with disabilities and to encourage a service approach that emphasizes independence and the development of full potential; Mental Health and Retardation- goal is to foster the independence of people with mental illness and mental retardation, and to encourage a community-based system of care.

New York Foundation

10 E. 34th St., 10th Fl.

New York City, NY United States 10016-4327

Telephone: (212) 594-8009

Contact: Maria Mottola, Exec. Dir.

E-mail: info@nyf.org

URL: www.nyf.org

The foundation is particularly interested in new models and helping new organizations thrive. Housing development and people with disabilities are two of its giving areas. Only supports projects in NYC. Does not support capital campaigns, but would support development of the service model.

Acquisition and Development

The Bank of America Charitable Foundation, Inc.

150 N. College St., NC1-028-17-06

Charlotte, NC United States 28255-2271

Telephone: (800) 218-9946

URL: www.bankofamerica.com/foundation/index.cfm

People with disabilities are one of many at risk populations of interest to the foundation. The foundation supports programs designed to preserve neighborhoods and revitalize communities. Special emphasis is directed toward programs designed to increase access to affordable and homeownership opportunities; supportive housing/shelter; immediate shelter needs and long-term housing for vulnerable individuals and families.

The Harry and Jeanette Weinberg Foundation, Inc.

7 Park Center Ct.

Owings Mills, MD United States 21117-4200

Telephone: (410) 654-8500

Contact: Craig Demchak, Dir., Marketing and Communications

Disabilities program contact: Stan Goldman, Prog. Dir., email: sgoldman@hjweinberg.org or tel.: 410-654-8500, ext. 263.

URL: www.hjweinbergfoundation.org

The foundation supports programs that respect and promote the independence, integration, individual choice, and civil rights of children and adults with intellectual, physical, and sensory disabilities as necessary preconditions for a good life. Goals of this program area include providing grants in the following areas 1) Housing; 2) Employment; 3) Early intervention; 4) Community-based services for those with psychiatric illnesses; 5) Integrated summer camps and other social programs; 7) Legal aid programs and access to benefits; and 9) Assistive technology. NY is listed as one of their giving areas, but not a primary location.

MetLife Foundation

1095 Ave. of the Americas

New York City, NY United States 10036-6797

Telephone: (212) 578-6272

Contact: A. Dennis White, C.E.O. and Pres.

Fax: (212) 578-0617

E-mail: metlifefoundation@metlife.com

URL: www.metlife.com/metlife-foundation

The foundation established its Social Investment Program in 1984 to expand its philanthropic activities. PRIs serve to underwrite projects in affordable housing, and people with disabilities are one of their target groups. PRIs are usually structured as loans and made primarily to nonprofit organizations and their subsidiaries. Occasionally, the foundation may take an equity position, guarantee a loan, or target a special bank deposit to achieve financial or program objectives. Specific purposes of PRIs have included interim financing, land acquisition and facility improvement, and capitalizing housing development projects and earned income ventures. In 1994, the foundation's activities were supplemented with a Social Investment Program using MetLife company funds. Since 1997, nearly all social investments were funded directly through the company.

Omron Foundation, Inc.

55 Commerce Dr.

Schaumburg, IL United States 60173-5302

Telephone: (224) 520-7650

Fax: (224) 520-7680

E-mail: OFI@omron.com

URL: www.omronfoundation.omron.com

Funding for both housing development and services for people with disabilities.

***Vallabh and Savitaben Patel Foundation Inc.**

101 Chestnut Ridge Rd., Ste 2A

Montvale, NJ United States 07645-1801

Trustees: Kiran Patel, Paresh Patel, Yashvant Patel

The foundation only funds pre-selected projects. It provides funds for building and renovations, capital and infrastructure, and program development. People with disabilities are one of their population groups and they do fund projects in New York.

Social Services and Operating Funds

The Bank of America Charitable Foundation, Inc.

The Harry and Jeanette Weinberg Foundation, Inc.

MUFG Union Bank Foundation

New York Foundation

Omron Foundation, Inc.

***The Little Family Foundation, Inc.**

P.O. Box 15014

Albany, NY United States 12212-5014

Officers: Mark M. Little , Pres. and Director, Teresa A. Little , V.P. and Director

General operating support for programs for housing accessibility and housing for people with disabilities, but only for invited applications.

***Roberts Charitable Foundation**

140 Broadway, 4th Fl.

New York City, NY United States 10005-1101

Brown Brothers Harriman Co N.A. , Trustee

General operating support for programs for housing accessibility and housing for people with disabilities, but only for invited applications.

****Foundation does not accept unsolicited applications. In order to obtain funds, potential projects need to make the foundation officers aware of the project through other mechanisms (social networks, social media about the project, etc.)***

Appendix B: Organizations interviewed for this report

A number of individuals were interviewed for this report, including parents, self-directed services staff, and others. This section lists the major organizations interviewed for the report.

Westchester Institute for Human Development

NYSCARA

OPWDD, regional office staff and statewide housing staff

NYC government

SCIOTO

AHRC

FREE

CFS

L'Arche

Kids Plus

Point Program

Home Connect

Disability Opportunity Fund

Dunn Development Corporation

JEVS Human Services Philadelphia PIN program

BCID

CHS, NY regional office

JChai Philadelphia