



To the editor:

Let me start this letter with a quote by Cornelia Suskind, mother of Owen, from the wonderful Oscar nominated documentary, "Life, Animated". When asked by an evaluator who worked with Owen, a young man who has Autism, "What do you think Owen's contributions are to his community and family?", she quotes her husband, Ron, "Who decides what a meaningful life is?".

In the context of the movie, it touched me profoundly at the time, even though I have worked in the field for more than 30 years, as it brings into sharp focus how many of us think about the value of people, especially people with disabilities. Who does decide what a meaningful life is? Is a person's worth about the size of their paycheck, how many hours they work, how funny they are, their fame or number of volunteer hours? Unless you have a family member with a disability, the issues surrounding this world are just not given a second thought... but you do notice how much it costs to support them. Is it really worth that amount of money when they may not change that much, get a job or contribute tax dollars?

When our culture finally saw that people in institutions needed to be free to live more "normal" lives in their own homes with their families or in smaller groups and that it would be at a much more affordable cost, the revolution began. There has been so much progress made, but one consequence of this has been more than 3 decades of disparity in the rates of pay for people doing this work as compared to almost any other industry.

For all the years I've been advocating before the legislature and speaking in public settings on behalf of people with intellectual and developmental disabilities, I have been saying that we all need to see the folks we serve as having enough value to deserve and receive enough funding to actually lead self-determined, purposeful lives. Everyone says, of course, that is what they believe too, but it is not followed up with the actions that prove that belief. As the years have gone by the funding level has deteriorated. Just think of what it would cost if everyone was still sent to institutions at birth?

This is a Civil Rights issue. People with ID/DD are still segregated, undervalued and often ignored. They have the same rights as every other minority, every other human being to live, work and play based on their own decisions, not what other people think they should have or become. We believe in the values of full participation of people with disabilities in all aspects of community life through providing person-centered services. This necessitates support that allows people to walk their own path, use their own unique talents, follow their own preferences. This requires a partnership with the individual and their family that leads towards a life full of opportunity, wellbeing and contribution to their community. Much of this is accomplished with the work of the Direct Support Professional.

Our private provider agencies who support many thousands of people in our area so that they have productive lives were having a crisis with attracting and retaining staff, especially the Direct Support Professional (Direct Care) for years before the pandemic, but this has been greatly exacerbated since then. Since we have been trying to return to the services we provide, we have been unable to bring back more than 20% of the people we serve because we cannot employ enough staff to allow them to return. Multiply that by all of our types of agencies in Massachusetts and 7,000 people have been waiting at home to get back to services after being at home for over 2 years, not including the hundreds of people who should be moving into adult services and cannot.

Now, imagine being their parents or caretakers who cannot work or get a break for more than two years. The world is coming back to normal, but not for them, as there are no staff for people with complex medical and behavioral needs.

Also imagine the residential homes staffed by DSPs whose individuals cannot go to day programs or out in the community because they do not have enough staff. Again, stuck at home for more than 2 years with staff who have to work many hours of overtime because there is no one to replace them.

We have grown from the time when we were considered just caregivers FOR people to focusing on empowering people to make their own decisions and helping people to do things for themselves. This requires the DSP to be a jack of all trades, being teachers, therapists, clinicians, counselors, chauffeurs, case managers, health aides, personal care attendants, nutritionists, vocational instructors, etc., etc. It is a complex job requiring many skills that really make a difference in people's lives. They are NOT babysitters. Yet, after their rewarding, but exhausting day, they have to work another job just to make ends meet. Some may even have a third job in order to stay in the field. Sometimes the person with a disability will get a job that pays more than the job coach that supports them. This system is not sustainable, so they eventually have to move on to jobs with higher pay and almost all other jobs have higher pay, causing turnover at close to 50%!

Again, almost every other profession pays more. Our folks live at poverty levels or close to it. Many other industries can pass the increased costs of their goods and services on to their consumers. We are dependent on state and federal funding. The meager increases we receive do not come close to addressing the cost of living.

Why does this disparity continue? It's a big price tag to have the government fund us adequately, but the consequences for not addressing it cost more... more regression in independence, more emergency room visits, more hospitalizations, more mental health issues, more institutionalizations, more dependence on state and federal benefits, more need for overtime rather than using those savings for better wages in a regular work week, etc.

The legislature needs to understand this, but so does the public. We cannot be short sighted. The investment in addressing the funding gap will bring competent, well trained people into the field who will contribute to the taxes that fund our programs, use less state benefits, use private health insurances and contribute to their economy.

More importantly, people with disabilities deserve to be treated with all the dignity and respect that every other human being deserves. That cannot happen with the current system. People do not stop having a disability because there is less funding. The pendulum is swinging backward. This is a moral imperative.

"Who decides what a meaningful life is?"

Respectfully,

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