The Long, Winding Road to Employment First

By Dale DiLeo

Advocating for real jobs for people with significant disabilities has been around for over 30 years. Meeting APSE founder Wendy Wood as the organization was first coming together led me to join the APSE Board. Enamored with the mission, I soon started the first state chapter in New Hampshire, while I was a consultant working with the infamous state “system change” grants. (They never really significantly changed the system, unfortunately.) I became APSE’s fourth president, and ending up serving on the board for nine years.

APSE has evolved and accomplished a great deal in very difficult circumstances. It has promoted training, shared new techniques, provided an annual conference for us to come together and collaborate, and recently has offered a path to certification for professionals.

Remarkably, though, despite all the advocacy and advancement, we haven’t seen any improvement over time in employment rates for the people whom we represent. The system has not really changed. What we have done is to painstakingly demonstrate a wonderful framework of what is possible and what can work in just about every region of the country.

I have witnessed many of you battling for individuals who were often dismissed as not being “feasible” for employment. This is no small feat for the many people whom we have helped realize job success. But this effort is not enough. It is one thing to succeed with some and show what can be done, and quite another to make it an everyday reality for all. Here’s the task that remains, as I see it.

- Highlight pay inequity where it exists – There is a disturbing pattern, especially in large agencies, of huge gaps among management, workers, and the wages of people in the employment programs they run. We must change a system that allows, and in some cases encourages, huge wage disparities. Studies have found that the average wage for private agency direct service staff was just over $10 per hour in 2009, leading to excessive turnover. Of course, staff turnover ultimately compromises services for people with disabilities. Meanwhile, in several recent media exposés, management staff of several large disability agencies have been found to earn six-figure salaries, been provided paid luxury cars, and even have extended high-paid positions for their family members.

Of even more concern is that many of the workers with disabilities in sheltered workshops run by such agencies earn less than the federal minimum wage. (Currently about 420,000 workers with disabilities in the U.S. earn sub-minimum wage.) There are documented examples of workers earning pennies per hour, with this practice vigorously defended by disability professionals who opine that these individuals are at their maximum productivity.

Yet, the very notion that someone would believe that each person has some mythical fixed productivity level should be disturbing in our field. We know that productivity is related to many different conditions, including job match, level of support, accommodations provided, and so on. The very fact that productivity is primarily a function of our disability service capabilities is really the core foundation on
which finding employment for people with job challenges is built. We must phase out special wage certificates that justify any subminimum wage, and stop using that approach to solve perceive low productivity. That simply is a cop-out.

**Support self-determination** – For self-determination to be successful, people with disabilities need meaningful experience, financial control, and information to exercise informed choices. We cannot allow the weak justification so often heard that a person “is happy where he/she is” to keep people in segregated programs, especially when the segregated program (or some token version of employment) is all the person has ever experienced.

**Advocate for real inclusion and ending segregation** – To believe you can obtain civil rights without acting to end segregation has been proven false with the long struggle for racial equality. It is the same in the disability field. Too many people verbalize how they are “pro-inclusion,” but then do nothing to act on segregated programs and practices within their own agencies. This is hypocrisy and it is often defended on the need to maintain a structure that people have just grown used to.

**Fight discrimination** – The broader context of the employment services we provide must move beyond the disability field’s own current and limiting services, and into communities that still have stereotypes about autism, mental illness, and physical and intellectual disabilities. We must continue to educate and counter false perceptions and promote the successes that others did not expect. In addition, we must not only advocate with our words, but with our actions.

**Continually develop quality** – While we fight for job opportunities, we cannot lose focus on improving the quality of what we already do. This requires us to continually press for well-matched individualized employment with custom task sets and supports. It also means we must terminate group employment models.

We need to expect direct support workers to use effective and efficient supports that lead to self-sustaining job situations. This involves developing and providing good training that reflects evidence-based and respectful practices. Organizationally, we also need to provide better career ladders and self-development opportunities for direct service professionals.

**Demand respect** – Globally, our field still uses labels and readiness training as a means to solving people’s disabilities. This has been proven not only to be ineffective, but also harmful. We must end the use of disability labels – they stereotype employment possibilities and have no bearing on vocational success as compared to job match and support. The practice of people being kept out of job placement services because someone deems them “not ready for prime time” also needs to end. Finally, we must call out those agencies raising money based on pity or fear.

**Summary**

The crux of all these issues, as I now see it from the lens of a 30-year history, is that control of employment still remains with too many large provider agencies that have no impetus for change, face no competition, and continue to protect historical models under the guise of “this is what people need.” When the norms act to restrain the lives of people, rather than enable them, then it becomes a matter of principle to speak and act out against them. This is the true nature of “Employment First.” We must not allow this to be just a phrase that will ring hollow if our core policies and attitudes do not change. Make Employment First real. Speak out when it isn’t.


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