Thoughts on Implementing the Vision for Housing Supports

Executive Summary

Innovation and flexibility in helping dreams become a reality has been an integral part of the evolution of the system that supports individuals with intellectual and developmental disabilities in New York State. Today, we have an exciting opportunity to build upon the foundation of four decades of work through a platform that utilizes the feedback of those individuals, their families, providers, and the governmental agencies who create the system of supports. Implementing the platform creates an opportunity for New York to provide a pathway to individualized and sustainable service delivery that will provide enriching opportunities for years to come.

Over time, the supports for people to move from their family home to live in the community have evolved into a bi-modal choice: on one side is the option of living in a certified setting, and on the other is self-direction or ISS rental subsidy along with community habilitation. Individuals and families must select a community life that has either a focus on "structure, rules and supervision" or a focus on "design it and manage it yourself". There are many individuals with IDD whose needs fit well with one of the bi-modal models, but often there is a mismatch.

The proposed platform fills the gap between the existing options, neither replacing the existing models, nor forcing anybody being supported in the existing models to change to the new platform. This platform will differentiate itself from the current system because it will have:

- fewer regulations,
- flexibility in how to support a person to achieve their goals, and
- the ability to adjust to meet a person's day-to-day needs.

It will incentivize a strong working relationship between the individual, their family and provider. This partnership enables a community life that maximizes independence and self-determination, balanced with safe and responsible decision-making.

The platform will have the following features:

- funded through actuarially determined rates adjusted for acuity and regional costs
- utilized money follows the person
- self-determination (not to be confused with self-direction)
- agency-managed to support the goals of the person
- separate supports from housing funding and enables innovation in supports

Those are all great features of the platform, but what really matters is that people with IDD will get closer to true inclusion, individuals and families will have more choices, providers will be in an excellence race, OPWDD will drive its Mission forward, and NYS will bend the curve towards sustainability.

This is not just a dream. An individualized sustainable service delivery platform is achievable in the near term. The features in this platform are in CMS approved waivers, have evidence-based

efficacy and follow the Tenets and Guiding Principles in the Vision for Housing Supports (Appendix A).

How it will operate

Fill the Gap and Opt-In

This platform will fill the gap between the current bi-modal models. To emphasize choice it will be an Opt-In platform, chosen by the provider as well as by the individuals with IDD and their families supported in that selection by the Care Manager. This is crucial, as it disproves any claims that the current models are being replaced.

From the Individual and Family Perspective

An individual's CAS score will result in a Tier level monthly amount in order to support an individual to live in the community. That amount of money will be Money that Follows the Person (MFP). The individual, with their family and the support of their Care Manager, will select a provider, and contract with the provider to support them to live in the community. The individual and the provider will partner to create an agency-managed, community living arrangement that follows the individual's person-centered plan.

For example, if the individual wants to move from Brooklyn to Albany, The individual would select a provider in Albany and begin designing the new community living arrangement. When they leave Brooklyn and go to Albany the money follows them, with a regional rate correction.

If an individual living in Buffalo is disappointed with the execution of the community living plan by their current provider, then the individual selects another provider to support them in the community, changing at the end of the contract. Because property is not funded as a bundle with the supports, the individual would not have to move.

From the Provider's Perspective

The provider partners with the individual and their family to design the community living arrangement. The provider, when supporting 20 or more people, will receive consistent monthly revenue made up of the monies that each individual brings based on their CAS assessment. The Provider uses this monthly revenue to creatively design the supports in partnership with the individual. Using supports, such as technology and transitional homes to build independence (see examples in Appendix B). The flexibility of this platform will enable providers to respond to the changing needs of the individual, without the need to seek additional authorizations. For example, if an individual has a temporary health problem, the provider can boost support at that time. When an individual has a significant long-lasting change in need, then the person's updated CAS assessment will shift them to a new Tier and bring additional revenue to support them. Again, there will be no need to go through a service authorization process.

From OPWDD's Perspective

Most importantly, this will drive OPWDD's Mission forward: *helping people with developmental disabilities live richer lives*, by giving individuals more choice and control on where and how they live. The platform will bring budgetary discipline and predictability by utilizing actuarially-sound, acuity-based rates, driven by an independent assessment process using well-trained assessors with interrater reliability. The platform will move us to a financially sustainable service delivery system because providers will have the ability to design supports that deliver the right service, at the right time, and in the right location.

This Vision for Housing Supports, if done properly, will be a WIN-WIN-WIN.

The Work

There are a number of major areas that need to be developed through good collaborative effort. Many of these will require out-of-the-box thinking, so it will be important to use Covey's construct: "Begin with the end in mind".

1. **Waiver**: Do we really need to modify the 1915c waiver? If so, how?
2. **Rate Methodology**: Assessment-based acuity rates adjusted for regional cost of living. How many regions (using OPWDD regions is not granular enough because costs for some regions very significantly)? How many tiers?
3. **CAS**: Can it really be used to create Tiers that have rates associated with them? Yes- Imagine the rate for a given Tier to be the "premium" the individual brings to the provider they select. That premium may not be exactly what the provider needs in order to support that particular individual, and that is okay. For some individuals, the premium will be too high, for others too low, but a group of 20 individuals will be large enough for a provider to support all of the individuals when premiums are combined. In this way, it will be similar to the premiums that people pay to a health insurance company. The health insurance company uses the premiums to pay the claims of all their members. Because Long-Term Supports and Services (LTSS) don't vary dramatically like healthcare costs can, a provider can have as few as 20 individuals in this platform. The premise that 20 people is enough individuals is based on provider experience in Kansas, where they have a similar funding model.
4. **Protective Oversight**: What is the purpose of Protective Oversight in an uncertified housing option? Is it to make sure that provider's operating in this space are providing the base level of service? If that is the answer, then Protective Oversight consists of a system that identifies providers that are not meeting the base level of service. How do the regulations for this platform honor the dignity of risk? To change the focus, do we call this the "Responsible Decision-Making Plan"?
5. **Outcomes**: Measuring efficacy and effectiveness: Determining these measures will be crucial to the long-term sustainability of this platform. Outcomes will drive actuarial rates, determine how providers do their work, help individuals and families see the

system priorities and provide OPWDD with a true measure of efficacy. Some factors to consider in the selection of the outcome measures: Don't select too many and use outcome measures that are objective, not anecdotal.

6. **ISS Rental Subsidy**: The ISS rental subsidy has to be adjusted annually to the regional Fair Market Rent as determined by HUD. If it is not adjusted annually, then having a platform to support a person to live in the community will be irrelevant because only a lucky few will be able to find housing they can afford – a basic pre-requisite to living in the community.
7. **Residential Habilitation (RH) and Day Activities (DA):** Does this platform only support RH or does it support DA also? If we want it to do both, do the actuaries create two sets of rate tables, and should there be two streams of money? If there are two streams of money, then can an individual contract with two separate providers, one for RH and one for DA?
8. **Guardrails to minimize financial manipulation by providers:** Some ideas**:** Caps on administrative percentage, bands on salaries for given positions within a region and periodic review of the surplus percentage generated within a region with the total surplus for the region not to exceed 4%. By looking at a regional roll-up level, OPWDD is incentivizing individual providers to be efficient.
9. **Benefits to the individual and their families**: Money follows the person – self-determination, true community inclusion, closer match to what the person/family wants and the ability to meet the changing needs of the individual without a process of service authorization change and partnering with the provider to co-create the community living experience. Agency-managed, so families will know the needs of their son/daughter will be met now and in the future.
10. **Benefits to DSPs:** Additional career ladder options, because of independence of the work and being part of a team. Being part of a team is not as easily achieved in the self-direction model. Full-time employment, which is difficult to achieve in the self-direction model. Focuses the DSP work on supporting quality of life rather than caregiving and protecting.
11. **Financial implementation in an economy impacted by the pandemic.** Some possibilities:
    - Use a portion of the American Rescue Plan eFMAP that will generate $400 million for OPWDD in the upcoming fiscal year
    - Limit number of people that can participate
    - Allow those that want to switch from certified to this platform (it has to have an opt-in by both the provider and the individual).

Process to do the Work

We are in a time of intense pressure on our systems of supporting people with IDD: DSP shortages, increases in the number of people on the emergency placement list, financial unsustainability, certified settings with vacancies and the pandemic impact. All stakeholder

groups are feeling discomfort from these pressures; now is the time to address them. *Diamonds are created from intense pressure over long periods of time; pearls are formed around irritants. Precious things are made from discomfort*. -from the book "Keep Moving" by Maggie Smith.

To create this platform out of our discomfort, stakeholders need to come together. *Transformational change involves the reconciliation of differing interests and perspectives…, negotiation of power shifts, and social invention through boundary altering and disruptive co-creation,* - John O'Brien

Group wisdom that comes out of meaningful dialogue among cross-stakeholders will make the development of the platform better and create ambassadors and followers. As expressed to me recently by Jim Karpe, to do this work well, we need to "do with" not "do to" or "do for". I strongly encourage the development of a steering committee comprised of all stakeholders to lead this effort consisting of no more than twelve people. It would be this group's responsibility to provide the group wisdom and report back to their group of stakeholders, gathering their feedback.

Closing

This new platform designed from the tenets and guiding principles in the Vision Statement will enable many individuals to enjoy true inclusion. The existing pressures and discomforts create the need for transformational change. Are we going to stay in our "Blockbuster" view of Housing Supports or be visionary, creating the "Netflix" view of Housing Supports? Are we going to drive change, or be run over by change?

Appendix A: Vision for Housing Supports 02-05-2021

For decades we have striven to acknowledge that each of us makes a unique contribution to the interwoven threads of the fabric that is true community. We celebrate true inclusion that comes about when individuals engage in meaningful relationships developed by common interests in the community. Support systems that empower individual choice through flexible regulatory oversight and financial support based on true need honor individuals while making the most efficient use of limited resources. Our current systems were built years ago and like any other system there are points of evolution that require significant restructuring and change in practice to ensure they meet the dreams for a future that provides true inclusion and fiscal efficiency. We have reached one of those evolutionary points.

We can choose to move to a totally different paradigm for housing supports or stay in the existing paradigm making "adjustments" to the current set of models. We contend that making adjustments will not take the current set of models to a financially sustainable model nor move us closer to true inclusion. The next evolution in our housing model should have the following tenets:

- People with IDD have meaningful relationships and connections in the community. A fulfilling life is about relationships and interdependence balanced with the right to take well considered and supported risks. A survey of 1,224 people in 2017 showed 76% believe they live safely, but only 40% reported having friends and only 25% reported that they choose where and with whom to live. Meaningful relationships cannot develop unless one is part of the community, not just living "in" the community. It is very hard to have a congregate setting* be more than living "in" the community and will always lean towards dependence and minimizing risk vs what we all want: relationships and interdependence.
- Families and guardians will trust that the new model will provide a lifetime of support for their loved one.
- Taxpayers want a financially sustainable model.
- Providers want a model that incentivizes them to create a fulfilling life for people with disabilities, that results in a stable workforce and enables innovation.

The current model cannot be "adjusted" to meet all four of these tenets. The congregate care model by its design results in a one-size fits all model of supports. It doesn't flex with the changing needs of the individual or the changing demographics of a community. Because it is a one-size fits all model, it over-serves some people and doesn't have the financial bandwidth to support even more complex people.

Proposals to expand and fix inflexible models, such as Supportive IRAs and Family Care, and modifying the rate structure for certified settings (to adjust an organization's revenue to match the needs of a person as reflected on their CAS), will not meet the housing needs and will be substantially disruptive.

One example: congregate care results in staffing that meets the need of the most complex person in the home. If the funding is changed to match the person's CAS for a house that has one person that requires line of sight at all times, the revenue to the provider goes down but it doesn't change the staffing pattern in that house significantly. It is a solution that will not achieve its intended objective, which is providers being willing to support individuals with complex needs.

The new model must meet all the tenets above and to do that it must efficiently deliver supports at the right time, in the right place and in the right amount from the perspective of the person with a disability. Flexibility and innovation will be key to the new model because the person and the world change too often to have a rigid system. In essence, the new model is NOT a model in the traditional sense, because a model assumes that we have knowledge of the models that every person in every stage of life will need. We may know right at this moment what those needs are, but tomorrow those needs will be different. The models of congregate care developed in the 1970's to de-institutionalize quickly, overserves some and underserves others, does not support the four tenets and is financially unsustainable. Having a staff person hanging around to provide a support in case it is needed is simply too expensive.

We need an evolutionary shift to a new paradigm that:

- enables fluidity in delivery modalities that gives people with disabilities more control,
- promotes independence,
- enables innovative solutions, and
- keeps costs down by delivering the right service at the right time and in the right amount.

The choice before us today is not "can this be done?", it is "do we want to drive this change or be driven into the ground because we don't change?"

Here is the simple analogy: We are acting like Blockbuster by investing in property and inventory with the message "come here to get your movie", rather than acting like Netflix and saying, "watch the movie whenever you want, wherever you want".

Guiding Principles of the new housing support model:

- Housing location and type are chosen by the person, not restricted to “these are the three openings from which you can choose”.
- Housing supports that can follow the person if they decide that another provider better meets their needs.
- Time from application to assessment to service planning to service delivery should be as low as possible, no waitlists. This also includes when a person’s needs change, not only initial assessment.
- Service options that address the demographic unsustainability of reliance on congregate care shift based staffing

- Assessment that drives funding through tiers adjusted for regional Cost of Living.
- Funding that enables consistent staffing, turnover under 15%.
- Funding that enables innovation in supports; use of technology and housing navigation, essentially turns providers into vendors creating real choice for people with disabilities.
- Funding that is assessment based, consistent, reliable, not cost based and sufficient for quality; Rates that are regionally adjusted for cost of living. Periodic review of revenue vs costs across all providers in a region to determine if an adjustment in the funding rates are necessary.
- Funding for supports varies quickly as needs change, flexibility.
- Regulations that drive quality of life outcomes and enable services to be delivered efficiently; via technology, telemedicine, telesupport, ability for medicine administration and other supports.
- Documentation that is reasonable and not intrusive, made feasible by requiring periodic certification for a program. This will push organizations to measure and therefore deliver quality person-centered supports, rather than just checking a box that we did X with Y.

A new model that meets the four tenets and uses the guiding principles will make the most efficient use of limited resources, creating true community, empowering individual choice and financial sustainability. A model based on these tenets and guiding principles is not a dream, it has been operating for many years in another State. Let's take this evolutionary step together!

* For purposes of this document congregate settings refers to a setting that is designed prior to the person's arrival, designed to generalized specifications and are not very customizable to changes in the person's needs.

Appendix B: Envisioned examples

Example one

Sally and her family had concerns that she might periodically need help in the bathroom, especially at night. The provider, Sally and her family had an intercom installed in the bathroom and a sensor installed on the bathroom door. The provider has a technology platform that is monitored 24/7 by a DSP in a remote location that is supporting many individuals. Based on criteria set by Sally and the family, the monitoring DSP will get a notice when Sally has been in the bathroom too long ("too long" as defined by Sally and the family). The DSP then presses the intercom button and asks Sally how she is doing? If Sally requests assistance, the provider has a DSP that can respond quickly. This is possible, because the provider is supporting several individuals in close proximity of each other.

Example two

Anna and John are a couple with disabilities and they were both living in separate residential settings. John had just lost a job that he had kept at Lowes for many years. Anna was pregnant and had lost custody of their first daughter. Anna and John, through their CAS assessment had money follows the person (MFP) premium and this was used to plan with them and the provider to achieve the following: move them into an apartment together and get custody of their daughters. Although there have been some bumps in the road for the family, they have been successful in achieving their goals.

Example three

Donny was a young man with IDD and mental health issues that had resulted in him spending long periods of time in inpatient units. Donny, and those who knew and cared about him, had lost sight of what a good life could look like for him. All the focus was on the problems and difficulties he was experiencing. Donny, through the CAS assessment had a money follows the person (MFP) premium and this was used to plan with Donny, his family and the provider with a focus on what a good life might look like for him. Having identified this, realizing it became the goal that everyone worked towards. Donny moved out of hospital and into the first apartment of his own.

With only one setback, when he briefly returned to the unit, Donny's life has transformed. His level of direct support has reduced as he wants time and space to enjoy the privacy of his own apartment. Donny's use of MFP and good planning has changed his life.