The Housing Resource Guide

NEW YORK
ALLIANCE FOR INCLUSION & INNOVATION
Strength Together

This Revised Edition published 2025 by
The New York Alliance for Inclusion and Innovation

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New York Alliance for Inclusion and Innovation

2025

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Westchester Institute for Human Development

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First Published December 2012 by:
Westchester Institute for Human Development

This Revised Edition published 2025 by
The New York Alliance for Inclusion and Innovation

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Suggested Citation:
Maltby, J. et al. (2022) "Housing Resource Guide" Albany, NY: New York Alliance for Inclusion and Innovation

Introduction

This Guide was created to help people with Intellectual and Developmental Disabilities (I/DD) to understand the systems and options for housing. It is intended for the use of people with I/DD, their families and their Circle of Support including Care Managers, Fiscal Intermediaries, Direct Support Professionals, provider agencies and oversight agencies.

New York State is home to just under twenty million people.[1] For the purposes of this project, we estimate the number of people in the state with significant support needs, that is, people who need some level of support all day every day, to be approximately 74,000 people or .5% of the adult population. Approximately 300,000 additional adults, 2% of the adult population need less comprehensive care, across a wide spectrum of need. In this work we will refer to "Certified" housing, sometimes called "licensed" housing in other states, and "Non-Certified" housing which is less regulated and less funded. NY State currently supports approximately 36,000 people with I/DD in certified congregate and community housing throughout the state, with an additional 6,500 people receiving some assistance with housing and support in non-certified settings.

In the 40 years since the Willowbrook Consent Decree, NY State has developed an extensive group home system. The costs of labor and administration which form the bulk of operating costs in this system are funded primarily from Medicaid and Medicaid Waiver.[2] The system is comprised of state-run facilities and homes run by nonprofit provider agencies sometimes called "voluntary" agencies because they are controlled by volunteer boards. Voluntary agencies cannot be compelled to provide services, and they have the right to select whom they serve. Group homes have been developed by agencies, sometimes with active family involvement, including funding, and sometimes independently. Medicaid is a medical, treatment-focused model and so given the Medicaid funding, the emphasis has been on health and safety and compliance with a significant body of regulation to govern operations and funding. Financial and programmatic transparency has been limited. This era is coming to an end. Certified settings are seen as expensive,[3] segregated, over regulated, and increasingly likely to be out of line with best practices. Federal and state reforms are pointing the way to more self-determination, personalized plans and budgets, lighter regulation, and more integrated settings. In the future, housing options will be more flexible, but the process of establishing a home will require more commitment by the people and their families and will demand more flexibility of provider agencies.

The last forty years have also seen many changes in the world of people with I/DD. Autism was not included as a diagnosis in the Diagnostic and Statistical Manual (DSM) until DSM III was published in 1980. The definition has significantly broadened over time. The overall population of the United States has increased by 50%,[4] and is expected to increase by another 35% in the next thirty years[5]. It has also been 47 years since the passage of PL 94-142 in 1975, the precursor of the Individuals with Disabilities Education Act (IDEA), and while the education system it created is not perfect, it has benefitted millions of people with disabilities and increased expectations of community integration at all stages of life. Residential settings have to address the reality of a much larger population that will expect to be more included in the community against a background of static or reduced funding.

1 Per the US Census Bureau 2010 estimate *https://www.census.gov/quickfacts/NY* Retrieved August 2022
2 Medicaid Waivers allow states to use Medicaid funding to provide care in non-institutional settings. NY Has a 1915(c) waiver, for more about waivers visit the Medicaid .gov website at *https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html* Retrieved August 2022
3 See State of the States in Intellectual and Developmental Disabilities report *https://stateofthestates.ku.edu/sites/stateofthestates/files/2025-07/NY_8pg_accessible.pdf2*
4 Trading Economics *https://tradingeconomics.com/united-states/population* Retrieved June 2020
5 US Population projections 2005 to 2050. *https://www.pewsocialtrends.org/2008/02/11/us-population-projections-2005-2050/#:~:text=Executive%20Summary,by%20the%20Pew%20Research%20Center.* Retrieved June 2020

Introduction

The Guide begins with an overview of Person-Centeredness. If historically the goal was to find "beds" and "slots" for people with I/DD who need Long Term Supports and Services (LTSS) the emphasis today is on the needs and wishes of the people themselves. The person must be involved to the greatest extent possible in all aspects of their housing objectives and planning. The more time and patience invested in early planning, the more sustainable the long-term housing solution will be. We discuss the creation of social capital, which in our context means the network of family friends, professionals and acquaintances that together support community participation and independence. Building social capital can provide sustainable connections that reduce reliance on system-based support. We review the income available to a person from their employment, family resources, public benefits and other sources. We review the person's support needs, their housing planning process, and finally the best means of sustaining their housing.

Throughout the guide we will refer the reader to useful supporting material listed on the NY Housing Resource Center website in the form of printed material or recorded webinar presentations. *https://www.youtube.com/watch?v=1gz53LRJrs0*

Your Guide to Housing offers three essential resources that work together to help you understand your housing options and plan for the future. Together they form Your Guide to Housing; including A Housing Journey Podcast and Companion Piece to the Housing Resource Guide. *https://nyhrc.org/*

Housing Navigation is a focused, outcome oriented, and time limited service that helps people with I/DD who need or want to move to community-based housing to obtain and maintain stable, long-term housing of their choice. Navigation services include:

- Developing an individual housing action plan.
- Implementing a housing action plan.
- Finding a Home.
- Coordinating a move.
- Housing sustainability plan and transition to ongoing service providers.
- Housing crisis resolution.

New York Alliance, with federal Balancing Incentive Program (BIP) funds granted through the Office for People with Developmental Disabilities (OPWDD), developed a comprehensive 10-week Housing Navigator course. The course provides essential knowledge and understanding of resources required to secure housing for people with I/DD and insight into how housing is funded, developed, and sustained. Currently there are almost 400 Housing Navigators throughout New York State, working with Care Coordination Organizations, Provider Agencies and independently

For more information on Housing Navigation access the Housing Navigator portion of the NY Housing Resource Center at *https://nyalliance.org/HN_Training*

Further help with this Guide

In the fall of 2021, the Housing Resource Center held a "Statewide Learning Community". Over the course of several weeks, we held a series of webinars and presentations that walked the attendees through this Guide, with presentations by the team that created it.

THE HOUSING RESOURCE GUIDE

Helping to create a safe, healthy, and comfortable home takes time.

The more effort invested in planning and due diligence, the more sustainable and fulfilling the eventual outcome will be. We are not looking to "place" people, or to put them into a box that will look safe but within which they will be unable to grow and enjoy their life. This section discusses Person-Centered thinking and ways to go about planning for successful outcomes.

This section was created in partnership with Christopher Liuzzo.

Everything begins with the person who is seeking housing. People with I/DD and their advocates have been stressing the need for genuine person-centered thinking for many years. Too often a "personalized" program or plan pays lip-service to person-centeredness while setting a series of meaningless pro forma goals and "hopes and dreams". While we still have a long way to go, we have seen improvement in recent years in New York. The federal Health and Human Services "Standards for Person-Centered Planning and Self-Direction in Home and Community Based Services (HCBS) programs" (per the 2010 Affordable Care Act) sets out clear and demanding requirements for States to follow. Training programs for support personnel provided by resources such as The Council on Quality and Leadership (CQL) and most importantly decades of Self Advocacy have moved the focus more towards the person at the center of any plan.

In its Waiver creation guidance to states, The Centers for Medicare and Medicaid Services, (CMS) which has federal oversight of all Medicaid programs, says the following; "*CMS encourages and supports the use of person/family-centered planning methods in service plan development. Such methods actively engage and empower the participant and person selected by the participant in leading and directing the design of the service plan and, thereby, ensure that the plan reflects the needs and preferences of the participant (and/or family, if applicable). Person/family-centered planning is an integral element of participant direction of Services.*"[6]

Per the federal Health and Human Services Administration, Person-centered Planning (PCP) assists the person to construct and articulate a vision for the future, consider various paths, engage in decision-making and problem solving, monitor progress, and make needed adjustments to goals and Home and Community Based Services (HCBS) in a timely manner. It highlights personal responsibility including taking appropriate risks (e.g., back-up staff, emergency planning). It also helps the team working with the individual to know the individual better.

Before any work on housing begins, a deep understanding of the person's wishes, desires, needs and resources need to be undertaken. For people who have difficulty communicating, this process may take many hours, but without a sound beginning no housing plan will be sustainable.

6 Application for a §1915(c) Home and Community-Based Waiver https://wms-mmdl.cms.gov/WMS/faces/portal.jsp Retrieved August 2022

1 Person-Centered Thinking

Beginning

Any good housing plan begins with the person seeking housing. Not with the building, the house, the apartment or the condo. The late Hank Bersani[7] often reminded planners not to "draw the bull's eye" before they had engaged in a quality person-centered planning process. Deciding where and with whom a person may live before doing this puts the cart before the horse.

The range of tools and definitions surrounding person-centered planning can be confusing, they include MAPS, Paths, Essential Lifestyles Planning, Personal Futures Planning, Liberty Plans and more. Of all these tools and definitions, perhaps one of the most cogent, concise and meaningful comes from John O'Brien and Beth Mount:[8]

"Person-centered planning facilitates a person and their allies' discernment of the person's purposes, gifts and capacities", so as to support the person to "show up in community life as a valued friend and a contributing citizen." Note the key words present: discernment, purposes, gifts, capacities, friend and citizen. Note the key words absent: client, interdisciplinary, skill development, ADL's, behaviors.

In the end, quality person-centered planning is really rather straightforward. All the tools and processes are secondary to these simple to understand but difficult to enact markers:

- Conversation grounded in deep listening. Excellent person-centered planners are deep listeners. They come to the conversation with no preconceived notions. They are deeply curious about the persons with whom they are planning. They *want* to listen and support the discernment of people's purposes, gifts and capacities. They love to be surprised by what is revealed during the conversation.
- Planning requires a profound respect for people and their life experiences, regardless of the complexity of impairments. Great person-centered planners do not consider planning as something done "to" or "at" people. They consider themselves to be co-creators acting *with* people. They have a minimal sense of their own importance and downplay hierarchy. Regardless of the credentials they may (or may not) hold, they see themselves as co-equals with the people they support.
- A lens which puts people's life experiences into context. Many people with I/DD have a history of isolation, marginalization and devaluation. They have been subjected to low expectations and years, if not decades, of "programs" of meaningless activities. Quality person-centered planning surfaces these experiences, supports others to understand them and addresses them in a healing fashion as part of the plan.
- Hearts are opened. When highest purposes, gifts and capacities are discerned and life experiences are exposed, compassion is aroused. If there are both belly laughter and tears during the planning process, that is a sign that good things are happening. Good person-centered planning is neither sterile nor clinical.

7 Among many other things, Hank was the president of the AAIDD, 2006-2007.
8 John O'Brien and Beth Mount, Pathfinders: People with Developmental Disabilities and Their Allies Building Communities That Work For Everyone, Inclusion Press, Toronto, 2015.

- People are inspired to "Imagine Better."[9] They are opened to possibilities not before seen or imagined. "Premature realism" is put aside. (Premature realism is marked by expressions like "that will never work", "we tried that before", "that is not realistic").

- Finally, quality person-centered planning is disruptive. Supporting people to move toward their highest purposes will call on others to behave differently. This especially applies to provider organizations, which may be called upon to try new models, utilize resources in untried ways, and change or even give up existing rules and structures. This may be the most meaningful result of effective person-centered planning.

So, Watch Out for Distractions

If person-centered planning really is about simple ideas such as listening, respect, curiosity and compassion, why do so few people have genuine and authentic experiences? Why are so many steered to existing "slots" in day programs and "beds" in group homes? Doesn't it make sense that slots or beds could not have been developed with a specific person in mind and must be bullseyes drawn before any planning was done?

Here are some distractions many people experience which are labeled "person-centered". It is good to be aware of them. When people are aware of these distractions, they can call planners to account and guide them back to authentic planning.

- Seemingly endless assessments with literally hundreds, if not thousands, of data points are distractions. In New York, there are the "I AM" assessment and the "Paths Assessment" tools developed by different Care Coordination Organizations (CCOs), OPWDD's Coordinated Assessment System (CAS), the Developmental Disabilities Profile (DDP), as well as other assessments such as the Council on Quality Leadership's extensive interview suite and the Adaptive Behavior Assessment System (ABAS). While these may yield some useful data, they are not a substitute for deep listening. They can often be completed, at least in part, by someone barely familiar with the focus person. They are frequently mechanistic, and algorithm driven, producing pre-determined drop-down service menus. A plan that comes out of a computer is likely not very person-centered, and may in fact be designed to facilitate billing rather than provide genuine support.

- When people are told they are "not ready" for their desired life, that is a distraction. Most genuine plans reveal people's desire for what has been called the Good Life: "I would like my own place; I'd like to marry my girlfriend; I want a job; I would like to have a dog; I'd like to go on vacation." All too often, so-called person-centered plans turn the onus back on the people who express these modest desires. They are told they have to earn the Good Life by developing new skills, like cooking and money management, learning to get along better with their "peers", showing they can manage to make their beds and clean their bathrooms. These are not-so-subtle expressions of authority and power over people, not respect and being "with" people.

- When people are told they aren't ready for their expressed Good Life, they may well be steered into services and especially settings, then told that even once they spend an indefinite amount of time in these services and settings, that it is a "we'll see" about moving toward the Good Life. This process may well, and often does, result in years spent in services and settings that look very little like the Good Life. The delivery of services becomes an end in itself rather than achieving the Good Life. This is a distraction.

9 An expression attributable to Michael Kendrick: *https://www.kendrickconsulting.org/*

How Will I Know It When I See It?

Authentic person-centered planning is generative: it creates outcomes. Experience of these outcomes is a good sign that authentic person-centered planning has occurred.

Authentic person-centered planning contributes to the experience of what Otto Scharmer calls "generative listening."[10] When this happens, Scharmer says, "you realize that you are no longer the same person you were when you started the conversation. You have gone through a subtle but profound change." People may well say things like "this was amazing" or "this was life changing" or "I can't believe what happened today." Authentic person-centered planning generates collective will; a commitment to move toward the person's Good Life is palpable across participants.

The Good Life is marked by what John O'Brien and Beth Mount, in their book "Pathfinders"[11] call the Five Valued Experiences. Authentic person-centered planning results in intentional movement toward these experiences:

Belonging in a diverse network of relationships and networks.

Being Respected, especially by engagement in playing valued social roles.

Sharing Ordinary Spaces with typical citizens.

Contributing to pursuits that make a positive difference to others.

Choosing in ways that reflect a person's highest purposes.

This intentional movement is evidenced by concrete measures that may include:

- Identification of resources that will be applied toward the five experiences
- Individualization of these resources (i.e., not shared with other persons)
- People and their allies experiencing increased control of resources
- Roles being redefined so that key actors' activities are dedicated to achieving the five experiences
- Person in leadership roles and with administrative authority pledging commitment to support people's plans

The Person's Story

All the assessment and planning instruments in the world will never be as effective as knowing a person's story. Services that are funded with public funds are compelled to report on outputs and outcomes. Taxpayers require it and our culture is imbued with the belief that public support should always be minimally and grudgingly disbursed. Over the decades since deinstitutionalization, we have accumulated layer upon layer of regulation, compliance and reporting requirements. We have tried, with limited success, to quantify quality and to create person-centered services. We convene Interdisciplinary Team meetings that draw upon multiple professions, but which can obscure the person beneath the paperwork. We have unconsciously absorbed the fallacy that if we can measure it, we have achieved the goal; that being able to tick the box means that we have accomplished something. As a person goes through the process of understanding housing they will go through a series of assessments, eligibility screens, planning instruments and programs -but be mindful that all of these instruments are tied to the funding, not necessarily about the person.

10 Otto Scharmer, Theory U, Leading from the Future as it Emerges. Society for Organizational Learning, Cambridge, MA. 2007.
11 PATHFINDERS People with Developmental Disabilities and Their Allies Building Communities That Work Better for Everybody. Pp 95-96 Inclusion Press 2015

Law, regulation and bureaucracy require planning and compliance formats and we have to adhere to them in order to continue to be funded. However, the real planning is done with the person themselves, and works best if it can be done one-on-one, or with their closest advocate, and is based on their story. It takes a long time to really understand someone's housing goal.

- Do they want to live with other people?
  - Will they have to?
- Do they want what their parents want, or do they want something more independent?
- Have they had time to learn how to make decisions, and are the people in their Circle ready to take some risk and to learn from mistakes?

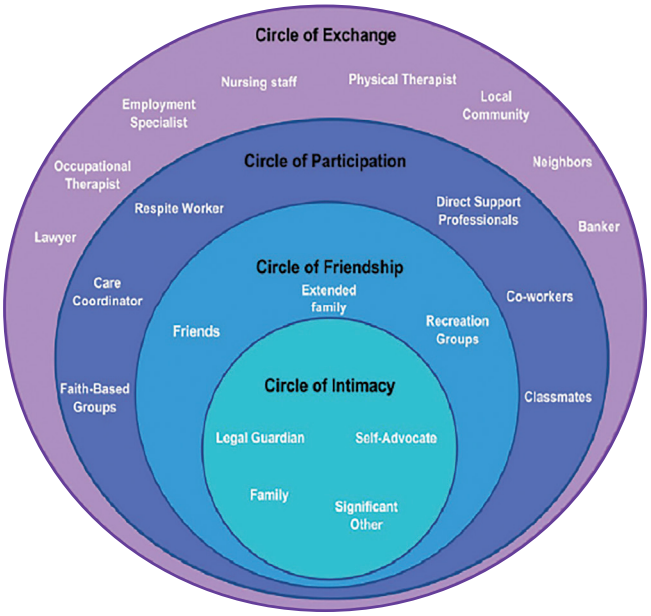
In the Planning Instrument that is used by Housing Navigators there is a strong emphasis on narrative and story. There are many tools that can provide checklists and things to do or not do, but fundamental to this housing planning process is the necessity to include the person at all stages and to have the patience to invest the time. Time invested in planning directly correlates to the sustainability of the outcome.

Creating a Circle of Support

One of the questions that every parent asks is "what will happen when I am unable to support my son or daughter?" In a traditional group home, the person's welfare is the responsibility of the agency and the person's guardian if the family is unable to provide support. There is an assumption of limited self-advocacy. Families take comfort in the permanency that an agency might provide, and they believe that they can rest easy now that their loved one is provided for. This is an understandable emotion, and rings especially true for the generation that saw how terribly neglected some of the patients discharged from institutions were in the 1970s and 80s. They live with fear as to what might happen when they are no longer alive to advocate for their son or daughter. However, experience shows that while some agencies do this work very well, there are risks. Agencies change, merge with others, leadership changes, founders retire, funding changes, standards shift. Given the Institutional Bias embedded in New York's residential system, an agency has little incentive to foster independence or self-advocacy. A person becomes more institutionalized if they lack contact with the outside world, and this institutionalization compromises both their quality of life and their lifespan. Whether or not they live in a certified or in a more independent setting, it is paramount that they and their family and advocates create a Circle of Support which can look out for their interests and advocate for them as their parents become less able to do so. This is especially important for people living in non-certified or non-agency-based settings.

The starting point for service planning should be the Circle, whether a person is receiving services through the Office for People With Developmental Disabilities (OPWDD) or from elsewhere. The Circle, in partnership with the person, addresses the person's needs, their health and safety, risks, goals and desires. The OPWDD system is primarily funded through Medicaid, and even with the flexibility of the Waiver the plan follows the prescriptive path of a medical model. People living in the traditional congregate care system will tend to have highly prescriptive plans, partly in order to meet compliance requirements. People living outside the congregate care system have more flexibility but need to be mindful that Medicaid funding will always be contingent upon a prescribed plan of services.

1 Person-Centered Thinking



A Circle of Support brings together family, friends and professional supporters who are focused on the needs and aspirations of the person with I/DD. The focus is not on "programs" or creating checklists and pre-formatted compliance plans, but on the long-term goals and interests of the person. A typical Circle will have an inner core of close family, with a series of concentric Circles to include extended family, professionals who work with the person on a regular basis, (for example, a Direct Support Professional (DSP)), and professionals who work with the person on an intermittent basis (for example their attorney or physician). Meetings do not have to be large gatherings; the use of social media today can bring in participants from anywhere in the world, and at different times. The more robust the Circle of Support, the more achievable and sustainable the person's goals are likely to be. Tools are available to help with creating Circles of Support[12] and to bring together resources for people who may at first seem to have little connection to family or other support[13].

OPWDD's Self-Directed Services regulations require a Circle but the creation of a Circle should not be driven solely by compliance, and the principles apply to providing for any one with significant support needs, regardless of ability or age. A well-constructed and sustained Circle is a powerful way to ensure that the focus remains on the person.

OPWDD stresses the role of the volunteer in the Circle, but to be comprehensive and sustainable the Circle should also include professionals involved in the person's life. Yes, they bring their knowledge and experience, but by being included they also gain a more intimate perspective on the person and are less inclined to see them as a "case". They get a chance to learn about the person's family life, their childhood, their progress and the things that matter most to them. Current literature refers to Paid and "Natural" (i.e., unpaid) supports. The reality is that many Paid support people perform their work with great love and kindness and are very close to the people they support. Be wary of too much distinction between "Paid" and "Natural" – find the right people with the right commitment and above all include them in the person's life.

Non-professional Circle members are not paid for their time and currently there is no provision for payment for the professionals in the Circle, other than the Care Manager and the Self-Direction broker. Meetings tend therefore to be called during the working day when the professionals can be paid. However, the context and setting for planning meetings matter, so, as much as possible, meetings should be in the person's home, at a time convenient to them and to the other non-professional members of the Circle.

12 Amado, A. McBride, M. *Increasing Person-Centered Thinking etc.* Helpful material on creating a Circle of Support. *https://rtc.umn.edu/docs/pcpmanual1.pdf* Retrieved August 2022

13 Family Finding connects people who may seem to have little family resources. *http://www.familyfinding.org/* Retrieved August 2022

Partnerships with Provider Agencies

The noted philosopher Sy Syms maintained that "an educated consumer is my best customer" – so how can a person get educated about the provider agencies that they will need to help to support them? There are some six hundred provider agencies in New York. The majority of them are small not-for-profits, with all of the vulnerability that being a small business entails.[14] Over time and with the advent of Managed Care many of these agencies may go out of business. Agencies have failed in the past for various reasons, but OPWDD has been able to prevent any harm befalling the people who were in the agency's care, transferring their services to other agencies. Consolidation of provider agencies will reduce choice, but is likely (at least in the near term) to make the system more financially sound. In the longer term it seems likely that nonprofit providers will have to compete with for-profit businesses in some of the fields in which they operate and they may be compelled to rethink their priorities and business models. The partnership between a provider agency, the person seeking support, and their family is a critical element in sustainability, and is likely to last for many years. Identifying an agency that aligns with best practices and principles, through the lens of how well they are positioned for and committed to providing genuinely person-centered support for independent housing, is vital; too often choices are made under pressure and based on near-term availability or convenience. Most agencies will deliver services that have the same descriptions, e.g., "CommHab", "Day Hab" or "Residential". They will be funded by the same streams of OPWDD and Medicaid funding. However, they all bring their history and character and the nature of the services and outcomes may be different. Before deciding to obtain all or some of their services from a particular agency the person or their advocates should perform their own due diligence.[15]

- Review the agency's IRS 990 report. The 990 details the funding sources for the agency. It will show whether they are dependent on one particular funding stream or have a diverse source of income. It will show what they pay their senior management, who the members of the board are, and whether there are related businesses. It will also show their contribution history.[16]
- Find out what kinds of training the agency provides to its staff and its volunteers, including its board. The most well-known course is provided by the Council on Quality Leadership (CQL) which teaches a fundamental rethinking of relationships and ways to understand people's interests, wishes and hopes. It is an excellent program, but not the only kind of training available and a vibrant agency will encourage professional training at all levels of the organization.
- Join a local social media group of people who have I/DD and their families and find out what kinds of experience people have had with different agencies.
- Who are the volunteers? Is the board mostly comprised of parents of people in the agency's programs? For such boards the good news is that the board will likely have a substantial long-term commitment; the downside is often a resistance to change.
- Meet with the management and staff, and if things don't feel right, express your concerns. For too long families have been in a role that is not in partnership with an agency, even with "progressive" agencies – It's time for a change.
- The Covid-19 pandemic showed us that even large nonprofits operate on very thin margins, and smaller entities may be driven out of business in a crisis. What plans does the agency have if they are faced with a significant revenue shortfall?
- Lastly – does the agency provide any services that are not funded through OPWDD? If its only business is to follow OPWDD mandates and compliance, is it sufficiently diversified?

14 Kendrick, M. *Thinking about what keeps people safe*. Belonging Matters Inc. Issue 34 March 2018

15 It must be said that there are parts of the State where there may be little choice of provider, and there is no easy solution when having to deal with such thin resources.

16 How to Read the IRS form 990 *https://roadmapconsulting.org/wp-content/uploads/2016/03/how_to_read_form_990.pdf* Nonprofit Coordinating Committee of New York. Retrieved August 2022

Guardianship & Supported Decision-Making

In any discussion or planning for Long Term Supports and Services for a person with a disability, the person themselves is always the primary focus and the one who has to make and live with the major decisions. When current guardianship law was created in 1969, in the early days of deinstitutionalization, it was assumed that a person with I/DD "had no realistic likelihood of change or improvement over time". Contrast this with the Olmstead language thirty years later: Institutional placement of [people] who can handle and benefit from community settings perpetuates unwarranted assumptions that [people] so isolated are incapable or unworthy of participating in community life". People with significant levels of disability are capable of choice and decision making, and as guardianship laws face reform new ways to support those decisions are coming into practice

When a person turns 18 years of age they are considered to be fully emancipated and responsible for their own decisions. If the person's decision-making ability is compromised by a cognitive disability, they may have difficulty in safeguarding their interests, making informed decisions about their health, or managing their finances. Historically people in such a situation have been subject to guardianship. In New York State Guardianship takes two forms. Article 81 of the Mental Hygiene Law "authorizes a court to appoint a guardian to manage the personal and financial affairs of a person who cannot manage for himself or herself because of incapacity"[17].

In 1969 The Surrogate's Court Procedure Act (SCPA) was amended to include article 17-A providing for the appointment of guardians for people with I/DD. The underlying assumption at the time was that I/DD was a permanent condition and the person had no hope for improvement or autonomy. This results in "an immense loss of person(al) liberty" and does not allow for partial decision-making authority for the person[18]. Unfortunately, 17-A has little room for nuance. If a person is subject to guardianship, they have no rights, but in many situations if the parent wants to help their adult son or daughter who has severely compromised decision-making capacity, they have to nonetheless obtain guardianship. There are resources to assist with the process provided by the Surrogate's court and also available through OPWDD Family Support Services for Guardianship guidance offered by provider agencies and Care Coordination organizations.

HealthCare Proxy

We all should have a Health Care proxy, someone chosen to make healthcare decisions "when your doctor has determined that you are not able to make healthcare decisions for yourself". [19] For people with I/DD which is associated with a higher risk for many chronic conditions a health care proxy is essential, and simple to execute.

Increasingly Surrogate Courts are concerned about the absolute binary nature of 17-A and the statute is being reconsidered. In other types of guardianship and in other states courts have leant towards granting more control to the person for whom guardianship is sought and limiting the power and control of the guardian.

17 Guardianship for incapacitated people in New York under Article 61. Senior Law.com *http://www.seniorlaw.com/guardianship-for-incapacitated-people-in-new-york-under-article-81/* Retrieved August 2022

18 "Constitutional Challenges to Article 17-A guardianships" is a learned article setting out the flaws in 17A *https://makofskylaw.com/wp-content/uploads/2020/01/Lisa.NYSBA_.Fall_.2019.Journal.Article.17A.-2.pdf* Retrieved August 2022

19 Health Care Proxy guide. NY State DOH *https://www.health.ny.gov/publications/1430.pdf* Retrieved June 2020

Supported Decision-Making

Supported decision-making is a *process* by which a person with an intellectual or developmental disability can be supported in making his or her own decisions. Supported decision-making draws on the common experience of consulting or seeking assistance from others when making decisions or choices in our own lives.

People with I/DD have a right to make their own choices and decisions, but may need more or different kinds of support to do so. Supports may include helping a person access information that is useful or necessary for a decision, helping her or him weigh the pros and cons, assisting in communicating the decision to third parties, and/or in carrying out the decision. But the decision is always the person's (the "decision-maker") and not the supporter's.

One common form of supported decision-making involves the decision-maker identifying and choosing a person or persons whom she or he wishes to support them in various areas. For example, they might wish one person to support them with regard to finances, another with health care, and a third with intimate relationships. There is no limit to the number of supporters a decision-maker may choose, but usually it is between one and ten. Supporters are frequently family members, and might also include friends, peers, neighbors, or service providers, but the relationship must always be one based on trust.

People with I/DD may want to record the arrangement they have made with their chosen supporter in writing in what is called a "Supported Decision-Making Agreement". The Supported Decision-Making Agreement spells out the rights and obligations of the parties, including an understanding by supporters that they are to assist the decision-maker, but never to substitute their own decision in lieu of theirs.

In a truly groundbreaking measure August 2022 New York Governor Hochul signed the "Supported Decision Making Agreement Bill" into law. "Drawing on *Principles* developed by SDMNY, the Supported Decision-Making Agreement Act is truly a civil rights bill for people with intellectual and developmental disabilities, embracing supported decision-making as an alternative to guardianship and preventing discrimination against decisions made by people with Intellectual and developmental disabilities… This puts New York in the forefront of promoting and protecting the rights of people with disabilities."[20]

To learn more about the Person-Centered Approach visit the NYHRC website to view "Person-Centered Thinking and Planning Introduction" by Kirsten Sanchirico, Certified Person-Centered Thinking Trainer and Planner with the NY Alliance. This presentation was originally aired during the "2019 Statewide Learning Institute"

https://youtu.be/xIYsy1Vxapw

20 For more information visit the SDMNY website at *https://sdmny.org/* Retrieved August 2022

2 Certified and Non-Certified Housing

In this section we will discuss the difference between "Certified" housing and "Non-Certified" housing in NY State. We will review different types of housing options such as Supportive, Supported and Affordable housing as well as Shared Living and Intentional Communities.

"Certified" or "Licensed" Housing?

"Family Care" is the oldest of OPWDD's "community-based" residential programs, founded in the 1930s and originally intended to move people from institutional settings into the homes of people living in the community adjacent to the institution, mostly Direct Support Professionals (DSPs) who worked there. The provider family cannot be related to the person. Since those early days the program has since been adopted by voluntary providers, and there are now two parallel programs, one operated by the state -State Operated Family Care (SOFC) and the other by the voluntary providers, Voluntary Operated Family Care (VOFC). Family Care residences are certified by the state. Family members are trained and oversight is provided by the state itself or by voluntary providers funded by the state. Family care providers are paid a (tax-free) stipend for each resident, with a maximum of four residents to a home.[21] Family Care operates successfully for many people, but some express concern that it can be akin to "Adult Foster Care" and that there is something amiss when families cannot receive support for their own son or daughter in their own home, while such support would be provided to a non-relative. This latter concern is increasingly relevant now that the IRS has ruled that "Difficulty of Care" payments, i.e., in-home support funding, may be made to family members, including parents.

Alongside its institutional system NY Began the **"hostel"** system in 1966, housing people who had left institutions with "house parents" who over time proved difficult to recruit and who were replaced by DSPs. Beginning in the early 1970s **Community Residences** (CRs) succeeded hostels. In 1974[22] the federal government addressed a mounting financial and programmatic crisis in state institutions by permitting states to create smaller settings for people with I/DD and others. In addition, this change was often driven by litigation against state institutions. These settings began with utilizing **Skilled Nursing Facilities** (SNFs), first created in 1970,[23] but as it emerged that the majority of people did not need the SNF level of care, states were permitted to create **Intermediate Care Facilities** (ICFs). These facilities were governed by rules and regulations set at the federal level, but the federal government devolved the task of enforcing those rules and regulations to the states. States in turn "certified" that these residences complied with federal standards. With costs rising and federal participation newly available, most CRs were converted to ICFs. (There are still some 68 CRs in operation serving 234 people). In 1981 with the advent of Medicaid Waivers and as it became clear that ICFs were expensive and that many people would do well in less restrictive settings, states were permitted to create smaller, less regulated settings. There are two types of IRAs; Supervised, where the majority of residents in the certified system live, which typically have 5-6 residents and staff who are on duty at all times, including overnight. Supportive IRAs typically have fewer residents, and depending on the needs of the people living there may or may not have staff on duty at all times. Services and supports were to be unbundled and made more personalized so that person-centered settings could be developed. Generally, IRAs were smaller than ICFs and with fewer residents. IRAs were also made subject to certification for any number of reasons the primary one being that the state's contribution

21 For more information on Family Care see OPWDD site *https://opwdd.ny.gov/providers/family-care-0* Retrieved May 2020
22 Technically ICFs were created in 1972 but there were no regulatory guidelines until January 1974
23 History of Nursing Homes and SNFs see Natl. Ctr. Biotech Info History of Federal Nursing Home Regulation, *https://www.ncbi.nlm.nih.gov/books/NBK217552/* Retrieved August 2022

to the Supplemental Security Income (SSI) rate is significantly higher for a person in a supervised congregate setting. The "Family Care" option was also brought into the certified system eventually. ICFs, IRAs and Family Care settings may be operated by the state itself or by nonprofit provider agencies, sometimes called "voluntary" agencies.

The average ICF in New York is home to ten people.[24] There are several in the state that house more than forty people. Most IRAs are home to five or six people but there are some with as few as one or two people. Family Care host families may have up to four people in the host home now but in the past could house more.

"What would you say if... you could create very affordable housing and not have to spend a dime on bricks and mortar?...the housing was unencumbered by government regulations, at the same time you could meet the special housing needs of seniors and persons with developmental disabilities.."

-It's time for change, NYS OMRDD (now OPWDD) 1996

In the past, people with I/DD or their advocates would put their name on a "waitlist" that would eventually lead to a placement in a certified group home. Families believed that this placement would take care of their son or daughter's long-term health and safety and that they would not need to worry about what might happen when they were no longer able to care for their child. In recent years, and for reasons we will discuss later, the state reduced the number of new certified group homes it would fund. This reduction in supply resulted in the growth of the waitlist of people seeking certified housing. By 2011 the waitlist had grown to almost 12,000 people statewide, and New York was not the only state faced with the issue. The federal Centers for Medicare and Medicaid Services (CMS), which oversee Medicaid funding, advised states to understand and better clarify their waiting lists. In response New York State passed legislation requiring OPWDD to gain a more detailed understanding of the needs of people on the waitlist in order to understand long term housing needs. In February 2016 OPWDD published its "Report to the Legislature Residential Request List"[25] , a thorough review of the waitlist. One outcome from the report was the creation of the Certified Residential Opportunities (CRO) protocol which uses three levels of housing need:

- **Emergency Need** – when someone is in imminent danger of homelessness or otherwise at great risk,
- **Substantial Need**, to include people whose family members are no longer able to support them and people returning from Residential Schools or Development Centers, and
- **Current Need** for people whose housing needs are not as pressing as the first two categories.

For the most part "beds" only become available when a resident dies or moves into a non-certified setting. In 2017 then Governor Andrew Cuomo announced plans to create 459 new certified beds over the next several years to meet demand, but given the level of need this will likely only provide support for people with very high levels of need who are in the *Emergency* or possibly *Substantial* Need categories. Meanwhile vacancies remain unfilled as providers are unable to deliver services for people with high levels of need at the rates they are given to do so. Opportunities for certified housing are limited and likely to remain so.

24 Braddock op.cit online NY State profile "Persons served by setting" Retrieved May 2018

25 Office for People With Developmental Disabilities. (2016). *Report to the legislature: Residential request list*. https://nyhrc.org/resource/report-to-the-legislature-residential-request-list/ Retrieved June 2020

That the" Emergency "category sees homelessness or the lack of a caregiver as sufficient reason to place someone in a certified setting illustrates the persistence of our institutional culture. Surely the solution to homelessness is to provide housing, and the lack of a caregiver is a reason to provide caregiving support.

Non-Certified Housing

This is a term that is used to describe any home outside of the certified system, - namely, a home like any other! These homes may be in apartments or houses, co-operatives, condominiums, owned by persons, agencies, families, or corporations. In other words, places where the typical population lives. It may be home for one person or more and they may share with other people with disabilities or with people without disabilities. There are typically fewer people than in a certified setting. Non-certified settings are not required to go through a Padavan process but they may have to contend with local "grouper" laws.[26]

It is most important to note that the Housing Subsidy ADM 2022-03 (of which more later) limits the number of people who can receive the subsidy to "the lesser of four (4) unrelated adults or the maximum number of unrelated adults allowed by local ordinance living together in the housing unit".

Padavan Law 1978 N.Y. Laws ch.468,2 The statute is named for State Senator Frank Padavan chair of the State Mental Hygiene and Addiction Control Committee at the time. In order to establish a non-profit owned Certified home, the provider agency must seek approval from the municipality and if that approval is not immediately forthcoming they may go through a "Padavan Law" process to establish that the home does not increase "concentration" of nonprofit property ownership and specific population housing in the municipality. This discriminatory process can be expensive and stressful for all involved. When institutions in New York were legally mandated to place many people with disabilities in the community rapidly (through the Willowbrook consent decree) the Padavan Law allowed agencies to develop community housing more quickly since municipalities often "zoned" out a group living situation. The criteria in the Padavan law, although discriminatory, did provide a pathway to establishing a home in the community when institutions were closing.

For people whose support needs do not warrant placement in a certified setting there are opportunities to create non-certified housing using Self Directed Services (SD) funding and other sources of funds. In parts of the state where regional administrators and provider agencies have been proactive, non-certified housing is now being created at a higher rate than certified housing and state and other systems are adapting to the new model. In other parts of the state with less "buy-in" from providers and perhaps more expensive housing, it remains extremely difficult for families lacking skills, experience, funding, and support from OPWDD to create workable sustainable housing on their own. Even with support it can take years of hard and sometimes frustrating work to create a sustainable home.

What are the differences between Certified and Non–Certified houses?

In meetings and surveys families have expressed a preference for certified housing, and for "traditional" group homes. (It is worth noting that the "tradition" only dates back to the deinstitutionalization changes of the 1970's and 1980's). There is a presumption that such a setting will ensure the health and safety of their son or daughter when they are no longer able to provide needed support.

26 Certified and Non-certified housing see the OPWDD website *https://opwdd.ny.gov/providers/housing* Retrieved August 2022

OPWDD's 2016 Report to the Legislature surveyed the families of people with I/DD who were on the "waitlist" for housing. The report noted that "a majority 62% of those surveyed", (95% of whom were caregivers) "indicated interest in a traditional, agency staffed Certified model". A small majority of the people surveyed in 2018 as part of the creation of "What Happens When I'm Gone?"[27] also stated they looked for certified housing, some stating that their son or daughter needed "24/7" support. Given the differences in funding, regulation, staffing and siting issues it is important that the types of certified settings and non-certified settings be understood.

The principle differences between certified and non-certified housing lie in their different **oversight** and **funding**.

Oversight and Regulation

Certified settings are subject to regulation under New York 's Mental Hygiene Law, principally Parts 624 (Incident Management), 625 (Events & Situations), and 633 (Protection in Certified Settings), of the Codes, Rules and Regulations of the State of New York (NY-CRR Code[28]). Operators are required to report incidents considered minor to the provider agency's "Incident Review Committee", more serious incidents in some cases to OPWDD, and most major incidents to the state's Justice Center[29]. They are subject to in-person inspection by OPWDD's Division of Quality Improvement (DQI) at least annually. The audit is designed to ensure that housing is healthy and safe and provides a positive quality of life. While the latter is difficult to audit, the tool used[30] is well crafted, requires significant training to administer and is sensitive to the need to focus on the individual person, even if the home in question has a large number of people living in it. Staff in certified settings and related professionals are considered "Mandated Reporters" and required to report any abuse or neglect. If a person is living in an IRA or in Family Care, they will also have the support of a Care Manager whose job includes monitoring for health and safety.

Certified settings are considered to be highly regulated. However, there is a persistent myth that **non-certified** settings are not regulated and that protections are not in place for residents. This is unfounded. Non-certified settings that receive funding through OPWDD are subject to parts 624 and 625 in reporting incidents or abuse. The Justice Center does not typically address incidents in non-certified settings, but does conduct background checks for any person who is to be employed by a provider agency, or a fiscal intermediary and who will be providing support to people with I/DD. Virtually all non-certified homes receive funding for rent support from either Tenant Based Rental Assistance vouchers (Section 8) from the Department of Housing and Urban Development (HUD), or through OPWDD's Housing Subsidy program (formerly known as both Individual Supports and Services (ISS) and Self-Direction housing subsidy). HUD requires that housing purchased with Section 8 vouchers meet their standards of safety and quality, as does OPWDD, set out in its ADM #2022-03.[31]

27 Published by NYSACRA 2018 available at *https://nyhrc.org/Resource_Library* Retrieved August 2022

28 Parts 624 625, 633 available at *https://govt.westlaw.com/nycrr/Browse/Home/NewYork/NewYorkCodesRulesandRegulations?guid=Icba70b30b7ec11dd9120824eac0ffcce&originationContext=documenttoc&transitionType=Default&contextData=* Retrieved August 2022

29 NY State Justice Center established in response to abuses within the OPWDD residential System in 2013 *https://www.justicecenter.ny.gov/about/vision* Retrieved September 2022

30 DQI Site Review Protocol Resource October 3 2016 *https://opwdd.ny.gov/system/files/documents/2019/11/site-review-protocol-digital-manual-impl-10.03.2016.pdf* Retrieved July 2020

31 ADM#2022-03 *https://opwdd.ny.gov/regulations-guidance/adm-2022-03-opwdd-housing-subsidy-program* Retrieved July 2022

2 Certified and Non-Certified Housing

ADM #2022-03 requires that the Care Manager include housing plans within the person's Life Plan. There must be a Participation Agreement which commits the Housing Subsidy provider agency or Fiscal Intermediary to safety and quality standards and oversight. There is also a Quality Assurance Expectations checklist outlining minimum standards for home safety. Both documents must be reviewed and signed annually. The ADM is detailed in its requirements and the members of the Circle of Support and the landlord should be familiar with it.

In many cases, non-certified settings are either operated, managed or owned by provider agencies who apply their own standards, frequently more exacting than those of part 633 and 624, and include the same incident reporting features as they do for their certified settings in part because it is administratively simpler to apply one set of best practices across all of the homes they operate or support. Most people living in a non-certified home who are receiving OPWDD waiver services in addition to the rental subsidy will be receiving Care Coordination from a Care Coordination Organization (CCO). In July 2018 CCO services began to replace Medicaid Service Coordination (MSC) support. In addition to ensuring access and compliance with Medicaid services CCOs monitor and coordinate health care. If the person is receiving SD services, they will also have a Support Broker who is paid to ensure among other things that their housing is safe and healthy and that their bills are paid. Their funding will be channeled through a nonprofit Fiscal Intermediary who is paid to also ensure that their obligations are met and their budget adhered to. It could be argued that in many non-certified settings the amount of oversight is more transparent and diversified than it is in a certified setting.

The preponderance of research reviewed in a NCD report – regarding HCBS beneficiary outcomes information -- supports the conclusion that smaller, more dispersed and personalized community settings further integration and positive outcomes" for persons with disabilities. Strong trends are found in the data on the impact of setting size and type for people with intellectual and developmental disabilities and for persons with mental health disabilities. The trends reveal factors such as greater personal choice, satisfaction, housing stability, and higher levels of adaptive behavior and community participation associated with living in residential settings of smaller size.

"HCBS Creating Systems for Success at Home, at Work and in the Community" NCD 2014

HCBS Settings Rules

In January of 2014 CMS, the federal Medicaid oversight agency, published the Home and Community Based Settings (HCBS) rules.[32] The "Settings" rules provide a series of standards that states receiving federal contributions in Waiver funding, which includes Community Habilitation (CommHab), should apply to residences and workplaces. States must also follow the Person-Centered principles of Section 2402 (a) of the Affordable Care Act. The rules are predicated on research based[33] factors that lead to an enhanced Quality of Life for people with I/DD. Community Habilitation which is the HCBS funded service that pays for staffing for most people in non-certified housing is a Waiver service and is subject to these rules.[34] OPWDD's Toolkit for

32 HCBS Settings rules *https://www.govinfo.gov/content/pkg/FR-2014-01-16/pdf/2014-00487.pdf* Retrieved August 2022

33 Long term research on the quality of life for people with I/DD conducted by the National Core Indicators project. See *https://www.nationalcoreindicators.org/* Retrieved August 2022

34 HCBS settings rules are specific in many respects, but contrary to myth the final version does not specify any limits on the number of people who can live in a particular setting.

HCBS settings is a helpful guide for agencies and families should also be familiar with it[35]. What CMS requires is that if a setting has "institutional characteristics" it be subject to "Heightened Scrutiny". OPWDD's Heightened Scrutiny reviewing protocol is available under the heading "Heightened Scrutiny" on the toolkit, although the review function is currently being performed by the State Department of Health, not by OPWDD. More information about what Heightened Scrutiny is and what it isn't is available at the CMS website[36]

Standards for Person-centered Planning and Self-Direction in HCBS programs

In June of 2014 the Secretary of Health and Human Services issued "Standards for Person-Centered Planning and Self-Direction in HCBS Programs" per the Affordable Care Act. These standards require that "Employment and housing in integrated settings must be explored, and planning should be consistent with the person's goals and preferences, including where the person resides, and who they live with."[37]

Funding

Certified ICFs are funded through "State Plan" Medicaid. IRAs are funded through the State's Medicaid Waiver. Historically each resident had an assigned budget, however in the mid 2000's rates were "rolled up" so that the provider agency received one "capitated rate" to cover all of the residences it operated. These rates were based on historical budgets with Cost-of-Living increases annually. Intended to simplify administration this has also had the unintended consequence of making it more difficult for people to leave certified settings for other options. This is because the people most likely to leave non-certified settings are people with moderate needs, while those coming into the certified settings are more likely to have a higher level of need. Because providers have to lobby hard and long to have their rate increased to reflect this increased need, they may be lacking in motivation to help people to move from their certified setting.

People living in **non-Certified** housing typically (but not always) have individual budgets that provide for residential support through the Housing Subsidy, and may also provide for staffing through CommHab. Staff are paid through the Medicaid Waiver funding model. (We will describe Medicaid Waiver in Part 4 of this guide). CommHab regulations require that staff report activity in 15-minute increments. Residents of all types of housing receive Supplemental Security Income (SSI) with those in certified settings receiving enhanced rates through the Congregate Care Supplement.[38] The Congregate Care Supplement that supports a person in a certified setting but not someone with the same needs who is living in a non-certified setting is an example of institutional bias that needs to be addressed. Some people with I/DD receive Social Security Disability Insurance (SSDI) through their own work history or as Childhood Disability Benefit (CDB) from their parents' retirement. Most will receive Supplemental Nutritional Assistance Program (SNAP) funding, and possibly Home Energy Assistance Program (HEAP) funding. All of these funding sources will be examined in Part 4. "How Independent Housing is Funded".

35 OPWDD *https://opwdd.ny.gov/providers/hcbs-settings-toolkit* Retrieved August 2022

36 CMS Website *https://www.medicaid.gov/medicaid/hcbs/downloads/q-and-a-hcb-settings.pdf* Retrieved August 2022

37 *Guidance to HHS Agencies for Implementing Principles of Section 2402(a) of the Affordable Care Act: Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs.* Secretary of Health & Human Services to Heads of Operating Divisions June 6 2014, *https://acl.gov/sites/default/files/programs/2017-03/2402-a-Guidance.pdf* Retrieved July 2020.

38 The CCS for 2022 is available at OPWDD's website *https://opwdd.ny.gov/providers/benefit-development-resource-toolkit-supplemental-security-income* Retrieved July 2022

The Need and Reality of "24/7" Care

The Home and Community Based Services: Creating Systems for Success at Home, at Work and in the Community report looks at the various models and respective outcomes for the persons living in each setting. It is known from research that *"people with disabilities living in smaller settings are more likely to achieve positive outcomes and to experience an improved personal and support-related quality of life"*

It is worth noting the costs involved when different options are available. A term often used when discussing residential options is the provision of "24/7" services; sometimes this includes "1 to 1" support. The term is shorthand used to convey that a person needs a significant level of care, but is a term that should not be taken literally, or implemented lightly. The greatest cost component for LTSS is labor cost. Since 2018 any organization employing more than 11 people in New York City is required to pay a minimum wage of $15 per hour, and the minimum wage throughout the state will gradually increase over the next several years.[39] Including even basic benefits, training and compliance time, supervisory overhead, turnover, and other management time the cost is closer to $20 per hour. One-on-one 24/7 care at $20 per hour would cost $174,720 per person annually. Not everyone needs this level of care. A more typical staffing pattern for a person with a high LTSS need might be sharing staff with two other people and attending a (separately funded) day program or job for six hours daily. The cost of the housing component of such an arrangement would be $20 x 18 hours x 5 days a week and 24 hours for 2 days at weekends for x 52 weeks a year, = $143,520 or ÷3= $47,840 per person. If the person does not require someone to be awake overnight and can be safe and secure as long as there is a Live-In Caregiver (LIC) who is asleep at night but ready to act in any emergency then the cost is further reduced – perhaps 10 hours of housing support (independent of any day work or program) per weekday and 16 hours per weekend shared by three people would cost $85,280 or $28,427 per person. Every hour matters.

It goes without saying that given the demands of the work, all stakeholders need to find ways to improve hiring, training, rewarding and retaining people who work as DSPs. Such demanding work merits greater status. The higher level of skill, the lower the necessary staff ratio, and the more effective the care. At the time of writing efforts to create training and certification for DSPs, and a Standard Occupational Classification are gaining momentum and funding through the American Recovery Plan. Fundamental change is essential if we are to create a skilled sustainable workforce.[40]

Are There Economies of Scale in Larger Settings that Make them more Sustainable?

Costs of housing and other LTSS vary across populations based on many factors - their level of support, where they live, who with, their own resources, their history and their medical needs. Pinning down the relative costs of different living environments is complex and research is not conclusive. It is clear that as people moved from institutions the costs for their personal care declined and the per capita costs of the people remaining in the institution increased due to the static facility costs. Equally true is that as people become more empowered to advocate for their community-based services, they are in some cases seeking higher levels of support. However, it is clear from research and experience that the following seem to be generally true:

39 For changes in minimum wage see https://www.govdocs.com/new-york-state-15-minimum-wage-paid-family-leave/ Retrieved August 2022

40 Visit the NADSP website at https://nadsp.org/ Retrieved August 2022

- When comparing levels of need arrived at using the Developmental Disability Profile (DDP) score, and the budgeting acuity scale of the Individual Service Planning Model (ISPM) it appears that people with moderate levels of support needs may be as well or better served in non-certified settings than in certified settings, although the population in certified settings is likely to be older.
- HCBS services are substantially less expensive than ICF services, evident for all comparisons involving similar person recipients. For HCBS recipients living in congregate settings, expenditures were above average compared to those recipients in non-congregate settings.[41]
- Given the option of directing their own budget themselves or through their advocate, people tend to spend less than the cost of a congregate facility.[42]
- As the number of people living in a house increases past a certain point the number of staff in ancillary roles increases (e.g., cooking and cleaning are no longer DSP or resident tasks) such that past a certain level, costs per capita actually increase rather than shrink. "Diseconomies" of scale begin to take effect.

> **"Size does have some relevance.** As the number of "beds" increases, so does the logistical complexity of providing meals, facilitating transportation, and just getting people up and dressed in the morning, not to mention encouraging individual expression. Managing the daily routine inevitably becomes the priority, regardless of how numerous, qualified, and well-intentioned the staff.
>
> *(attributed to Professor Steve Taylor)*

The Perspective of a Person Living in a Certified Setting or a Non-Certified Setting

The best certified home would feel little different from the best non-certified home for the same number of people. It would feel like a home, not a mini-institution. There are several important differences however:

- A certified home is likely to have more residents. Of people living in certified settings the average number of people living in an ICF is 10 people, with some housing many more. This is often due to pressure from the state to reduce the waiting list and "add one more person". In a Supervised IRA the average is 5.5 residents[43]. We know that the more people living in a setting, the more likely they are to feel loneliness,[44] or experience bullying and a compromised quality of life. In research conducted at Brigham Young University and since replicated it became evident that isolation and loneliness reduce life expectancy.[45]
- A certified home is likely to have more staff who are engaged in support functions such as cleaning and cooking. Non-certified homes will be more likely to have the residents performing a share of the chores.

41 Lakin C. K., Doljanac R., Byun S., Stancliffe J. R., Taub S. & Chiri G. (2008). Factors associated with expenditures for Medicaid Home and Community Based Services (HCBS) and Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) services for persons with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities 46*(3), 200-214. Doi: 10.1352/2008.46:200–214

42 re LTSS via HCBS. AARP meta analysis https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/state-studies-find-hcbs-cost-effective-spotlight-AARP-ppi-ltc.pdf and Cost Efficiency in Medicaid LTSS, the role of HCBS published by NIH 2013 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3710567/ Retrieved August 2022

43 Braddock, D. et al (2017) op.cit. Note that the "State of the States" project is now at the University of Kansas and an update of the report is in preparation at the time of writing. When released the NYHRC will actively disseminate links.

44 National Core Indicators op.cit.

45 Hadfield, J. *Prescription for living longer: Spend less time alone*, BYU News March 2015 https://news.byu.edu/news/prescription-living-longer-spend-less-time-alone Retrieved April 2020

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A certified home may be more likely to have people sharing a room. Of the Family Survey respondents in certified settings 63% shared a room.

A certified home may be governed more by schedule and routine than a non-certified home. The schedule will tend to be built around the shift staffing model. Life is governed by the need to feed, bathe and medicate up to ten people. Travel outside of the setting is limited by the availability of a van and the number of staff available, and it is unable or unlikely to be individualized.

"There is a common assumption that any community integration yields positive benefits on quality of life, however, successful community inclusion is hard to achieve and can be more stressful if not achieved successfully"

Housing support needs of people with I/DD into older age.

https://www.researchgate.net/publication/51522643

Early indications are that staff turnover in smaller settings is not as acute. Nationally, the turnover rate for direct support staff is 45% annually. It is very difficult for people to form relationships with DSPs given this type of turnover. This broken connection to society represents a loss of humanity that is worsened by the very intimate functions that some people need support for. In the more segregated settings, it is unlikely that a person with a high level of need will have contact with anyone who is not paid to provide support, or is likely to be around for long.

The Future of Certified Settings

The "24/7" setting was designed to provide low-risk healthy and safe housing that was better than the institutions it replaced. In many ways it succeeded admirably, there is no comparison between a well-run certified group home and historical institutions. However, the model's success has come at a high cost in loss of liberty, in a controlled and perhaps impoverished quality of life for the residents, and at a high financial cost. What does the future hold? Rahm Emmanuel, former mayor of Chicago, famously said "Never let a good crisis go to waste". While the shortage of housing and the need to transition from certified settings to more non-certified settings are not yet seen as a crisis, a critical mass of factors is driving policy makers and funders to engage with alternatives.

- We know that certified settings are costly and tend to increase isolation and segregation.
- There is a growing body of research that reports that smaller, more integrated settings lead to a better quality of life for the people who are supported.
- Research shows that smaller settings tend to cost less.
- A series of legislative and regulatory measures dating back almost fifty years stresses the need for more independence and choice for people with disabilities, including I/DD.
- Best practices stress that the Ownership of Property be distinct from the Provision of Services. In a situation where the provider of services is also the landlord, a person seeking to find a more suitable living environment may not be able to move from the house because they will lose their support services if they do; their landlord is their only provider.
- The labor force that is prepared to do the hard work of a DSP at the pay offered is shrinking.

- Funds available to the state from federal matching are unlikely to increase; in fact, they are more likely to decrease.
- Most importantly, people who have I/DD and are looking for long-term housing do not want to live in segregated, routinized and highly-regulated group homes.

An established and growing body of research demonstrates that smaller settings are most cost-effective, and that they provide the best option for people with I/DD. This knowledge surely compels all stakeholders to work diligently and urgently to ensure that settings are adapted to fit the needs of people with I/DD. Persisting with settings that are known to be less than appropriate is untenable.

All of these factors are reflected in state policy that is increasingly focused on finding ways to make a finite budget go further, to ensure equity in use of resources, and to access a wider range of housing and staffing options.

In the survey conducted as part of "What Happens When I'm Gone" 54% of respondents checked that they hoped that their family member would "age-in-place" in the certified setting they currently lived in. As people with I/DD now live close to a typical lifespan, issues associated with aging are increasingly pressing. However, there is limited preparation for support for people who need a higher level of support as they age. Most homes do not have fully accessible entrances, bathrooms, bedrooms, or strengthened beams to accommodate Hoyer lifts or stair lifts. In practice people will move to a different location, perhaps one with increased medical care, or to a nursing home.

To learn more about Certified and Non-Certified housing visit the NYHRC website and view "Overview of Housing - Certified and Non-Certified" which was originally shown as part of the "2019 Statewide Learning Institute". *https://youtu.be/wdn9XYBzKHM*

Affordable Housing

"In order to thrive, lower income families need housing in healthy neighborhoods with low crime rates, access to quality education, meaningful job opportunities, and affordable and reliable transportation options". (National Housing Trust)

In addition to the housing available through rental and purchase subsidies from HUD Section 8 and Public Housing agencies through Section 9, there is a wide range of housing created by for-profit and not-for-profit housing developers that people with low incomes and people with disabilities may qualify for. The initiatives that create affordable housing take different forms but their common goal is to increase the supply of quality housing and to sustain communities. This goal might be framed as maintaining economic diversity and permitting people who work in a community to live there – municipal workers, teachers and other essential professions. It might also be to help people who are aging to remain within their communities when they can no longer afford high real estate taxes, or for people with disabilities to remain in familiar and supportive communities. Public policy nowadays seeks to encourage inner-town inner-village density and to reduce sprawl, creating more vibrant downtowns. Affordable housing is an essential element in creating a cohesive community.

The term "Affordable" means that in exchange for agreeing to limit rents and rent increases, the developer has received a financial incentive, typically through Low Income Housing Tax Credits (LIHTCs). From the tenant's perspective, "Affordable" means that they spend no more than 30 percent of their income on housing. Affordability means different prices in different places. Generally, affordable housing vacancies are allocated on the basis of a range of income tiers that reference the Area Median Income (AMI). For example, a development might consist of 100 dwelling units of which 80 are to be rented out at market rates, and 20 set aside to be rented at affordable rates to families earning 50% of AMI.[46] It is important to remember that the properties are allocated to people with *low* income, not *no* income, but people with I/DD who have Supplemental Security Income (SSI) and some earnings and a housing allowance through OPWDD's Housing Subsidy or other means will qualify for the lower income levels. The rents they will pay may be as low as 50% of the market rent for the property, allowing them to live in a decent home and remain part of the community, while making the property more accessible and financially viable for them and for the taxpayer in the event they are receiving a residential subsidy.

To some people "Affordable" might imply that the housing is of poor quality or in an undesirable neighborhood. There is an historical basis for that prejudice, but the world of affordable housing has changed as the breadth of need has changed. In a series of case studies examining ways to create affordable housing[47] the nonprofit organization *Business and Professional People for the Public Interest* highlighted six important observations:

- "Affordable housing can be built in character with the rest of the community
- Affordable housing can be constructed with little public subsidy
- Affordable housing will work in affluent areas
- Affordable housing does not have to be constructed in high rise or dense developments
- Affordable housing can reach a mix of household incomes
- Affordable housing can be built without a decline in real estate values."

46 NY State HCR Publishes a listing of AMI levels by county ranging from 30% AMI to 166%. List is available at *http://www.nyshcr.org/Topics/Home/AHCIncomeLimits.pdf* Retrieved August 2022

47 Affordable Housing How-To Guide. US Dept. of the Treasury/HUD A Community Guide to creating Affordable Housing. *https://home.treasury.gov/system/files/136/Affordable-Housing-How-To-Guide.pdf* Retrieved August 2022

How is Affordable Housing Created?

Government has a long history of intervention in the real estate market. The federal government has provided infrastructure to facilitate development, tax abatements to encourage employment in construction trades, tax deductibility of mortgage interest and other incentives through HUD. Much of the affordable housing creation however takes place at the local level. Local authorities have a range of zoning tools to encourage development. These include "Mandatory Zoning" – requiring that any new development include affordable units, or less formal voluntary guidelines that are negotiated with each new development. Sometimes these "set-asides" rely on the market rate unit sales or rentals to offset the affordable units without public subsidy; sometimes there are direct rental subsidies or property tax incentives. The field requires considerable expertise and experience but there is a mature industry of for-profit and nonprofit development companies that are well-versed in the structuring of incentives, zoning, community needs and preferences and federal and state subsidies. From the perspective of people with I/DD, the question is less about how to create affordable housing and more about how to connect with developers, real estate agents, and nonprofit groups that act as the gatekeepers to affordable housing.

Where to Find Affordable Housing

New York State Housing and Community Renewal (HCR, formerly DHCR) has an interactive website that provides information on available rental housing, "NYHOUSINGSEARCH.gov" *https://housingsearch.hcr.ny.gov/housing/s/*. The site lists properties by city and county, across different sizes and includes developments that have reduced rents as low as 50% AMI. Your Housing Navigator will be familiar with other resources.

As described above, affordable housing is a very local affair. Your community may already have an Affordable Housing Corporation, a Community Land Trust, a Land Bank, a Housing Partnership or a Redevelopment corporation. The municipal or regional administrator of HUD Section 8 programs can be a resource for connecting with developers and property managers of affordable housing.

Supportive Housing

The group home system for people with I/DD that we have now was created in the 1980s and subsequent years in large part by the then newly established Office of Mental Retardation and Developmental Disabilities (OMRDD now OPWDD), the requirements of the Willowbrook Consent Decree, and the advocacy of provider organizations and families. The mid 1970s furor over Willowbrook and other institutions for people with I/DD was happening at the same time that deinstitutionalization was scaling down psychiatric hospitals and mental health institutions. People with mental health needs did not receive the same level of support as people with I/DD. People with mental illness who had been discharged from institutions in the late 70s and the 80s frequently had little discharge planning or support and became homeless, with meager resources to provide for their daily needs or their long-term care. The rapid deinstitutionalization period

coincided with a shrinking of available housing stock and Single Room Occupancy (SRO) hotels in New York City that had formerly been a housing option, but which had degenerated over time. The emergence of Supportive Housing was in response to this desperate need and is itself a triumph of practical advocacy.

To quote the Supportive Housing Network of New York website,[48] "Supportive Housing is just that; *Housing plus support*." Originally created to address the housing needs of older adults it has since evolved as an effective way to address the housing and long-term supports and services needs of a broad range of people. The primary format is for a nonprofit organization to own or control the property, rent the accommodation to tenants at an affordable rate, and to either import services from a separate organization or to provide them themselves. Services include benefit optimization and physical health and mental health care, but they may also include recreation, food services and other support. NY State now has 45,000 units of supportive housing, most of them in New York City.

Housing for people with I/DD from the 1970s until now has developed differently to housing provided to people with mental health disorders, substance abuse disorders, and chronic health conditions including HIV or AIDs. In some ways people with I/DD have been provided for more generously, perhaps because as a result of advocacy and the visible horrors of Willowbrook there was more funding per capita than that provided to some other people with long-term support needs.

Systems tend to categorize people, steering them to the service providers that appear to be the best fit for their primary diagnosis – whether those systems be run by OPWDD, or the Office of Mental Health (OMH), or the Office of Addiction Services & Supports (OASAS). Real people do not fit so neatly into categories. Per the Medicaid Redesign Team Final Utilization report (2017)[49] "The OPWDD Expansion Program serve(d) persons with developmental disabilities (n=51), most of which fall under the ICD-9 category of mental disorders. However, 61% additionally have an active Serious Mental Illness diagnosis. Forty-one percent of this population has a chronic medical condition, and 10% have a substance use disorder. None have HIV. Four percent have a mental health diagnosis, a substance use disorder, and a chronic medical condition in addition to their developmental disability. Only 29% do not have any of these conditions". As a community we have to learn about other housing options that will work for real people with complex needs and supportive housing is a model that is already serving thousands of people effectively and sustainably. This is the case with Affordable Housing. It is a mature industry with professionals who know how to negotiate the system. Families, advocates and I/DD provider agencies would do well to reach out to the Supportive Housing industry, to understand how Supportive Housing can be created, and to collaborate with existing providers.

Shared Living

The term "Shared Living" is used to describe arrangements where a person or persons with a disability live(s) with other people who do not have a disability. Typically, the person without a disability is provided with a lower rental cost or a (possibly tax exempt) stipend in exchange for providing agreed upon supports to the person with a disability. These arrangements can be fostered by a provider agency that assists in finding roommates providing training and back-up

48 http://shnny.org/learn-more/what-is-supportive-housing/ Retrieved August 2022
49 Footnote 52 (current) https://www.helio.health/wp-content/uploads/2018/06/Medicaid-Redesign-Team-Supportive-Housing-Evaluation.pdf Retrieved August 2022

staffing, or they can be negotiated privately. There are many examples of such relationships working extremely well, but to be successful they require significant planning and relationship building. Agencies have adopted some of the funding methods used in Family Care to create shared living environments in which the person or persons with a disability moves in with a person or family. In the event that the relationship doesn't work there needs to be an exit strategy with an alternative home for the person with a disability. If the person with a disability is the homeowner/lessee and the relationship sours they may be required to evict their support person. In some instances, there may be personal risk to living with the support person and the homeowner may even have to leave his or her own home until a solution is found. Shared living has worked in many instances and is used in other states but requires significant scaffolding and planning to be practical. The National Association of State Directors of Developmental Disabilities Services (NASDDDS), the American Network of Community Options and Resources (ANCOR), and the National Association of States United for Aging and Disabilities (NASUAD) have developed a model shared living contract designed to be used as a template by providers entering into certain shared living arrangements.

In 2017 NYSACRA, (now the NY Alliance) developed a "Shared Living Toolkit". It is an invaluable resource that provides detailed guidance on practical steps to Shared Living including information on relevant labor law and practices. To quote from the Shared Living Toolkit (p.5) "There is no single definition of shared living…..Most definitions share common elements:

- Persons with and without disabilities share their lives, especially in their domiciliary arrangements.
- Typically, the person without a disability provides supports to the person with a disability, although the extent and nature of those supports vary widely.
- Shared living is not a "placement" of one person into another's home. It is a mutually agreed upon arrangement.
- Shared living encompasses both persons who live together in the same four walls and those who live quite near to one another (e.g., in adjacent apartments). These are referred to as live-with and live-near support arrangements.

When properly designed and supported, shared living provides an alternative to group living models predicated on shift staffing. Typical staff-client relationships are disrupted and the boundaries between work and personal lives become blurred. As the NASDDDS states, "shared living offers the opportunity for both a close personal relationship and a place to live."

To learn more about Shared living visit the NYHRC website and view the webinar "Shared Living" presented by Christopher Liuzzo as part of the 2019 Statewide Learning Institute"
https://youtu.be/kxQqrEizJoo

Intentional Communities

The language we use when talking about services for people with I/DD frequently refers to "community". "Community-Based services" are seen as superior to Center-Based, or Institutional services. People living in group settings go for outings "in the community", CMS created "Home and Community Based Services", which are carried out by DSPs providing "Community Habilitation". It is a fair bet that every Life Plan in the state includes a goal to spend more time "in the community". While well-intentioned, too often "going into the community" means being shuttled around in a controlled group with little genuine interaction while still being visibly segregated.

What is an Intentional Community?

An Intentional Community "is a group of people coming together in a place they create to live in some particular way."[50] Intentional Communities have been part of our history for many hundreds of years. They include religious and spiritual communities, convents, monasteries and, in modern times, communes, kibbutzim, ecovillages, artist retreats, homesteads, farmsteads and co-housing. In the world of housing for people with I/DD "Shared Living" is also a form of Intentional Community. In 2018 the NY Alliance received funding from the Falco Foundation to create the publication "What Happens When I'm Gone".[51] Pages 38-51 of the publication report on a series of visits to Intentional Communities and observations on the relevance to housing for people with I/DD in New York State. In brief, an Intentional Community would include the following factors:

- An intention
- A core belief in specific values and goals
- An established system of governance
- Clear entry criteria and processes including the choice for each member to remain or to leave the community
- Inclusion at all levels for people with I/DD in making decisions on issues that concern them

What Works?

- **Intention.** Sometimes expressed as a "vision statement" or a "mission statement". Simply put, the key element in sustainability is the core Intention. The Intention needs to be clear and realizable. For example, if a community is to be devoted to self-sufficient farming there need to be members with farming experience, an agreed location, markets, and a strong commitment to work by all involved. Communities that by intent include people with I/DD as part of their mission have an additional challenge.

- **Communal activity.** Well-structured communities have regular get-togethers. Typical Intentional Community meetings include extensive discussion of communal business issues and governance.

- **Work.** Successful communities expect all members to help in providing for the community, whether that be conventional paid work off-site or on-site farming, craftwork, or maintenance. People who choose not to work are essentially choosing not to be part of the community and should leave.

50 Website of Meadowdance *http://www.meadowdance.org/basics.htm* Retrieved August 2022
51 *https://nyhrc.org/resource/what-happens-when-im-gone/* Retrieved August 2022

- **Volunteers and life-sharers.** The communities we met with while preparing "What Happens When I'm Gone" were in some ways conventionally funded IRA or ICF houses with DSP shift work. However, they were able to change the shift-based atmosphere by the infusion of volunteer support. Having more people of all ability levels in the social mix disrupts the supervision culture and replaces it with an easy familiarity and a balance of natural and paid support.

- **Integration.** An Intentional Community does not mean an isolated one. The majority of the successful Intentional Communities we met were also active members of their local communities and represented in civic and social . A healthy Intentional Community is not a place to hide from the world.

What Does Not Work?

- **Being founded just to alleviate housing needs**

Successful communities have a clear idea and articulation of their core tenets - which do not include "there are no other housing options available". Successful communities require commitment from the new member, (not just the new member's parents!) to endorse and willingly accept the community's values and practices and their induction processes identify where such acceptance is present or potentially likely.

- **Failure to adapt to changing society**

The last 40 to 50 years, the age of deinstitutionalization, have seen a transformation in how disability is seen by people with disabilities and by society in general. Disability rights advocates have been able to bring about anti-discrimination legislation, increase accessibility and reduce social stigma associated with disability. People with I/DD expect to be treated without condescension as peers of the people they live with. They want to be self-determined and have choice as to where they live and with whom they live. Sometimes this is different to the direction their parents or family members might be intending for them. In its publication "There's No Place Like Home" the National ARC noted that 87% of the family members whose relative with I/DD lived in a planned community or campus *where only people with I/DD live* were happy with where their loved one lived. By contrast only 16% of the people with I/DD who were surveyed and who lived in planned communities wanted to remain there.[52]

- **Failure to adapt to new funding**

Since the introduction of Money Follows the Person (MFP) funding in 2005 public funding has begun to gradually shift from the agency provider model to individualized budget control with the agency acting more as a vendor than a provider. Long standing communities have adapted to varying degrees to this change and have had to develop financial sophistication to match the new diversity of funding sources.

52 "There's no place like Home" CQL and the Arc *https://www.c-q-l.org/resources/guides/theres-no-place-like-home-a-national-housing-study/* table 6b Retrieved August 2022

Why are Public Funding Sources Wary of Intentional Communities?

The state is not averse to Intentional Communities in principle

Depending on the experience of each Regional office and other variables New York State has been supportive of different shared living arrangements for many years and has been receptive to expansion of small scale urban single residence settings. However, the state is also clear that it does not wish to support any new large-scale settings.

Regulation & Funding

Public service regulators are bound by what they are permitted to fund and by the need to avoid risk, especially anything that will create political pressure. The HCBS Settings rules do not permit waiver funding in settings "that have the effect of isolating persons receiving Medicaid-funded HCBS from the broader community of persons not receiving Medicaid-funded HCBS"[53].

History

New York's institutional history, chronicled so thoroughly in Paul Castellani's "From Snake Pits to Cash Cows"[54] is shameful. Institutions that were created with the best of intentions such as the "model" self-sufficient agricultural community of Letchworth Village in Rockland County, founded in 1911, deteriorated into the "Snake Pits" that Robert F. Kennedy described after his visit to Willowbrook in 1965. Advocates for people with disabilities, including self-advocates, sued the state to end the terrible abuses occurring in the institutions. Every aspect of services for people with I/DD in New York is infused with the history of Willowbrook, Letchworth, Rome, and the twenty or so institutions that at one time warehoused tens of thousands of people. The Office of Mental Retardation and Developmental Disability, (OMRDD), now OPWDD, was created as a direct result of the institutional scandals and essentially charged with ensuring that such conditions were eliminated and never happened again. OPWDD staff are deeply imbued with the historical perspective that large-scale settings inevitably lead to isolation, neglect and abuse, and they will not tolerate the potential for that to happen on their watch.

The Precautionary Principle

The precautionary principle is used by public funding agencies to provide a basis for financial decisions when they have evidence of best practice. Its purpose is to "protect the public from exposure to harm, when scientific investigation has found a plausible risk. These protections can be relaxed only if further scientific findings emerge that provide sound evidence that no harm will result."[55] As noted above there is a substantial body of research that demonstrates that smaller more integrated settings generally lead to an improved quality of life and sense of fulfillment for people with I/DD.[56]

53 Summary of key provisions of the HCBS settings rule Op.Cit
54 Castellani, P.J. (2005). *From Snake Pits to Cash Cows*. Albany, NY: SUNY Press.
55 From The Precautionary Principle website https://eur-lex.europa.eu/EN/legal-content/summary/the-precautionary-principle.html Retrieved May 2018
56 National Council on Disability meta Study "HCBS Creating systems for success at home at work and in the community" https://ncd.gov/publications/2015/02242015 Retrieved August 2022

4.1 Public Benefits Based on Income and Disability

In this section we describe public benefits that are available to people with low incomes and/or to people with a disability, but not specifically I/DD. We include Supplementary Security Income (SSI), Social Security Disability Insurance, (SSDI), Childhood Disability Benefit (CDB), Medicaid, 1619 b, Medicare, Vocational Services, SNAP (Food Stamps) HEAP, WAP and Transportation Services.

Independent housing requires an understanding of what resources a person might already have. We begin by determining the federal and state supports and services for which a person may be eligible, and what they need to do to obtain those services.

While still in high school a student is entitled to receive Transition Planning Services[57], and these should include plans to become qualified wherever they are eligible for the adult services and opportunities listed below. Too often transition planning does not focus on Long Term Supports & Services needs, including housing. People with I/DD and their families should insist that all Transition Planning include a comprehensive review of all the benefits we describe, and, if necessary, the services of a qualified benefit planner.

Whereas children and young adults under the age of 21 are entitled to a Free and Appropriate Education, services for adults over the age of 18 are based on a person being eligible. Eligibility criteria vary from one state to another and within states from one agency to another, and the fact that a person is deemed eligible does not necessarily guarantee that services will be provided.

The first step in the application process is to apply for **Supplemental Security Income (SSI).** SSI pays benefits to adults and children with disabilities who have limited income and resources. The Social Security Administration (SSA) focuses on a person's ability to be self-supporting. To qualify for SSI, the person must be a U.S. citizen, or qualify under certain non-citizen classifications.[58] the person must demonstrate that they are unable to achieve "Substantial Gainful Activity" (SGA). In 2022 SGA is set at $1,350 income per month[59], by virtue of a disability, and that the disability is expected to last for one year or more. In addition, a person maybe eligible for SSI if they are at least 65 years old, blind, or have a disability, and have limited income and resources. If the application is for a minor child, family income is taken into consideration. For people over the age of 18, their personal income is the only one considered. In order to qualify, a person may not have assets in excess of $2,000, although there are several opportunities described later in this Guide to preserve savings at a much higher level.

The Person should contact their local Social Security field office to apply. In most cases family physician reports will be sufficient to establish the disability need. In most states a person receiving SSI automatically qualifies for Medicaid; in 11 states the application follows SSA guidelines but is separate and in seven states the state's own criteria apply.[60]

57 NYS Ed Law requires transition planning begin at the IEP preceding 15th year. Federal IDEA requires at beginning of 16th year.
58 See "SSI for non-citizens" *https://www.ssa.gov/pubs/EN-05-11051.pdf* Retrieved November 2022
59 To confirm the SGA visit SSA website. *http://www.socialsecurity.gov/oact/cola/sga.html* Retrieved March 2020
60 To learn the rules in your State go to *https://www.ssa.gov/disabilityresearch/wi/medicaid.htm*. Retrieved March 2020

4 How Independent Housing is Funded

In addition to the Federal Benefit Rate (FBR) most states provide an additional State Supplement, which may vary depending on where the person lives and with whom they live. A person can apply for SSI by phone or in person and he or she may have assistance from a family member or other representative. For more information about how to apply, go to the Social Security website at *http://www.ssa.gov/ssi/text-apply-ussi.htm*. SSI is intended to provide for basic food and shelter and as such should not be used for other purposes. If support for food and housing is received from other sources, what Social Security terms "In-Kind Support and Maintenance" it may affect a person's SSI.

In New York State a person receiving SSI automatically qualifies for Medicaid. New York State Office of Temporary Disability Assistance (OTDA) supplements the Federal Benefit Rate (FBR) at different rates depending on where someone lives and whether they live with others. For example, a person living alone might receive $87 state supplement in 2021, whereas the agency operating a certified setting might receive between $400 and $700 in addition to the FBR. The OTDA also stipulates how much of the SSI payment must be set aside as a "Personal Allowance" for the person with I/DD. The different state supplement rates are available at: *https://otda.ny.gov/programs/ssp/*

It is essential that the housing planning process include a qualified Benefit Adviser whenever possible to ensure that a person receives the optimal amount of public benefits to which they are entitled or for which they are eligible, while incentivizing employment and other sources of support as much as possible. Your Housing Navigator will also be informed on the different benefits and pitfalls to avoid.

SSI may be paid to the person directly, or to someone they designate as their **Representative Payee**, usually a parent or relative. The "Rep Payee" acts to ensure that the Social Security payments are spent appropriately and that the funds are accounted for annually in the Representative Payee report provided to the SSA.

When a person resides in Congregate Care, the Provider agency generally becomes the Representative Payee. This is technically at the person's option, but agencies might pressure a person to have them become rep payee. The person with I/DD receives a modest allowance, reset annually by Social Services legislation, for personal expenditures, administered from their SSI by the Provider agency.

It is possible to work while receiving SSI. Social Security exempts the first $65 of a person's earnings for consideration in calculating their SSI benefit. Thereafter, for every $1 they earn through employment, they will lose 50 cents of their SSI. When their earnings reach the Break-Even Point, (BEP), i.e., where their SSI is reduced to zero, they will no longer receive SSI but may still retain eligibility for Medicaid. (See 1619(b) below)

A person may also qualify for **Social Security Disability Income (SSDI).** SSDI is an insurance program funded through payroll withholdings so it requires that a person has worked for pay and made at least the minimum monthly contribution to the insurance fund over a specified time. That time is measured in "units" or quarters, the number of which will vary according to the person's age. A

person may also be eligible for SSDI if they have a parent (or in some circumstances a grandparent) who is retired or deceased and who paid into the fund. This is known as "Childhood Disability benefit" or CDB (formerly known as "Disabled Adult Child" payment). The amount of CDB a person receives is based on the parent's "Primary Insurance Amount"[61] (PIA) which is determined by the parent's Full Retirement Age (FRA)[62]. While the parent is alive their child will receive an amount equal to half the amount of the parent's PIA. When the parent dies, that amount will increase to three-quarters of the parent's PIA. SSDI payments, including CDB, are considered when calculating SSI. Once SSDI reaches a certain threshold it may reduce SSI to zero and potentially affect continuance of Medicaid, so people with I/DD and their service coordinators need to monitor the SSDI level. Parents can find out what their retirement income will be by creating a "My Social Security" account on the Social Security Administration website[63]. This will help them to predict what their son or daughter's CDB will be.

1619(b) and Medicaid Continuation

Even if the person's SSI is reduced to zero as a result of their SSDI being increased or by their income from employment it does not have to result in the loss of Medicaid. Under regulation 1619(b) a person who has been an SSI recipient can continue to be eligible for Medicaid. Some states permit people to continue to receive Medicaid even if they exceed the state's eligibility threshold by allowing them to "Buy-In" to Medicaid.

SSDI by itself does not qualify persons for Medicaid, but once they have been receiving it for 24 months, they will be eligible for Medicare. Medicare is the federal health insurance program that provides access to health care for people with disabilities. While people with I/DD may be enrolled in Medicare it is a medical insurance policy and is not directly involved in housing. People who receive both Medicare and Medicaid are sometimes referred to as "Dually Eligible" or "Duals".

In New York State a person may continue to receive Medicaid if their income exceeds SGA.

"to qualify for the Medicaid Buy–In program for Working People with Disabilities you must:

- Be a resident of New York State;
- Be at least 16 years of age (coverage up to 65 years of age);
- Have a disability as defined by the Social Security Administration;
- Be engaged in paid work (includes part–time and full–time work);
- Have a gross income that may be as high as $68,988 for an individual and $92,950 for a couple; and
- Have non–exempt resources that do not exceed the MBI–WPD resource level of $20,000 for a one–person household and $30,000 for a two–person household."

https://www.health.ny.gov/health_care/medicaid/program/buy_in/
(Retrieved July 2022)

61 Primary Insurance Amount or PIA, the benefit (before rounding down to next lower whole dollar) a person would receive if he/she elects to begin receiving retirement benefits at his/her normal retirement age. At this age, the benefit is neither reduced for early retirement nor increased for delayed retirement *https://www.ssa.gov/OACT/COLA/piaformula.html* Retrieved August 2022

62 Full Retirement Age varies with the age of the beneficiary. See SSA *https://www.ssa.gov/planners/retire/retirechart.html* Retrieved August 2022

63 Social Security website *https://www.ssa.gov/myaccount/?gclid=CjwKCAjwnIr1BRAWEiwA6GpwNQEmmhyEfbLO1mMnOJZhHGQ6IUnpOHr4_NHq5SG91BfR4h9mHkMwRhoCfo4QAvD_BwE* Retrieved August 2022

(i) Medicaid is a health insurance program for people with disabilities, as well as senior citizens and people with low incomes. Medicaid is a federal program administered by the states. Funding is at least 50% from federal sources, with the balance being paid by the state. States with higher rates of poverty may receive as much as 75% federal contribution. States have to administer Medicaid funded programs in adherence to guidelines agreed to with the federal Centers for Medicare and Medicaid Services (CMS). Medicaid is rooted in a "medical model" that views disability as a deficit to be assessed, treated and prescribed for. As such Medicaid funding brings a welter of rules and regulations that have accumulated over the decades and may inhibit best practices. Medicaid is the primary foundation of funding for Long Term Supports & Services (LTSS).

(ii) Medicaid Waiver States may negotiate with CMS to be permitted to "waive" certain elements of the Social Security Act, to allow them more flexibility in delivering Medicaid funded services. These generally fall under the mantle of a **"Home and Community Based Services" (HCBS)**[64] Waiver. HCBS waivers allow for funding to be directed to the person's need rather than to an agency program, and their introduction in 1981 was intended to increase opportunities for personalized services.

Under the waiver, CMS requires that Medicaid Waiver programs be more person-centered and personalized.

a. Waivers should encourage **Self-Direction.**
b. Waivers should include **Person-Centered Planning.**
c. Every participant should have **a Person-Centered service plan (In New York that is now the Life Plan, formerly the Individual Service Plan or ISP).**[65]
d. Every participant should have a Personalized Budget, and a **Personal Resource Account (PRA).**
e. The state must provide Information and Assistance in support of **Self-Direction.**
f. The state must monitor for **Quality Assurance** and improvement.

Observance of these stipulations varies from state to state but it is important for people with I/DD and their families to insist that the state and its providers adhere to the federal requirements in spirit as well as in letter.

Employment and Rehabilitation Services

The Rehabilitation Act of 1973 "authorizes the formula grant programs of vocational rehabilitation, supported employment, and client assistance. It also authorizes a variety of training and service discretionary grants administered by the U.S. Department of Education. The Act also includes a variety of provisions focused on rights, advocacy and protections for persons with disabilities".[66] This act includes section 504, (the source of "504 plans"). Depending on the state these services may be delivered by a stand-alone agency or through the education system.

(iii) Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR) OPWDD is the principal agency serving people with I/DD in the state, and as such, provides

64 HCBS services were created in 1981 but were not taken up in NY until 1992.
65 *https://www.medicaid.gov/sites/default/files/2019-12/1915c-fact-sheet_0.pdf* Retrieved October 2022
66 From U.S. Department of Labor *https://www.dol.gov/agencies/eta/disability/laws* Retrieved August 2022

employment-related support to people with I/DD who need significant support. People who aspire to paid employment should also seek support from ACCES-VR. ACCES-VR work training and support services can be applied for directly from the regional office, and the application process should begin when a student enters the last year of high school. The application should be included in the student's Transition Plan and school counselors should connect the student with the ACCES-VR process.

(iv) Supplemental Nutrition Assistance Program (SNAP). Administered by the US Department of Agriculture through state agencies. In New York those are the New York Office of Temporary and Disability Assistance, (OTDA) through local Department of Social Services offices and in New York City, the Department of Social Services Human Resource Administration. Previously and colloquially known as "Food Stamps", this is a federal program originally created in the 1930s to support farmers while feeding the hungry cities. It was put in place permanently in 1964 and is renewed annually as part of the Farm Bill. SNAP can only be used to purchase household foods, and may not be used to purchase prepared foods or household supplies. It can also be used at participating farmers' markets and Community Supported Agriculture (CSA) cooperatives. SNAP eligibility is determined by the income of a household, currently set at or less than 130% of the Federal Poverty Level (FPL) which will vary with the number of people in a household [67] and must be renewed annually. States may enforce or waive work requirements, and resource requirements will vary from state to state. Most states have moved from issuing actual stamps in favor of Electronic Benefit Transfer or EBT.

(v) In New York State SNAP is administered by local Social Security offices but you can apply for SNAP online through the *myBenefits* website. *https://mybenefits.ny.gov/mybenefits/begin* Retrieved August 2022

(vi) Low Income Home Energy Assistance Program (HEAP). HEAP was created in 1980 to help families facing rising fuel bills. The program, administered federally by the Health and Human Services administration (HHS), is renewed annually by Congress and funds are allocated to the states for their distribution. Eligibility is based on FPL and state median income guidelines. Funding is released annually and generally is only available on a first-come-first served basis.

In New York HEAP is applied for in the same way as SNAP, through the *myBenefits*[68] website. Funds are released in November so applications should be made in a timely manner HEAP can also be applied for through certain energy providers -for example Con Edison in New York City. *https://www.needhelppayingbills.com/html/consolidated_edison_bills___lo.html#:~:text=Dial%201%2D800%2D293%2D,disabled%20keep%20their%20heat%20on.* Retrieved August 2022

(vii) Weatherization Assistance Program (WAP) WAP was created in 1976 to increase energy efficiency in the homes of people with low incomes. Overseen by the Department of Energy, as with HEAP the program is funded by Congress annually and eligibility is based on the FPL. WAP teams audit a property for energy efficiency and install weatherization measures to reduce energy consumption.

In New York WAP can be applied for through the *myBenefits* website. Funds are limited and are applied on a first-come first-served basis.

67 For federal poverty guidelines check *https://aspe.hhs.gov/poverty-guidelines* Retrieved August 2022
68 *https://www.mybenefits.ny.gov/mybenefits/begin* Retrieved January 2021

Transportation

The Americans with Disabilities Act of 1990 prohibited discrimination on the basis of disability, including in the availability and accessibility of transportation. The ADA "requires public transit agencies that provide fixed-route service to provide "complementary paratransit" service to people with disabilities who cannot use the fixed-route bus or rail service because of a disability. The ADA regulations specifically define a population of customers who are entitled to this service as a civil right. The regulations also define minimum service characteristics that must be met for this service to be considered equivalent to the fixed-rate service it is intended to complement".[69] In most states provision of paratransit is devolved to the local level depending on the transportation authority,

It is an unfortunate fact that 30 years after the passage of ADA compliance is still far from complete. Many rural counties have no public transportation and therefore no obligation to provide paratransit. In urban settings accessibility remains an issue; for example only a quarter of New York City subway stations are accessible.

In New York State paratransit is typically provided on a county level. Fares are based on the fares in the broader system, and depending on the needs of the person with a disability and the local authority the ride may be from door-to-door or to points on the bus routes. Application is made locally and requires proof of disability and often an in-person assessment. *https://nyconnects.ny.gov/consumersite/index.php* NY City has a city-wide system, "Access A Ride" that uses private contractors. *https://access.nyc.gov/programs/access-a-ride/.* (both retrieved August 2022)

ConEd CONCERN. The Concern program covers billing options, third party notification, and other services. Con Ed also has a **"Low Income Rate,"** where the account holder can receive a discount on the monthly Basic Service. The discount can range from $7 - $12 per month. The **Energy Share** program is a grant up to $200, which works in tandem with HEAP. This program is only to be used in an emergency; it requires that the customer has an active "disconnect notice", and it can only be used once every 5 years.[70] These programs are available to those receiving SSI/Medicaid. The application process begins in mid-January, and is the responsibility of the person.

PSEG has Residential Energy Affordability Partnership (REAP). Representatives will come in and perform energy efficiency surveys and provide light bulbs and possibly replace appliances. *https://www.psegliny.com/myaccount/customersupport/financialassistance/reap*

National Grid *https://www.nationalgridus.com/media/pdfs/billing-payments/cm6862-energy-affordability_li-282729-28329.pdf* (both retrieved August 2022)

LifeLine This is a basic phone service which is supported by the Federal Communications Commission, and by the Universal Service Fund. The program provides discounts on monthly telephone service (landline or wireless) for people with low incomes. Income levels need to be below 135% of the FPL, (=$18,346 for 1 person in 2022) and only one LifeLine is available per household. The application may take up to 90 days to process for approval and it must be renewed annually.

69 ADA & Paratransit NADTC *https://www.nadtc.org/about/transportation-aging-disability/ada-and-paratransit/* Retrieved March 2020

70 *https://www.coned.com/en/accounts-billing/payment-plans-assistance/special-services*

Advocacy

The low Income and disability benefits in this section are administered by a wide range of federal agencies including Social Security, the Departments of Education, Health and Human Services, Energy, Agriculture and Transportation - their state counterparts may be just as diverse. It is important to keep this diversity of funding and legislation in mind when working to ensure continuation of existing benefits and advocating for system changes.

For a summary of Benefits view the webinar originally created for the 2020 Statewide Learning Institute "IDD & Optimal benefits" at *https://youtu.be/JO4xanmSaDc*

4.2 Public Benefits Specifically for people with I/DD

In this section we review public funding support that is specifically for people with disabilities and in particular for people with I/DD.

Medicaid Waiver, discussed above, is the primary means by which states pay for staffing. These services will typically be divided between those provided during the day – for example habilitation, work readiness etc. and those provided in the person's home or licensed residence. The most frequently accessed Waivers are 1915 and 1115 waivers and you should identify which waiver or waivers your state is using, whether they include Self-Directed services, and how they affect you.

States may also provide other options including rental supplements, non-Medicaid respite, Information and Referral, and in-home supports

Support for people with I/DD in New York State

The first step is to apply to the **Office for People With Developmental Disabilities (OPWDD)**. OPWDD is responsible for coordinating services for New Yorkers with developmental disabilities, including intellectual disabilities, cerebral palsy, Down syndrome, Autism Spectrum Disorders, and other neurological impairments. The person should apply to one of the five Developmental Disabilities Regional Offices (DDROs)

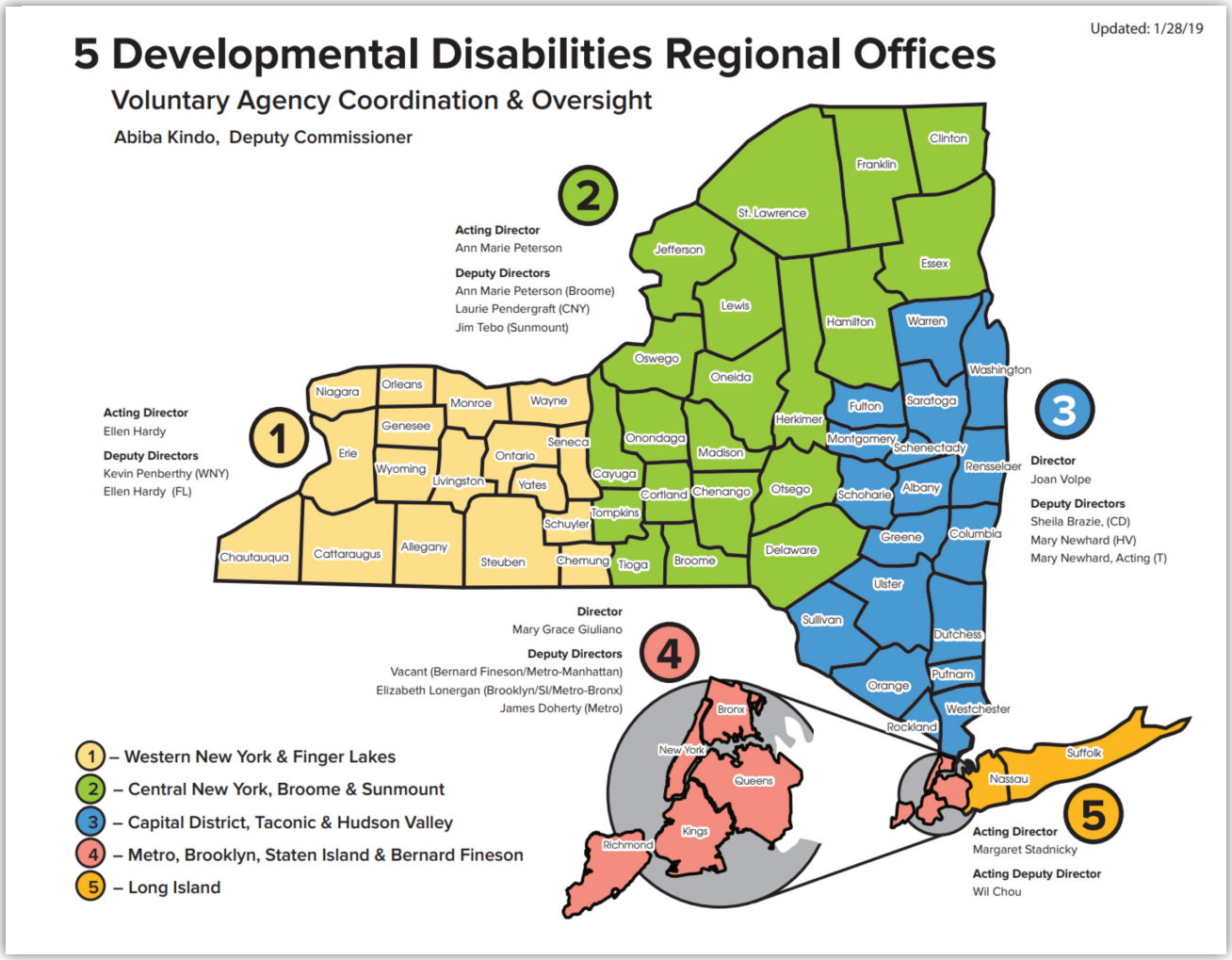
Once deemed eligible by OPWDD, the current route to obtain services is through the **"Front Door"** process,[71] which is handled directly by the DDRO. The Front Door and all aspects of planning are governed by OPWDD's **Individualized Community Supports (ICS)** philosophy, which stresses self-direction and choice.

The Front Door process includes an assessment of a person's needs, which is intended to guide the services that will be provided and the budget associated with those services. Since the 1980's NY State has used an assessment instrument called the residential **Developmental Disabilities Profile 2 (DDP2)**.[72] The DDP2 generates a score across three domains: Adaptive, Behavioral and Health. These scores are used to generate a budget and **Personal Resource Account (PRA).** The algorithm used to generate the PRA is not transparent. The DDP2 also generates an **Individual Service Planning Model (ISPM)** score on a scale of 1 to 6 with 6 being the highest level of need. This is used to help determine a person's level of budgeted services. The DDP2 instrument was revolutionary when introduced as a post-institutional model in the 1980's, but it is deficit-based and implicitly incentivizes applicants to highlight their disabilities in order to achieve a high level of services and a larger budget. New York State is now introducing the **Coordinated Assessment System (CAS)**. This is the OPWDD version of an instrument used across the Department of Health subsidiary agencies which seeks to gather data that may help to rationalize and report on services. The instrument [73] seeks to identify a person's functional needs for support rather

71 Refer to OPWDD Front Door site. *https://opwdd.ny.gov/get-started/front-door* Retrieved August 2022

72 Medicaid requires that states implement a Preadmission Screening and Resident Review (PASRR). The move to CAS is required to maintain compliance. Medicaid's 2014 report on PASRR described the existing processes as inadequate in much of the country.

73 The CAS is based on the "Inter RAI". For more information see their website *https://www.interrai.org/* Retrieved November 2022



than to simply highlight their deficits. Functional need connects to the eventual development of a budget and PRA. The PRA is critical to developing a service plan, and is based on the principle that **"Money Follows the Person" (MFP).**

The principle that funding for a person's services should be "attached" to the person ,instead of the agency that provides services, was enshrined in the Supreme Court's Olmstead decision in 1999 in a suit brought under the Americans with Disabilities Act (ADA). The court ruled that as long as health and safety were assured, a person could require that services be delivered in a milieu of their own choosing, as long as the costs of the new setting did not exceed those of the institutional setting in which they had previously been. Six years later, under the Omnibus Budget Reconciliation Act of 2005, President George W. Bush signed the principle into law affirming that wherever possible money for services and supports should "Follow the Person". This change in how services are controlled, funded and delivered is the most significant change in policy and practice since the deinstitutionalization of the 1970's; while it is only slowly being implemented it has far-reaching consequences for all stakeholders.

Eligibility for OPWDD services is narrowly defined; a person must test as having an I.Q. of 60 or lower - or must have significant adaptive needs if their I.Q. is higher than 60. As OPWDD services have become more expensive, eligibility criteria have narrowed. A significant population of people with I/DD who need LTSS risk being shut-out unless the state can adapt the ways in which services are delivered to be more flexible and personalized to support a spectrum of need.

If a person is approved by OPWDD for its services at the Front Door they should apply for Medicaid. If they are a recipient of SSI, they are already Medicaid eligible. If they do not already have Medicaid, they should apply through the New York State Department of Health website [74] which also has links to Medicaid Navigation services[75].

The next step is to apply for Medicaid Waiver, again through the DDRO. Once approved the person will be offered a choice of Care Coordination organization from which to select a Care Manager. There are currently seven Care Coordination Organizations (CCOs) in the state, but not all seven are represented in each of the five regions. At the time of writing two are, effectively, merging. In choosing a CCO the person should follow the same due diligence as they would with choosing a Provider Agency. The Care Manager is responsible for ensuring that the person receives the state and Medicaid services to which they are entitled or eligible.

Self-Direction Two critical concepts that are fundamental to personal choice and to which the federal and state funding agencies refer frequently are Self-Direction (SD) and the Circle of Support. (OPWDD recently adopted the term "Planning Team" as part of the Self-Directed services process, but we prefer to continue to use the term of art, "Circle of Support" in the context of housing). As discussed in the section on Person-Centered Planning, while the Circle of Support is involved in planning it is also designed to be part of the person's life for years to come, to be adaptable to change and to advocate for the person.

Self-Directed Services The term "Self-Directed" is used by the CMS to mean that "participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process."[76]

For SD a person must apply through the Front Door, where the DDRO will assess whether they would be best served by the Self-Directed model. If a person is approved for SD the DDRO will provide them with a list of brokers. The Start Up broker will help them and their Circle of Support to create a Person-Centered Plan and budget for the services they need, including residential support. Under SD the Care Manager (CM) must be a member of the Circle of Support, and cannot simultaneously function as a broker and a CM. Care Coordination Organizations (CCOs) were in part established to eliminate the conflict of interest that formerly arose when an agency providing service coordination was also the agency providing services. Once the budget has been approved by the DDRO and by the Division of Budget in Albany, the broker will either continue to work with the person as their Support Broker or alternatively forward the brokerage role to another Support Broker, who will work with the person to implement and sustain the plan. Under SD people may choose to obtain services from a provider agency, or, subject to certain restrictions and requirements, hire someone they select themselves. This is known as self-hire. Services that are not directly purchased from an agency are paid for through an OPWDD approved **Fiscal Intermediary (FI)**, formerly known as Financial Management Service agency or

74 Apply through the NY DOH site *https://nystateofhealth.ny.gov/* Retrieved August 2022
75 Navigator links at *https://info.nystateofhealth.ny.gov/IPANavigatorSiteLocations*. Retrieved August 2022
76 CMS Website *https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.htmll*. Retrieved August 2022

FMS, which acts as the employer of record for any self-hires. The first iteration of Self-Direction was the "Self Determination Project" funded by the Robert Wood Johnson Foundation in 1995 out of which NY State's "Consolidated Supports and Services" (CSS) was created in 2002, so this is nothing new. SD evolved from CSS in 2009 but there are frequent operational changes as the system evolves. These changes can be frustrating to all involved, but the principle behind SD - Money Follows the Person - is essential to realizing housing independence, and Self-Direction - sometimes coupled with the Housing Subsidy Program, formerly known as "Individual Supports & Services" or ISS, is the current mechanism within OPWDD services that is built around that principle.

The Role of the Circle of Support

At this point It is vital that the person and their Circle of Support become informed on the service options available to them and take the opportunity to do at least some preliminary planning. Consider the person's occupation; day services range from full time "Day Habilitation" to full time employment and variations in between. What do they do with their day – what would they like to do with their day outside of programming or employment? Consider where they will live; In terms of housing plans the person should be thinking about the level of support they will need, where they want to live, and whether they will want or need to live with other people. An important fork in the road is deciding whether to pursue certified housing or non-certified housing and whether to pursue Agency based services or Self-Directed services, bearing in mind that there can be considerable interaction between the two. The Care Manager should participate in the discussion and can provide information as to what services are likely to be available.

"I AM" or "PATHS" and the Life Plan. The Care Manager meets with the person and their representatives and administers an assessment tool known as the "I AM". The purpose of the I AM tool is to create a Life Plan intended to reflect a person's needs and wishes through a menu of "Valued Outcomes" that can be related to available and billable services. At some point in the future this process will develop a budgeted Personal Resource Account; however, at this time the budget is still based on the DDP2 and the ISPM score.

OPWDD's new website includes a helpful guide to OPWDD services "Front Door" which gives a broad overview of some of the housing options.

To learn more about how to optimize Social Security benefits visit NYHRC's website and view "Income and Eligibility. Optimization" presented by John Maltby as part of the "Statewide Learning Institute" in 2019

https://register.gotowebinar.com/recording/1581138804753288450

4.3 Income from Employment and How to Preserve Savings

In this section we discuss how to be employed but still receive necessary benefits and supports, as well as how to save and receive support from non-governmental sources.

Employment

As described by the US Department of Labor, **"Employment First"** "is a concept to facilitate the full inclusion of people with the most significant disabilities in the workplace and community. Under the Employment First approach, community-based, integrated employment is the first option for employment services for youth and adults with significant disabilities."[77] Since 2012, New York State has been an Employment First state, and its principles have been adopted by OPWDD.

In the past a person with I/DD might have been directed automatically towards a day program of segregated enclave work in Day Habilitation. They may have worked in a Sheltered Workshop for wages or received Supported Employment (SEMP) services or the Employment Training Program (ETP) funded through OPWDD. As part of OPWDD's Transformation Agreement with CMS, Sheltered Workshops are closing. Day Habilitation services will be encouraged to be "without walls," not center-based, and to increasingly emphasize Pathways to Employment, a new program with the goal of paid work for as many people as can achieve it. This major social, cultural and financial transition will take many years. Its impact will be that people with I/DD who in the past were not expected to earn their own money will now be more able to do so without affecting their necessary services.

Protecting Earnings

There is a persistent myth that when a person goes to work, they lose their benefits. This is not true. Social Security legislation encourages work. When a person begins employment the first $65 of their earnings is exempted from consideration when calculating their countable income, i.e., the amount that Social Security attributes to employment and any unearned income other than the General Exemption for Unearned Income of $20. Thereafter every dollar they earn will result in a loss of 50 cents from their SSI. As the person earns more their SSI will diminish but this is because their overall income is increasing. At the Break-Even Point (BEP), currently $23,292 in NY State in 2022, their SSI will have been reduced to zero.

As previously discussed, even if a person's SSI is reduced to zero because of their earnings they are likely to remain eligible for Medicaid through Social Security's 1619 (a) or 1619 (b) Continued Medicaid Eligibility. In New York State they will remain eligible until their earnings reach $50,534 (in 2022) and may be able to "buy-in" up to an income of $64,836 for a single person.[78]

If this seems complicated, it is. It is vital to consult with a Benefit Advisor or Housing Navigator versed in benefit optimization as a person's resources begin to increase. Benefit Advisement is a service offered through OPWDD and/or ACCES-VR funded agencies such as Independent Living Centers or through private fees to agencies that provide this service

Social Security Administration (SSA) programs such as Impairment Related Work Expenses **(IRWEs)**[79] and Plans for Achieving Self Support **(PASS plans)**[80] are designed to help people get a foothold in the

77 Employment First at the US. Department of Labor. *http://www.dol.gov/odep/topics/EmploymentFirst.htm* Retrieved August 2022

78 *https://www.health.ny.gov/health_care/medicaid/program/buy_in/working_people_with_disabilities.htm* Retrieved August 2022

79 Impairment Related Work Expense. See Social Security website *https://secure.ssa.gov/poms.nsf/lnx/0410520001* Retrieved August 2022

80 PASS Plans see Social Security website *https://www.ssa.gov/disabilityresearch/wi/pass.htm* Retrieved August 2022 and "PASS Online" from Cornell University *http://www.passonline.org/* Retrieved August 2022

workplace by agreeing to exclude an agreed upon amount of earned income from consideration of their countable income for SSI purposes. An IRWE can be claimed when a person with a disability pays for the support themselves, said support is related to an impairment, and the person would not be able to work without it. Eligible support includes Supported Employment, work related equipment, transportation and certain medical costs. A PASS plan is a work incentive that allows income or assets to be used to achieve work-related goals. Under an approved PASS plan income or resources will not count when determining eligibility for SSI.

For people living in public housing the department of Housing and Urban Development (HUD) provides support through the **Earned Income Disregard (EID)**[81] which reduces and defers the impact on rent cost of a person going to work.

The Social Security Administration (SSA) also discounts earnings for people receiving SSDI who are deemed to be covered under **"Subsidies"** and **"Special Conditions".** These may occur if an employer is paying an employee with a disability the same wages as someone else who is doing the same work but producing a greater output for example, or for someone who is receiving job support either paid for by an agency or from natural support[82]. This would include people working in Supported Employment (SEMP) or in an Employment Training Program (ETP).

Earned Income Tax credit (EITC)[83]

(i) The IRS program provides a cash payment to people with Extremely Low Income (ELI)[84] who file tax returns. Intended to support working families, benefits are modest for single working adults, but can make a difference of up to several hundred dollars for a person working at minimum wage.

(ii) Credit and Credit Score As with anyone else who will be purchasing or renting a home, the lender or landlord will want to see if a person is creditworthy. The lenders will look at income, whether from an entitlement, a trust, or from work. They will also look to see if there is a sound history of paying back any credit owed and that the person is reliable with bills and obligations. There are companies that track personal credit history and it is important to have developed and demonstrated a good credit history if a person wants to obtain a mortgage or other financing.

Obtaining a "Secured Credit Card" or being an "Authorized User" on another person's such as a parent or guardian's credit card, and having a history of making regular payments (e.g., rent) are all ways that a person's credit usage can contribute to building a credit history. It can take one or more years of payment history to build a credit history but it is a helpful way to learn money management skills and to build independence. The sooner a person gets started the better. Support in learning how to manage finances, prepare a tax return, receive an EITC, and other skills are available through Volunteer Income Tax Assistance (VITA) programs that provide free assistance to people with low incomes or disability.[85]

To learn more about the CA$H Coalition and how to improve a person's credit history you can access recorded webinars by Melinda Burns of the CA$H Coalition at *https://youtu.be/a1Gr-1UFKNg* and *https://youtu.be/kW-ynT2nBIw*

81 EID, see HUD Website *https://www.hud.gov/program_offices/public_indian_housing/phr/about/ao_faq_eid* Retrieved August 2022

82 For "Subsidies and Special Conditions" see SSA website *https://www.ssa.gov/disabilityresearch/wi/subsidies.htm* Retrieved August 2022

83 For an EITC Calculator and information check the IRS website *https://www.irs.gov/credits-deductions/individuals/earned-income-tax-credit* Retrieved August 2022

84 "Extremely Low Income" as defined by HUD is income that is 30% of the Area Median Income.

85 To find a Vita program in your area go to *https://otda.ny.gov/workingfamilies/vita.asp* Retrieved August 2022

4.4 Protecting Savings

Public benefits can help to provide long-term sustainable support, but as people with I/DD have increasingly become more integrated into the community other sources of income and support have become available.

A significant impediment to increasing employment for people with disabilities has been the perception that earning an income will reduce or eliminate benefits. Much publicly available information concerning this issue is misleading or false. The reality is that most people receiving benefits will add to their net incomes if they are paid for the work that they do.

SSA rules cap individual savings at $2,000 if a person is to continue to receive SSI. As people go to work, however, they may be able to accumulate savings that can be protected from consideration by SSA when determining a person's assets.

Individual Development Accounts (IDAs) which may be funded federally or, increasingly, through foundation support, will incentivize savings by providing a match of as much as 4:1. The IDA must have a defined purpose and the range of savings objectives is limited to housing or employment objectives, e.g., the down-payment on a first home [86]. Savings in *qualifying* IDAs are not counted as assets when SSA considers SSI eligibility. Credit cooperatives and banks may provide **Matched Savings** programs which match a person's savings up to 4:1 if directed towards a down payment for a home. IDAs and Matched Savings programs are intended to support people with low incomes and are subject to asset and income restrictions. Qualifying matched savings programs are also exempted from consideration in Social Security's countable income.

People living in HUD-funded housing may be able to enroll in a **Family Self Sufficiency (FSS)** plan [87], usually to purchase a home or to achieve an education or employment goal. The plan will set aside rent increases that might be incurred due to increased income when a person goes to work, and repay them to the family once the plan is successfully completed.

Achieving a Better Life Experience (ABLE)

The federal ABLE Act was passed in 2014 and New York State created its accounts in 2017. An ABLE account is similar to a 529 College Savings Plan and is based on the same IRS regulation. A person may only have one ABLE account and annual contribution from all sources is currently capped at $16,000 in any year[88]. If the amount in the account ever exceeds $100,000 the account holder will lose their SSI until the amount goes back below $100,000 again. When they die any remainder in the account will be subject to a Medicaid lien in the same way that any remainder in a First-Person trust would be. There are other rules and regulations that should be understood by the beneficiary before opening the account. The virtue of an ABLE account is that it is simple to open and to keep track of, and the funds may be used for a wide variety of purposes (including housing) without impacting SSI eligibility.

86 "Everything you need to know about IDAs *https://www.ssa.gov/ssi/spotlights/spot-individual-development.htm* Retrieved August 2022

87 Not to be confused with "Family Supports and Services" (FSS) from OPWDD!

88 This is designed to match the federal "Gift Tax" annual exclusion

Family and Other Resources

Supplemental Needs Trusts (SNT) An SNT holds funds that can be used to *supplement* the public benefits received by a person with a disability without compromising their public benefits, including SSI and Medicaid. Funds may be used to pay for personal items and necessities with limitations on their use to buy food or shelter. Trusts are not solely for people of means, and can be used to provide for housing support and, with restrictions, for housing itself. Trust law is a specialized field; the laws vary from state to state and it is essential that an individual and their family consult with a New York licensed Special Needs or Elder Law attorney before creating or joining a trust.

There are three primary types of SNTs that are established for individuals with I/DD.

Third-Party/Supplemental Needs Trust (SNT) These are usually established by a parent or other guardian or relative. Funds may be invested immediately or over time, or they may be funded through an insurance policy payable upon the death of a parent. Upon the death of the beneficiary funds revert to the trust to be disposed of at the trustee's discretion.

First-Party Trust This type of trust is established by an individual, their parent or guardian or court, and funded with the assets of the beneficiary, for example from an insurance or lawsuit settlement. In New York a first-party trust may also receive income from SSDI or CDB in excess of the Medicaid threshold to prevent the need for a Medicaid "spend-down". Assets must be used for approved purposes. When the beneficiary dies, the state has a right to be paid back for medical assistance (e.g., Medicaid) if there are any assets left in the trust. This is sometimes referred to as Medicaid "claw-back ".

Pooled Trust This is an SNT for an individual that is managed by a nonprofit organization and established by a sponsor, such as an OPWDD provider agency. The sponsor manages the trust for the beneficiary in the same way as the other SNTs, with the difference being that when the beneficiary dies any remaining funds may revert to the sponsor rather than to Medicaid.

As noted above, Trust law is complex, and creating or funding a trust requires significant qualifications and expertise. A consultation with a specialized attorney is essential.

4.5 Funding specifically for housing

In this section we review funding that is specifically for housing both from an income perspective and from programs designed to support people with I/DD.

HUD Housing Benefits Based on Income

United States Department of Housing and Urban Development (HUD)

HUD has a range of programs that help housing developers to create housing while helping people to pay for it.

(i) **Housing Choice Vouchers** Section 8 of the US Housing Act of 1937 administered by the US Dept. of Housing and Urban Development (HUD)[89] was created "For the purpose of aiding lower-income families in obtaining a decent place to live and of promoting economically mixed housing, low-income housing support and Housing Choice Vouchers". Section 8 vouchers allow for a person with low income to limit their housing cost to 30 percent of their gross income (in some circumstances as much as 40 percent) with the remaining balance paid by the program. Housing Choice vouchers also allow for a tenant to save towards the purchase of a home. Each municipality in each state has a quota of vouchers. Waiting lists can be long and many are closed to new entrants. Notwithstanding these constraints a person should seek to be included in any open list where they live; vouchers are portable, and waiting lists are not infinite.

Housing vouchers are intended to be used by people with lower incomes. While the HUD guidelines are complex in detail, **Low Income** is defined as 80 percent of the Area Median Income, (AMI), **Very Low Income** as 50 percent of the AMI and **Extremely Low Income** as 30 percent of AMI.[90] Housing agencies must provide 75 percent of their vouchers to applicants whose incomes do not exceed 30 percent of the AMI.[91] To determine your AMI you should visit the US Census Bureau website and sort by your county or municipality. There is a wide range of income in the state; per the US Census Bureau (2021)[92] household income in Allegany County was $51,227, in contrast to Nassau County's at $120,036. The median value of owner-occupied housing in Westchester County is $544,100, while that of Allegany County is $78,400. Per capita income in New York County is $78,771, while in adjacent Bronx County it is $22,749. These contrasting levels of wealth are relevant to the provision of housing and services. Housing costs, including local taxes, help to determine where people live. The availability of DSPs and other service providers is influenced by the cost of housing and commuting, and affected by potential earnings from other work in the region. The reimbursement rates paid to providers vary from region to region depending on the service provided. As noted above the typical income from SSI in NY in 2022 is $11,136. Most people with I/DD whose income is primarily from SSI will qualify for Section 8 vouchers. While these vouchers are intended for those with low incomes, there may additionally be "preferences"

89 Section 8 of the US Housing Act of 1937 as amended, *http://portal.hud.gov/hudportal/HUD?src=/programdescription/cert8* Retrieved August 2022

90 HUD Schedule of income guidelines. *https://www.huduser.gov/portal/datasets/il/il2022/select_Geography.odn* August 2022

91 HUD website. *http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/about/fact_sheet* Retrieved August 2022

92 *https://www.census.gov/quickfacts/fact/table/US/PST045219* Retrieved August 2022

for people with disabilities. To apply for a Section 8 voucher a person should contact their municipal Housing Authority directly.

(ii) Does Having a Trust or Other Assets impact Section 8 Eligibility? In general, some assets, particularly those that could be used to pay rent or pay medical expenses, often known as "investable" assets, can be considered part of a person's resources. The Section 8 office may calculate an annual hypothetical income from those resources at a 2 percent rate. Even though a Third-Party Trust is not under the control of the person who is the beneficiary, it could be included as one of these assets. The Evelyn Frank Legal Resources program of the NY Legal Assistance Group has a helpful publication, "Supplemental Needs Trusts, Impact on Medicaid and Other Public Benefits" (2013) which includes information on how public benefit oversight agencies view trusts[93]. As with any legal matter the person should consult an attorney.

Section 811 Section 811 housing is designed for "non-elderly disabled" and is a collaboration between a housing developer and a provider agency. "The newly reformed Section 811 program is authorized to operate in two ways: (1) the traditional way, by providing interest-free capital advances and operating subsidies to nonprofit developers of affordable housing for persons with disabilities; and (2) providing project rental assistance to state housing agencies."[94]. Funding for this program is limited and competitive between states.

Section 9 of the Housing Act provides for funding for **Public Housing Authorities (PHAs).** HUD funds both capital and operating expenses for the PHAs in NY State, 25 of which are listed on HUD's website[95]. PHAs provide housing for low-income people (80 percent to 50 percent of AMI). As with the individual Section 8 vouchers, the person pays approximately 30 percent of their income for rent with the balance assumed by the PHA. PHAs maintain their own separate waiting lists.

Housing Resources from New York State OPWDD

OPWDD Housing Subsidy Program (formerly Individual Supports and Services (ISS)/Self-Direction Housing Subsidy) The Housing Subsidy is supported by "state only" funds derived directly from state taxation, and independent of Medicaid funding. As such they can be used at the state's discretion, allowing for more flexibility. In the past, the housing subsidy came through either "Individual Supports & Services" (ISS) which at one time could be used to pay for a wide range of services, or the "Self-Direction Housing Subsidy". Since 2022 the support is known simply as the Housing Subsidy. The Subsidy is based on guidelines from the New York State Department of Housing and Community Renewal (HCR). The guidelines state that the person should not pay more than 30 percent of their income and the rental subsidy will cover the remaining 70 percent. In April 2022 OPWDD announced that it would return to basing its Housing Subsidy on the HUD FMR following ten years without an increase.

View Webinar "OPWDD's Housing Subsidy" at: *https://youtu.be/-j14xnez1Co*

93 Available online at; *http://www.wnylc.com/health/afile/44/9/* Retrieved August 2022

94 For more information see HUD's site *https://www.hud.gov/program_offices/housing/mfh/progdesc/disab811* Retrieved August 2022

95 Look for your closest PHA on the HUD site *http://portal.hud.gov/hudportal/HUD?src=/states/new_york/renting/hawebsites*. Retrieved August 2022

(iii) County Based Departments of Social Services (DSS) The Department of Social Services (DSS) is under The New York State Office of Children and Family Services (OCFS). The DSS within New York State's Medicaid program covers personal care services, also known as home attendant services, for those that qualify for these services. This is a type of unskilled, custodial care provided in the home to people with physical or mental impairments that interfere with their ability to independently perform activities of daily living. They can provide funding for personal aides and other support and, critically for people with I/DD, medication management - which Direct Support Professionals working under the OPWDD waiver are not able to do, but they can through the **Consumer Directed Personal Assistance Program (CDPAP).** These funds cannot be used to purchase housing services but they expand the options for residential supports. Applications should be made through the DSS using a 1050 form. Eligibility is based on the level of need, and applicants must have Medicaid.[96]

Housing Resources from US Department of Agriculture (USDA)

The USDA provides financing to developers, municipalities and nonprofits to build housing for older adults, people with disabilities, or people with low income living in rural multi-unit housing complexes. Despite being home to the most populous city in the country, New York State ranks seventh in overall density, with extremely low density in some parts of the state including the Finger Lakes and Western New York regions The USDA provides housing support for ownership and Environmental Modifications. To understand USDA housing programs, visit their site at *https://www.usda.gov/topics/rural/housing-assistance* (Retrieved November 2022)

People with I/DD may be eligible for services from providers other than OPWDD. As the paths to housing change it becomes clearer that people with I/DD need to understand these other services and forge alliances with other groups that seek to find LTSS and housing.

(iv) New York State Office of Mental Health (OMH). The NYS OMH is charged to assist those with mental illness with medical care and related support services. Historically OMH provided housing through its Community Residence Program which ranged from highly supported "Congregate Treatment" settings to less restricted settings with all day support, to Single Room Occupancy (SRO) settings with varying levels of support. In the past the emphasis has been on transitioning back to the community wherever possible, with several of the housing options designed to enable that transition rather than to provide permanent housing. In 2012, recognizing the importance of permanent housing in providing a predictable and stable environment, the state implemented the **Supported Housing Program** in order to increase permanent housing options and with "recipient-specific support services designed to assist people in succeeding in their housing."[97] This model is designed to reduce the revolving door effect of transitional and institutional mental health programs. This is a stipend program, when Section 8 or other sources are unavailable, that limits housing cost per person to approximately 30 percent of their income. The stipend is paid to the rental agency, not to the person. A diagnosis of a mental illness is required in order to be eligible for these programs.

96 Contact information for County DSS at NYS DOH website. *https://www.health.ny.gov/health_care/medicaid/ldss.htm* Retrieved November 2022

97 "Supported housing" from OMH website. *https://omh.ny.gov/omhweb/adults/supportedhousing/supportedhousingguidelines.html* Retrieved August 2022

(v) Administration on Aging (AoA). AoA programs, funded under the **Older Americans Act of 1965**, provide assistance to older persons and their caregivers and support services that help older adults remain independent and involved in their communities. The Section 202 **Supportive Housing for the Elderly** program (similar to Section 811) is provided by private, nonprofit housing and service-oriented organizations that have received capital advances from HUD to finance the construction and rehabilitation of housing for older adults with low incomes. This program provides rent subsidies, and the supportive services include meals, transportation, and accommodations for residents with disabilities.

The New York State Office of the Aging assists older persons with living independently and accessing necessary resources. The Office of the Aging directs those wishing to live independently to the NYS Housing Websites *(https://housingsearch.hcr.ny.gov/housing/s/) and http://www.nyshcr.org/AboutUs/affhsg.htm*,. These sites are funded through the NYS Homes and Community Renewal (HCR).

We have reviewed the range of supports, benefits and eligibilities that a person may qualify for and have access to. The next stage is to use that knowledge to create a plan for housing.

5 Support Services

Housing is not just about being able to afford rent or mortgage, or bricks and mortar. An essential part of a successful Long-Term housing solution is the creation of services that support the person and that can be sustained.

What do we Mean by Supports and Services?

In addition to the physical building that the person with I/DD will live in, the other aspect of housing that is equally or more important is securing the services and supports that the person will need to live independently. In the traditional group home, the provider agency will control the property and will also provide the services. In an independent setting the provision of residential support services is separate from the provision of property. Support services are required across a spectrum of need for people with I/DD. Some persons require a nominal amount of support – an occasional visit to make sure that the person is safe and healthy and that they are sustaining themselves. Some require oversight of budgets, food shopping, home maintenance, and monitoring of medication, while others need round the clock support to ensure safety and health related care. There are different routes through which to obtain these services.

IRA Certified Settings and Agency Operated Non-Certified Settings

In an IRA setting support services are funded by Medicaid Waiver funds. The person's CM will develop their Life Plan, which will set out what services are provided and how they will be delivered. The provider agency will create a Residential Habilitation Plan[98] based on the Life Plan, and a DSP employed by the agency will provide the services and the management of the property. The agency will typically become the representative payee for all SSI and SSDI funds and will administer the person's SNAP and HEAP funds. They will also receive funding from the state to assist with establishing the home, any necessary conversions or modifications, and a letter known as a Prior Property Approval (PPA) which is an implicit state guarantee of funding that is critical in obtaining a commercial mortgage to purchase the property. A Supervised IRA (as described on page 37) is built around 24 hours a day 7 days a week support setting, while a Supportive IRA provides a more limited level of support depending on the person's level of need.

In a non-certified setting support services can be provided for in a variety of ways. At the simplest level they can be provided in exactly the same way as they are in a certified setting, (i.e., by an agency that owns the property and employs all of the staff). The only distinction is that they are not certified, and thus will not receive the Congregate Care Supplement to the resident's SSI payments. In addition, they will also not receive the funding for start-up costs, or the PPA.[99]

An agency may also provide services to a person or group of persons living in a home that is not owned by the agency. The property could be owned through any of the mechanisms described elsewhere in this guide. In this setting the agency may, for example, provide a full array of services as described above. Funding for the services would be provided through the same mix of funding which is directed through the agency but which is "unbundled". In such a setting the funding for services is derived from a person's Self-Directed Services budget which can include Community Habilitation (the delivery of habilitation services in a non-certified setting, where the service delivery is recorded in 15-minute intervals), plus funding from the OPWDD Housing Subsidy.

98 "Community Habilitation" funding used to be known as "Residential Habilitation" funding. The term is still used when creating the plan.

99 For a fuller understanding of how certified housing is funded check out "Reclaiming Innovation" Appendix A *https://nyhrc.org/Housing_Models_and_Reports* Retrieved August 2022

The plan may include funding for a Live In Caregiver (LIC) which in the past was only fundable through an ISS contract but which is now a Medicaid service. Per OPWDD, the LIC is "an unrelated (by blood or marriage) care provider who resides in the same household as the waiver participant and provides as-needed supports to address the participant's physical, social or emotional needs in order for the participant to live safely and successfully in his or her own home." The LIC position requires an LIC agreement as set out with the person and their FI which will set out exactly what the LIC's role is, including the scope of work, hours, time off, expectations etc. The OPWDD housing subsidy will include the LIC based on the same criteria outlined in the ADM 2022-03. This person may have outside employment or they may be employed by a provider agency to provide CommHab services in addition to their LIC duties. In the event that the LIC provides CommHab to a person they live with their income is exempt from taxation per Section 131 of the IRS Code[100]. Agencies have to monitor the number of hours spent on both tasks carefully, in particular if the LIC is required to be awake for much of the night as the federal Department of Labor (DOL) rules limit the number of hours that can be provided "in kind" and require overtime payments above a certain number of hours worked. These rules, designed to protect workers may have the potential unintended consequence of pricing out people who are seeking self-directed services or non-congregate care.

Self-Directed resources also include SSI/SSDI, SNAP and HEAP funds which are controlled by the person. In some settings, these funds can be paid directly to the agency, or they can be paid through the person's Fiscal Intermediary. One of the virtues of this latter approach is that if the person wishes to change the service provider, they are able to do so. Such a change is a complex undertaking and would only be contemplated if the provider systematically failed to provide adequate services.

People who have a Self-Directed plan that includes funding for residential services and who want to be more independent may seek to purchase some of their services from an agency, but they may also seek to hire support personnel themselves. They may do this in one of two ways. They can typically work with their broker, or in some cases collaborate with their Fiscal Intermediary (FI), to advertise for, interview, train and hire their staff, or they can do so personally, becoming the employer themselves. If they work with the FI, it will be the FI who becomes the employer of record and provides payroll, benefits, insurance, Workers Compensation, liability coverage, scheduling, training and background checks[101]. In exchange, the FI is paid a percentage of the person's budget. If people choose to become the employer of record themselves, they are required to fulfill all of the same requirements. While it is important that this latter option be available, the level of paperwork and knowledge required and the compliance risk involved make it inadvisable as currently formulated.

100 See *https://www.irs.gov/pub/irs-drop/n-14-07.pdf* Retrieved August 2022

101 A state authorized criminal background check is required of any employee whose employment is funded through OPWDD funds, whether they work for an agency or for a person directly.

Individually Directed Goods and Services (IDGS)

IDGS is a waiver service under Self-Direction which provides funds that can be used to purchase equipment or supplies that are related to an identified plan or goal, will increase independence, and can promote inclusion. For example,, these funds can be used for staff training programs, service-related transportation, paid neighbor, interpretation and Self-Direction staff support, summer camp, community classes to enhance independence, health club memberships, and assistive technology. It can also be used for Household Related Items and Services, for example, small appliances, snow removal, lawn maintenance and housekeeping and personal use transportation. It can also be used for other goods and services to support independence or which are related to health and safety and for Assistive Technology needs like medication dispensers and alarm monitoring. The funding stream is still evolving and at present each expenditure is subject to individual capping with an overall annual cap of $32,000.

Other Than Personal Services (OTPS)

OTPS can fund items that are not eligible under Medicaid, for example internet, utilities, clothing, food that isn't covered by SNAP, phone service, software, and staff training. OTPS may not be used for any medical support. OTPS funds are capped at $3,000 annually.

Consumer Directed Personal Assistance Services (CDPAS)

Funding for support services can also be obtained through CDPAS. These funds require that the DSP work for an agency and that they be subject to a background check as well as a health screening. The person is responsible for all aspects of hiring and employment and compliance.

One feature of CDPAS that fosters independence is that trained CDPAS employees may administer medication, while Direct Support Professionals employed under OPWDD's 1915-C waiver may not, for the most part, administer medication outside of a certified setting.

While we commonly think of people with I/DD living in group homes, the fact is that many of them would like to live alone or with other people who do not have I/DD. After all, a group home is primarily an economic construct rather than a social one.

Paid Neighbor Program

This is a Medicaid funded program that provides additional support to a person with a disability. The Paid Neighbor (PN) can be any person other than an immediate family member not residing at the same address. They can be as far as 30 minutes away, although they should be available to respond on foot if needed. The PN receives a monthly stipend of up to $800 per month to be "on call". If they are needed to help the recipient, they may also provide Community Habilitation services. There must be an agreement between the PN and the FI, and there can be more than one PN within the monthly fee cap.

This program offers companionship and support to persons who want to live on their own but would benefit from having immediate access to 24-hour supports. Paid neighbors can provide 24-hour emergency supports. They are hired by the person they support and provide personal services depending on needs. Employment and screening requirements are performed by the FI.

We have discussed why a Housing Plan must be Person-Centered, the different types of Housing that may be available, and how to pay for them and to provide support to a person seeking to live in the community. Armed with this knowledge we can begin to create a Housing Plan for the person.

Person-Centered Planning (PCP)

PCP needs to acknowledge the hopes and aspirations of the person, while being firmly rooted in the practical. True person-centered approaches are not confined to planning, they should infuse all aspects of services and supports. The Self-Advocacy slogan "nothing about us without us" sums up the approach perfectly.

Planning for housing begins with the person. As the plan takes shape it will need to address some fundamental housing questions – "rent or buy?", "alone or with others?" and as those choices are addressed and expressed in practical terms, the range of options is progressively defined and simplified.

Following the path laid out in this Guide, the first step is to review and inventory the assets, income from private and public sources, and eligibilities and entitlements that people may be able to mobilize in their search for their own home. It is recommended that they consult with a Benefit Specialist to ensure that they have optimal access to all of the options available to them. "Benefits Advisement" is a service provided through ACCES-VR, through OPWDD's Family Support Services, and through Fee for Service providers. This evaluation will help persons and their families to answer one of the most important questions in their search for housing: "Is it in my best interest to obtain housing through the certified group home system or will I be better served by putting together my own plan for Independent Housing?"

Who is on Your Team?

School Transition Officer

Many school transition officers are not familiar with non-certified housing options or the necessity to begin planning for housing at an early stage. However, transition services are an entitlement, and if the school is made aware of the need and the resources, they should include housing information and planning in their transition services. This planning is especially important for students who have I/DD who are in institutional or congregate Foster Care who may have no prospect other than homelessness once they leave the Foster Care system.

Care Manager (CM)

"Your Care Manager will share his or her knowledge of available resources to help you make informed choices. He or she will make referrals, find service providers, [and] offer housing options. He or she also will coordinate how you receive your supports, including through both natural supports and funded services"[102]. The CM is a benefit coordinator and should assist with SNAP, SSI, SSDI, Medicaid compliance and recertification.

102 OPWDD website *https://opwdd.ny.gov/access-supports/plan-your-services* Retrieved November 2022

Self-Direction Broker

Your Self Direction broker will help to create your residential budget, including rental subsidies, transition funding, and wrap-around supports. They will also help convene your Circle of Support.

Fiscal Intermediary

A person who is using Self-Direction must connect with a Fiscal Intermediary (FI). The FI will be the conduit for Medicaid and State funds, including all accounting and reporting. An FI is also required if a person intends to employ a Live-In Caregiver, obtain Community Transition Services, or get help with moving expenses among other supports. The FI is responsible for ensuring that the QA checklist and other important housing documents related to obtaining and maintaining the housing subsidy each year are completed. The FI must submit the yearly recertification with the local DDRO

Housing Subsidy Coordinator

Each DDRO has an OPWDD staff person who is responsible for coordinating rental subsidies in their region. They can also supply you with a list of provider agencies who administer rental subsidies. Housing Subsidy contracts require housing standards be maintained.

Provider Agency

Whether you choose to have support from an agency, to self-hire your staff, or somewhere in-between it is advisable to partner with a provider agency while your housing search is underway. They may be able to help with staff planning and rental issues, connecting to housing, and connecting with other people seeking the same housing solutions.

Benefit Adviser

Managing a person's benefits and optimizing their income can be extremely complicated. Professional Benefit Advisers are frankly essential to avoid easy-to-make mistakes that could shut off benefits, perhaps for good. Advisers can help to highlight incentives for a person to be employed while remaining secure.

Assistive Technology Adviser

Assistive or Enabling Technology runs the gamut from a free app to high-cost Durable Medical Equipment (DME). It is important to review the appropriate, sustainable technology that a person might need. Given the breadth of capabilities and costs of technology today it is helpful to have a professional Assistive Technology professional as part of the team.

Housing Navigator

As noted in the introduction, Housing Navigation is a focused, outcome-oriented, and time-limited service that helps people with I/DD who need or want to move to community-based housing to obtain and maintain stable, long-term housing of their choice.

To find a Navigator go to *https://nyalliance.org/HN_Directory#!directory/ord=lnm*

All of these professionals are compensated for their time. While it is necessary to bring a group together for some meetings it is usually far more productive to meet one-on-one, or in small groups.

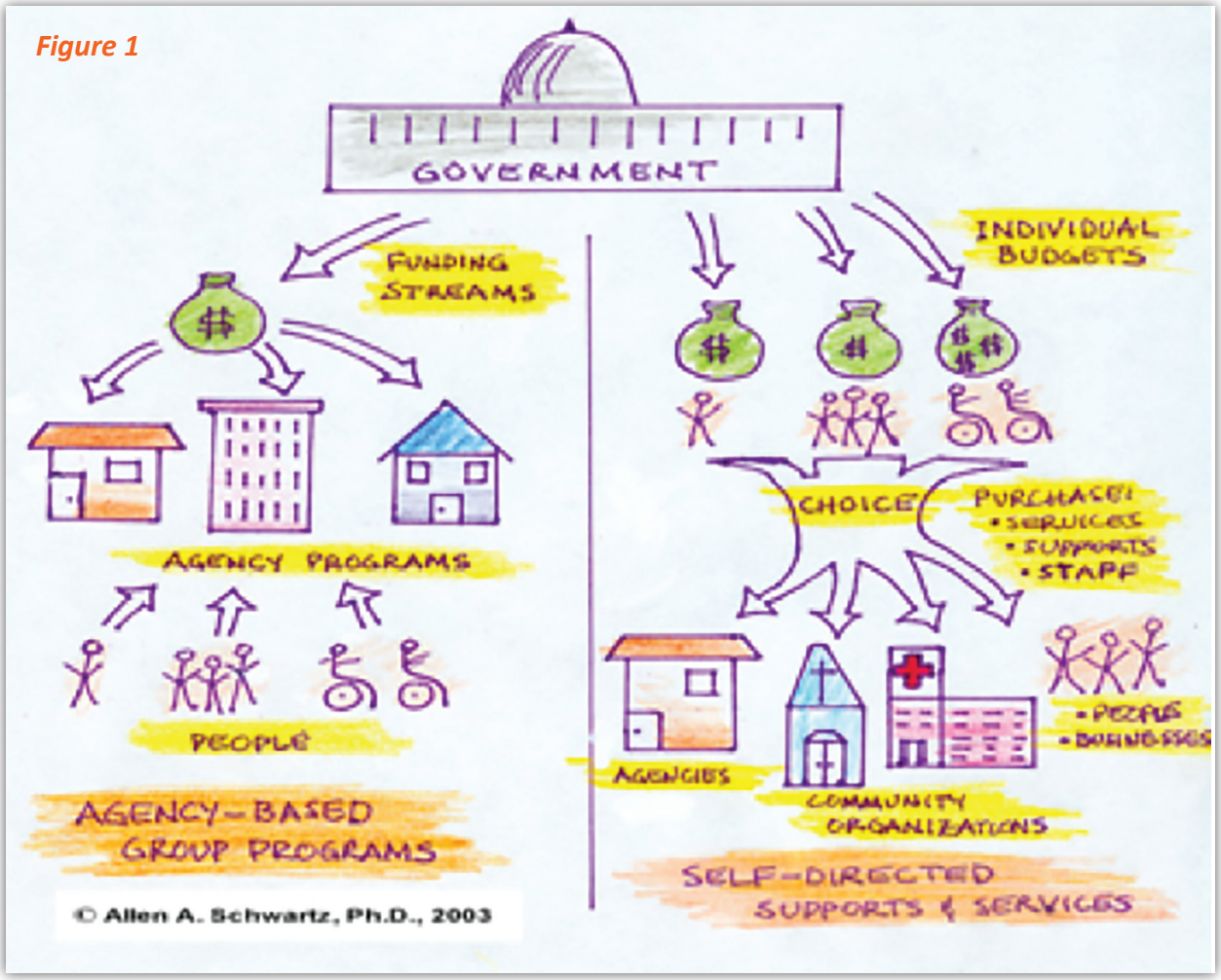
Deciding on Independent Housing

Independent or non-certified housing can take as many forms as there are people seeking it. The primary differences from the certified settings described above are that independent supports tend to be less intensive, although not universally so. Settings tend to be smaller, typically three to four people or less. Property is independently owned, either by a commercial landlord, by the person themselves, or by a for-profit or nonprofit housing corporation. The provision of accommodation is separated from the provision of services, meaning that the agency that provides support services does not also own or control the home where services are provided. This means that if a person likes where they live but they are not satisfied with the services provided by a provider agency they can choose to have services from a different provider. Conversely, if they want to move to a different location but wish to retain the service provider, they have the option to do so. People are not locked into a legacy group home model. There are people with I/DD who live alone and receive a few hours of support per week, and there are people who live in partnership with two or three others, with caregivers living alongside, who receive around the clock support. The key is flexibility and the ability to adjust service and support levels when necessary, or to fade them out if the needs become less critical.

The choice as to whether to opt for the legacy group home or the independent route is to some degree left to people and their families. Families should do their own due diligence on both types of housing as described in Part 2 of this Guide. The legacy congregate model tends to be more costly to the taxpayer and as such is increasingly rationed in an era of attention to budgets and growing demographic pressures on supported housing**.** While OPWDD describes congregate care as a "choice," it is a choice dictated and rationed by the state budget and regulatory considerations, rather than an option that is available to all.

In 2003 the late and much missed Allen Schwartz Ph.D., working for OMRDD, created a graphic (Figure1) that illustrates the change in how services will be delivered in the future – a future that only now, almost twenty years later, is beginning to be implemented. In the traditional model on the left, funding is directed to provider agencies that create programs which people with I/DD attend. Programs may be well designed and implemented but they will be from a set menu. In the Self-Directed environment on the right, the funding flows to the individual, and they have the choice as to whether they purchase services from an agency or use alternative means to provide their support. Given the direction of best practice research, financial demands of a broadening demographic, and federal and state policy, the agency-based model of home ownership and service provision is unlikely to continue indefinitely.

Figure 1



(i) Planning for Independent Housing

After a careful review of the pros and cons of certified housing versus independent housing, if a person chooses to seek independent housing, they should consider the steps we have outlined so far:

a. Review the resources that are available to them, including employment plans and prospects, and seek help from a Benefit Adviser.

b. If eligible, apply for SSI, Medicaid, ACCES-VR, and OPWDD services, Care Coordination, Medicaid Waiver, and SD. Establish qualification for HUD benefits and other low-income benefits, and the level of availability. These steps are vital, and while cumbersome they can be negotiated with the help of qualified eligibility specialists, funded through OPWDD, or available on a private-pay basis.

c. Whether eligible for all of the above or not, every person seeking independent housing should conduct a thorough review of their resources from government benefits, private income from work, and support from a trust or from friends and family in cash or in kind. Bear in mind that support in the form of in-kind food, rent, or shelter may compromise public benefits.

d. If a person has assets, is likely to receive assets, is the beneficiary of a trust, or seeks to establish a trust they must seek the advice of an attorney. There is much misleading information bandied about regarding trusts and housing. In order to have reliable and sound information the advice of an attorney specializing in New York Elder or Disability Law is essential.

e. While this Guide focuses on finding the right accommodation there are other important elements to consider when making a housing plan. These include the need for staffing support, but also consideration of daily living skills (shopping, cooking, self-care), transportation needs, and the emotional aspects of living away from family and living with others (roommates, staff, etc.) which will need to be considered.

A thorough review process is necessary to establish how much funding is available to pay for accommodation. Typical householders are advised to spend no more than 30 percent of their income on housing. People with I/DD are not typical; their income from all sources may include a mix of benefits that are tied to specific needs (e.g., SNAP), or housing (e.g., HUD) and they are likely to have very low incomes, even if their Personal Resource Account (PRA) for services can reach the low six figures. That said, their income is likely to be stable. Public benefits, while occasionally in political jeopardy and subject to administrative error, tend to be stable and to keep pace with inflation. The key element is sustainability. How much will consistently be available to pay for rent or a mortgage payment and other housing costs?

(ii) Determining Factors for Location and Collaboration

In addition to financial considerations a person with I/DD will need to consider other factors in determining where and how they live.

a. Urban, Suburban or Rural? Each has their advantages and disadvantages. Urban areas tend to offer greater options in employment, services, transportation infrastructure, and social opportunities. They also tend to be more crowded and expensive. Suburban areas offer a slower pace of life, perhaps less expensive but with fewer support and employment options, socialization, and access to labor for provision of Direct Support Professional (DSPs). Rural areas may offer peace and quiet, a connection to nature, lower costs and access to USDA benefits, but they can be isolating, lack services or transportation, and be lonely. Idealized rural life can disappoint when the weather is gloomy and the work is hard

b. Alone or with other people? A person might like the peace and quiet of living by themselves, or they might relish the opportunity to spend time with others. Ultimately the decision as to whether to share an apartment or a house is an economic one. The economics are not simply determined by how much rent or mortgage one or more people can afford, but on the cost of the support staff they might need. The greater level of staff support required, the larger the impact on the budget, and the more important the task of finding and retaining staff or working with a provider agency to ensure staff continuity. In many instances it is more effective for two or three people to pool their support resources and to share staff services. Again, the reality is that a group home is a financial construct as much as it is a social one. Sharing services requires planning for staff time, the range of services that each person receives, time spent, etc.

c. **A Room of Your Own**. Having one's own room and the privacy it affords is an essential element of adult life. CMS requires that settings that receive HCBS funding have privacy, including lockable doors, but a room of one's own is more than just the opportunity to get peace and quiet; it is a statement of a person's independence and adulthood. Congregate care facilities will often have more than one person in a room, as it is a way to optimize revenues. The room-mates may have no choice as to who they share with. Most people would prefer to have their own room.

d. **With whom?** While the factors that determine who we live with are both financial and social, there is no need to be encumbered by stereotype. People with I/DD do not need to live with other people with disabilities, and certainly not just with other people whose clinical diagnosis matches their own. While budgetary limits might necessitate collaboration with people with similar needs, it is important to have as diverse a group as possible, where one person's strengths may balance with another's needs. The more people are able to support each other, the less need there is for paid support, and the richer the quality of social interaction.

(iii) How to Connect?

A person may have grown up with a group of students with special needs who attended the same schools and the same programs. Sometimes groups form around those familiar relationships, but sometimes, and perhaps in contrast to their parent's wishes, the person may want to make new friends or to live with a different kind of person. Making those connections can be facilitated by social groups and social media, but there are other resources to help families to get together.

a. **Self-Advocates** Self-Advocacy Association of NY State (SANYS)[103] can identify a regional or local group of self-advocates, some of whom may have experience with housing or may be interested in combining their efforts with others.

b. **Regional groups such as "In the Driver's Seat",** based in Rochester, New York but covering much of western New York, bring together people with I/DD seeking housing partners and Direct Support Professionals. There is clearly a demand for more such connections**.** [104]

Rent or Buy?

Now that the person and their family have thought about issues concerning budget, housemates and living costs, the next decision is whether to purchase a property or to rent. For a typical person or family seeking accommodation the decision as to whether to rent or to buy represents an assessment of their economic security, and a judgment as to the state of the property market and the cost of borrowing. They will also consider whether they are putting down roots in a community, convenience to their employment, quality of schools, level of taxes and tax deductibility, and more. Given the costs of purchasing it is a long-term decision. People with I/DD will have additional considerations.

103 SANYS can be reached at *http://sanys.org/*
104 Go to *https://inthedriversseat.org/*

(i) Renting

In addition to the economic issues that must be taken into consideration there are other specific factors that people with I/DD need to consider.

a. Accessibility Newer rental properties, particularly housing that has been built with federal or state subsidies or tax concessions, may be more physically accessible to people with disabilities than older housing stock will be.

b. Universal Design Universal design is an approach to the development of "products and environments that can be used effectively by all people, to the greatest extent possible, without the need for adaptation or specialized design"[105]. Several counties and municipalities in the state have adopted principles of Universal Design, notably New York City, but the guidelines are voluntary. In 2012, Westchester County adopted a Universal Design protocol. The law requires that "no-step entries, one-story living spaces, wider doorways and hallways, turn-around floor space, grab bars, removable cabinets and reachable switches and controls—be designed into at least 50% of the construction of residential housing that receive support from Westchester County fair and affordable housing programs and all entities seeking to improve new residential housing units with support from County "Fair and Affordable" housing programs."[106] This ordinance should serve as a model for other regions of the state, and possibly a state-wide initiative. It has been demonstrated that if accessibility and environmental considerations are included in the earliest stages of a development the additional cost can be offset through incentives in some cases and be immaterial in most. For more about Universal Design principles visit the University of Buffalo, New York "IDEA Center".[107]

View the Webinar from the IDEA Center, Universal Design & Home Modifications" at *https://youtu.be/s9FoGTA1z1s*

c. Environmental Modifications "E-Mods" All new construction will comply with the ADA, and many will design to "ADA +" per Universal Design principles, but older construction and smaller housing units may need modification. Modification may be an entry ramp, support bars, wider doorways, removal of door thresholds, or technology such as flashing lights for smoke alarms. A CTL (Ceiling Track Lift) can assist people with getting to and from their bed to the bathroom and other possible areas. A VPL (Vertical Platform Lift) can assist people in wheelchairs or with walkers. These lifts make the home more accessible for people with mobility challenges. Funding for E-mods is available to people who are receiving Waiver services from OPWDD. A provider agency as the Project Manager is central to this process. The DDRO provides the list, and the Care Manager applies to the agency to be the Project Manager.

105 (North Carolina State University, 1997).
106 See more at: *https://homes.westchestergov.com/index.php?option=com_content&view=article&id=2554&Itemid=100007* Retrieved April 2020
107 Visit *http://www.buffalo.edu/ubnow/stories/2019/10/universal-design.html* Retrieved July 2020

In addition, the person should work with their Housing Navigator, Care Manager, Fiscal Intermediary, and if needs be an Occupational or Physical Therapist as well as the E-mods committee at their DDRO to prepare for the application to ensure that it takes into account their needs but also fits with OPWDD's regulations requirements. "Those physical adaptations to the participant's home, required by the participant's service plan, that are necessary to ensure the health, welfare and safety of the participant or that enable the participant to function with greater independence in the home and without which the person would require institutionalization and/or more restrictive and expensive living arrangement."[108] The Waiver sets out in some detail what modifications can be made using OPWDD funding. In addition to modifications paid for through OPWDD, New York State Department of Health (DOH) may fund "internal and external physical adaptations to the home, which are necessary to ensure the health, welfare and safety of the waiver participant" (in this case the DOH Waiver). DOH has a broad array of possible modifications mainly designed to increase accessibility and (as underlying much of public health programs) to enable a person to live outside of an institutional setting), designed to enable a person to live outside of an institutional setting.[109] NY State Homes and Community Renewal (HCR)'s "Access to Home" program, based on income and disability, can provide for modifications - "Examples include: wheelchair ramps and lifts, handrails, doorway widening, and roll-in showers."[110] For people living in rural areas the USDA Section 504 Home Repair Loans can provide very low interest rate loans to homeowners with low incomes who need to repair or make their home accessible for a person with a disability.[111]

d. Reasonable Accommodations "People with disabilities are protected against housing discrimination on the basis of mental or physical disability by a series of federal, state, and local human rights and civil rights laws. These laws include Section 504 of the Rehabilitation Act, 1; the Americans with Disabilities act (ADA), 2; the Fair Housing Act (FHA), 3; the New York State Human Rights Law (NYSHRL), 4; and the New York City Human Rights Law (NYCHRL),5; Not only are people with disabilities protected from discrimination, they are also entitled to certain accommodations so that they can use and enjoy their homes"[112]. The laws governing which buildings that predate the laws can be "grandfathered" into compliance, what accommodations are reasonable, and who pays, are different depending on jurisdiction and the vague nature of the term "reasonable". Depending on perspective, a dog may be an acceptable Support/Service animal, whereas an iguana might not be. More practically, widening a door might be very expensive in an older building but necessary for a tenant using a motorized wheelchair – in which instance the landlord might prefer to offer a different more suitable apartment. Depending on jurisdiction a tenant might be required to reimburse any costs of alteration if they do not stay for some time in the apartment, and they may be required to restore the home to its original configuration when they leave. The New York State Division of Human Rights has a helpful website and is open to calls and questions.[113]

108 OPWDD HCBS Waiver 2021 Page 118 *https://opwdd.ny.gov/news/comprehensive-home-and-community-based-services-hcbs-waiver-amendment-amendment-14-approved* Retrieved November 2022

109 For the range of DOH modifications see *https://www.health.ny.gov/facilities/long_term_care/waiver/nhtd_manual/section_06/e-mods.htm*. Retrieved November 2022

110 Access to Home at *https://hcr.ny.gov/access-home* Retrieved November 2022

111 USDA Section 504 loans see *Single Family Housing Programs | Rural Development (usda.gov)* Retrieved August 2022

112 From NY State Bar Association Disability Rights and Building codes of New York *https://www.nycbar.org/pdf/report/uploads/20072100-DisabilityHousingRightsandBuildingCodesofNewYork.pdf* Retrieved November 2022

113 NY State DHR *https://dhr.ny.gov/* Retrieved November 2022

e. **Discrimination** Since 2019 it has been illegal for landlords to discriminate on the basis of a tenant's "Source of Income" in New York State. "Source of income" may include a HUD voucher, or an SSI check, and the landlord may not refuse to accept a tenant who relies on such public funding. In the past landlords were able to deny housing based on source of income, which was often code for racial, disability or other discrimination. The law is enforced by the NY State Attorney General's Office through the Division of Human Rights (DHR). If a person believes they have been discriminated against on the basis of their income, they can file a complaint at the DHR website.

To understand more about the rights of people with disabilities to fair housing, view the webinar "NY State Human Rights Law" at *https://youtu.be/90b9rznjIbA*

f. **Availability** If the service and economic reality mean that people with I/DD need to share their accommodations, then they will typically need a three, four- or five-bedroom home to accommodate each person with a room of their own, and to allow for a live-in caregiver or other staff. They will seek a long lease. Properties that fit this description may not be readily available in the higher cost regions of the state. It is important to note that per the Housing Subsidy ADM 2022-03 the housing subsidy cannot be used to support more than four people living together or the maximum number of unrelated adults allowed by local ordinance living together in the housing unit;

g. **Utilities** Some rentals include the cost of utilities and perhaps superintendent services in the rent while others do not. Renters need to be clear as to what costs are included in the rent. If energy costs are not included, they should plan for potential energy price increases and seasonal fluctuation, and if they are in Self-Direction make sure such costs are budgeted.

h. **Rents May Inflate** Rent subsidies provided through OPWDD or DSS are based on guidelines set down by New York State Homes and Community Renewal (HCR) on behalf of HUD and are generally modest. Private landlords are free to raise rents at each lease renewal based on rates varying between 2.5 percent and 4 percent. There is no such requirement embedded in HUD subsidies. A tenant must be careful not to be trapped by rising rents without sufficient income. As discussed in Section 3, Earned Income Disregard may provide some cushion to rent increases in housing that is supported by HUD.

The decision as to whether to rent or to buy is one that requires considerable deliberation and supporting advice. HUD counselors and social service agencies are able to provide first-time homebuyers with guidance and social service agencies can also help. For a listing of HUD-approved Housing Counseling Agencies please visit the HUD website [114]

114 Visit *https://www.hud.gov/hud-partners/housing-national-agencies* Retrieved November 2022

(ii) Help in Renting a Home

People with disabilities and people with low incomes have several programs and options open to them to assist with rental payments.

a. **Section 8 Housing Choice Vouchers** As discussed above these are also known as Housing Choice Vouchers, and they are applied for through the municipal and county level Section 8 offices. Currently the waitlists are long, and many offices have simply closed their waitlists. When available, the voucher allows the person to pay only a maximum of 30 percent of their income (or SSI if they have no other income) for rent. The remainder of the rent is paid to the landlord by the Housing Authority.

b. **Public Housing** There are separate Public Housing offices in each municipality through which a person can apply for public housing units. There are also waitlists for public housing. An important distinction between public housing and Section 8 is that with public housing, the landlord is the Public Housing Authority and with Section 8, the landlord is the owner of the property that accepts the voucher.

c. **Multifamily Subsidized Housing** There are also affordable housing units known as Multifamily subsidized housing. These have typically been created through the LIHTC benefit to the developer. (See section 3). These units may have a certain number of units set aside for the elderly or for people with disabilities. If the funding is through Section 811 (see above) then the units may be exclusively for "non-elderly" people with disabilities. The landlord is the property owner and sometimes there is a property management company that acts as the primary contact. If the housing has been developed using Section 811 the developer or landlord may be required to work with a provider agency to provide support services to the people living in the "set aside" units, and to also be liable for the rent. The developer has the protection of knowing that the rent will be paid and that the people in the apartments will not be neglected. The tenants have the comfort of knowing that they will have secure tenancy and that their support needs will be addressed. However, the tenants are required to receive their services through the same single agency and may not readily have the option to switch providers. CMS in its HCBS Settings ruling of January 2014 (See part 2)[115] leaned very strongly towards the provision of smaller scale settings. While the 811 type of setting may create more affordable and sustainable housing the concentration and limitation of options must still be addressed.

(iii) Renting an Affordable House/Apartment

The NY Housing Resource Center (NYHRC) provides links to affordable housing search tools and additional information to help in your housing search. Visit the Affordable Housing page on the NYHRC to learn more.

https://nyhrc.org/resource-category/housing-types-funding/affordable-housing/

Independent Living Centers (ILCs) may provide registries and other housing connection opportunities. To find the ILCs in your area check the NYSED website: *http://www.acces.nysed.gov/vr/independent-living-centers*

115 HCBS Settings ruling CMS Jan 20 2014 *https://www.govinfo.gov/content/pkg/FR-2014-01-16/pdf/2014-00487.pdf*. Retrieved November 2022

(iv) Buying Considerations

Home ownership is within reach for many people with I/DD, but as with renting there are unique considerations.

a. **Owning a home does not compromise social security or Medicaid benefits** If a person chooses to purchase a primary residence it does not affect their eligibility. However, if they sell the property at a future date and do not reinvest the proceeds in a primary residence, the gain on the sale may be subject not only to tax but also to a potential "claw-back" from Medicaid.

b. **A person with a disability may qualify for lower Real Estate and School taxes** Certified group homes operated by nonprofit corporations do not pay local taxes which is a privilege that can sometimes become a source of community friction and "NIMBYism." Individual homeowners do pay taxes; although people with permanent disabilities may be able to pay taxes at a lower rate through a School Tax Relief (STAR) exemption.[116]

c. **Maintenance** OPWDD provides funding to certified group home operators to maintain their property. However, the state is not permitted to provide funds that improve property values for an individual homeowner. The funds it provides for routine maintenance are limited to very basic items. Housing support budgets through SD may include some modest funding for upkeep but the homeowner is liable for any significant repairs. There are several programs that can provide Home Equity style loans to help with repairs for homeowners with low income, such as the Neighborhood Preservation Company grants, available through NY State HCR[117] or a Community Development Financial Institution (CDFI) such as the Disability Opportunity Fund which is headquartered in Long Island but is active throughout the state.

d. **Owning in partnership** Some people with I/DD have established home ownership in partnership with others. This shares the cost, but requires careful planning for an exit strategy to address what will happen when one or more of the homeowners want to move and to sell their share. After all, very few of us spend all of our adult lives in the same house. Each home ownership situation will be unique. Several home ownership groups have created their own agreements to govern how property is owned, and how a property partnership can be changed or dissolved if one member of the partnership needs to leave. A partnership agreement should be created by an attorney, and it may need to be reviewed by the Surrogate's Court in the event that any of the persons involved are subject to guardianship.

Home ownership is the American dream for many people. There are also economic incentives to purchase such as assistance in down payments, deductibility of interest and potential accumulation of equity. For people who are reliant on public funding though, the accumulation of equity is not necessarily a significant benefit at this time, given that they may forfeit such equity to Medicaid. Interest deductibility from income taxes is irrelevant if income is extremely low. Property ownership in partnership with others requires significant effort at the outset to ensure that each partner's interests are protected in the event that one partner wishes to sell their share. Considerable attention must be paid to providing for conflict resolution, and to governance.

116 For information about the STAR and Enhanced STAR exemption visit https://www.tax.ny.gov/pit/property/star/default.htm Retrieved April 2020

117 NY State HCR Neighborhood Preservation Program https://hcr.ny.gov/neighborhood-and-rural-preservation-programs Retrieved March 2020

(v) Buying a home

After a thorough review of a person's assets, income and choices of where to live, with whom, and how to obtain services, the person may decide they want to buy their own home rather than rent. Or, they may have spent some time renting, and decided that they want to put down deeper roots and that they are ready to own their own place.

a. **Budget sustainability** A person's budget will need to address not just the costs of a mortgage, but the cost of real estate taxes, insurance to cover each homeowner and partners, and perhaps to cover any liability to visitors. The most significant additional item is the cost of maintenance. "Murphy's law" holds that if something can go wrong it will, and it seems that every new homeowner inherits an (unexpected) failing boiler/water heater/roof, etc. Expenses can be significant and untimely. As previously noted, state-based budgets do not allow sufficient funds for maintenance. The homeowner needs to begin with some funding set aside, ensure that necessary maintenance is performed, and put away a portion of funds each month to save for the eventual need to replace a major item. Sensible homeowners also carry a line of credit to be able to draw on in an emergency. For condominiums and cooperatives there are typically common charges and Home Owners Association (HOA) fees that must be included in the budget.

b. **Real estate agents** A person may want to contact a real estate agent to assist with the housing search. Real estate sales professionals who have a real estate license designation have the credentials and training and are required to maintain a higher level of ethical standards. Bear in mind that real estate agents are paid through commission from the property owner, the seller, and represent their interests. There are also "buyer's agents" who will work for a fee for the purchaser. Real estate agents are in business to buy and sell real estate, and they will tend to want to move properties as promptly as possible. They will not readily adjust to the lengthy processes that we are accustomed to in the social services field so before engaging with a realtor a person should know their budget financing options and be ready to act if presented with an opportunity. The person should speak with the broker in the office, and ask if there is anyone in that office that has experience working with people with disabilities or working with accessibility issues. The relationship with the broker is important, as the client will be working closely with them for the duration of the housing search which could take many months. The New York State Association of Realtors recommends interviewing at least three agents to make sure that there is a personality and skill set fit.

(vi) HUD Certified Housing Counselors

Some lenders may require that a homebuyer attend a course provided by a HUD certified housing counselor. The person can be an invaluable resource for income-qualifying people to access in pursuit of home ownership. There may be more than one counselor in an area, so it is important to find someone to whom the person can relate.

a. **Assistance for first time home buyers** People with disabilities and people with low incomes can access a range of supports and financial incentives to help them to achieve home ownership.

b. **Down payment** There are state programs that will help with funding for down payment and closing costs when purchasing a home. For example, the Federal Home Loan Bank (FHLB) of New York's "Homebuyer Dream" program can provide up to $15,000 towards down payment and closing costs[118]. Municipalities and counties may also have programs that help with down payments and closing costs.

118 *https://web.secure.wellsfargo.com/mortgage/get-prequalified/?gclid=cdf44c9cadfb15d66aff24169518b149&gclsrc=3p.ds&&dm=DMICA7AVGG&msclkid=cdf44c9cadfb15d66aff24169518b149* Retrieved November 2022

c. **SONYMA Down Payment Assistance Loan (DPAL)**[119] is one such program that provides funds to home buyers for down payment assistance. The funds provided are the greater of either $3,000 or 3 percent of the home's purchase price, to a maximum of $15,000.

d. **Assets for Independence/Person Development Accounts (AFI/IDA)** The federal Savings for Down Payment program allows a person to save earned income (not SSI) and provides up to an 8 to 1 match. Savings of $1,000 may receive a match of $8,000 for a total of a $9,000 to be used for a down payment on a home. This program has not been funded since 2017 but could potentially be revived in future administrations.[120]

e. The **Affordable Housing Corporation (AHC)** issues grants to municipalities and non-profit organizations for the building or renovating of housing for those with low incomes. The corporation provides funds to promote home ownership and to revitalize neighborhoods. There are AHC grantees across the state, and the list of these can be found at the NYSHCR.ORG website.[121]

f. **Federal Housing Administration (FHA) Mortgage** These mortgages are insured by the Federal Housing Administration and created through commercial banks. They feature lower interest rates, low down payment options, and both fixed-rate and adjustable-rate options. Some lenders or banks may also provide grants that can offset closing costs. Whereas most of the low-cost mortgages above are limited in the amount that may be borrowed, and do not permit the addition of a second mortgage, an FHA loan has more scope and permits the addition of a second mortgage. This is especially important in areas where house prices are higher than average, such as New York City and the downstate counties.[122]

g. **State of New York Mortgage Agency (SONYMA)**[123] SONYMA provides a Low Interest Rate Program for first time home buyers. Up to 97 percent financing is available to people with low incomes and for property within a purchase price limit, which is based on the number of bedrooms and the region and ranges from $99,750 for a single-family home in a low-cost non-target areas to $1,896,200 in high-cost target areas for a four-family home. There are also regional income limits.[124] The annual income limit is also based on the family size and location. These mortgages are offered through participating lenders. SONYMA has a range of programs for first time homebuyers and those seeking to remodel or create access.

h. **Section 8 Home Ownership Program** This program allows people who are already in possession of a Section 8 housing choice voucher to convert it to first-time home ownership through a Public Housing Agency (PHA). The monthly tenant payment is generally 30 percent of the tenant's adjusted family income. People with disabilities receive certain preferences; for example, they do not have to be working full time to qualify, and there is no time limit on the duration of the housing subsidy.[125]

119 *http://www.nyshcr.org/Topics/Home/Buyers/SONYMA/DownPaymentAssistanceLoan(DPAL).htm* Retrieved November 2022
120 *https://www.acf.hhs.gov/ocs/programs/afi* Retrieved November 2022
121 *https://hcr.ny.gov/affordable-housing-corporation-0* Retrieved November 2022
122 *https://www.fha.com/fha_loan_requirements* Retrieved November 2022
123 *https://hcr.ny.gov/sonyma-programs#overview* Retrieved November 2022
124 *https://hcr.ny.gov/system/files/documents/2021/01/application-kit-for-pi-pf-cp.pdf* Retrieved November 2022
125 *https://hcr.ny.gov/section-8-home-ownership-program-0* Retrieved November 2022

(vii) New Models for Housing

In the past it was assumed that any home that housed people with I/DD would be owned by a state or provider agency. As Self-Direction and Money Follows the Person have become more of an option, new ways to create housing have emerged.

a. **A family or group of families owning** Families can singly or with other families combine to jointly own a home that houses their sons or daughters. The families share the property costs, upkeep and other maintenance costs, including replacement of major items like a boiler or a roof. As with home ownership by a person or persons with I/DD they have control over who provides services and supports, and much more autonomy than they would in a typical group home. This kind of arrangement requires thoughtful planning and a clear understanding of who is responsible for what and how the property owners interact with the provider(s) of services. Funding any mortgage or carrying cost is dependent on the DDRO establishing a "fair market rent" based on the typical property cost in the same area for a similar property[126], and ensuring that the amount is sufficient to cover carrying costs and "useful life" costs. Most importantly, how will the property owners resolve any differences with each other and what are their succession plans when they are no longer able to manage the property? Some families have been able to make this work, but there are many instances where the financial and social tensions that can arise from any joint business have led to the owners seeking another solution. The owners have significant responsibilities for upkeep, property management, financial management and commitment and tax reporting. They must make sure that the various stakeholders get along. Families must ensure that the people living in the home are able to leave if they wish, and if ownership is held jointly, that there are provisions to address the liquidity risk of joint ownership – there has to be a "prenup" and an exit strategy.

b. **Ownership by a Limited Liability Corporation, (LLC)** Creating an LLC is a relatively easy task for an attorney. The creators of the LLC can establish a board, preferably with a majority of members who are not related to people living in the home, and board members may be able to donate professional skills. A well-planned LLC ownership will include a Memorandum of Understanding with a provider of services, and may also include a relationship with a property management company. The LLC mechanism may ease the tensions that can arise from personal ownership by people with I/DD or their families. The LLC can borrow funds to purchase the property, or to improve the property. It can issue equity (for example, to a family member) to reduce the amount it needs to borrow, thus keeping carrying costs down. The LLC structure protects the residents from any Medicaid lien on their equity, and there is no lien on their property when they die. The rent can be supported by OPWDD at a "fair market rent" allowing for planning for maintenance costs

These three types of ownership structure are hardly exhaustive but are the basics from which to build an ownership that is not tied to services, creates more autonomy, and allows for preservation of capital. Any home ownership should only be considered after experience of living in a community and thorough planning including deep understanding of the needs and wishes of the people who might live there (and not just their parent's wishes!).

126 Not to be confused with **F**air **M**arket **R**ent ("FMR") HUD's rental support standard see *https://www.huduser.gov/portal/datasets/fmr.html* Retrieved November 2022

(viii) Residential Property Management

Provider agencies that operate certified settings receive an administrative fee and an overall budget that assumes they will monitor their properties for maintenance issues, ensure payments are made in time for utilities, insurance, mortgage payments, etc. Some agencies recognize the nature of this work and create internal property management roles. As people move into non-certified homes, the job of property management is assumed to be absorbed by the landlord - or if they own their own property, by the individual themselves or their family. For people new to property ownership, or who have difficulty in tracking funds and obligations, this can be a difficult task with opportunity for failure. Many nonprofit and for-profit residential property management companies have little experience supporting people with I/DD. Capacity for residential property management as a distinct function for provider or other agencies should be developed as a service option. Capacity needs to be expanded, possibly through more flexible Housing Subsidy administration or an expansion of Other Than Personnel Services (OTPS) in Self-Directed budgets.

Making the Decision! There is an excellent tool for understanding the factors involved in the decision to buy or rent available on the NY Times website *https://www.nytimes.com/interactive/2014/upshot/buy-rent-calculator.html*

7 Transition

Having planned for how to pay for housing and having located a future home, the transition process requires careful attention. For people relying on multiple strands of financial and social support ensuring continuity is paramount.

Seth Greenman, Master Housing Navigator from Region 1 provided significant advice and input to this section

Leaving a place where a person has lived for some time is always a challenging prospect, whether it is their family home, a certified setting, or moving on from an existing home. For a person with I/DD the challenges are compounded by the need to ensure preparedness for their new environment and continuity of their support. The person will need to prepare for the tasks of day-to-day living and taking care of themselves with help as needed. They will need to think about how they will feel about leaving where they have lived, how to stay in touch with people with whom they want to continue to be friends, and the initial shock of living alone or with different people. They will need to ensure a smooth transition of their support services and the funding for those services, especially for people who are changing systems or entering a new system of funding and support.

In person-centered planning we have learned that the people we support too often hear that they “are not yet ready”, or “we will do that sometime”, and in housing people hear “they are not quite ready to move on”. These responses tend to turn into an indefinite delay - no one is ever fully ready. While it is important to understand risks in transition and to address those risks as much as possible, it should not amount to an infinite delay.

Early focus on the knowledge and skills a person will need is helpful. Including these skills as tailored to the individual person in the person’s Individualized Education Program while in school, in their transition plan from school to adult life, and in their Life Plan as an adult are important. Learning these skills requires that the person assume responsibility for themselves and the people they live with. These skills need to be learned over years, preferably from the earliest point possible; frankly they may be more helpful than many of the academic skills we tend to focus on in schools. Each person is going to be different and will need to learn different situation-based skills. This Guide does not seek to provide that education but there are various curricula that focus on the basic skills that someone might need if they are to live more independently. These skills include things like laundry, food shopping, health management, safety, travel and money management.

Transitioning benefits and supports

OPWDD provides two types of transition subsidy for people who are moving into a home where they are responsible for the residence (i.e., their name is on the lease or mortgage). For those who are moving from certified settings, the transition subsidy is Medicaid-funded and is termed Community Transition Services or CTS. In OPWDD's 2019 Medicaid waiver the stipend was limited to $5,000 per person inclusive of security deposit and for one occasion only. [127] For people moving from any other setting into their own place (e.g., from a family home into their own apartment), the stipend is limited to $3,000 plus security deposit, and it is state-funded through OPWDD's Housing Subsidy Program (formerly ISS). The state-funded stipend, termed the OPWDD Transition Stipend, is also a once-per-lifetime service, with a few exceptions for emergency situations that are at the discretion of each Regional Office. Emergency Stipends are possible in situations such as damage to furniture, e.g., bedbugs or chronic incontinence, eviction through no fault of their own, such as hospitalization, theft or acts of nature. The stipends are not advances; they are reimbursements for actual (qualified) expenditures to provide for the basic furnishing of the new home.

The NY Alliance created a brief explanatory webinar regarding the transition subsidies, available at *https://www.youtube.com/watch?v=4rRODGrfYu0&feature=youtu.be*

A smooth transition requires that all of the person's benefits and supports are transferred to the new environment. For example:

SSI or SSDI If the person is coming from a certified setting it is possible that the provider agency operating the certified setting is the Representative Payee ("rep payee"). That role needs to be transferred either to a trusted family member or friend, or to a professional rep payee such as a Fiscal Intermediary or another community-based agency outside of the pool of OPWDD provider agencies. The person may have accumulated savings while in the certified setting that must be transferred; for example, some agencies deposit any excess in a resident's account into a Pooled Trust, and the person may or may not wish to continue such an arrangement. Any funds held at transition by the certified provider agency as rep payee are sent back to social security, which then sends them to the new rep payee agency. This is time consuming and often produces a lag in benefits, which is why the person should consider two options:

(i) That the savings be withdrawn by the person and moved first into a separate account which they can access during their move.

(ii) That the rep payee transition happens prior to moving while the person is still living with the support of the provider agency.

SNAP Similarly, a person receiving SNAP benefits will need to take control of their own Electronic Benefit Transfer (EBT) card, either in person or with the support of someone they trust.

127 OPWDD Application for 1915(c) HCBS waiver NY 0238.RO6.00 Oct 01 2019 page 371

Community Habilitation Services must be scheduled to commence on the day that the person moves into their new home. If they are coming from a certified setting, the services at the certified setting stop on their final day and the CommHab must begin immediately. It is possible for a person to pursue residential CommHab while still living in the certified setting, as long as they are not in a Day Habilitation program full time. This can be done either through an agency-supported/direct provider CommHab option or through Self-Direction. Even though it may be limited, it allows the person to begin hiring and training CommHab staff prior to the move.

It is not possible to have any parallel transition time as Medicaid only funds one service at a time, so planning is essential to ensure continuity.

Assistive Technology If the person requires enabling technology it is important to identify who owns their current equipment, what they will need to do to ensure continuity of their support needs/ internet service, and who will help them to make sure that their technology works and is reliable.

The range and capability of Assistive Technology as it relates to housing is very broad. To learn more about the subject view "Assistive Technology" presented by Meghan O'Sullivan as part of the "Statewide Learning Institute" in 2019 *https://youtu.be/kTR-J13WTlk*

Personal Finance To varying degrees, people living in the community will exercise control over and access to their own money. They and their support people will need to establish a local bank account, obtain an ATM card, and have help in ensuring that they use their resources wisely, including planning for everyday or major purchases. The person and their professional and nonprofessional support should agree on a degree of oversight which preserves autonomy but addresses risks such as being taken advantage of or missing critical payments.

Medical Services

A person coming from their family home may have to transition from a pediatric care practice (many people with I/DD continue to receive primary care from a pediatrician well into adulthood) to an adult primary care doctor. If they are coming from a certified setting the provider may have been linked to an Article 16 or Article 28 clinic and been providing regular clinical visits and wrap-around medical services. Living more independently will necessitate establishing new relationships, as well as learning how to interact with physicians. For many people seeking to live more independently, they may be leaving a setting (certified or otherwise) where someone is responsible for oversight of their medical information, including appointments, lab work, physician recommendations, etc. Online patient portals in conjunction with a plan for ongoing check-ins and support are important considerations to ensure continuity. If a person receives additional behavioral health support that must also be considered, especially if it is likely that long-term relationships with providers may change. A helpful resource in this transition is "My Health, My Choice, My Responsibility", a series of seminars created in partnership with Self-Advocates to assist people with I/DD transitioning to adult medical resources.[128]

Medication Administration "Under the state's Nurse Practice Act the only person permitted to administer medication if an individual is not living in their family home or a certified setting and is unable to administer the medication themselves is a Registered Nurse (RN). This clearly

128 My Health, My Choice is available at *https://www.wihd.org/resources/resource/health-self-advocacy-my-health-my-choice-my-responsibility* Retrieved May 2020

limits how many people with even modest medical needs can live and be supported in the community."[129] Assistive technology can enable many people who need scheduling or dosage reminders to help them take their medication. A provider agency may agree to train the CommHab staff per Approved Medication Administration Personnel (AMAP) procedures, or have the work closely supervised or coordinated by a Registered Nurse. An alternative is the ability of self-hired staff working under Consumer Directed Personal Assistance Services (CDPAs) funding from the New York State Department of Health to perform nursing duties. These duties can include assistance with medication by the personal assistant, who is trained by a family member or another person who acts as the consumer's surrogate. It is not clear why this is available under the DOH Waiver and not under OPWDD's Waiver, but it is possible for a person to receive services under both waivers as long as services are not provided at the same time.

If a person's medication is delivered to them, their new address must be in effect to ensure continuity.

Moving

Creating a plan for the movement of furniture and belongings is an important step in a successful move. The person and their Circle of Support may be able to work with local furniture retailers to schedule delivery for the day of the move, or furniture may be delivered in advance as needed. Either way, the person's belongings and any transition stipend purchases or furniture must be prepared and ready to move. Also, a moving company could be considered if not cost-prohibitive, and this expense may be eligible for reimbursement through transition stipend funds. Additionally, if furniture will require assembly, it is important to plan for this to prevent furniture orders from sitting in boxes and remaining inaccessible to the person. If equipment is needed for safety or accessibility, ensure a plan for its installation ahead of time as much as possible, which may require advanced communication with a property manager or landlord.

While it may appear obvious, ensure there is a plan for turning on and starting utilities prior to the move day to prevent disruptions in service. This is especially important for phone and internet services if the person will be relying on these services for communication or technology support. It is important to discuss who will be notifying the post office of the address change to prevent missing mail. Prior to the move, it is also beneficial to review local emergency services and make contact to inform them of the needs of the person who is moving, especially if they may need specific help in the event of an emergency. As part of this process, the person and their supports should establish and review an emergency plan, including an evacuation plan and emergency phone numbers with a contact list. Prior to the move, it is also beneficial to outline a plan for the presence of paid and unpaid supports during the move and in the immediate days and weeks after. Frequent check-ins or visits can allow for discussion of new concerns and direct observation of challenges in the home that the person may not be communicating.

Amid all the move planning, it is important to ask what the person's plan on the day of the move is. Some people prefer to keep a typical schedule by heading to work or day program and then to their new home. In these situations, it is important to ensure transportation has been notified and plans confirmed prior to the move day. Other people prefer to be a part of their move directly by moving boxes and setting up furniture or indirectly by sitting and watching. Either way, it is essential that the person who is moving be central to the planning process, including identifying his or her role on the day of the move.

129 Report to the Housing Task Force, NYSACRA 2015 p.28 https://nyhrc.org/resource/report-to-the-housing-task-force/ Retrieved June 2020

8 Sustaining

Once a person is secure in their home the work enters a new phase; the creation of long-term sustainability and security. Some of the people involved in creating the housing will be less involved while others in particular the professional wrap-around services, will assume a greater role.

Hank Lobb, Master Housing Navigator in Region 2, provided significant advice and input on this section.

Throughout the process of developing a housing solution our focus has been on the person and their Circle of Support. Bringing all of the necessary participants together and addressing all of the considerations from benefits, employment, housing supports, locations and companions will have taken considerable time. Patient and thorough planning, learning, and due diligence increase the likelihood of long-term sustainability for the Circle of Support and a lasting housing solution. For people seeking independent housing this process does not end when a person moves into their new home.

Professional Support

Housing Navigation, by its nature, is a relatively short-term service and the Housing Navigator will begin to reduce their involvement once the person is settled in their new home. Many Housing Navigators report that they remain involved in the person's life and attend periodic Circle of Support meetings for years afterwards but that is their own choice. The reality is that not every housing solution is right for a person forever. A person's needs and desires change, so the Housing Navigator may be needed again. However, other professional members of the Circle of Support will be required to remain involved. These include the Care Manager to ensure they receive the services they need; their Self-Direction broker to maintain their plans and to make sure they are able to sustain themselves; their Fiscal Intermediary, to ensure that their staff are vetted, trained, and paid; the agency that administers the Housing Subsidy contract, which should make sure that rent and utilities are paid on time; their Representative Payee to make sure their Social Security benefits are received and used appropriately; their Community Habilitation staff to provide continuing services and to make sure they are doing well; and their medical providers to ensure good health. All of these professionals are of course "Mandated Reporters". They are required to notify the authorities if there are any signs of abuse or neglect. If a Benefit Adviser has been involved from the start it would be helpful to have them perform a periodic review to ensure that benefits remain optimized. If the person has a Trust or an ABLE account, then the trustee is responsible for ensuring the funds are spent appropriately. If the person is subject to guardianship of their funds or of their person, then the guardian must assume overall responsibility and be at the heart of the Circle of Support.

The web of compliance and billing requirements will ensure formal oversight, but such oversight is limited. Given the turnover rate in the service world the professional ring of the Circle will be difficult to sustain.

Volunteer Support

While the professionals in the Circle of Support can perform many supportive functions, the heart of a Circle of Support is likely to be a volunteer, a relative, a family friend, or a friend of the person. We can have all of the professional resources in place but what will matter most is love and affection for the person at the heart of the Circle. It is not necessary for those people to be constantly in the person's life, but there must be commitment and dedication to the person; someone who takes an interest in their life, who they know as a family member or a friend who cares for them. In a world of high turnover in Direct Care, the constancy of family and friends is vital to the person's wellbeing. If a person does not have family or friends who will care about them, the role will fall to the professional staff. There are exemplary social workers and Direct Support Professionals who love their work and bring that love to the people they support every day. Finding and retaining people with that high level of commitment is not easy, but it can make a huge difference for people who do not have people who are close to them.

All parents ask the question "What happens when I'm gone?". The only honest response is that this is an unanswerable question. In addition to the uncertainties we all face, people with I/DD must maintain or be supported in many ways. In the past, parents assumed that having their child live in an institution was best for the child and for the family. With the advent of group homes, the assumption shifted to trusting that while their son or daughter might still be segregated or congregated, they would be forever safe and well-supported. We have learned, though, that the more congregated a setting, the lonelier the people within it, the more liable they are to experience neglect and abuse. We know that the legacy group homes are so costly as to be unsustainable. The more diversified the support networks we can create, the more "eyes on", the more independence we can help someone achieve, the more rewarding and sustainable their life is likely to be. The answer to "what happens when I'm gone" is that we just don't know. The more we can build a safety network for the people we love, the better the outcome is likely to be - but the solutions don't come in a package.

Advocates have sought and continue to seek to create a role for a long term, well qualified professional with a modest caseload and a market-based compensation to take on the role of being the person's representative. Call the role Social Work, Coordination, Advocacy – all of the aspects that parents and family would have performed in their lifetime. Their job would be to make sure that the eligibilities, entitlements, rights, and responsibilities are maintained, but also to know the person well, to be their "go to" person, to be the focal point for service providers and staff. Hiring and retaining people of the necessary caliber may be demanding, but the rewards will be substantial. A person in this role could give families sufficient comfort to enable them to support transitioning from institutional settings to community settings, and to help the person with I/DD create a long-term robust support network, make friends, and find their place.

8 Conclusion

Finding an affordable and desirable place to live is always a complicated business. For people with disabilities, it can be made more complicated by additional needs and by the maze of eligibility and funding options that they have to navigate. New York State agencies, in particular OPWDD, are changing how they do business. What emerges will hopefully be more person-centered, fairer, more transparent, and more sustainable than the current certified housing model. While this change is underway, no new system resources have been created to help people to find a home. It is up to the person and their Circle of Support, including their family, their friends, and their service coordinators to create and implement their housing plan.

Throughout the Guide we have referred to "independent housing", but the reality is that future housing will be "interdependent." People with I/DD will rely on their Circle of Support but will also connect with their peers, their employers, and all housing related professions: bankers, real estate agents, attorneys, developers, and contractors. The housing advocacy issues for people with I/DD increasingly will have much more in common with those of people with other disabilities, people with low incomes, and older adults. It will require all of us who advocate for housing to collaborate with others rather than focusing solely on our own needs.

At last, Money is Following the Person, but with that new freedom comes more work and more responsibility. Although supported by law, regulation, and best practices, people who have sought independent housing have nonetheless experienced frustrating obstacles. These range from the institutional bias embedded in custom and regulation, to family and provider unwillingness and trepidation when confronted with change. We created this Guide to help people with I/DD and their families understand the issues and learn how to negotiate the path to housing. We will continue to refresh our knowledge and to work with families who set out on this sometimes intimidating, but always worthwhile journey.

In 2012, Westchester Institute for Human Development (WIHD) was awarded a grant by the Organization for Autism Research (OAR) Applied Research program to create a Resource Guide for families seeking housing for their adult sons and daughters with Autism Spectrum Disorder and other Intellectual and Developmental Disabilities (I/DD) in Westchester County, New York.

In 2014, WIHD received additional funding through a community grant awarded by Autism Speaks to augment the original work to cover the whole state of New York.

In 2018 the New York Alliance for Inclusion and Innovation received a grant from the Vivian and Peter Falco foundation to create "What Happens When I'm Gone", an examination of how people with I/DD, their families, and advocates can establish support networks and other measures to ensure sustainable housing for individuals with I/DD as they become adults.

The creation of this guide was supported, in part, through these generous grants.

This edition, which includes additional material and considerable revision, was created under the auspices of the New York State Developmental Disabilities Planning Council and the New York Alliance for Inclusion and Innovation. There are many people to thank for the continued interest in providing accurate and up-to-date information to people with Intellectual and Developmental Disabilities and their families, advocates, and people who provide support to them. Many thanks to my colleagues at the NY Alliance, Carol Napierski, Co-Director of the NY Housing Resource Center, an invaluable partner, friend and a consummate professional, and to Chris Liuzzo, a lifetime thought leader and advocate who created the bulk of the work on person-centeredness. Additional thanks to my NY Alliance colleagues Kate Connally, Jennifer Ivery, Desiree Loucks Baer, Susan Kittle, Katie Mayo, Lisa Mount, Kate Ng and Kirsten Sanchirico for their constant support, and to Ann Hardiman and Michael Seereiter for their advice and leadership in maintaining the NY Alliance as a unique organization. I am indebted to my former WIHD colleagues Karen Edwards, Marilyn Vitale, Lucille Rossi, Nicki Turano, Aparna Tantri, and Katie Borras for their invaluable insight advice and support. I am grateful to Susan Fox, Ph.D. President and Chief Executive Officer of WIHD, for her support in continuing this work. NY Alliance Master Housing Navigators Seth Greenman, Hank Lobb, Derek Taylor, Theresa Manuel, and Patricia Calandra have provided valuable insights from their direct experience. Thanks to Ashley Greenman for her thoughtful editing and to Kate Ng for her design work. Lastly, thanks to my daughter Zöe for her help in this latest revision and to her sisters Emma and Sophie for their devotion to their brother.

Beth Mount Ph.D. has been the standard bearer for Person-Centeredness and Self-Determination for people with I/DD in New York for many years. I am very grateful to her for allowing us to use her brilliant quilt design as our cover.

Westchester Institute for Human Development

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John Maltby

November 2022

The Housing Resource Guide

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Revised Edition Published
August 2025 by
New York Alliance for Inclusion and Innovation

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