NEW YORK
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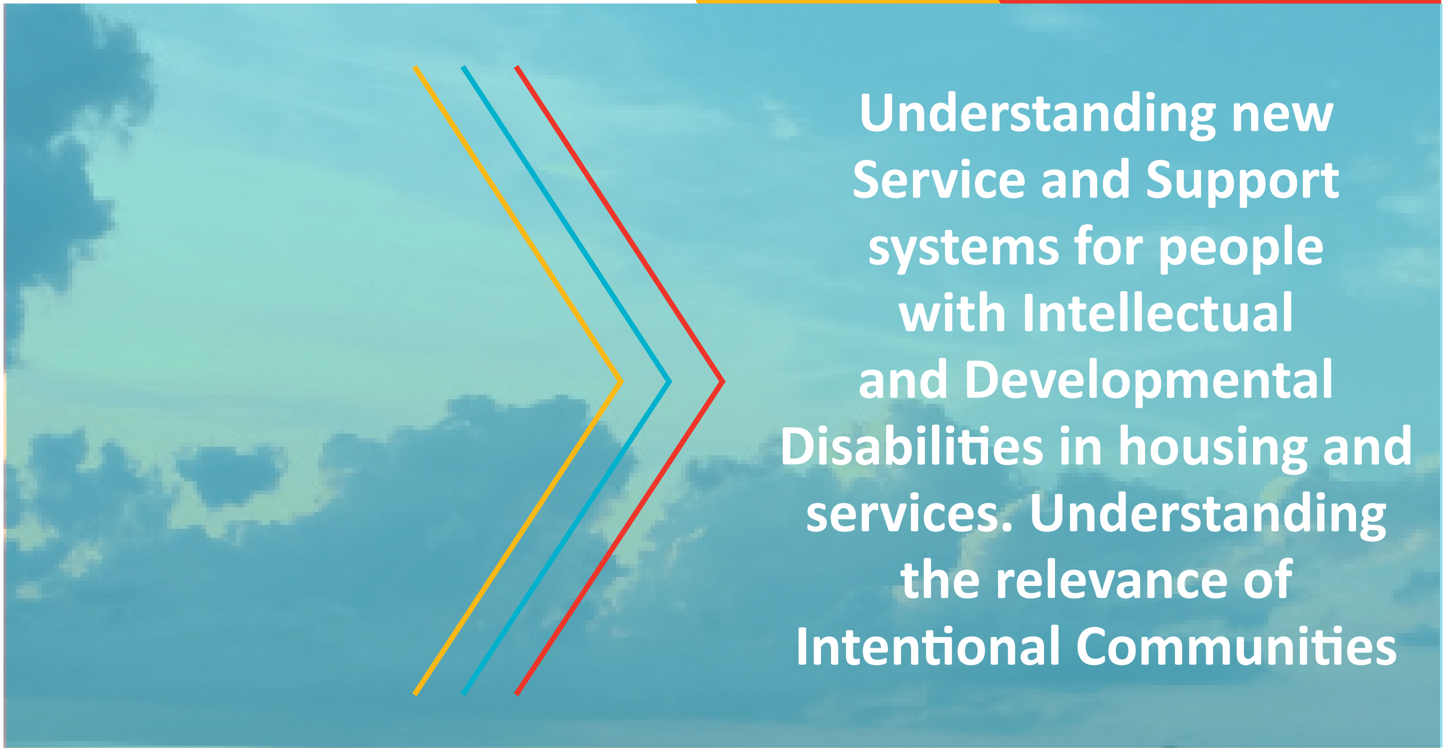
"WHAT HAPPENS WHEN I'M GONE?"

September 2018



Understanding new Service and Support systems for people with Intellectual and Developmental Disabilities in housing and services. Understanding the relevance of Intentional Communities

NEW YORK
ALLIANCE FOR
INCLUSION & INNOVATION
Strength Together

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Executive Summary

Support systems for people with Intellectual and Developmental Disabilities need to be healthy, safe, person-centered and of high quality, and they need to be sustainable for the long term. New York is going through significant changes in how its support systems are structured and how they will be paid for. These changes raise concerns from people with Intellectual and Developmental Disabilities and from their parents, family members and advocates. Parents ask “What will happen when I’m gone”, and the answers are unclear. This report seeks to provide some ways to address that question.

The report consists of six chapters that describe ways that people can prepare for the future using existing State and local services, as well as, generic or family resources. Additionally, it describes how support for decision making is essential to any truly person centered approach. The report describes current housing systems and reviews the differences between Certified and Non-Certified housing and new service options, particularly in housing, including Intentional Communities. The report concludes by highlighting some system flaws and providing suggestions for systems advocacy at a time when systems are evolving and perhaps open to change.

Research has established that smaller settings are more favorable for people with disabilities, and that these settings need to be genuinely community based. For many reasons systems have been far too slow to follow these best practices, but a sense of urgency is necessary now. Rahm Emmanuel, the mayor of Chicago, famously said “you never want a serious crisis to go to waste”. As systems in New York go through major change they are potentially open to rethinking how services are provided, who provides them, how can funding be used more effectively, equitably and sustainably, and how can people with disabilities become ever more part of the broader community.

Understanding new Service and Support systems for people with Intellectual and Developmental Disabilities in housing and services. Understanding the relevance of Intentional Communities.

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Introduction:

New York's institutional history, as chronicled in Paul Castellani's "from Snake Pits to Cash Cows" [1] 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.

When the Office for Mental Retardation and Developmental Disabilities ("OMRDD"), was created in 1977 its primary goal was to address the crisis in residential and day services that had been building for many years but which the Willowbrook expose had brought to the center of public attention. (OMRDD changed its name to "The Office for People With Developmental Disabilities ("OPWDD") in 2010). Over the next decades in partnership with nonprofit provider agencies the State created a system of group homes and day programs that transformed the lives of many thousands of people with Intellectual and Developmental Disabilities ("I/DD"). The system was built just as new funding mechanisms such as Medicaid and Supplemental Security Income ("SSI") were coming into wide application. The role of the federal government in supporting people with I/DD was increasing and the partnership between State and federal government became a crucial element in the creation of new services.

Forty years on, that system is still largely in place, but in some ways has become so braided through with structured funding streams and regulations that any innovation requires a level of financial engineering not normally seen outside Wall Street. The system has become unsustainably expensive. Even with strong encouragement from State leadership new ways to provide supports such as Self Directed Service Options ("SDSO") , first implemented in the 1990's and Money Follows the Person ("MFP") which passed into law in 2005 have been slow to catch on given the disincentives embedded in the current systems and the lack of incentives for innovative ideas. In the past several years however, the growth of advocacy for new solutions, threats to funding, and other capacity issues have added momentum to the movement for change.

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[1] Castellani, P.J. (2005). *From snake pits to cash cows*. Albany, NY: SUNY Press.

The system created forty years ago drifted back to institutional principles rooted in a more medically based approach to disability even though the Home and Community Based Services (”HCBS”) Waiver showed great promise of more person centeredness and community direction. The new ways to fund services, MFP and Self-Direction strive to overturn the assumptions of the old model. When people have the ability to choose services from multiple nonprofit and for profit providers, live where they feel best suited, with whom they wish to live, supported by people they choose to employ – then the system of supports is more open in design and more adaptable. People with I/DD in New York are at a crossroads as the new service delivery systems begin to replace the old, while at the same time new funding structures such as Managed Care Organizations (“MCO”s) will change how services are paid for.

Families are understandably frustrated by the different messages they are receiving from different providers and from the State and from the federal government. They are concerned about the future. Implicit in the legacy system was the expectation that at some point a person with significant support needs would be given a place in a group home, and that they would be thus “guaranteed” health and safety for the rest of their lives. This expectation still lingers in the system. In reality, even if there ever was an understanding or implicit guarantee of lifetime support it can no longer be said to exist. Under the new paradigm in order to provide long term health, safety and a decent quality of life people with I/DD and their families have to learn about, advocate for and be part of the creation of a new set of long term supports and safeguards that utilize a wider range of options than those provided solely by the I/DD system.

The current work seeks to clarify the issues involved in providing Long Term Supports and Services for people with I/DD in a system of Non-Certified supports and to describe some ways in which people with I/DD, their families and advocates can build sustainable support networks that can outlive their parents and to highlight areas where advocacy can be directed to ease the task of building support outside of the Certified system.

In 2015-16 NYSACRA[2] conducted a series of regional fora, parent meetings and community training sessions. One persistent question that arose in many of the meetings was “What Happens When I’m gone?” Parents of people with I/DD living in Certified and Non-Certified housing, or at home with their families are worried about how to ensure that their son or daughter’s health, safety and quality of life will be assured once they are no longer able to provide support or advocacy. Frustrated at the difficulty of accessing State or voluntary agency supports and housing, and a growing waiting list for supports as well as the difficulty of creating a home using the tools of Self Direction.[3] Some families want to learn more about “Intentional Communities” as a potential way to provide a home for their son or daughter and to address the “What Happens” question. While there are many variants of Intentional Communities the model runs counter to trends in federal and State views of best practice and funding and regulation. This misalignment has led to an impoverished dialogue between the principle funders and creators of housing and the people seeking alternative solutions.

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[2] The NY State Association of Community and Residential Agencies, merged with the NY State Rehabilitation Association (NYSRA) in 2018 and is now the NY Alliance for Inclusion and Innovation (“NY Alliance”)

[3] Self-Directed service overview at OPWDD website https://opwdd.ny.gov/selfdirection retrieved June 2018

The person with I/DD must be at the center of any discussion of their own future. Questions about how they will be supported, whether they wll live with other people, have to address the reality that in all likelihood they will outlive thier parents and perforce be independent of them.

Finding ways to reduce the anxiety expressed by individuals and their families is critical to creating long term support systems that can work in an environment of reduced spending, labor shortages and a recognition that the current models do not often comport with best practices or the desires of the people who receive services from them. The current work does not aspire to answering the "What Happens when I'm gone" question, but does seek to set out options and ways of planning that will help people with I/DD and their families to reduce risk and anxiety.

With generous funding from the Peter and Vivian Falco Family foundation, this project set out to understand the concerns families had voiced, and to find ways to develop support options that can be of practical use.

Method.

• Literature search.

Reviewed were scholarly literature, periodicals, government regulations and guidance and websites. Search Terms included “Long Term Supports & Services I/DD”, “Sustainability”, Independent Living”, “Shared Living” “Group Homes” “Intentional Communities”. “Founding texts” for two communities which had strong religious or spiritual underpinnings were reviewed, as well as, any available IRS 990 forms.

• In person visits.

The principal author made site visits to eleven Intentional Communities, seven in New York and three in neighboring states and one in Canada and met with representatives of a long established community in Europe. The communities were diverse: for example seven had a faith-based core, one was specific to a particular disability, one was focused on a broader population than just people with I/DD. The visits were informal and were undertaken to gather information and not to “audit” or critique the community. In every visit our hosts were exceptionally courteous and welcoming, and very open about their experiences, what works for them, what doesn’t, and their hopes and concerns for the future. The Communities were founded at different times within the last ninety years, were regionally diverse with at least one in each New York Developmental Disability Regional Office area (DDRO) of NYS OPWDD, each had different funding streams and types of regulatory oversight. Our work was not intended to arrive at a recommendation or rejection of any particular kind of community, but to learn from the wide range of experience of the people and places that were visited.

• Survey.

The most important individual in any discussion of housing is the person with I/DD who is seeking a home and support. Our task with this project was, however, primarily directed at parents and family members in order to understand the issues and concerns that they bring to the process of creating a home and a life of quality with their son or daughter as family members, advocates and guardians. Bearing this in mind the survey questions were directed at parents. The survey was sent to advocacy groups including Parent to Parent of NY State, Partners in Policymaking, the Self Advocacy Association of NY State (SANYS), NY Alliance members and social media groups of families throughout the State. Some 752 responses were received. The full report on the survey is attached as Appendix A.

A Note to the Reader

Understanding the issues involved in Housing for people with I/DD can be difficult. The person seeking housing and their advocates need to understand non-housing factors such as public benefits and how to preserve earnings and savings while optimizing them. They need to understand the kind of housing supported by the different State agencies and the federal government, and the nature of long term support systems. It is outside the scope of this present task to detail all of these factors. We recommend three publications that should accompany the present work.

1. The Housing Resource Guide ("The Guide") is designed for people with I/DD, their families and advocates who want to create a sustainable home. It is available at *http://nyhrc.org/images/WIHD-Housing-Resource-Guide---UCEDD.pdf*

2. The Shared Living Toolkit ("The Toolkit") is designed for people with I/DD, their families and also Provider agencies. It describes the range of Shared Living options that a person might consider, and the legal and regulatory mechanisms that govern Shared Living that includes paid support. It is available at *http://nysacra.org/images/Shared_Living_Tool_Kit_Report_new_FINAL.pdf*

3. In 2015 NYSACRA was funded through the Balancing Incentive Program to examine ways to increase Non-Certified housing options. They convened a task force comprised of experts from all of the housing related professions, and through a series of fora met with stakeholders throughout the State. In 2016 they issued a "Report to the Housing Task Force" – "The Report". It is available at: *https://nyhousingresourcecenter.starchapter.com/images/Report_to_the_Housimg_Task_Force_Final_Page_01.jpg*

Chapter 1. Preparing for the Future

Housing options are expanding and becoming more individualized. Housing is fundamental but housing by itself does not ensure a life of quality. Health and safety are important as are comfort in the home, recreation, friendships, engagement in the working world, economic independence and peace of mind about the future. This chapter describes how when services are “unbundled” people with I/DD and their families will create their own support and safeguards, and their own “Safety Networks”

To create safe healthy long-term support for a life of quality for people with I/DD their family and advocates have to be engaged in creating a new system, one that utilizes State resources but which does not entirely depend on them. The key to sustainability is to develop a well thought through plan and partnerships and resources for the person with I/DD that will be there when the parents or family are no longer able to provide support. Most families do not plan for the future. A survey conducted by Julie Lounds Taylor and colleagues [4] found that only 3.6% of the families surveyed had completed a basic list of planning tasks and a significant number of respondents had no plan at all. The reluctance to contemplate our own mortality is understandable but with State systems unable to assume the role of family caregiver it is vital that the work be done. What follows are practical steps that families can take.

Acknowledging the RISK

In developing plans for people with I/DD the concept of “Dignity of Risk” is often cited. As people become more autonomous, self-determining, the potential for risks to health and safety and the consequences of poor decisions have to be balanced with the “duty of care” of a supporting professional and the desire of the person to have control over their own life. Risk is a fact of life, it can be measured, predicted, evaluated and safeguards can be created but it can never be eliminated. Risk is a “Whack-a-mole”, just when you think you have calmed the risk frontier another risk appears. It has become clear that while institutional settings of all kinds in all walks of life may have structures that are designed to control behavior and risk, that they in fact simply divert it into other channels. The risk of abuse for people with I/DD rises in direct proportion to the number of people, the degree of segregation and the level of transparency of a particular setting. Agencies can fail, people can behave badly, and safeguards can be ignored. The best we can ever do is to be thoughtful about how safeguards are created and implemented, and to be wise to the ever-changing risk environment.[5]

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[4] Lounds-Taylor,J.et al Training Parents of youth with ASD to advocate for Adult Disability Services: results from a pilot Randomized Controlled Trial. Journal of Autism and Developmental Disorders, 47:846-857, 2017.

[5] In a famous attempt to eliminate risk General Electric implemented “6 Sigma” risk management, that is on any given event the chance of failure is .0003% - essentially infinitesimal. In 2018 a Southwest Airlines plane powered by GE engines lost a fanblade in mid-flight resulting in the death of a passenger. Risk is never conquered.

Assessment for services and budgeting - be careful what you wish for.

> *"It's understandable that people hope and wish that governments could be the ultimate safeguard when families are no longer able to protect and support their family member yet counting on this would be extremely unwise." Michael Kendrick "Safeguarding the Future."*

As required by the Centers for Medicare & Medicaid Services ("CMS") the federal overseer of Medicaid[6], New York State is transitioning to a more person-centered functionally based system. That is, rather than developing an individual's services based on a diagnostic label, the assessment will consider what a person needs in order to get through their day most successfully. The degree of support needed will relate directly to the budget [7] that an individual will be allocated. In the past families and agency staff understood this relationship between the degree of disability shown by the person being assessed and the size of the budget. The assessment process has been susceptible to this bias, hence, in part, the CMS directive. While it might seem a smart course to obtain the highest budget amount possible there are sometimes unforeseen negative consequences. There is a correlation between the cost of services and the degree of segregation and isolation[8], and we know that loneliness and isolation are killers[9].

Person Centered Planning

> *"I am interested in finding more appropriate roommates and using self-directed services so that we have more control over the staff and what the staff does to help our family member. We also want our staff to be part of the community which is not happening now."*
>
> *Parent Comment from Survey*

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 an "Individualized" program or plan pays lip-service to Person Centeredness while blithely setting a series of pro forma goals that are often unnecessary. While we have a long way to go we have seen improvement in recent years in New York. Partly in response to the years of Self Advocacy and promulgation of best practices, the HHS "Standards for Person-Centered Planning and Self-Direction in HCBS programs" per the Affordable Care Act, to training programs for support personnel provided by resources such as Council on Quality Care ("CQL") the focus is moving more towards the person at the center of any plan. Before any work on housing is undertaken 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. Included in the plan should be a letter of intent written by the person with I/DD and their caregivers, setting out their hopes and their intentions.[10]

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6 Note re Waiver conditions for CMS 1915 C on Medicaid.gov site https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html retrieved April 2018

7 See "ISPM" on page 12 of The Guide.

8 Fisher R. K. & Purcal C. (2010). Effective personalized housing support for people with disabilities – case study analysis. Australian Journal of Social Issues 45(4), 527-440. Retrieved from: https://search-proquest com.ezproxy.cul.columbia.edu/docview/821561127?pqorigsite=summon&accountid=10226

9 Holt L., et al. Loneliness and Social isolation as Risk factors for Mortality: A meta Analytic Review, Perspectives on Psychological Science 2015, Vol 10(2) 227-237

10 A guide to creating a letter of intent is available at https://www.specialneedsalliance.org/the-voice/letter-of-intent-3/ the website of the Special Needs Alliance. Retrieved May 2018

Partnerships.

• Create a circle of Support.

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 or 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 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[11] and to bring together resources for people who may at first seem to have little connection to family or other support.[12] The person with the disability should be in charge of who is in their circle.

• Partnerships with provider agencies.

> *"Analysis revealed that over half of adults with ID had no choice regarding where they lived"*
>
> *National Council on Disability*

The noted philosopher Sy Syms maintained that "an educated consumer is my best customer". 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. [13] Over time and with the advent of Managed Care many of these agencies will be vulnerable. Agencies have failed in the past for various reasons, but OPWDD has been able to prevent any undue 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 re-think 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, and that is focused on the individual is essential, but too often choices are made under pressure and on the basis of near term availability or convenience. Before deciding to obtain all or some of their services from a particular agency the person should perform their own due diligence. [14]

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[11] Amado,A. McBride, M. Increasing Person Centered Thinking etc . https://rtc.umn.edu/docs/pcpmanual1.pdf retrieved April 2018

[12] Family Finding connects people who may seem to have little family resources. http://www.familyfinding.org/

[13] Kendrick,M. Thinking about what keeps people safe. Belonging Matters Inc. Issue 34 March 2018

[14] 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.

- Review the Agencies 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 the composition and nature of their contribution history.[15]

- 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 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 a partnership with an agency, even with "progressive" agencies – It can be time for a change.

Building Personal Resources

There are many resources available to people of low income and people with disabilities that are designed to encourage savings and employment. What follows is a summary of the principle possibilities, it is not exhaustive. Planning to optimize income from employment and public sources is complicated with competing variables, - professional assistance is necessary.

• Basic Benefits.

People with disabilities that constrain their ability to work are eligible for a range of benefits. Most readers will be familiar with Supplemental Security Income (**SSI**), Social Security Disability Insurance (**SSDI**), **Medicaid** and the opportunities available through **OPWDD** and Adult Career and Continuing Education Services (**ACCES-VR**). These benefits are set out in the *Guide* (pages 11-13). The principle means of funding for non-certified living supports are available through Individual Supports and Services **(ISS**), Self Directed services options (**SDSO**), (pages 14-15), Supplemental Nutritional Assistance program (**SNAP**), Home Energy Assistance Program (**HEAP**) and supports for low cost phone coverage and energy continuation. (Pages 16-17). SSI, Medicaid, SNAP and HEAP are key elements for Certified and Non-Certified housing. ISS and SDSO are also important components of Non-Certified living. These are all vital to sustaining Long Term Supports and Services (LTSS). If a person is not familiar with all of these elements their Care Coordination professional should be consulted.

The following additional elements enhance the basic benefits and should be understood by anyone planning for long term sustainability.

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[15] 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 April 2018

• Employment.

For good or ill we are often defined by the work we do. Deeply embedded in our American culture is the idea that work is central to life, and that everyone who is able to should work if they can. Not only do people gain materially from work, but they join the larger society, increase social contact, and grow in their self-esteem. In 2012 OPWDD affirmed New York as an “Employment First” state,[16] an approach that seeks employment, at some level, for as many people with I/DD as possible. The Guide (Page 18) describes different forms of agency supported work. As people with disabilities increase their presence in the workplace new doors open up. People with disabilities who are joining the workplace will often do so in entry level jobs that do not pay well, and they may not be able to work many hours at first. However, by working they gain access to a range of programs that can allow them to work but to continue to receive their Supplemental Security Income (SSI) and retain their Medicaid eligibility. The oft touted myth that a person who receives SSI will lose their benefit if they go to work is simply wrong. However, navigating and optimizing benefits without compromising eligibility is a complex task, requiring expertise and perhaps professional help. (See Benefit Advisement later in this chapter).

Addressing Reluctance to Work

Participating in all of the above benefits requires participating in the workforce, but sometimes people with disabilities may elect not to work. We can’t “force” people to do anything. People have a right to choose, from the options available, the services that they need according to the level of support that is needed. Choosing to receive support, regardless of the type, comes with a variety of responsibilities. If you are a citizen of the United States you receive a social security number. This number entitles you to certain benefits. Depending on the decisions you make your citizenship entitles you to certain benefits, as well as it requires you to comply with rules created by the Social Security Administration. If a person wants to participate in the Medicare and Medicaid system they must comply with certain rules in order to continue to receive these benefits. Some states have imposed a work requirement in order to remain eligible for Medicaid.

As citizens of the United States we are required to follow laws set by the United States Government. Various decisions that we make or circumstances that occur in our lives may determine our ability to participate in the system. Living with a disability does not automatically allow one to be exempt from the expectations that all American Citizens must be a contributing member of society depending on their ability to do so, it does however, determine the capacity in which one contributes.

Person Centered Planning is a process that can assist us in actively listening and supporting someone to determine the capacity in which they can contribute to society. If a person chooses to receive services but electively disregards the rules associated with those benefits then advocates and providers need to support the natural consequences that occur when those decisions are made. People living with disabilities have a right just like the rest of the citizens of the United States to experience the consequences of our justice system. [17] Helping the person with I/DD mitigate risks can be a helpful direction.

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[16] Employment First, an initiative of the US Dept. of Labor adopted by NY State in 2012 https://www.dol.gov/odep/topics/EmploymentFirst.htm retrieved April 2018

[17] I am indebted to Kirsten Sanchirico of NY ALLIANCE for her thoughtful advice on “reluctance to work”.JM

• Protecting Earnings

Social Security Administration (SSA) programs such as Impairment Related Work Expenses **(IRWEs)**[18] and Plans for Achieving Self Support ("**PASS Plans**") [19]are designed to help people get a foothold in the workplace by agreeing to exclude an agreed amount of earned income from consideration of their "countable" income for SSI purposes. For people living in public housing the department of Housing and Urban Development (HUD) provides support through the Earned Income Disregard ("**EID**")[20] which reduces and defers the impact on rent cost of a person going to work.

The SSA also discounts earnings 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[21]. This would include people working in Supported Employment ("SEMP") or in an Employment Training Program ("ETP")

• Earned Income Tax credit ("EITC") [22]

The IRS program provides a cash payment to people with Extremely Low Income [23]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. (See "CASH coalition later in this chapter).

• Parent Earnings and Childhood Disability Benefit (CDB)

If a parent paid Social Security Contribution[24] in their working years then they will be entitled to a Social Security payment when they reach the age of 62. The amount payable will depend on the parent's lifetime earnings and will increase for each year that they defer receiving Social Security, reaching a maximum if they wait until the age of 70 to start taking the payment. If they are the parent of a child with a disability that meets certain conditions, then their son or daughter will receive an amount equal to half of the amount the parent receives while that parent lives, and an amount equal to three-quarters of the amount of the parent's payment when the parent dies. The amount is capped at a family

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[18] Impairment Related Work Expense. See Social Security website https://secure.ssa.gov/poms.nsf/lnx/0410520001 retrieved May 2018

[19] PASS Plans see Social Security website https://www.ssa.gov/disabilityresearch/wi/pass.htm retrieved May 2018 and "PASS Online" from Cornell University http://www.passonline.org/ retrieved May 2018

[20] EID, see HUD Website https://www.hud.gov/program_offices/public_indian_housing/phr/about/ao_faq_eid retrieved May 2018

[21] For "Subsidies and Special Conditions" see SSA website https://www.ssa.gov/disabilityresearch/wi/subsidies.htm retrieved May 2018

[22] For an EITC Calculator and information check the IRS website https://www.irs.gov/credits-deductions/individuals/earned-income-tax-credit retrieved May 2018

[23] "Extremely Low Income" as defined by HUD is income that is 30% of the Area Median Income or "AMI" as defined by the US Census.

[24] Federal Insurance Contributions Act ("FICA") includes Social Security, Hospital Insurance (Medicare) old age and disability payments. Strictly speaking these are insurance payments rather than taxes and beneficiaries should feel entitled to receive them.

level, and to the amount the parent would receive had they deferred payment until the age of 67. The amount can be substantial. For someone who has paid the maximum amount into Social Security throughout their lifetime and who has reached the age of 67 in 2018 the monthly amount payable to their child would be \$2,788÷2=\$1,394 in their lifetime and \$2,788÷1.3=\$2,091 upon their death. This amount would be paid monthly for the remainder of the child's life and will be adjusted for Cost of Living changes during that time. In this example a person living for thirty years after their parent's death would receive \$752,760 in present day dollars. There are effects on SSI and Medicaid that need to be understood in consultation with a benefit adviser.

Benefit Optimization

The information above is only an outline, and each person's circumstances may be different. People with disabilities can work and continue to receive their benefits, although the income from benefits will decline once they begin to earn more, their overall income will increase through employment.

- **Protecting the person's Savings.**

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 and these too can be protected from consideration by SSA when determining a person's assets. Individual Development Accounts ('**IDA**"s) which may be federally funded or 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. [25] Savings in *qualifying* IDAs are not counted as assets when SSA considers SSI eligibility. Credit Cooperatives and banks may provide **Matched Savings** programs[26] 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 as such are subject to asset and income restrictions. Qualifying matched savings programs are also exempted from consideration in "countable income". People living in HUD funded housing may be able to enroll in a Family Self Sufficiency ("**FSS**") plan, [27]usually to purchase a home or to achieve an education or employment goal. The plan will set aside rent increases due to increased income and repay them to the family once the plan is successfully completed.

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[25] "Everything you need to know about IDAs https://prosperitynow.org/everything-you-need-know-about-individual-development-accounts-idas retrieved May 2018

[26] As an example of Matched Savings see Federal Home Loan Bank website "First Home Club" http://www.fhlbny.com/community/housing-programs/fhc/ retrieved May 2018

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

• Other Sources of savings.

The Guide (p.19) describes the three main Supplemental Needs Trusts (**SNT**s) – **First Person, Third Party and Pooled.** It is beyond the scope of this report to describe trusts in full but there are many sources of information that are helpful[28]. It is important to consult with an attorney whose practice includes Disability Law rather than simply Elder Law. If there is an expectation that a person's CDB is expected to exceed the Medicaid income threshold then a first person trust should be considered to reduce the impact of any Medicaid "spend down". For families who can afford to place assets in a third party trust or to fund it with a life insurance policy there is the advantage of flexibility in disposition of assets when the beneficiary dies. Of the people surveyed in this project more than half had created an SNT.

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 $15,000 in any calendar year. Account holders may also set aside an amount equal to the Federal Poverty Level of $12,140 from their own earnings annually. 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 liened. 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. ABLE accounts have been slow to catch on in New York- of the people in the Family survey only 5% had created an account.

Credit.

The use of credit can have mixed results. Just like everyone else people with disabilities may need a credit record in order to obtain a loan, make purchases or to obtain housing. Properly used credit can open opportunities, if abused it can be destructive. Financial education is essential (See CA$H below). People can build a credit record through having a credit card in their own name perhaps with a pre-agreed spending limit or be an authorized user on a parent or family member's account. People who have used their SSI to pay rent as their share of the family home cost, or to a landlord, or to a provider agency that operates a Certified setting should ask their landlord to report their punctual payments (that is, assuming they are punctual!) to one of the credit agencies[29]. They will build their Fair Isaac Corporation (FICO) score over time which may literally open doors for them.

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[28] Among other sources, "Special needs Answers" https://specialneedsanswers.com/what-is-a-special-needs-trust-13601 or Justia Lawyers https://www.justia.com/lawyers/social-security-disability-ssi/new-york retrieved April 2018

[29] Experian http://www.experian.com/rentbureau/renter-credit.html

Benefits and Financial Advice.

Bringing all of the elements of employment and savings together requires knowledge of how to make sure that important eligibilities and benefits are optimized and not jeopardized.

- It is vital that someone entering the workforce consult with a Benefit Adviser. Benefit Advisement services are available from provider agencies and Independent Living Centers[30] and are funded through two sources; ACCES-VR a service of the NY State Education Department and Family Support Services ("OPWDD FSS"). It is important to verify that the Benefit Adviser has been trained. The online training and certification program at Cornell University is highly recommended.[31]
- Free tax preparation, assistance in obtaining EITC, financial literacy training and first time homebuyer training are all available at no charge from members of the Creating Assets Savings and Hope (CA$H) Coalition[32] and the Volunteer Income Tax Assistance (VITA) program which is available in every county in the State.[33]
- The federal Consumer Financial Protection Bureau ("CFPB") publishes a guide; "Your Money, Your Goals" with a Focus on people with disabilities. The guide can be used by a person with I/DD themselves or with support. The guide is available from the bureau's website which also includes a financial literacy and planning toolkit. [34] At a more advanced level the Federal Deposit Insurance Corporation ("FDIC") has a series of trainings in adult financial literacy that can be provided in multiple formats and languages.[35] A third resource that provides easy to follow information on good financial habits including how to obtain credit, save and follow a budget, is available from the Khan Institute and Bank of America.[36] [37]

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[30] Independent Living Centers, created by the 1973 Rehabilitation Act and funded primarily through NY State Depot. Of Education. For an ILC near you check http://www.ilru.org/projects/cil-net/cil-center-and-association-directory-results/NY retrieved May 2018

[31] Benefit and advisement training http://www.yti.cornell.edu/ and http://edionline.org/productdisplay/work-incentives-planning-and-utilization-benefit-practitioners-certificate-series retrieved May 2018

[32] CASH. A listing of CA$H Coalition advisory centers is available on the NY Housing Resource Center website https://nyhrc.org/about.php

[33] VITA information available from the Office of temporary and Disability Assistance (OTDA) at http://otda.ny.gov/workingfamilies/vita.asp retrieved May 2018

[34] CFPB Websitehttps://www.consumerfinance.gov/practitioner-resources/your-money-your-goals/toolkit/ retrieved May 2018

[35] FDIC Website https://www.fdic.gov/consumers/consumer/moneysmart/adult.html retrieved May 2018

[36] Bank of America https://bettermoneyhabits.bankofamerica.com/en retrieved May 2018

[37] I am indebted to Melinda Burns from Wildwood agencies (Albany) for her work on financial literacy.

Chapter 2. Tools and Supports to Guide 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 that states, "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. This chapter describes some of the history and new approaches.

Guardianship

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"[38] and also article 17A.

In 1969 The Surrogate's Court Procedure Act ("SCPA") was amended to include article 17A 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 individual liberty" and does not allow for partial decision-making authority for the person[39]. 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 nonetheless to obtain guardianship. There are resources to assist with the process provided by the Surrogate's court[40] and also available through OPWDD FSS for Guardianship guidance offered by provider agencies.

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[38] Guardianship for incapacitated people in New York under Article 81. Senior Law.com http://www.senior-law.com/guardianship-for-incapacitated-people-in-new-york-under-article-81/ retrieved May 2018

[39] I am indebted to Farrel & Fritz website "Surrogate's Court Procedure Act Article 17-A and its Ever Changing Landscape" http://www.farrellfritz.com/surrogates-court-procedure-act-article-17-ever-changing-landscape/ retrieved May 2018 (JM)

[40] NY State Unified Court System http://www.farrellfritz.com/surrogates-court-procedure-act-article-17-ever-changing-landscape/ retrieved May 2018

Health Care Proxy

Common sense dictates that everyone should have a Health Care proxy, someone chosen to make health care decisions "when your doctor has determined that you are not able to make health care decisions for yourself". [41] 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 to granting more control to the individual for whom guardianship is sought and limiting the power and control of the guardian.

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 common experience of consulting or seeking assistance from others when making decisions or choices in our own lives.

People with intellectual or developmental disabilities 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 it out. 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 intellectual or developmental disabilities 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. Although not as yet legally binding on third parties (like banks or healthcare providers) in New York, supported decision-making agreements, and the relationships that underlie them may be used as an alternative to guardianship.[42]

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[41] Health Care Proxy guide. NY State DOH https://www.health.ny.gov/publications/1430.pdf retrieved May 2018

[42] I am indebted to Desiree Loucks Baer from NY Alliance for her discussion of Supported Decision Making.

Independent Living Centers.(ILCs)

ILCs were originally created through the Rehabilitation Act of 1973 “key language in the Rehabilitation Act, found in Section 504 of Title V, states that: No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.” [43]ILCs are found in almost every county in NY State. They can be an invaluable resource in ensuring individual rights under the ADA and other anti-discrimination legislation including the Fair Housing Act. ILCs participate in identifying and promoting accessible public and private housing and collaborating with the NY State Division of Human Rights to ensure people with disabilities have an advocate if they encounter illegal discrimination. They run educational and training programs for people with disabilities and for advocates and are often an important presence in local politics and activism on behalf of people with disabilities. One key characteristic is that ILCs are run by and for people with disabilities with the majority of their board and staff required to be people with disabilities. It is important to know the local ILC and to be supportive and involved in their work. A link to the NY Directory of ILCs is below.[44]

Assistive technology (AT)

AT is a field where change is happening at a rate faster than regulators and funders can keep up with. AT from apps, Mainstream Technology: technology devices such as tablets, Smartphones, PDAs and laptops, broadly categorized as mobile personal computing devices that can be purchased in stores or on line to vendor products such as medication dispensers and telehealth equipment.

In the 10 years since 2008 when the first “app” became available the ease of use, availability and reduced cost of technology that can help people with disabilities has greatly increased potential for independence. There are several principle ways in which AT can help to augment the role of personal staff and family support.

• Communication/Alerts

Cell phones are ubiquitous and adaptations for people with cognitive disabilities allow for use by a wide range of people. When someone is not able to use a phone there are wearable devices that can help with emergency communication, identifying locations and alleviating concerns about wandering, from pendant systems to GPS watches.

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[43] For his quotation and other historical information regarding the ILCs see a History of Independent Living http://cilncf.org/cil-history/ retrieved May 2018

[44] ILRU Directory of ILCs in New York State http://www.ilru.org/projects/cil-net/cil-center-and-association-directory-results/NY

• In-Home Safety.

Learning to cook for oneself and others, alone or with support, is a key to independence, not least the fact that home cooking tends to be both more nutritious and less expensive than processed or restaurant foods. Alerts that can sound and also notify support staff directly or remotely if a stove, or other appliances, are left on, or that will turn the appliance off automatically within a certain time. Alerts can be used to notify whether a fridge is empty or being opened too frequently or a person gets up more or less than expected at night. Motion detectors can provide an alert if someone falls, or if someone is inactive.

• Health.

- **Medication administration** is highly regulated under New York's Nurse Practice Act and this regulation by itself may limit a person's ability to live independently. (See "the Report" p.27). Self-administration of medication may be made possible with a range of medication dispensers that, for example, have an audible alert, control the amount that can be released within a defined time period and notify support staff of adherence.

- **Telemedicine.** A Management tool for chronic conditions and general health. People with I/DD are diagnosed with chronic health conditions at a far greater rate than the typical population. "Significant disparities in health and medical care utilization were found for adults with developmental disabilities relative to non-disabled adults". [45] Telemedicine can use app –based and other technology to monitor vital signs on a regular basis, in the low stress environment of a person's home rather than in the more demanding (and expensive) environment of a clinic freeing up time, reducing transportation costs and providing more accurate measurement. Telemedicine can be used to visually diagnose and monitor skin conditions or injuries for example. The Veterans Administration, one of the nation's largest health providers has been using telemedicine for more than a decade to monitor long term health, including diabetes, blood pressure, weight etc., to provide case management and to vastly improve health care options for people living in rural or underserved communities. The technology is proven, the field of Developmental Disabilities needs to catch up.[46]

- **Staffing.** AT can be used to allow staff to record their arrival at a location, track tasks performed and fulfill compliance recording requirements as well as for communication and skills training.

People with I/DD, their families and the people who support them still struggle with how to pay for even low cost applications and issues around surveillance, control, privacy of health information and other issues. As the use of AT becomes more generalized in the non-disabled population it is time for advocates to insist that all options be made available, by right, to people with I/DD and that Medicaid and State regulations recognize

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[45] Havercamp S.H. et al. Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina, Public Health Reports, 2004, Jul-Aug, 119. (4) 418-426

[46] Telehealth is the broad term which includes using video links to provide training and other non-clinical activity. Telemedicine refers specifically to clinical services.

the new reality. In 2015 NYSACRA received a grant from OPWDD through the Balancing Incentive Program (BIP) which included funding for Person Centered thinking & Planning, Housing Services and Assistive Technology (AT). The AT segment of the grant included the creation of a comprehensive assistive technology (AT) curriculum and pilot program to assist a person in transitioning to a least restrictive home environment with the support of AT. This report, NYSACRA BIP Grant Data Report, is a product of the AT pilot program segment of the NYSACRA BIP Grant through which at least two individuals were able to successfully move to a Non-Certified home with the use of technology. To learn more about AT visit **http://nyalliance.org/Assistive_Technology**

Housing Navigation

Finding a home can be a difficult process. For people with I/DD there are additional hurdles and barriers to housing. People with I/DD are finding housing of different kinds: alone, with roommates in apartments and houses in cities, suburbs and the country. They are entering a market where safe affordable and accessible housing is scarce. They have to be knowledgeable regarding public benefits, earning income and protecting savings. Balancing all of these factors and creating and executing a housing plan is a daunting challenge fraught with pitfalls and impediments.

In 2016, the then NY State Association of Community and Residential Agencies (NYSACRA, now the New York Alliance for Inclusion and Innovation – "NY Alliance") received funding from the State through the federal Balancing Incentive Program to explore ways to increase housing options for people with I/DD in the State. One of the products of that work was "The Report". It was evident from the stakeholder input that there was negligible guidance and support for people with I/DD, and their families who were seeking to create individualized long-term housing. NYSACRA created a "Housing Navigator" training which was aligned with the guidance from CMS -"Coverage of Housing-Related Activities and Services for Individuals with Disabilities"[47] but which also focused on how to acquire and optimize benefits and earnings, and how Affordable and Supportive housing is created. The course includes 28 hours of in-person training and 8 hours of online education. Since the first class was held in 2015 some 170 people have been graduated from the course, from all parts of the State, and from all types of stakeholder constituencies including OPWDD staff, provider agency executives and staff, board members, parent organizations and housing professionals. Housing Navigation is a powerful way to assist people in planning their future and helping them to achieve a sustainable home. The Housing Resource Center at NY Alliance can provide information on Housing Navigators in different regions of the state.[48]

The creation of a "Safety Network" that will preserve a person's health, safety and quality of life takes a lot of work. The resources we have described are just some of the ways that the network can be created. It is important to access services that are not solely within the world of I/DD, to make alliances with other disability groups, people who are aging, people who are seeking affordable housing and secure employment. There are many opportunities to work and advocate together.

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[47] CMS Informational Bulletin June 26, 2015 "Coverage of Housing Related Activities and Services for Individuals with Disabilities https://www.medicaid.gov/federal-policy-guidance/downloads/CIB-06-26-2015.pdf retrieved May 2018

[48] HRC Website http://nyhrc.org/directory.php

Chapter 3. A Housing Overview

Housing is not only a critical Social Determinant of Health but is the essential foundation on which people build a life. Because it is so central to Long Term Supports and Services ("LTSS") it is necessary to review housing options first. Chapter 3 describes Certified group homes and Non-Certified group homes, providing some history and discussion of how they are operated and funded, and the outlook for both types of housing. Ideally housing options would follow a continuum from highly supported Certified settings to Non-Certified settings that provide only modest support. NY State is not yet in a position where all options can be made readily available across the spectrum of need. Ways to change this are discussed.

Housing Sustainability.

There is a critical shortage of housing opportunities for people with I/DD in New York State. This shortage of housing has deeply affected the families of people with I/DD. As parents age and they are less able to provide support to their son or daughter they become understandably anxious about the future. They fear that with no housing available their son or daughter will become homeless, destitute and uncared for. They yearn for reassurance that the State and Voluntary sectors will provide a guarantee that their son or daughter will be taken care of once they are gone.

The Certified group home options developed in the 1970's and the decades since the deinstitutionalization movement began are no longer able to provide for the housing needs of a growing population. While a vast improvement on the institutions it has replaced, the system can often be segregated and expensive. There are great challenges to the recruitment and retention of the workforce and it no longer comports with best practices. Housing that is Non-Certified is increasingly an option, providing flexibility, individualization, lower cost and follows many different modalities but it is difficult to establish, and operating Non-Certified supports is not incentivized in New York

The "Report to the Housing Task Force" ("the Report") (NYSACRA 2016[49]) described many of those issues, and while some have been alleviated in the time since its publication many obstacles remain. Central to the report was the recognition that based on conservative estimates of prevalence there are some 225,000 adults with I/DD living in New York who will need Long Term Supports and Services (LTSS),[50] including some level of housing support. The State Office for People with Developmental Disabilities (OPWDD) serves some 126,000 people[51], 67,000 with residential support, including 38,000 in certified settings[52]. This implies that there are 100,000 adults in our State who are either receiving

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[49] Maltby, J., & Napierski, C. (2015). Report to the housing task force. Albany NY 2016

[50] Prevalence: the Arc https://www.thearc.org/learn-about/intellectual-disability Retrieved May 2018 and Braddock et al. (2017) The State of the State in Developmental Disabilities, AIDD p.74

[51] OPWDD website https://opwdd.ny.gov/ and variants used throughout.

[52] Braddock et al. The State of the State in Developmental Disabilities, University of Colorado http://www.stateofthestates.org/ online charts for NY State

their services from the Office of Mental Health, or the Office for Alcoholism and Substance Abuse Services, or from the Office for the Aging, - all of which provide support to people with I/DD and /or a co-occurring condition, or they are receiving no support at all other than basic economic support from Social Services. Some may be incarcerated. This implies in turn that there is a large number of people who may not be receiving optimal services or support.

What is Certified Housing?

In 1974,[53] the federal government addressed a mounting 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. As it emerged that the majority of people did not need a nursing home or institutional level of care states were permitted to create Intermediate Care Facilities ("ICF"s). 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. In 1981 with the advent of Medicaid Waivers[54] 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 and potentially less regulated settings. In New York these became known as Individualized Residential Alternatives ("IRA"s). Services and supports were to be unbundled and more individualized, person centered settings could be developed. Funding would come through a Home and Community Based Services Waiver ("HCBS"). Generally, IRAs were smaller than ICFs and with fewer residents and might utilize apartment buildings as well as houses. IRAs were also made subject to certification for any number of reasons but the primary one being that the SSI rate was higher for an individual in a supervised congregate setting. "Family Care" a model of adult foster care established in 1931 under which an (unrelated) host family is funded to provide a home for a person with I/DD was also brought into the Certified and HCBS system eventually. ICFs, IRAs and Family Care settings may be operated by the state itself or by not for profit provider agencies, sometimes called "voluntary" agencies.

Padavan Law 1978 N.Y. Laws ch.468,2 The statute is named for State Senator Frank Padavan chair of the State Senate Mental Hygiene and Addiction Control Committee 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. The Padavan Law however, did allow, when institutions in NY were legally mandated to place many people with disabilities in the community rapidly (through the Willowbrook consent decree) 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.

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[53] Technically ICFs were created in 1972 but there were no regulatory guidelines until January 1974

[54] See The guide p.13

The average ICF in New York houses ten people,[55] there are several in the state that house more than forty people. Most IRAs house 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 many more.

> *"For now while I am here and living I can help with his Self-Direction ("SD") plan. As I age and can no longer oversee this plan is where I am concerned-but SD is the best alternative for him to live his best life now even with all the work/effort I need to put forth"*
>
> *Parent comment to the Survey*

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. 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 oversees Medicaid funding advised states to understand and better clarify their waiting lists. In response NY 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"[56] a thorough review of the waitlist. One outcome from the report was the creation of the Certified Residential Opportunities ("CRO") protocol which initially created a numerical priority scale but in June 2016 identified 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 the Governor announced plans to create 459 new certified beds over the next several years to meet demand,[57] 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. Given the reduction in capacity, opportunities for Certified housing are limited and likely to remain so.

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[55] Braddock op.cit online NY State profile "Persons served by setting" retrieved May 2018

[56] Office for People With Developmental Disabilities. (2016). Report to the legislature: Residential request list. Albany, NY: Author .https://opwdd.ny.gov/sites/default/files/documents/Residential_Request_List.pdf retrieved April 2018

[57] https://opwdd.ny.gov/news_and_publications/press-release-news/governor-cuomo-announces-459-housing-opportunities-new Retrieved June 2018

Non-Certified Housing.

Non-Certified housing may be in apartments or houses, co-operatives, condominiums, owned by individuals, agencies, families or corporations. In other words, places where most of us live. It may be home for one person or more, they may share with other people with disabilities or with people without disabilities. There are typically fewer residents 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. [58]

> *"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*

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 Option ("SDSO") 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.

> *Grouper Laws. These are municipal rules on how many unrelated people can live in a residence per the zoning code. Historically these laws were used to discriminate against same sex couples, student housing and certain types of home based businesses. These laws may often be only loosely enforced.*

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), in the belief 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.

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 the present work 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.

For the purposes of this question the principle differences between the two types are in their <u>oversight</u> and <u>funding.</u>

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[58] Certified and Non-certified housing see the OPWDD website https://opwdd.ny.gov/opwdd_services_supports/residential_opportunities/housing_options April 2018

Oversight and regulation

- **Certified** settings are subject to regulation, 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,[59]) 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 [60]. 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 [61] is well crafted, requires significant training to administer and is sensitive to the need to focus on individuals, 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 Medicaid Service Coordinator whose job includes monitoring for health and safety.

NY State's Mental Hygiene Law led to the creation of Codes, Rules and Regulations (CRR) Chapter 14 for the OPWDD, and parts 624,625, etc. which agencies are required to follow . OPWDD website includes guidance on all of the relevant CRR

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 staff through and rent support from either Tenant Based Rental Assistance vouchers ("Section 8") from the U.S. Department of Housing and Urban Development, ("HUD") or through OPWDD's Individualized Supports and Services ("ISS") housing subsidy. HUD requires that housing purchased with Section 8 vouchers meet their standards of safety and quality. More typically people with I/DD will be supported by an ISS subsidy. Depending on the OPWDD region that is administering the ISS funding, Quality Assurance documentation and ISS Funding Criteria may differ. All of the DDROs require that the ISS provider develop an Individual Support Services [62]plan that addresses the types and nature of services being delivered.

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[59] Parts 624 625, 633 available at https://govt.westlaw.com/nycrr/Browse/Home/NewYork/NewYorkCodesRulesandRegulations?guid=Icba70b30b7ec11dd9120824eac0ffcce&originationContext=documenttoc&transitionType=Default&contextData= Retrieved May 2018

[60] NY State Justice Center established in response to abuses within the OPWDD residential System in 2013 https://www.justicecenter.ny.gov/about/vision retrieved June 2018

[61] DQI Site Review Protocol Resource October 3 2016 https://opwdd.ny.gov/sites/default/files/documents/SiteReviewProtocolDigitalManualImpl.pdf retrieved May 2018

[62] OPWDD Individual Support Services Plan. Office for People with Developmental Disabilities. *2016 ISS funding criteria/conditions.* Albany, NY: Author.

The plan should state the responsibilities of the agency managing the ISS contract and those of the person benefitting from the subsidy, and the nature of the support network. There must be a Participation Agreement [63] which commits the agency to safety and quality standards and oversight and a Quality Assurance checklist[64] covering home safety and support which is reviewed annually. 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.

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 will monitor and coordinate health care. If the person is receiving SDSO 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 (FI) who is paid to 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.

HCBS Settings rules.

In January of 2014 the Centers for Medicare and Medicaid Services, ("CMS") the federal Medicaid oversight agency published the Home and Community Based Settings ("HCBS") rules. [65] The "Settings" rules set out a series of standards that states receiving federal contributions in Waiver funding, which includes Community Habilitation ("Comm-Hab"), should apply to residences and workplaces and follow the principles of Section 2402 (a) of the Affordable Care Act. The rules are predicated on research based[66] 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. [67] OPWDD's Toolkit for HCBS settings is a helpful guide for agencies operating Certified settings, and for families[68]. 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.[69]

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[63] OPWDD Individual Support Services Participation Agreement October 2010.

[64] OPWDD Individual Support Services Quality Assurance Checklist October 2010.

[65] HCBS Settings rules https://www.medicaid.gov/medicaid/hcbs/downloads/hcbs-setting-fact-sheet.pdf retrieved April 2018

[66] 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 May 2018

[67] 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.

[68] OPWDD https://opwdd.ny.gov/opwdd_services_supports/HCBS/hcbs-settings-toolkit retrieved May 2018

[69] CMS Website https://www.medicaid.gov/medicaid/hcbs/downloads/q-and-a-hcb-settings.pdf retrieved May 2018

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 individual’s goals and preferences, including where the individual resides, and who they live with”.[70]

• Funding

Certified ICFs are funded through “State Plan” Medicaid, or traditional Medicaid services. 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 roll-up 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. The provider has to advocate effectively in order to have their rate increased to reflect this increased need.

> *The preponderance of research reviewed for this NCD report -- regarding HCBS beneficiary outcomes information -- supports the conclusion that smaller, more dispersed and individualized community settings further integration and positive outcomes for individuals 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 individuals with mental health disabilities. The trends reveal factors such as greater individual 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*

People living in **Non-Certified** housing typically (but not always) have individual budgets that provide for residential support through Individual Supports and Services (ISS), and may also provide for staffing through Comm-Hab. Staff are paid through the Medicaid Waiver funding model. Comm-Hab 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.[71] 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.

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[70] 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

[71] The CCS for 2018 is available at https://otda.ny.gov/programs/ssp/2018-Maximum-Monthly-Benefit-Amounts.pdf retrieved May 2018

The need and reality of "24-7" care.

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 (24 hours a day/ 7 days a week); 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 a model that should be implemented lightly. The greatest cost component for LTSS is labor cost. By the end of 2018 any organization employing more than 11 people in NY City will be 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.[72] 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 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 individuals do not require someone to be awake overnight and can be safe and secure as long as there is a Live In Caregiver 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 Direct Support Professionals ("DSP"s). Such demanding work merits greater status. The higher level of skill, the lower the necessary staff ratio, and the more effective the care. Based on overwhelming support from its members the President's Committee for People with Intellectual Disabilities (PCPID) made the crisis in recruiting and retaining Direct Support Professionals the focus of the Committee's "Report to the President 2017" published by the federal Administration on Community Living.[73] The report highlights the "untenable crisis" stemming from high turnover, growing demand for services and the lack of economic or career opportunities for DSPs.

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[72] For changes in minimum wage see https://www.govdocs.com/new-york-state-15-minimum-wage-paid-family-leave/ Retrieved April 2018

[73] Report to the President 2017. Available at https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF Retrieved August 2018

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, history and 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 individual 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;

- 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.[74]
- HCBS services are substantially less expensive than ICF/MR services, evident for all comparisons involving similar individual recipients. For HCBS recipients living in congregate settings, expenditures were above average compared to those recipients in non-congregate settings. [75]
- 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.
- 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.

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[74] For more re the DDP2 and ISPM score see page12 of the Guide.

[75] 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

The perspective of a person living in a Certified setting or a Non-Certified setting.

" 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 best Certified home would feel little different from the best Non-Certified home if it were 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 ten 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[76]. Research has shown that the more people living in a setting, the more likely they are to feel loneliness, [77]or experience a compromised quality of life. In research conducted at Brigham Young University it became evident that isolation and loneliness reduce life expectancy.[78]

- A Certified home may have more staff who are engaged in support functions such as cleaning and cooking, although residents may participate. Non-Certified homes will be more likely to have the residents performing a share of the chores.

- 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 more governed by a 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 prepare food, oversee and help with bathing and administer medication up to ten people, travel outside of the setting is limited by the availability of a van and the number of staff available and unable and unlikely to be highly individualized.

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. Considering the intimate personal functions that a DSP may be called upon to support, the high turnover can only add to the stress and isolation felt by the person with I/DD. It is unlikely that a person with a high level of need will have contact with anyone who is not paid to provide support.

"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.

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76 Braddock, D. et al (2017) op. cit.

77 National Core Indicators op. cit.

78 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 2018

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 freedom and independence, in a controlled and perhaps impoverished quality of life for the residents, and at a high financial cost. What does the future hold? While the shortage of housing and the need to transition from Certified settings to more Non-Certified settings is 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.
- 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. [79]
- A series of legislative and regulatory measures dating back almost fifty years establishes the need for more independence and choice for people with disabilities, including I/DD.
- Best practices support the principle that the Ownership of Property be distinct from the Provision of Services[80]. 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 largely 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 more segregated, routinized and highly regulated group homes.

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[79] An easy to read summary of the research is "Home Care might be cheaper, but States still fear it" is available at https://www.npr.org/2010/12/10/131755491/home-care-might-be-cheaper-but-states-still-fear-it retrieved August 2018

[80] Substance Abuse and Mental Health Services Administration. Permanent Supportive Housing: The Evidence. HHS Pub. No. SMA-10-4509, Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, 2010.

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.

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 our Survey 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 people who need a higher level of support as they age, and providers are having to find new ways to address all of the issues. Most homes do not have fully accessible entrances, bathrooms, bedrooms, 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.

Chapter 4. Creating New Options

The introduction of Self Directed Services in the late 1990's and Money Follows the Person in 2005 presaged the inversion of the funding model from one where funding flowed from government to provider agency which then created programs, to one where funding flows from government to the person who then selects services and supports. The full impact of this radical change has yet to be felt or understood. However, the disruption caused by the change in service delivery demands the creation of new skills, roles and services. This chapter describes emerging forms of property ownership and management and how transportation and staffing might be made more flexible.

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.

• Home of Your Own.

The OPWDD "Home of Your Own " ("HOYO") program which began in 1998 provides low down payment, low interest fixed rate thirty year mortgages to people with I/DD and in some instances their families, as well as DSPs who qualify based on income. When combined with other subsidized financial products that encourage home ownership – for example IDAs or Matched Savings Programs (See Chapter One) this represents a low cost entrée to first time home ownership. The person, (or persons) control their home, who lives there, who works there, and they become part of the local community of taxpayers. They may be able to garner some equity for their future needs as well. On the downside, there are no maintenance funds provided by the state, which will only subsidize mortgage payments, not upkeep, and it is very important that, in particular, where more than one person is sharing the home that there be clear understanding of individual and shared responsibilities. The homeowner should have an exit strategy against the day when they may need a different level of support. Homeownership is attractive, but requires significant investment in planning, education and support. Homeownership is not liquid, is not guaranteed to create a capital gain, and any capital gain may be subject to a Medicaid lien.

• A Family or group of families owning.

Families can 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 do 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[81], 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.

- **Ownership by a Limited Liability Corporation, ("LLC").**

Creating a 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 thought through 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" rather than the cost of mortgage in HOYO, allowing for planning of maintenance.

These three types of ownership structures 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!)

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 ISS administration or an expansion of Other Than Personal Services (OTPS) in Self Directed budgets.

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[81] Not to be confused with Fair Market Rent ("FMR") HUD's rental support standard see https://www.huduser.gov/portal/datasets/fmr.html Retrieved May 2018

Transportation.

People who are unable to use typical public transport may be able to use a Paratransit service, originally created under the Americans with Disabilities Act, and administered at the county/local level. Per New York State law the route must mirror the regular fixed bus system. If there is a bus route operating in any designated area then Paratransit must be provided within ¾ of a mile of the route. This is considered the "Mandated Service Area" and is the standard operating procedure under the ADA. Additionally, counties may provide service in what is considered the un-mandated service areas, however if there is no bus service then Paratransit does not have to be offered at all. [82] With the growth of ride-sharing, car-sharing and the promise of autonomous vehicles more flexible and individualized options are becoming available and progressive counties look to these changes to provide for better service at a lower cost.

Staff-sharing

People who use Self Directed services have difficulty in recruiting and retaining support staff. For their part people who provide support are loath to work split-shifts or to work for limited and unpredictable hours. Even if a DSP works for several people they are required to log in and log out separately for each person/location they work. This would not be necessary if they worked in a Certified group home. There is a need to find ways to enable a DSP to work for several people within a limited area (such as in the Key Ring model) [83], to respond when a person needs support to the degree the person needs it without having to work a daily shift. The DSP would have flexibility to go where needed and, affiliated with an agency, could call on extra support if required. Any flexibility of this kind would have to comply with Labor Laws and best practices, and this need merits research.

"A supported living network is made up of a number of ordinary homes. People who need support live in all but one of them. These people are KeyRing Members. They help each other out and meet up regularly.

A Community Living Volunteer lives in the other home. The volunteer is a person who helps Members out. They help with things like reading bills, forms and letters. The volunteer supports Members to meet up, map their community, explore what's going on in their neighbourhood and get involved." Key Ring website

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82 I am indebted to Evan Latainer, Director, Westchester County Office for people with Disabilities for this summary.

83 The Key Ring model see http://www.keyring.org/what-we-do/network-model Retrieved April 2018

Impact on Provider Agencies

While Self-Direction offers many opportunities for people with I/DD to control their environment the great majority will need to continue to partner with a Provider agency. Learning about, accessing and optimizing the wide range of public benefits that were created to improve employment opportunities, independent housing and economic independence are essential for provider agencies of the future. Simply acting as a conduit for OPWDD and SSA funding adds less value and starves initiative. Many of the leading progressive agencies are already using the tools outlined above and are increasingly familiar with "generic" i.e. non-I/DD specific ways to support people. Agencies are moving from viewing themselves as the benevolent provider of (publicly funded!) services to becoming vendors designing individual services in partnership with the people they support.

Provider agencies remain essential. The best have decades of dedicated experience in supporting people with I/DD, a Person Centered culture and are financially stable and well managed. The challenges facing them in a future of Self-Directed funding and Managed Care are daunting.

Chapter 5. Intentional Communities

The world can be a harsh place, especially for people with disabilities. For centuries people have sought to create their own communities of like-minded people seeking to live in a more spiritual, social or ecologically peaceful way. Families of people with I/DD worry about the ability of their family member to thrive in the larger world and see intentional communities as an option, perhaps looking to create their own ideal community. There are successful Intentional Communities that include people with I/DD but communities are not easy to create or sustain and many do not make it. This chapter examines some types of Intentional Communities in the New York area and what works and what doesn't.

Community

The language we use when talking about services for people with I/DD frequently refers to "Community". "Community based services" are seen as better than 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 Individualized Service Plan ("ISP") 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 in a controlled group with little individual opportunity while still being visibly segregated.

> *"Community is not for producing things outside of itself; it is not a gathering of people struggling to win a cause. It is a place of communion where people care for others and are cared for by others; a place where they become vulnerable to one another". (Vanier, p.23)*

In the broader world "Community" may mean a neighborhood but it also means relationship and interconnection, shared values, or being recognized as a certain kind of person, or political group. It is used to euphemize advocacy groups or economic, ethnic or racial blocs. "Community is the spoonful of sugar that makes the othering go down"[84]. The sense of the word is increasingly debased by social media with "online communities" that amount to nothing more than agglomerations of marketing targets.

Communities may include, but they can also exclude; "Community as an automatic source of the 'good life' may be quite a wishful, if not naïve, understanding of how communities actually work."[85] Historically "the Community" has segregated and sought to ignore the needs of people with disabilities. So when we discuss the nature of "Community" and its interaction with people with disabilities we have to be clear about whether we are simply paying lip-service to the terms of the funding source, or whether there is a real community that welcomes people with disabilities, and where there can be genuine participation.

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[84] Chocano, C. *What Good is "Community" when someone else makes all the rules? "*NY Times Magazine, April 17 2018.

[85] Kendrick, M. Longing for Virtuous Community"

What is an Intentional Community?

Simply put an Intentional Community "is a group of people coming together in a place they create to live in some particular way." [86] 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. Of the 544 respondents to the 2017 Fellowship for Intentional Community survey the majority self-describe as Co-housing, Co-living and Eco communities. Some identify as Religious or Spiritual.[87] In the world of housing for people with I/DD "Shared Living" is also a form of Intentional Community. In our discussion we include some forms of all of the above. While there is a great deal of anecdotal history of Intentional Communities of all kinds, there is none that we found that was focused on people with I/DD, other than that self-published by Intentional Communities, or consisting of a very limited number or type of subject. We do not consider "gated" communities such as those built for elder communities, or "planned communities" such as might be built from the ground up to include all amenities (e.g. the town of "Celebration", Disney Co.'s "planned community" in Florida). In the present work we determined that 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.

The Federation of Intentional Communities broadly defines five types of Intentional Community, in summary;

- **Housing Cooperatives and Student Co-op houses.** Based on the Rochdale Principles of Cooperation.[88] Open voluntary membership without discrimination, Democratic governance one person one vote. Economic participation, surplus belongs to members. Education of public in co-op principles, concern for the broader community.

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[86] Website of Meadowdance http://www.meadowdance.org/basics.htm retrieved March 2018

[87] Blue,S., Morris, B. *Tracking the Communities Movement, 70 years of History and the modern FIC. Wisdom of Communities* Vol 1.1.FIC, Rutledge MO.

[88] Principles laid out in 1844 by a pioneering cooperative group in Rochdale England that have held up remarkably since. See https://www.rochdalepioneersmuseum.coop/about-us/the-rochdale-principles/ retrieved May 2018

- **Communes.** Typically involve higher levels of economic involvement, social engagement, accountability and participation. Historically combined with religion and ethnicity e.g. Hutterites [89] and Bruderhof[90]. All resources are held in common. The commune assumes responsibility for members, "from all to each". Decisions are arrived at by consensus or direct vote.
- **Cohousing.** Participatory design, Neighborhood design to balance privacy and communal spaces, extensive common facilities, resident management, non-hierarchical leadership and independent incomes which do not include community business.
- **Ecovillages.** A full featured settlement in which human activities are harmlessly integrated into the natural world, in a way that is supportive of healthy human development, and can be continued into the indefinite future". "Communities in which people feel supported by and responsible to those around them". They provide a deep sense of belonging to a group.
- **Religious Communities.** Including those unaffiliated with any particular tradition, or who consider themselves religiously ecumenical while still having a dominant spiritual practice.

These definitions are limited, in practice Intentional Communities may incorporate several different approaches and systems of governance and funding. The communities visited included elements of most of the types described.

The principal investigator (PI) met with eleven different Intentional Communities in New York, adjoining states and Canada and with representatives from a European community. Given the range and types of communities in the USA this is a limited sample but nonetheless representative of the current communities and opportunities for people with I/DD in New York.

Small Urban Settings.

The PI visited or met representatives from seven small urban communities each part of three separate but related movements that began in the early days of deinstitutionalization to provide homes for people who were leaving institutions in European countries. The movements spread to the United States in the late 1960's and early 1970's. They were all in urban settings ranging from a major city to a small suburb. A fundamental feature of those visited is an adherence to spiritual concepts or in some communities to religious principles of loving and caring for the "weakest and most oppressed" members of society, and the early history of virtually rescuing people from institutions is instilled in their ethos. We met with four well established communities in two different states that each had several homes, and with a fledgling group that is only beginning its first home. Where there were multiple houses they are intended to be within a mile or so of each other and to interact frequently.

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[89] Religious community based on Anabaptist teachings. See http://www.hutterites.org/ retrieved April 2018

[90] The Bruderhof community. An international Christian community of 2,900 people in 23 settlements. https://www.bruderhof.com/en retrieved May 2018

In these communities, people with I/DD share their lives with volunteers, supplemented by paid DSPs and supported by professional management teams. A typical home may have three or four residents with I/DD and a similar number of resident volunteers. Volunteers are drawn from all parts of the world, of different ages, skills, religions and ethnicities. Some of the overseas volunteers are in the USA on "R-1"[91] visas that permit the person to be employed in a religious occupation for some of their time for up to five years. Volunteers from within the USA and overseas may be students on a "gap year" and the communities visited included several people who had been in the community for many years who had begun their commitment in this way. Some come from lay religious communities (e.g. lay Franciscans), or from the Intentional Community movements such as the Bruderhof. From meeting the volunteers in each of the different settings it became clear that those who stayed were very committed to the idea of community, were essential to its functioning and sustainability, and entered fully into the lives of their community members. The volunteer element was a vital one.

Volunteers provide support in all the activities and aspects of a home and there is an easy familiarity and affection among all the community members. The volunteer presence changes the staffing model from shift-based and ratio dependent to a more flexible mix. Members of the community gather at least weekly and usually more frequently for prayer and discussion and to share what is going on in the life of the community. People are referred to the community from a range of sources including the county or state agencies. Before joining the community, an individual will spend several weekends and depending on the community perhaps a week or two or longer to see if the community is the right place for them. Joining is a commitment; everyone is expected to contribute their labor and to support the core mission to the best of their ability. The more well-established homes have had the same people living in them in some cases since they left institutions many years ago and the aging of the people who need support is an issue the communities have had to address. The communities support people as they age and make every effort to have individuals age in place. If an individual requires hospital or hospice care, then there will always be a community member with them. Each of the established communities had at some time to address the need for a member to leave, in most cases because they clearly did not wish to be there or because of major behavioral issues. In each case the community had committed to facilitating and easing the transition as best they could. In the Family Survey respondents were asked what they hoped for their son or daughter when they were aging and a majority expressed the how that they would "age in place". Given the current state of Certified settings this is unlikely to happen as it would require adapting properties and accessing different funding streams, but it does seem to be more likely in most of the Intentional Communities that were visited.

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[91] R-1 Temporary Nonimmigrant Religious Worker Visa. https://www.uscis.gov/working-united-states/temporary-workers/r-1-temporary-religious-workers/r-1-temporary-nonimmigrant-religious-workers retrieved May 2018

The communities are funded in much the same way as a conventional ICF or IRA. Those of long standing being more secure in the aspects of property ownership. Residences are Certified with all that certification entails including enhanced funding and stringent regulatory requirements. The communities also raise funds to supplement State funding in order to provide for the volunteers and to enhance the quality of life of the community members. Fund raising may amount to as much as 50% of the annual budget.

As with most other Shared Living environments, the administrators have to walk a delicate balance to ensure compliance with Labor law. While striving to make relationships as natural and familial as possible, it is also necessary to track hours, make sure that there is sufficient time off-site, time not working, time to sleep etc. Much of their sustainability is due to their long record of providing genuinely community based services within the OPWDD world even if the nature of their structure requires that the regulator be enlightened and flexible. In practical terms from the regulator perspective the reality is that they have been established for many years and perform good work.

Rural Communities.

The PI visited two different rural communities. The first drew from the same history and religious/spiritual roots as the communities above but was much larger and more rural, albeit within thirty miles of two mid-size cities. There were approximately 100 people with I/DD living and sharing their lives with approximately 140 people without disability and with a paid staff of approximately 40, which includes administrative personnel, some business related maintenance workers, medical staff etc. The property includes several hundred acres of woodland, farmland and a central hamlet which includes most of the housing, workspaces and administration. Houses are clustered in groups of three or four and are each home to approximately eight people, including families with children. The house is generally run by a married couple with children of their own. Also living in the home are trained residential volunteers as well as adults with I/DD. The home functions as an integrative and supportive family environment.

Some of the people who live in the community go to school or work in the local area, while others work in the village. The creation of hand-crafted goods, and biodynamic-based farming is a core tenet of the community, dairy, vegetables, and baked goods produced on the property feed members of the community, as well as provide purposeful work that contributes to the whole. There are also several therapeutic craft studios, including a woodworking shop, a weavery that uses wool from the community's sheep and a stained glass studio. Community members who choose to share their lives may be drawn from the original founding families or perhaps from other Intentional Communities, with additional volunteers coming from the same sources as in the urban communities – gap year students and people on R-1 visas in all coming from 25 countries on six continents. The community includes an accredited higher learning institute and attracts members from around the world on student visas

The community has strong traditions of communal meetings, family togetherness – e.g. sharing meals, services etc. In recent years they have created or supported the creation of other communal business in the region, and they are part of a national and international association of similar communities. Recognizing the downside of rural isolation, they consciously reach out to their area towns and villages and to other organizations within the State.

Funding is different from the self-contained IRAs and ICFs in the urban homes. Given the long presence and history the primary public funding is on a capitated single contract basis, plus the SSI for those who qualify and CCS at a residential school rate. The community also relies on fundraising, including the sales of the goods it produces, for half of its funding.

The second community we visited was also in a rural area in a less prosperous region of the State, but similarly within an hour of two major cities. The community includes a residential school which serves about 20 students, and homes of 4-5 people for 80+ adults of all ages. Homes are organized around a village green which is also connected to small businesses including an inn and a bakery-coffee shop and a growing specialty agriculture business.

All of the staff and management are professional with no volunteer involvement. The challenge of recruiting and retaining staff is made no easier by the rural location even though the region has experienced economic decline and unemployment is high.

New entrants begin with a series of family visits, perhaps including some time in the Summer Camp or in the post-secondary school. Families who visit have often visited other communities in other states. The admission process, which includes discussion of funding sustainability may take a minimum of six to eight months, often much longer. All of the people with I/DD who live in the community have the same diagnosis, albeit across a broad spectrum of age and ability. The community was founded almost one hundred years ago and the nature of care in that time and subsequent history shapes the present structure. The community is adapting to the changes in people's lives that Early Intervention, full time and integrated schooling and much improved health care have wrought. The younger people entering the Community are different in many ways to the earlier generations. The Community's challenges now include managing the use of social media and devices and fostering independence with a balance of risks. At the other end of the lifespan as people with I/DD confront issues of aging the community strives to find ways to continue to support and include people who need an increased level of medical care.

The community has felt the impact of the closure of Sheltered Workshops more keenly given the high local unemployment rate and difficulties in finding work and transportation. They are also addressing the challenge of HCBS settings rules that require "heightened scrutiny" for campus style groups of housing, but they are more than willing to accommodate such scrutiny given their understandable pride in the quality of life that the people who live in the community can achieve.

Funding is a mix of private and public revenue. The adult community fees are of the order of $50k-$60k annually, with some being much higher. This compares favorably with other Certified settings in the region. As many as half of the people living in the community may come from other states, with or without the assistance of that state. People from New York are funded in conventional ways, e.g. with ICF and IRA funds for residential purposes and Day Habilitation and Comm-Hab for daytime support. They see the integration of Self Directed funding sources as a challenge but also as having great potential for flexibility. In addition to Private Pay there is fundraising through a related foundation, and income from providing training and educational services.

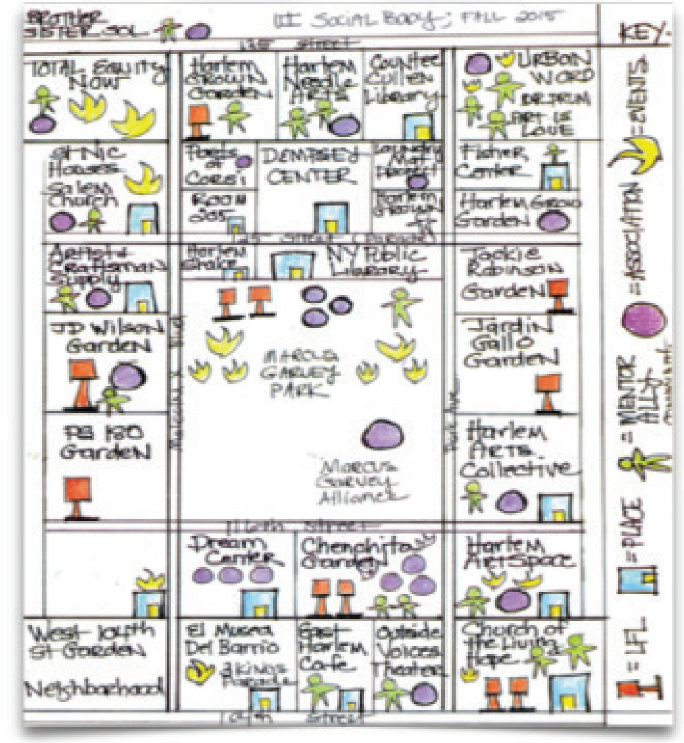
Large Urban Community.

The PI visited a community in Canada that was primarily located in a newly built work and living space created using principles of Universal Design. The workspace includes gardening, crafts, training in social skills and meeting rooms. Apartments are located on the second floor and are fully accessible. The community is founded by an agency with strong religious roots but is not limited to members of any particular faith. With the help of tax credits and government subsidies rents for the tenant members are kept low. Including the 20 apartments in this community the agency provides support services to more than 150 apartments in the city that are home to people with a wide range of disabilities. The community believes that individual and family resources must be mobilized along with public resources if housing solutions like this are to be brought to scale. Funding is from a mix of individual earnings, family support, fund raising and public money. The founding agency is a large organization and balancing volunteer time with professional time is difficult but, volunteers are included in many aspects of the community.

In addition to these eight communities the PI visited a suburban development that was created using Tax Credits that gave preference to elders and to "special populations". The community brought together children in foster care, their adopting families, and elders who looked to be involved as mentors and support. The families were supported by dedicated social workers seconded from the County, and by a small administrative and services staff. Intergenerational communities may have to address issues of aging of the elders and age-out of the youth in foster-care but the arrangement seemed to work for the betterment of all.

An emerging community was creating a Farmstead near a major city, supported by local business and civic groups. It is intended to employ people with I/DD in producing food and crafts for local sale.

In New York City the PI met with a community of people with I/DD and their advocates and supports who live in the same neighborhood. The community is focused on visual and performing arts and among other projects



The map shows resources that the members have created over time, and their connections to the broader community has created a series of "little libraries" providing no cost reading material to people of all ages. The community is built on the Key Ring principle connecting people in Central Harlem with each other and with volunteer and paid support.

In a variant of the "Circle of Support" model the community builds on the person's local network of resources, creating an individualized map of the places they connect with and gradually building a robust network. This Intentional Community is part of a larger long vibrant community that is tightly knit but stressed by gentrification and other urban forces. Their challenge includes how to help to maintain the ties that have bound the community together. An example of the obstacles they face in keeping vital connections is the conflicting policies of NY City Housing Authority (NYCHA) which strictly limits the degree and number of family members in a unit of Public Housing, thereby eliminating the possibility of Shared Living or a Live In Caregiver. In contrast OPWDD regulations restrict Comm-Hab work to non-relatives. The net effect is, that in order to receive services, the person with I/DD may have to leave their home and community.

Shared Living.

All of these Communities are rooted in principles of Shared Living. Shared Living is a form of Intentional Community. 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." [92]

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[92] Shared Living site NASDDDS http://www.nasddds.org/resource-library/general-information-on-administering-state-programs/family-living/ retrieved May 2018

What Works?

In reviewing literature about Intentional Communities, the reader has to be aware of "survivor bias". That is, the organizations that report on their progress and success are the ones who survived, - the ones that did not survive do not report, and it is generally acknowledged that there is a significant failure rate. That noted, there are many accounts by people who were members of communities that succeeded for a time and then failed, and by some who went on and created future communities that learnt from the experience and there are some common observations from those personal experiences and other literature.

• Intention.

Sometimes expressed as a "Vision Statement" or a "Mission Statement" simply put the key element in sustainability is the core Intention. Fundamentally 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, 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. Since the first such communities were established more than fifty years ago with very clear intentions to help people leaving institutions there needs to have been an evolution. Through "doing for" to "doing with". From "Service" to "Support". From thinking of people with I/DD as "wounded" and "damaged" to being equals and peers. This evolutionary transition sometimes has to occur within the same faith-based urge to charity that created the community in the first place, during a period when attitudes to religion and belief have also changed. People with I/DD who join an Intentional Community today are in a very different position to those who participated in the founding communities fifty years ago. They are more educated, generally in better health, more empowered; they assume their right to be fully integrated. They are expected to assume greater responsibility. The communities that recognize these different forces and adapt to address them seem to be the most successful and sustainable. These communities were transparent, welcoming, but also proactive in ensuring that they were better understood by public funders and local stakeholders.

• Communal activity.

Well-structured communities have regular get-togethers of different kinds. In typical Intentional Communities meetings include extensive discussion of communal business issues and governance. Intentional Communities with members with I/DD have regular community meetings on functional matters but also bring people together regularly to talk about their lives and how things are going, have meals communally, create art together and if religious pray together. If people are not acting communally there is no community.

• 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 or craftwork and maintenance. There are no passengers or observers, people who choose not to work are essentially choosing not to be part of the community and should leave.

• Volunteers and life-sharers.

The communities visited 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 in collaboration with the DSPs. 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 to the benefit of all involved. Volunteers who consider themselves to be committed life-sharers rather than simply unpaid supports are the most effective, in particular where the age of the life-sharers is approximately the same as that of the other members of the community. It is noteworthy that most of the families of the people in our survey who lived in Intentional Communities assumed that all of the staff were volunteers. On the one hand this speaks to the warmth of the relationships, but it also points to a misunderstanding of the working structure.

• Integration.

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

What does not work?

• Commitment Failure.

In discussing the purpose of the visit with one Intentional Community one of the leaders stated, “Do not think of us as a housing option”. Successful communities have a clear idea and articulation of their core tenets, they do not include “there are no other housing options available”. Successful communities require commitment from the new member to endorse and willingly accept the community’s values and practices and their induction processes identify where such acceptance is present or potentially likely. A community that is essentially a residential facility and communal in name only, staffed by shift-based professionals is unlikely to attract the essential volunteer and community support needed to sustain itself outside of government funding. It is unlikely to be a place where the community members feel cared for and supported. If it is not much more than a large group home, then it will possibly run afoul of the HCBS settings rules and invite Heightened Scrutiny

• Failure to adapt to changing society.

The last forty to fifty years, the age of deinstitutionalization, has 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. The first Intentional Communities saw the people they were rescuing from institutions as profoundly harmed and yet as having a special quality of innocence and viewed their work through a spiritual perspective. Fifty years later people with I/DD expect to be treated without condescension as peers of the people they live with. The wishes of their parents notwithstanding they want to be self –determined and have choice as to where they live and who with. They are more educated, healthier, more supported by technology, empowered by the advocacy of their forebears and with expectations of being integrated. Communities that fail to adapt to this long-term cultural change are likely to fail to attract new and younger members while older members will become less active.

- **Failure to adapt to new funding.**

Since the introduction of Money Follows the Person 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. Others are severely challenged by the need to comply with multiple state funding systems and the requirements of the HCBS settings rules. Successful communities have developed fundraising and development partnerships locally, and in some cases, nationally to supplement income from public sources and from their community businesses.

- **A note on Governance.**

Intentional Communities that succeed place a great deal of importance in creating the right governance structure. The literature[93] describes multiple instances where idealistic intentions come to grief through inter personal conflicts that are all the more intense because of the deeply held values. In some ways Intentional Communities that support people with I/DD have skirted this issue because the governance structure has had to align with the tight regulatory protocols of the funding systems they rely on. For example, the need for a 501C-3 structure, OPWDD State funding, OPWDD Medicaid funding, Social Security payee rules, Congregate Care Supplement requirements certification of sites and so on. For good or ill most have a conventional structure of a board comprised of stakeholders, an executive including professional social workers, administrative staff and Direct Support professionals.

- **A note on Funding.**

Similarly with funding typical Intentional Communities require members to “buy in” or to make ongoing financial commitments. Difficulties arise when costs are higher than expected, spending priorities are disputed, or waste and fraud occur or are thought to occur. Intentional Communities that include people with I/DD began similarly with the goal of sustaining themselves through self-sufficient agriculture or other businesses along with fund raising. In practice this is very hard to achieve given the vagaries of production and marketing factors and the growth pangs of a small business. Over time, and in ways similar to the gradual process of assimilation that overtook provider agencies in the mainstream DD system, they adapted to include and ultimately depend on the same funding streams as conventional providers, State funds, Medicaid funds, SSI etc. as well as community product income and fund-raising. While no doubt they suffer the same funding anxieties as any social services organization their current structure resembles a typical provider agency rather than a typical Intentional Community.

Intentional Communities that include members with I/DD are not immune to issues of governance or finance but, they experience them differently to conventional Intentional Communities.

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[93] We have relied on material from the Fellowship for Intentional Communities and especially their “the Wisdom of Community” series of publications.

Why are Public Funding sources wary of Intentional Communities?

• The State is not averse to Intentional Communities in principle.

Depending on the experience of the NY State OPWDD Regional office and other variables different DDROs have been supportive of different Shared Living arrangements for many years and have been receptive to expansion of small scale urban single residence 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 primary funding for services for people with I/DD is now Medicaid Waiver Home and Community Based Services (HCBS), Medicaid being a funding source that provides a 1:1 match for NY State funds. The HCBS Settings rules do not permit waiver funding in settings "that have the effect of isolating individuals receiving Medicaid-funded HCBS from the broader community of individuals not receiving Medicaid-funded HCBS"[94] The rules require that where there is an institutional character or potential for such the setting is subject to "heightened scrutiny". Contrary to popular myth the settings rules do not place a limit on the number of people in one location, but the State has an informal limit of four people – a limit which coincidentally aligns with most "grouper" laws. Without HCBS funding it is very difficult to pay for staffing, the largest component of any budget, so from the regulator's perspective, a setting that must deal with "Heightened Scrutiny" with a risk that it may not receive waiver funds will have difficulty surviving and is not to be encouraged.

• 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. Briefly 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."[95] 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. [96]

On the one hand State regulators have long and bitter experience of the damage that can occur in institutional settings, they have firm guidance from their federal partners and they have evidence based best practices that should guide their decision making. They have built a powerful, and in many ways, effective provider based system that is secular, professional and not reliant on charity or fundraising. They have no incentive to encourage start-ups that envisage the creation of large scale communities that may tend to become segregated or isolated and which will be susceptible to funding changes, particularly if dependent on "private pay" for a large share of their funding.

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[94] Summary of key provisions of the HCBS settings rule Op.Cit

[95] From The Precautionary Principle website http://www.precautionaryprinciple.eu/ retrieved May 2018

[96] National Council on Disability meta Study "HCBS Creating systems for success at home at work and in the community. https://www.ncd.gov/publications/2015/02242015 retrieved May 2018

Can Intentional Communities be part of a housing plan?

As quoted earlier one of the leaders of an Intentional Community pointed out that Intentional Communities are not a housing solution, they are communities with specific core beliefs and governance. In order to be comfortable in a Community, a person with I/DD needs to take the mission and structure to heart and commit to it, as will their family, who may be also required to provide financial commitment. Successful Intentional Communities tend to rely on significant volunteer and life sharing support, people who have made a lifetime commitment to the beliefs and structure of the community. Although there is no reliable research to make the determination, from the experience gained through community visits and interviews with provider and OPWDD professionals, it is clear that in the absence of this deep commitment, Intentional communities will likely fail. By contrast, it has been established that simply putting people together to solve a housing issue, regardless of the how the living situation is structured, does not achieve economies of scale and can result in an environment that is at best sterile and at worst, desperately miserable.

Chapter 6. Systemic Issues and Advocacy

The ways in which services and supports are created is changing. For the last seventy years or so advocacy for people with I/DD has been directed towards the State agency responsible for all services, now known as OPWDD. In the future people with I/DD and their advocates will need to make alliances with other people seeking to protect Social Security benefits, obtain affordable housing, and ensure flexibility in labor laws and many other fields. Advocacy will require partnerships and savvy politics.

Systemic issues and options for Advocacy

"The Report" described a series of impediments to the creation of more independent housing for people with I/DD and proposed seventeen ways to amend the system to increase housing options at low or no cost. Some of those recommendations have been put into effect. Creating long term sustainable supports requires a vigorous approach to addressing the remaining impediments.

> *"We are now faced with the fact that tomorrow is today. We are confronted with the fierce urgency of now. In this unfolding conundrum of life and history, there is such a thing as being too late. This is no time for apathy or complacency. This is a time for vigorous and positive action."*
>
> *Dr. Martin Luther King*

Creating supports for the 21st Century does not always require more funding but, it does require initiative and innovation. Being an advocate in the age of Self-Direction, Money Follows the Person and growing utilization of non-I/DD system resources requires a new approach. If in the past advocates for people with I/DD focused on advocating directly to OPWDD or through lawmakers to influence OPWDD this is no longer the only requirement nor necessarily effective. In order to increase housing options, advocates need to partner with Affordable and Supportive housing coalitions, impress on their representatives the importance of Low Income Housing Tax Credits, A Farm Bill that provides for SNAP, and the maintenance of HUD subsidies across the board. Meet with Community Boards to make their needs and presence known, and join with other disability organizations to find common cause.

The following key advocacy pressure points should be addressed. Ten recommendations for system change and advocacy are suggested.

Systemic Issues

- **Provider agencies should be incentivized to create Non-Certified settings.**

There are financial advantages for Provider agencies to choose to develop Certified residences rather than Non-Certified residences. Over the forty plus years since the Group home model first took root a closed end system has developed that provider agencies and the state have become comfortable with. Deeply embedded direct and indirect subsidies have made the creation of Certified residences financially attractive when compared to Non-Certified residences. Some of this Institutional Bias was described in the Report to the Housing Task Force, and a detailed discussion is outside the scope of the current work, however three particular aspects that bias the system to create Certified housing rather than more flexible lower cost options are the Prior Property Approval letter ("PPA"), compliance reporting and the Congregate Care Supplement, ("CCS").

- **Prior Property Approval (PPA).**

OPWDD does not typically fund the purchase of property for residences. However, in the event that a provider agency seeks to establish a Certified residence, and there will be 459 established in 2018-2019, assuming that their budgeting and other aspects of the plan are appropriate, OPWDD will provide them with a PPA that commits the State to fund the services provided to the residents of the facility. While this is not a guarantee commercial banks recognize that the State is committed to providing a long-term revenue stream and are comfortable lending on favorable terms to provider agencies creating Certified housing. The State payments to the provider include a property component sufficient to cover the mortgage that is not limited in the same way that an ISS payment is limited. The agency has title to the property without restriction. The State does not currently provide an equivalent to the PPA to agencies or individuals seeking to establish Non-Certified housing, even though the long-term commitment to supportive services may well be similar to that provided in a Certified setting.

- **The Congregate Care Supplement (CCS).**

Individuals who qualify for Supplemental Security Income (SSI) by virtue of their disability receive their benefit from two sources, the federal government which pays the Federal Benefit Rate, and the State which pays a State contribution. In 1974 following the implementation of SSI payments and recognizing that the needs of people with I/DD were high, New York state provided a supplement to support people who were living in congregate care, whether that be in an ICF or in Family Care. With the advent of Medicaid Waiver in New York in 1992 and the creation of IRAs the supplement was extended to both Supervised and Supportive IRAs. When the CCS was created there was an assumption that people who had an I/DD and who had LTSS needs would mainly live in Certified settings. The rates were set at the inception of the supplement and are adjusted by a Cost of Living factor annually. The current CCS is published by the NYS Office for Temporary Disability Assistance ("OTDA") [97]. The supplement represents significant support for providers operating Certified settings. As the executive director of a progressive provider agency put it "This is the single most important factor keeping people in Certified settings". Times have changed since the CCS was first introduced. In the 1970's it was assumed that people with I/DD would live in the new group home environments, and that as the federal funding match for Medicaid required, those settings would be Certified. With the increase in the numbers of people seeking to live in more integrated settings, and the introduction of Waiver which permitted more flexible use of Medicaid funds the same people who might be served in Certified settings are now being supported in Non-Certified settings. However, the people in Non-Certified settings are not receiving CCS.

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[97] NY State SSI & SSP Benefit Levels 2018 Congregate Care Supplement https://otda.ny.gov/programs/ssp/2018-Maximum-Monthly-Benefit-Amounts.pdf retrieved May 2018

- **The 15 minute increment.**

Most people living in a Non-Certified home will have their support staff services paid through "Community Habilitation" a Medicaid funding stream. Current compliance requires that services be recorded every fifteen minutes. Payment is made to the provider based on the ratio of the number of people served/the number of staff. If during the course of an evening at a person's home they begin with a one to one ratio, as other residents come home, or other staff arrive the ratio will change. Each ratio pays differently. In a home with three or four residents and one or two staff that ratio may change throughout the evening, it is not uncommon for a single shift to necessitate twenty to thirty different records of time spent providing support. It is highly doubtful that this level of record keeping provides any useful data, reduces fraud or misuse, or adds in any way to the residents' quality of life. It is however, a level of regulatory cost and audit expense that would be considered intolerable in the real world. By contrast, the Certified setting has only to record the number of people living in the residence each day. There is no 15 minute increment requirement.

There are other ways in which Institutional Bias continues to favor Certified settings over Non-Certified settings but for the purposes of this project these were the most relevant.

Advocating for Sustainability

Family anxiety regarding the creation and sustaining of a safe healthy home for their son or daughter has historically been channeled into advocacy for the creation of more group homes. However as discussed there are implacable facts that limit the creation of more Certified settings; - cost, laws (for example the ADA and the Olmstead decision), regulation, staffing shortages and quality of life concerns being the principle ones. Informed advocacy needs to focus on how to improve existing services through simplifying regulation, improving inter-agency collaboration within the State and at local levels on issues such as transition services, employment, transportation and affordable housing, and making existing generic services more available to and informed about the needs of people with I/DD. What follows are some issues that advocates might consider.

1. Individual Budgets.

Assign or re-assign individual budgets. By "rolling up" rates for Certified settings the State created a disincentive to agencies to help people to move to less supervised settings. E.g., if a person with moderate needs leaves an IRA to be replaced by a person with high level of needs the budget for operating the facility will remain the same, even though the support need may increase. Historically the State had an individual budget for people living in Certified residences which allowed for more granular planning, even if it required more attention to administration. The State should adhere to Medicaid Waiver guidelines and reinstate the individual budget at Certified houses.

2. Address the myth that Certification is the only safe setting.

Families have been acculturated to think of Certified settings and "24-7" as the only secure option. As discussed, Non-Certified settings are also regulated, in some ways perhaps more so than Certified settings. The State should consider the following;

- Provide education to families on the nature of various state funded settings across the spectrum from Development Center through Certified settings to Non-Certified, including information about the nature of State safeguards
- Provider associations and the State create a voluntary review protocol for Non-Certified settings

3. Address the shortfall of the ISS rental subsidy in supporting accessible safe housing.

The ISS Subsidy was originally calculated in the same way as the Tenant Based Rental Assistance ("Section 8") vouchers supported by the federal Department of Housing and Urban Development ("HUD"). Since 2012 however the rates have been frozen. In the time since rents have increased in most areas of the state and in some areas substantially so. The Section 8 subsidy was designed to help working families, with an expectation of income and possible savings. Despite some small improvement since the 2007-2009 recession the employment rate for people with disabilities remains very low, and the appreciation of public benefits such as SSI has fallen far below the appreciation of housing costs. The ISS subsidy has proven effective in helping people with I/DD to find housing, including people who would otherwise have had to go into Certified settings at a much higher cost. Regional offices should be given increased discretion to use ISS rental subsidies to provide safe accessible housing at market rates higher than the 40th percentile base used for Section 8.

4. Create a "comfort letter" for lenders and landlords.

A "comfort letter" in this context would be an assurance by a state agency to the lender or supplier to an enterprise that it will support the enterprise in timely settlement of its obligations. It is not a performance guarantee but nonetheless carries weight with lenders. OPWDD should consider creating a "PPA" style commitment to services letter to people seeking Non-Certified housing, or to the entities created to provide housing in order to provide landlords and lenders with comfort in helping to house people with Long Term Support needs.

5. Provide Guidance to people seeking to own their own home or families establishing ownership structures.

Home Ownership is complicated, requires personal, community, family and financial planning that is typically not available through the MSC or Self Direction broker. Housing Navigation is a service that can help to inform and guide people through their options and should be provided as a distinct service.

6. Increase Options for people to stay in their family home.

Many people with I/DD and their families want to stay in the family home for as long as possible, but families may struggle to maintain their own employment and take care of other family members while providing support for a person with a disability. As a result, a person with I/DD may move earlier than they wish into a Certified or Non-Certified home where their support consists entirely of paid workers at much higher cost than the natural supports they previously had. Helping people to stay in their family home if they wish can be done by;

- Paying a stipend to family members, as is the case for Consumer Directed personal Assistance Services under the Department of Health waiver.
- Increasing Paid support through more flexible use of "Respite" funding which has proven effective at supporting families and reducing overall costs.

7. Increase access to Assistive Technology.

AT cost and ease of use have greatly improved but regulation still lags

- Currently the State will only reimburse physicians if the telemedicine connection, which could report on vital signs for example, is between two certified settings. Legislation has been passed to address this so that telemedicine devices can be used between a person's Non-Certified home and their physician's office or a remote monitoring location, but regulations have yet to be created at this writing.
- CMS has become more flexible in agreeing to pay for "Durable Medical Devices" that are generically available, e.g. "apps". The State should do the same.
- The State should clarify the requirements for devices used to support medication administration.

8. Get rid of the "15 minute increment"

The reporting every fifteen minutes of services provided is cosmetic compliance at its worst. The increment diverts at least 4 minutes (7%) per hour to paperwork that is rarely read, is overly prescriptive and which does nothing to reduce fraud. It is an intrusive institutional bias that demeans the person supported and the DSP providing support and it should be eliminated.

9. Encourage ABLE Accounts

A person receiving SSI may not have more than $2,000 in savings. This limit has not increased since 1989, when it was worth roughly double what it is worth in 2018. The introduction of the ABLE account has made this barrier less relevant, and people receiving SSI can now save for a wide range of needs. The State should actively promote ABLE accounts for people with I/DD. Trust attorneys and Non Profit operators of pooled trusts may not like it but it is in the best interests of the people they purport to serve.

10. Make Transportation more flexible.

Paratransit's Mandated Service Area, restricted by State Law, should be made more flexible, particularly in parts of the State where public transport is limited. Counties should be incentivized to use ride-sharing systems s to supplement Paratransit as a cheaper more individualized and flexible option.

The impact of Care Coordination Organizations (CCOs) and Managed Care Organizations (MCOs)

Beginning with the inception of CCOs in July of 2018, the publicly funded system of support for people with I/DD will begin a five-year transition to full Managed Care of Health Care and Long Term Support Services such as Day and Residential supports. The reason for the change is the expectation that Managed Care will reduce medical costs and allow for more flexibility within a capitated system. In many ways this is a foray into the unknown and such comprehensive Managed Care has barely been attempted anywhere else within the United States and when it was attempted met with mixed results. The State's own Medicaid Redesign Team report noted that people with I/DD were not typically heavy users of Emergency Rooms and did not experience exceptional hospitalizations, - the two main drivers of medical inflation.[98] It is also hoped that capitation will allow for people's needs to be addressed as they change over time, whether those support needs increase or decrease.

An "open architecture" system of support that draws from the existing range of I/DD services but also incorporates services from other provider-based systems as well as commercial systems may lend itself to an efficient Managed Care system. Such flexibility may lead to more individualized services. However, an MCO, whether created by an existing Provider Agency or by new entrants from Mainstream Managed Care will be bound by the requirement to be efficient, and it will do that not only by welcome innovation, but also by rigid control of costs. If for-profit MCOs enter the market their profit imperative will govern their behavior. Everything will depend on the degree of leverage that can be exerted by oversight agencies and individual and family board members and monitoring groups.

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[98] MRT Utilization report Page 46. Retrieved June 2018 https://shnny.org/images/uploads/Utilization%20Report%201%202017_single%20pages.pdf

Conclusion

People with I/DD, their families, advocates and the people who provide support and oversight are confronted with significant changes in how future services and supports are to be provided and coordinated. The systems that were created over the last forty years were developed under a post institutional but still heavily clinical and medical paradigm. However, much has changed since the 1970's in terms of integration and education for all, Disability Rights as Civil Rights, better healthcare for people with I/DD, longer lifespans, the introduction of Self-Directed services and Money Follows the Person. All of the stakeholders must now be involved in the creation of services and supports that take these changes into account. These services will have to be designed to access individual and family resources wherever possible, and for profit as well as nonprofit provider options, and all this in an environment where public support for funding services seems to be withering away.

Considerable obstacles remain in the form of the Institutional Bias that is deeply embedded in the current system. This bias which includes the obvious such as the Congregate Care Supplement, the Prior Property Approval, exemption from local taxes and the less obvious such as simpler regulation and emphasis on certified settings made in community education. Research from reliable and diverse sources shows that smaller more integrated settings provide a higher quality of life, and probably cost less in most cases. It is imperative that funding follow the Precautionary Principle and shift from outdated systems to those that follow current best practices.

While the task of creating new services and supports may be daunting it is one that many stakeholders have been working on for years. In meeting with people living in Intentional Communities, as well as with provider agencies it becomes clear that successful support systems, that is, those that create an independent life of quality, have much in common with each other. Whether the support context is Certified, Non-Certified, Independent or Intentional Community, the key elements are that people with I/DD have choice as to where they live and how they receive their support, the nature of that support and from whom they receive it. Providers have to look to, and genuinely live by, their values and mission which they need to constantly affirm. They do not see themselves simply as conduits for OPWDD/Medicaid or other public funding sources or view their highest goal as being fully compliant. They identify their future relevance by the degree to which they can innovate and provide options, and to build a sense of genuine community for all.

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John Maltby, September 2018

Appendix A

Family Survey

In March of 2018 the New York Alliance created the survey described in “Method'. The survey was sent to over 2,500 people in all parts of the State, and 752 responses were received from parents or family members of people who have an I/DD. As indicated in the subsequent tables, comparisons were made based on the individual’s current living situation including;

- Non-certified setting with paid supports,
- Own home/ apartment, non-certified, with only non-paid supports,
- Certified residential setting with 24/7 support,
- Certified home or apartment with minimal staff support, and
- Intentional community specifically for people with developmental disabilities.

The results from each of the questions which may prove of interest have been included. Readers may draw different conclusions from the answers but there were some common themes;

- The survey received the highest number of responses from Region 3 (Hudson Valley) in part because of the active social network groups in that region and also because of the number of people living in an Intentional Community there.
- Families are extremely worried about the future. The level of concern for “when I am no longer here” is high in all groups, no matter where the person lives. At its best, the level of concern is neutral (in Intentional Communities) but there is no group where the level of concern is low.
- People in Certified Settings and Intentional Communities were on average older than those living in Non-Certified settings. This is emerging as a pattern across the State. In Region 1 (Western NY) for example, there is little divergence in ISPM scores between people living in Certified vs. Non-Certified other than age.
- According to the National Council on Disability study[99] most people with I/DD living in group homes do not get to choose who they live with. 77% of the people in Certified settings shared a room including those living in Intentional Communities.
- Of the 177 people indicating they are pursuing some kind of on-going support, no one indicated they were pursuing supports to maintain a family member at home. On the other hand, this was not given as a choice in the survey. Supports to keep a family member at home are one means of addressing sustainability.

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[99] NCD *The State of housing in America in the 21st Century: A Disability Perspective*. NCD 2010

- Of those same 177 people, about the same percentages are pursuing certified and uncertified settings. It might be interesting to take a deeper dive to learn why about the same numbers of people are pursuing very different options.
- Included with the table are family comments on their plans for the future. Many families had very little in place.
- Many of the comments indicate that the family member “needs” 24/7 support. This may be worth revisiting as this “need” may or may not be warranted or such supports may be delivered in a more sustainable fashion than 24/7 shift staffing, the least sustainable of the models discussed.
- About 1/3 of respondents whose family member lives in a 24/7 certified setting believe their family member will “age in place”. This is an unwarranted faith in the system. At this time very few residences have the capacity to adapt to the needs of an aging population
- 60% of those whose family member lives at home have no plan for the future. This is not only disconcerting but is a concern for systemic sustainability.
- Only 5% have taken advantage of the ABLE Act.
- Only 35% of respondents from Intentional Communities say that there are paid staff involved in their supports. All of the Intentional Communities visited employ paid staff alongside volunteers. This may mean people do not fully understand how the Community operates and is funded.

Table 1: Overview of Results

Category	# of respondents	Ave. Age	% with Roommates	Looking for alternative	Overall Decision-making	Overall satisfaction
At home not looking	271	21.6	10.15%	5.2%	2.16	3.76
At home and looking	188	26.1	7.73%	51%	2.11	3.40
Non Cert-paid support	61	31.4	37.7%	27.5%	2.92	3.71
Own Home non paid	26	31.2	11.5%	10.5%	2.78	3.39
Cert with 24/7	113	36.28	76.79%	17.17%	2.02	3.87
Cert w/min support	24	35	33.3%	27.27%	3.04	3.39
Intentional Community	60	44.7	53.3%	8%	2.50	4.40

Table 2: Age

Category	# of respondents	Mean	Median	Mode	Range
At home not looking	271	21.6	11	26	4 to 60
At home and looking	188	26.1	25	24	3 to 57
Non-cert with paid support	61	31.4	29	28	22 to 65
Own Home non-paid support	26	28.8	27	30	7 to 70
Cert with 24/7	113	36.28	35	30	13 to 76
Cert w/min support	24	35	31	23	23 to 57
Intentional Community	60	44.7	44	48	12 to 81

Table 3: Satisfaction with current living situation

Answer Key 1- **Very dissatisfied** 2- **Dissatisfied** 3- **Neutral** 4- **Satisfied** **Very Satisfied**	**Lives at home with family- not pursuing alternatives**	**Lives at home with family -pursuing alternatives**	**Non-certified setting paid supports**	**Own home/ apartment, non cert., non-paid supports**	**Certified residential setting with 24/7 support**	**Certified home or apartment minimal support**	**Intentional community**
Health care issues	4.22	3.78	3.58	3.65	4.15	3.6	4.39
Financial management	3.95	3.38	3.43	2.94	4.16	3.55	4.16
Health lifestyle (i.e. nutrition, exercise, weight management)	3.89	3.58	3.6	3.5	3.76	3.1	4.39
Social support (making friends, community participation, maintaining/ supporting religious affiliation, support with problem solving etc)	3.57	3.23	3.66	3.67	3.78	3.38	4.74
Vocational skills development	3.24	2.99	3.14	3.33	3.6	3.06	4.3
Personal skills development (self-care)	3.71	3.46	3.71	3.71	3.74	3.65	4.44
Average	**3.76**	**3.40**	**3.52**	**3.47**	**3.87**	**3.39**	**4.40**

Demographics: Location

The following table provides information regarding where the respondents' family member lives (i.e. person with a disability). This information is categorized by OPWDD DDRO regions:

- **Region 1 Western New York Counties:** Allegany, Cattaraugus, Chautauqua, Chemung, Erie, Genesee, Livingston, Monroe, Niagara, Ontario, Orleans, Schuyler, Seneca, Steuben, Wayne, Wyoming, Yates
- **Region 2 Central New York Counties:** Broome, Cayuga, Chenango, Clinton, Cortland, Delaware, Essex, Franklin, Hamilton, Herkimer, Jefferson, Lewis, Madison, Oneida, Onondaga, Oswego, Otsego, St. Lawrence, Tioga, Tompkins
- **Region 3 Capital District/ Hudson Valley New York Counties:** Albany, Columbia, Dutchess, Fulton, Green, Montgomery, Orange, Putnam, Rensselaer, Rockland, Saratoga, Schenectady, Schoharie, Sullivan, Ulster, Warren, Washington, Westchester
- **Region 4 Metro New York Counties:** Bronx, Kings, New York, Queens, Richmond
- **Region 5 Long Island Counties:** Nassau, Suffolk

Table 4: Location

Category	Region 1	Region 2	Region 3	Region 4	Region 5	totals
At home not looking	41	51	85	29	57	263
At home and looking	24	28	52	71	7	182
Non-cert with paid support	10	6	18	7	17	58
Own Home non-paid support	3	4	9	2	2	20
Cert with 24/7	9	9	73	7	4	102
Cert w/min support	2	1	11	2	8	24
Intentional Community	1	3	47	1	1	53
	90	102	295	119	96	702

Own Home/non-paid staff- 1 from Connecticut

At Home not seeking alternative- 1 from Oklahoma

At home / seeking alternative- 1 from Connecticut, 1 from Pennsylvania

Intentional Community- 1 from Connecticut

Certified setting with 24/7 support- 1 from Massachusetts

**Results including city and county can be found on a separate spreadsheet.

Table 5: What type of long term supports are in place to maintain your family member's living situation after you are no longer able to? Select all that apply

Answer Choices	#of responses	Lives at home with family-not seeking alternatives	Lives at home with family pursuing alternatives	Non-certified with paid supports	Own home/ apartment, non-certified, non-paid supports	Certified residential setting with 24/7 support	Certified home or apartment with minimal staff support	Intentional community
Partial Guardianship	34	3.4% (6)	3.5% (5)	6.1% (3)	0.0% (0)	13.0% (12)	9.1% (2)	11.1% (5)
ABLE account	32	8.0% (14)	4.9% (7)	12.2% (6)	11.1% (2)	3.3% (3)	0.0% (0)	0.0% (0)
Supported Decision-making plan	46	8.5% (15)	6.9% (10)	12.2% (6)	0.0% (0)	5.4% (5)	22.7% (5)	11.1%(5)
Other (please specify)	86	12.5% (22)	20.8% (30)	20.4% (10)	22.2% (4)	13.0% (12)	9.1% (2)	13.3% (6)
Health care proxy	156	25.6% (45)	30.6% (44)	24.5% (12)	27.8% (5)	28.3% (26)	27.3% (6)	40.0% (18)
Individualized Support Services (ISS)	152	27.8% (49)	29.9% (43)	51.2% (25)	38.9% (7)	9.8% (9)	50.0% (11)	15.6% (7)
Established circle of supports of family and friends	186	39.8% (70)	35.4% (51)	42.9% (21)	33.3% (6)	18.5% (17)	36.4% (8)	26.7% (12)
Full Guardianship	232	42.6% (75)	43.8% (63)	32.7% (16)	27.8% (5)	55.4% (51)	18.2% (4)	37.8% (17)
Supplemental needs trust (third party or self-funded)	290	43.8% (77)	56.9% (82)	71.4% (35)	33.3% (6)	55.4% (51)	40.9% (9)	64.4% (29)
Self-Direction	223	51.7% (91)	49.3% (71)	69.4% (34)	50.0% (9)	6.5% (6)	36.4% (8)	4.4% (2)
Siblings or other family members are in succession to assume role of supporter	297	55.7% (98)	46.5% (67)	69.4% (34)	55.6% (10)	53.3% (49)	50.0% (11)	53.3% (24)

Written response themes: No plans or working on plans, guardianship, financial planning, other family members, service providers, trusts

- eventually after us parents dead and not guardians, the agency will be the guardians
- We have not been able to define a plan yet. He is wait listed for community ISS
- Self direction, but not totally applicable
- Insurance policy for future funding
- pre-paid funeral costs
- None. We are starting to look at the options
- Working toward Self-direction
- researching options
- Brother to watch over his care
- None
- POA
- State and philanthropic support.
- We don't have anything in place at this point
- We are pursuing a group home with 24 hr. support
- current integrated community provides care throughout lifetime
- this community offers end of life care
- working on getting some of above established
- choose not to answer
- Unsure
- I don't know yet
- I don't know
- just got OPWDD eligibility
- In process of setting up trust
- none
- full guardianship until death parents
- his sister or family members.
- He does not have any housing options if something happens to me, and I'm 70 this year!
- none at this time
- I hope to get power of attorney, and hope fully her twin sister will step up and help her when she is finished with college and gets set up as an adult she will be able to help with natural supports
- We have a stand by guardian that's about all
- No staff support exists for our 2 family members who will require 24 hour supervision for the remainder of their lives once we are gone. We need residential options.
- We have not put anything formal in place at this time.
- SNT to be completed
- we need help with this
- We are with ISS and are doing self direction, but this plan has to be changed when we can no longer take on the responsibility of hiring staff.
- He has a Special Needs Trust
- This is my fear. We don't know what is out there where he could thrive without us. If there was a facility like an assisted living that are out there for the elderly where he could have his independence with staff available checking in would be ideal. I don't know of such a facility.
- no supports in place
- None made at this time ... however, we are in the process of seeking options and making long term sustainable plans.

- Not enough coordination of these supports. Siblings can't take on guardianship as it would be so onerous they would never be able to get to work themselves
- None at this time
- Don't know
- The two items marked are being worked on, and are not yet in place.
- Parents run self-direction. He's happy but needs the next step to his own life always with family's love.
- We have no funds or people to take over our sons long term care
- verbal commitments from few family members, but worried how things might change with time.
- He has been approved through OPWDD, has an MSC and has the Medicaid service waiver.
- Oversight through Life Services for the Handicapped
- Not much. His siblings live out of the area (one lived in England)
- None for now.
- none yet
- No one has addressed this with me or told me what I should be doing to prepare!
- None as of yet
- family members are in Chautauqua county, he has no family members in Montgomery county
- Home Health Aides
- No plan
- Trustee of SNT is "Disabled & Alone" provides advocacy too
- Family members will become guardians
- Working on Self-direction and Able account
- move him into a group home
- I don't know.
- None
- FSS
- We have no plan for where he will live after we are gone. There are no appropriate options available that will meet his needs.
- OPWDD supports
- I will place her in a Residential setting.
- We are very concerned and don't have answers at this point
- Working on a trust and guardianship
- He has a brother who will be full Guardian
- still in beginning process of this
- FIDA-IDD maintenance oversight, father has established trusts, close family members will participate and cousins.
- cdpap
- Financial planning to support him
- WE NEED HELP FOR HER WHEN WE NO LONGER CAN ASSIST. THIS IS A BIG WORRY SINCE WE HAVE NO ONE.
- Using a nonprofit for financial management
- CDPAP
- He will need someone to keep the circle together when I am not here. Like a house manager.
- Special Needs Trust in place
- We own his home

Table 6: What is the plan for residential supports for your family member as he/she ages?

Answer Choices	Responses		Lives at home with family- not pursuing residential alternatives	Lives at home with family while pursuing residential alternatives	Non-certified setting with paid supports	Own home/ apartment, non-certified, non-paid supports	Certified residential setting with 24/7 support	Certified home minimal staff support	Intentional community
Age in place with paid supports	21.90%	127	13.8% (26)	14.1% (21)	49.0% (25)	25.0% (5)	33.3% (32)	27.3% (6)	22.5% (11)
Age in place with natural supports	13.45%	78	10.6% (20)	2.0% (3)	3.9% (2)	20.0% (4)	19.8% (19)	13.6% (3)	51.0% (25)
Transition to another residential opportunity	16.55%	96	13.2% (25)	31.5% (47)	5.9% (3)	0.0% (0)	13.5% (13)	9.1% (2)	12.2% (6)
The community or residential program that supports my family member has no stated plan/policy	5.69%	33	2.7% (5)	8.7% (13)	7.8% (4)	10.0% (2)	8.3% (8)	0.0% (0)	2.0% (1)
I don't know yet	42.41%	246	59.8% (113)	43.6% (65)	33.3% (17)a	45.0% (9)	25.0% (24)	50.0% (11)	12.2% (6)

Table 7: How would you rate your family member's decision -making abilities as related to:

Answer Key 1-Unable to make decisions 3- Able to make decisions with supports 5-Independent	Weighted average all respondents	Lives at home with family- not currently pursuing residential alternatives	Lives at home with family while pursuing residential alternatives	Non-certified setting with paid supports	Own home/ apartment, non-certified, non-paid supports	Certified residential setting with 24/7 support	Certified home or apartment with minimal staff support	Intentional community
Daily Living (what to wear, eat etc.)	3.09	2.95	2.88	3.94	3.83	2.68	3.91	3.55
Social/ recreation	2.83	2.74	2.5	3.53	3.22	2.62	3.7	3.32
Employment	2.05	1.92	1.97	2.81	2.44	1.76	2.42	2.19
Healthcare	1.86	1.76	1.74	2.35	2.22	1.62	2.76	1.98
Finance	1.54	1.42	1.44	2	2.17	1.43	2.43	1.48
Average	**2.27**	**2.16**	**2.11**	**2.93**	**2.78**	**2.02**	**3.04**	**2.50**

Table 8: Please rate your level of concern in the event that you are no longer able to provide support to your family member regarding the following:

1= Very concerned, 3=Neutral, 5 Not at all concerned	Total Average	Lives at home with family- not currently pursuing residential alternatives	Lives at home with family while pursuing residential alternatives	Non-certified setting with paid supports	Own home/ apartment, non-certified, only non-paid supports	Certified residential setting with 24/7 support	Certified home with minimal staff support	Intentional community
Health care decision-making	1.88	1.78	1.39	1.67	2	3.32	1.73	3.06
Financial decision-making	1.87	1.69	1.35	1.79	1.76	2.42	1.81	3.22
Finding/ maintaining a living situation with appropriate supports	1.78	1.60	1.21	1.58	2.11	2.28	1.67	3.33
Maintaining connections to and involvement of family and friends	2.16	2.06	1.63	2.35	2.5	2.37	2.1	3.4
Maintaining current levels of community involvement	2.23	2.03	1.61	2.32	2.39	2.63	2.52	3.86
Overall physical safety	2.13	1.94	1.51	1.98	2.56	2.63	2.35	3.62
Overall social and emotional well-being	1.94	1.80	1.35	1.84	2.11	2.34	2.05	3.45
Average	**2.00**	**1.84**	**1.44**	**1.93**	**2.20**	**2.57**	**2.03**	**3.42**

Intentional Community Summary

- 60 responses in this category
- Average age- 44.7
- Length of time living in the community
    - Less than 1 year- 5
    - 1-5 years- 13
    - 6-10 years- 12
    - 11-15 years- 5
    - 16-20 years-2
    - Over 20- 23
- Of the 53 who provided zip code information, 47 lived in the same community- see table 4 for all results.
- As indicated in the table below, other than the descriptors, “People with and without disabilities live together” and “Every member of the community works to support the functioning of the community regardless of disability” there seems to exist a difference in understanding/perception regarding many of the other characteristics considering that most live in the same community.

Table 9: Intentional community descriptors

Answer Choices	Responses	
People with and without disabilities live together	70.31%	45
Paid staff support my family member	35.94%	23
All residents of the community have equal status and responsibility	45.31%	29
Every member of the community works to support the functioning of the community regardless of disability	76.56%	49
All residents of the community eat together	56.25%	36
Meals are prepared and served by staff	42.19%	27
Then main purpose of the community is the safety of people with disabilities	37.50%	24
Other (see below)	21.88%	14

- Education, entertainment
- Main purpose is full and rich life
- The main purpose of the Community is the fulfillment of each person’s best development in a shared mutually supportive life.
- The main purpose of the community is helping each person on his/her path through life

  - Each member of the community works and strives toward their full potential
  - The purpose of the community is to treat all people with respect and dignity
  - Community living of handicapped with non-handicapped families in a residential farm setting; working together in accordance with their abilities. A normal family setting for handicapped people providing an excellent quality of life with opportunities for growth and learning.
  - disabled work to promote the community with social functions
  - The main concern is that each resident has the opportunity and the support to achieve and to participate in a full life setting and their social, physical, and mental wellbeing is achieved through work and daily living opportunities.
  - Safety first but a full and purposeful life!
  - the main purpose of the community is to allow each individual to develop to their fullest potential
  - They have become a close family each with their own abilities and needs
- As with the community descriptors, other than in the area of "Household chores, maintenance and other responsibilities" and "Friendship and support of house/roommates" there was a significant departure among respondents regarding their family members function within the community

Table 10: Intentional Community resident contributions to function

Answer Choices	Responses
Household chores, maintenance or other responsibilities	92.0%
Social- arranging and/or implementing plans	32.0%
Friendship and support of house/roommates	80.0%
Financial contributions	36.0%
Participation in governance or decision-making	28.0%
Other (see below)	12.0%

  - Our family member experiences himself as a fully contributing member of the community. His work and our family member has full-time work which contributes actively (edited for spelling)
  - everyone in the household has something to contribute
  - He has a job there
  - Board Member of the community and the Foundation
  - simple work assignment in wood shop, etc
  - Very little participation because the IRA is diverse and he does not truly fit in there

- Of all respondent groups, families of individuals living in Intentional Communities expressed the highest level of satisfaction in all but 1 area surveyed with a score of 4.4 out of 5. The only exception was financial management where they scored the same as the 24/7 respondents: 4.16- see table 3
- Respondents rated the overall decision-making abilities of those living in an Intentional Community 2.5 out of 5 with the highest in daily living (what to wear/eat etc.) at 3.55 and finance at 1.48 as the lowest level of decision making- see table 7
- Respondents indicated the lowest level of concern in all areas for those living in an intentional community- with a score of where 1 is very concerned and 5 is not at all concerned- see table 8

Appendix B Glossary

- ABLE account. Achieving a Better Life Experience account 529A. A savings plan for people with disabilities that allows the creation of assets and expenditures that are protected from consideration as Countable Income under the rules of Social Security.
- ACCES-VR Adult Career and Continuing Education Services. Rehabilitation, job training and other employment services.
- CCO. Care Coordination Organization. Service to ensure access and coordination of Medicaid and other services for people with I/DD.
- CCS. Congregate Care Supplement – a supplement to federal SSI paid by the State for people served in Certified residences.
- CDB. Childhood Disability Benefit (formerly known as DAC Disabled Adult Child) payment made to disabled child of a parent receiving Social Security.
- CMS. Centers for Medicare and Medicaid. Federal oversight agency for Medicaid, in partnership with State.
- CQL. The Council on Quality Leadership. A non-governmental organization that researches and promotes best standards in supporting people with I/DD.
- CRO. Certified Residential Opportunities. Protocol for admission to certified group homes.
- DDP. Developmental Disability Profile. Assessment instrument used when reviewing need and type of services
- DDRO. Developmental Disabilities Regional Office(s) the five regional centers of the OPWDD.
- DSP. Direct Support Professional. A person providing support to people with I/DD at home and in the community.
- EITC. Earned Income Tax Credit. Payment to people of very low income who are working.
- FI. Fiscal Intermediary. Conduit and oversight agency for State and Medicaid funds provided through an Individual’s budget.
- FSS . Family Self Sufficiency program of HUD that incentivizes employment by rebating rent increases incurred due to increased earnings if plan is completed.

- FSS. Family Support Services, State funded services from OPWDD
- HCBS. Home and Community Based Services Waiver. Federal/State funding through Medicaid that gives states flexibility in funding Medicaid services.
- HEAP. Home Energy Assistance Program. Federal funding to assist with energy costs.
- HOYO. Home of Your Own. OWDD program providing long term low rate funding for housing for people with I/DD and also DSPs.
- HUD. Federal department of Housing and Urban Development.
- I/DD. Intellectual and Developmental Disabilities. Per NY State Mental Hygiene law for eligibility for OPWDD supports or services, the developmental disabilities that are defined as 'qualifying conditions' include: intellectual disability (known as "mental retardation" in Mental Hygiene Law), autism, cerebral palsy, epilepsy, familial dysautonomia, and neurological impairment (injury, malformation, or disease involving the Central Nervous System)
- ICF. Intermediate Care Facility a highly supervised 24-7 service environment
- IDA. Individual Development Account. Savings plan for an approved goal that can be exempted from countable assets for SSI.
- ILC. Independent Living Center
- IRA. Individualized Residential Alternative. Supervised (typically 24-7 support) and Supported group homes
- IRWE. Impairment Related Work Expense. A plan approved by the Social Security Administration permitting a worker to set aside certain work related expenses from their countable income for SSI purposes.
- ISPM. Individual Service Planning Model. Instrument used to develop a budget based on DDP assessment.
- ISS. Individualized Supports and Services. NY State funded services for people with I/DD, currently used to provide rental subsidies similar to Section 8 from HUD
- LTSS. Long Term Supports and Services, for example housing, employment support.
- MCO. Managed Care Organization. A corporation provided with a single rate to provide services for a group of people as opposed to Fee For Service funding which pays for each service provided to each individual. MCOs are expected to produce savings in medical costs.
- MFP. Money Follows the Person. The principle that an individual's service budget is attached to their person rather than to a provider agency.

- MSC Medicaid Service Coordination. Service provided to people receiving Waiver services to coordinate benefits and maintain compliance. Subsumed into CCOs in 2018.
- NY ALLIANCE. The New York Alliance for Inclusion and Innovation
- NYCHA. NY City Housing Authority, creator of public housing.
- NYSACRA. NY State Association of Community Residential Agencies (merged with NY State Rehabilitation Association in 2017 to form NY Alliance.
- OMRDD. The New York State Office for Mental Retardation and Developmental Disabilities created in 1977 and renamed OPWDD in 2010
- OTDA. Office for temporary Disability Assistance, pays the CCS.
- PASS. Plan For Achieving Self Support. A plan approved by Social Security for a worker developing a career and setting aside funds from consideration as countable income for SSI purposes.
- PPA Prior Property Approval letter from OPWDD confirming that it will support people with I/DD in a certified group home.
- SDSO. Self Directed Services Option. Gives a person with I/DD more control over how their services are provided, who is employed to provide them and where they access their services.
- Section 8. Named for Section 8 of the 1978 Housing and Community Development Act as Tenant Based Rental Assistance they permit the holder to pay only 30% of their income in rent with the balance paid through the voucher within preset limits.
- SNAP. Supplemental Nutritional Assistance Program. US Department of Agriculture food support payment (Formerly known as “Food Stamps”).
- SNF. Specialized Nursing Facility or nursing home
- SNT. Special Needs trust. Funds to benefit a person with a disability that are used to supplement benefits and that are not considered as countable income for SSI.
- SSDI. Social Security Disability Insurance. Federal insurance for workers who become disabled and who have contributed via their Federal Insurance Contribution Amount (FICA).
- SSI. Supplemental Security Income. Federal and State income paid to people whose disability prevents them from achieving gainful employment

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NEW YORK
ALLIANCE FOR
INCLUSION & INNOVATION
Strength Together

CORE VALUES

Community: We foster choice and independence in diverse, inclusive communities and also inspire creativity and innovation, where people thrive and succeed

Leadership: We will build strong coalitions and engage key stakeholders to advocate for all people with disabilities, shape sound public policies which respond to people's needs and support initiatives which advance positive, high quality outcomes

Collaboration: We will purposely develop strategic alliances to ensure that people with disabilities and all stakeholders embrace a truly person-centered system of supports and services

Integrity: We believe responsible words and actions which should be held to the highest standards of honesty, fairness, respect and professionalism

Equality: We value the rights of all people by fostering equal and fair treatment, respecting ideas and personal values and embracing diversity

VISION STATEMENT

The New York Alliance for Inclusion & Innovation (New York Alliance) envisions a society where individuals with disabilities are contributing citizens with equal rights and the ability to live full, productive and meaningful lives.

MISSION STATEMENT

To serve as a catalyst for positive change and leading resource for individuals with disabilities, their families, and the organizations supporting them.

We do this through:

- Advocacy
- Education & Training
- Technical Assistance & Practice Improvement
- Advancing Sound Public Policy

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