

## Testimony of Care Design Individual and Family Advisory Board before the:

- ❖ **Assembly Standing Committee on People with Disabilities**
- ❖ **Assembly Standing Committee on Labor**
- ❖ **Assembly Subcommittee on Employment Opportunities for People with Disabilities**

October 20, 2021

Good morning. My name is Karen Azarian, and I am here today to present testimony on behalf of the Individual and Family Advisory Board for Care Design, NY. Care Design is a Care Coordination Organization that represents over 27,000 individuals with Intellectual and/or Developmental Disabilities (IDD) and their families throughout the State. We appreciate this opportunity to offer the perspective of individuals with IDD and families to your Committees. We will focus on the structural barriers to accessing the current system of employment supports, possible ways to improve those supports, and the impact of COVID on individual participation in training and jobs.

### **Importance of Employment for People with IDD**

For most adults, including people with IDD, having a job provides us with motivation, direction, opportunity, and personal growth. No matter the title, the company, the hours, or the salary, work provides people with purpose. Being employed gives meaning to our day and affords us a sense of pride. Access to meaningful work is an essential component of a well-rounded life and full community integration.

### **Goals**

When evaluating employment supports and opportunities, it is critical to keep in mind the breadth of differences in not only interests, but in the abilities of those who have IDD. Some may be able to train for and hold down jobs that are more readily available in the competitive employment market; some will need more intensive training to do so; and some may need an environment which allows them to use their strengths but which provides continuous support, often for the duration of their employment. To put it bluntly, as in all aspects of support for those with IDD, the touchstone is an individually customized approach and flexibility in the way the programs are designed and operated. Unfortunately, this is not the case today.

## The Problems

On average, the State is spending \$11,000 a year on each person in an OPWDD employment program, excluding the costs for ACCES-VR, which is funded through the State Education Department (SED). Yet little is known about the successes or failures of those who have gone through the system. We do understand that far too many individuals and families of those with IDD are unaware of the availability of existing employment supports. We also understand that those who do seek those services often feel that access is limited to people who are initially determined to possess a higher level of skills to hold traditional jobs.

At the same time, assessments can seem arbitrary and subjective. My own brother, who had been successfully employed for 20 years until his company relocated, was soon after assessed to lack the competencies to qualify for Supported Employment (SEMP). He thankfully entered an OPWDD pilot program that did not rely on the traditional assessment system, and has been working continuously for the past eleven years. When people with IDD are assessed to be “unemployable” during their schooling or soon after, before they have a work history, that initial determination can be devastating.

Even for those who are allowed to enter training, the job opportunities currently available drive the training. Individuals are trained for and encouraged to participate in *available* jobs, rather than jobs that are more suitable for the skills they possess -- skills which may need enhancement.

We believe the problems begin with the uneven preparation for employment and development of employment skills for those of school age in Special Education programs. It is our understanding that some school programs excel at offering training in employment skills and others fall far behind, offering very little to school-aged children before they “age out”. When an individual leaves school and seeks support from OPWDD, their employment skills are often not communicated. If they enter existing employment programs, an appropriate assessment of their skills which concentrates on the individual and not simply the available job is not being accomplished. Individuals are often not receiving appropriate preparation for interviews. One mom painfully recounted the frustration she and her high functioning autistic son have experienced in securing a computer tech job for which he trained, because he has been stymied by the demands of the interview process.

Another critical barrier is the overly restrictive time limits for support in some programs, such as ACCES-VR, Pathways to Employment, or Employment Training Program (ETP). What if the individual needs 18 months of support rather than one year? More flexibility needs to be built into the training to promote success.

An overly bureaucratized system responds too slowly to adjust training to changing demands of the job. If an employer wants to give new job responsibilities to someone who has been working well, the request to temporarily return to a more intensive level of support in SEMP requires the program to submit a request for approval to the local DDRO. This approval is often so delayed that by the time it arrives, the employer has had to give the responsibilities to another employee.

Reimbursement criteria and rigid regulations also impede agencies' flexibility in working with individuals. For example, a Direct Support Professional in a Day Habilitation program who located a paid employment opportunity was unable to support that person to start to work until a wholesale change in programs and assignment to a Job Coach was made. Of course, by then, the job has gone elsewhere.

### **The New Normal**

As we discuss these issues, we also realize that our recent history with COVID has impacted all the programs we now examine, the job sectors we want to access, and the individuals who are supported. It bears repeating that the workforce crisis which existed before the pandemic has only worsened. All frontline professionals, including job coaches, have been affected, and many agencies and programs, including employment programs, had to be suspended.

Unfortunately, the lack of programs and the loss of structure and supports have personally impacted people with IDD. Some have lost skills they gained prior to COVID, and some have been needing new mental health and behavioral supports. Certainly, even more intensive and flexible employment supports are essential.

## What is Needed

1. We need a seamless transition between education and adult services, and a true continuum of care between day habilitation, prevocational programs and employment supports
2. We need a person-centered assessment process whose aim is to identify what the prospective employee can do rather than to determine that someone who wants to work is “unemployable” within a narrow set of constructs or without a trial
3. We need to eliminate bureaucratic, regulatory and reimbursement criteria that impede personalization and flexibility
4. We need Government and Agency investment in customized employment opportunities for individuals with more intensive support needs who wish to work without completely segregating them into “IDD only” workplaces
5. We need increased transparency by OPWDD and SED on the outcomes of the ACCES-VR, SEMP, and other employment initiatives as well as rejection rates as a basis to implement improvements

We thank you all for considering the unique and challenging employment needs of people with IDD. We are trusting you to help them succeed.

Thank you