

## RECOMMENDATIONS FOR THE OPWDD 5.07 STRATEGIC PLAN

JULY 2021

### INTRODUCTION:

The recommendations below are a combination of comments and concepts provided by the members and leadership of the QCDD (Queens Council on Developmental Disabilities). The QCDD is committed to working with individuals, families, providers and our government partners to ensure the long-term quality and sustainability of our service delivery system.

### **A PLAN FOR OPWDD TO MEET THE GROWING DEMAND FOR SERVICES THROUGHOUT A PERSON'S LIFE TO ASSURE SUSTAINABILITY, EQUITY AND ACCESS:**

We need to start quickly at making improvements to the delivery system while continuing to retain the best of the old system. We need to be focused on two key outcomes. First, for people with developmental disabilities, we should seek to maximize their opportunities to live with dignity and with purpose throughout their lives. Second, for the Direct Support Professionals who serve them, we should seek exactly the same.

There are practical steps that we can take to achieve these outcomes. We need to focus on three key elements in the 5.07 plan:

- Adequate funding
- Increased flexibility
- Accountability

### **ADEQUATE FUNDING:**

Funding needs to be addressed at two levels--system and individual.

At the system level, 15 years ago DSPs were paid substantially more than minimum wage. Some say 50% more, others calculate 35% more. Everyone agrees there was a significant difference between DSP wages and the minimum wage. DSPs are essential to ensuring that the individuals we serve have meaningful, safe lives and are integrated into their community, with choices and options available to them. The work of a DSP requires special training, skill and compassion for which they must be appropriately compensated, so becoming a DSP is a desirable career path.

Additionally, organizations need predictable funding with ongoing increases to appropriately support the increased costs of operating programs. We need to ensure that there are programs and agencies available to serve the growing need for services.

At the individual level, adequate funding requires rates that are based on the individual's needs.

### **INCREASED FLEXIBILITY:**

**Adequate funding by itself is not enough. We also need to be allowed to use that funding in appropriate ways to meet the needs of individuals with IDD.**

Services in NYS should allow for more flexibility to meet the needs of the individuals, rather than *fitting* the individual into the limited service options available. Other states have been successful in receiving CMS approval for more flexible service delivery and billing requirements. Flexibility is discussed further later in this document.

### **ACCOUNTABILITY:**

**To achieve quality, we need accountability. To achieve accountability, we need to be able to see what is happening, and we need to be able to take action.**

Three changes will produce this increase in accountability.

- Readily available data, so that current behaviors can be seen. Investments in technology should be made to ensure that data collecting and analysis is accurate and reliable.
- Clear-cut appeals process for any decision, so that there is a way to enforce flexibility at the level of the individual.
- An independent oversight organization, so that individuals and their family have expertise available to them in understanding the data and the appeals process.

That independent oversight organization must be authorized to help individuals, and it must be adequately funded.

## **BUILDING AND SUSTAINING A VARIETY OF HOUSING SUPPORTS/RESIDENTIAL OPPORTUNITIES:**

- Ensure there is a full range of appropriate residential options available to individuals of varying needs currently, and as their needs change with age.
- More residential opportunities need to be available for individuals living at home with their families: Housing as stated at the recent forums discussed individuals leaving hospitals, residential schools, and state operated group homes. Older individuals still living at home were not addressed. Many families tried to keep their adult child home longer rather than seek residential placement. In recent years, as fewer residential options were available, OPWDD encouraged such decisions by promoting more

community supports. Those parents are very concerned, because future residential placement for their children seems very limited, and these parents are getting older.

- ISS: The ISS rent subsidy needs to be increased so individuals that can live more independently can actually obtain housing. The rent amount for the ISS subsidy has not increased in years despite numerous discussions with the State and advocacy initiatives. It's often very difficult, especially in NYC, to find an affordable apartment especially in the neighborhood that is familiar to and/or the choice of the individual.

## **STRENGTHENING OUR WORKFORCE TO PROVIDE QUALITY SERVICES:**

- Our DSP workforce is the backbone of our service delivery system. We are in an unprecedented staffing shortage that threatens the quality and stability of our system for the individuals we support. The crisis is caused by years of underfunding that eliminated a wage gap in earnings for our DSPs and that of minimum wage workers. As previously mentioned, in years past DSPs made several dollars more per hour than the minimum wage, compensating them for the unique and necessary work that they do for our most vulnerable citizens. The responsibilities of a DSP are vast, and require a high degree of skill and compassion. We must invest in our DSPs with appropriate compensation and a career ladder with professional credentials to recognize the valuable work they do.
- Clinical/Supervisory staff salaries need to be considered and adjusted accordingly with the increase of DSP salaries. Many supervisory staff are earning salaries close to those they supervise.

## **DAY PROGRAMS AND EMPLOYMENT SERVICES:**

- Day and Employment services are expected to be person centered, and therefore should be designed with flexibility to meet the person's wants or needs. An individual's program should have the flexibility to be a combination of Day Hab/PV/SEMP. Day Habs will work on various life skills as well as the interests of the person that can be used to prepare a person for employment and reach their life goals. At the Life Plan meeting, the team can work with the person, Care Manager and family to design a program that will meet individual requests. In addition, Self- Direction is available to also assist the person in meeting their life goals.
- Allow telehealth/remote as an option when needed/desired by the individual.

## **Care Coordination:**

Care Managers must receive intensive and ongoing training to learn how to effectively support the individual and family. Additionally, there needs to be resources/services available for Care Managers to secure for the people they serve, rather than waitlists and endless processes that create a barrier to services.

## SELF-DIRECTION:

**How can the self-direction program better address the needs of the person and support for family caregivers, as well as assure equity of access and sustainability of self-directed supports?**

The self-direction program can better address the needs of the person and support the family caregivers, by first ensuring the families understand the program. After a lifetime of being told about and preparing for group services, the two- hour Self-Direction session that the person and family is required to attend is not enough.

There needs to be a long-term educational campaign about the program. People with developmental disabilities deserve to be brought up knowing about the choice and opportunity available to them, as well as assuming that they have a place in society.

Many families do not fully understand the role they have in self-directed services. All services work best when there is an understanding of the commitment and responsibility from the family, and this is especially true of individualized services.

There needs to be a real conversation about what the program is and easy access to follow-up trainings which clearly explains what will be required of families, Brokers and Care Coordinators.

The Circle of Support must become an integral part of raising a child with developmental disabilities at the same priority level as finding the child a school and a pediatrician. The long-term campaign must extend into the schools, and the medical offices.

Just like with physical health, the “social health” represented by a Circle of Support must take its rightful place as another long-term goal to be nurtured. The goal is that the teachers through the Individualized Education Plan (IEP) meetings and doctors will help families realize what is working or not, and where they already have connections. Some families will feel that they do not have a Circle of Support and will need help to identify small steps they can take to make changes.

The Circle of Support is a vital piece of the puzzle for the person and their family. The official New York State definition of a Circle today is the Care Coordinator and Broker—paid individuals that are forced to be in the life of the person through their jobs. This does not compare well to the circle of support that non-disabled people have.

COVID-19 made it even more evident that many people with disabilities lack the relationships that are formed throughout the person's life in school, work, sports, hobbies, and other interests. We must find ways to support the person and their families in building natural

supports. If we do not, then we are participating through our passivity in the segregation of individuals with I/DD rather than being seen as a neighbor, friend, or buddy.

### **HELPING FAMILIES IN SELF DIRECTION THINK DIFFERENT:**

In addition to training for the professionals who impact the family during the years of childhood, we must also directly impact family caregivers of adults. Families need an understanding of the ongoing processes, continual changes, as well as personal development as they support their child with their goals, dreams and hopes for the future. Training will provide the family caregiver the empowerment skills necessary as they work along with the Circle of Support.

We must help families to overcome negative patterns of behavior and attitude. The challenge is particularly difficult in low income, underserved, unserved and multicultural communities where there are very few examples of positive outcomes for people with disabilities. Mindset challenges are common even among those with economic and social privilege, but are almost inescapable in communities that lack those advantages. Some common mindset challenges include:

#### **1) Diagnose and manage.**

Seeks to identify, and or remediate the family's perceived deficiencies of knowledge or attitude. The individual with disabilities is "sick" or "damaged". They need to be fixed, and to get that done they are to be turned over to the professionals who have the specialized skills needed to provide treatment. Until then, the individual with disability is often hidden away.

#### **2) Blame and give up.**

Declares the family immovable and retreats from any changes. The professionals fail to fix the person, and the family gives up. One spouse blames the other. One of the parents gives up on the family, gives up on their child.

#### **3) Deter and retreat.**

Delegates unquestioned power over the person to the family. The child with disability is taught that the parent is the decision-maker and always will be. Absolute power is given first to the parents, and then later transferred to the professional providers. The individual with a disability has no voice or say.

### **What we need instead is Dialogue and Invent.**

The goal of dialogue and invent is to strengthen power with and among all who care about the person. This path involves honest conversation that leads to agreed action. Test perceived limits of what is possible, which is a fundamental purpose of person-centered planning.

## **EQUITY OF ACCESS TO SELF-DIRECTION**

To achieve equity of access we must seek out underserved and unserved individuals. The schools are a great place to start. Although in recent years there has been an increase of the number of children served in OPWDD, there still are many children and young adults that go through the educational system and do not connect to OPWDD supports and services. Many special education districts and community schools are not knowledgeable about OPWDD, so individuals/caregivers struggle to get support outside of the NYC DOE (Department of Education). By collaborating with the DOE through counselors/social workers, parent coordinators, and teachers, OPWDD can develop constructive relationships between the schools, service providers, and natural supports. This does not guarantee success, but does increase the likelihood that the system will deliver on a promise to walk with the person and caregiver together as they imagine a journey into a desirable future.

## **SUSTAINABILITY OF SELF-DIRECTED SUPPORTS**

As we look at the long-term goal of sustaining this program it is imperative that we focus on being intentional with applying good person-centered planning for each person. Constraints are the conditions a design has to satisfy in order to fulfill its purpose. Constraints form a system: each affects and is affected by the others. Some constraints are imposed externally, like system regulations, some are embraced voluntarily. Constraints that serve purpose are:

- 1) community
- 2) relationships
- 3) valued roles
- 4) power-with
- 5) resilience
- 6) commitment
- 7) inner journey

These constraints open a search for possibilities in the life of the person. When the focus becomes intentional, we then create the ability to imagine a good life as an engaged and contributing citizen and stop perpetuating the notion that the person is best off “with other people with disabilities ” in special settings overseen by specialists.

We must also recognize that while self-direction works for some families and individuals, it does not work for all. It is time consuming and requires a certain level of organization and acumen to “manage” all of the elements of self-directed services. Additionally, the self-direction model doesn’t sufficiently address a long-term plan when the caregiver is no longer able to manage the self-directed services. A very small number of families will have adult siblings or other family members to assume the responsibility of the self-direction program.

## HOW CAN OPWDD, WORKING WITH OTHER STATE AGENCIES, BEST PLAN FOR AND SERVE CHILDREN AND ADULTS WITH COMPLEX NEEDS:

- Request that the NYS Education Department gather ongoing data of special education students expected to be eligible for OPWDD services. This data will enable OPWDD to plan accordingly, ensuring that services are available for these students as children, and when they enter adult services.
- Regarding Medical and Dental services for the I/DD community: The American Academy of Developmental Medicine & Dentistry (AADMD) has a program called the National Curriculum Initiative in Developmental Medicine with medical school partners across the country. Currently, they are only showing Einstein and the Renaissance School of Medicine in Stonybrook listed as partners from NY. We should be more involved in this initiative. We should also review the outcomes of the initiative to date, that may help us provide medical services better tailored to our population.
- Work with SUNY/CUNY (and private) medical schools to ensure that curriculum related to those with developmental disabilities is included. To better support our clinics, require medical Students/Interns/Residents rotate through the clinics and their different specialties. It would serve to expose more medical personnel to the needs of our population and potentially encourage more providers in clinics or private practice to the field. Perhaps there could be incentives such as credits towards a course or some small remuneration towards their education costs.