

Unseen Diversity: March is Developmental Disabilities Awareness Month

Many Vermonters are being overlooked in our important conversations about diversity. Having worked in the field of intellectual and developmental disabilities (I/DD) for over two decades, the last six years as the executive director of Champlain Community Services (CCS), I see how the neuro-diversity of Vermonters is still an uncomfortable and unacknowledged part of our community. We can change that by promoting greater acceptance and inclusion in our communities.

In 1987 President Ronald Reagan proclaimed March “Developmental Disabilities Awareness Month.” Each year nation-wide councils on disability and inclusion partner with universities to highlight ways that people can come together to create robust and diverse communities. The National Association of Councils of Developmental Disabilities (NACDD) nicely summarizes this month’s goal: “The campaign seeks to raise awareness about the inclusion of people with developmental disabilities in all areas of community life, as well as awareness to the barriers that people with disabilities still sometimes face in connecting to the communities in which they live.”

Often people become aware of the role of agencies like CCS when they know someone or have a family member in services – but we impact many Vermont systems including health care, business, and diversity. The Vermont Developmental Disabilities Service System is among the most successful and well-respected in the world. Our data reflects successes in satisfaction, supported employment, community-based support, housing choices and medical oversight. I believe that the way neuro-diverse people live in Vermont is better than most states, and most countries. I’m proud of our state and our work.

It often comes as a surprise that we support people for their entire lives - adjusting services as individual needs change, decline or grow. As Medicaid providers our success relies on supporting people in crisis, with clinical needs, housing, transportation, respite, community-supports and employment – in a “medical”-like program. The effects of our services are far-reaching and can impact all areas of a person’s life.

It may also come as a surprise that over 55 percent of the people served in our provider network also have complex, co-occurring mental health diagnoses. In many cases effective mental health care is provided efficiently and personally.

Nearly 60 percent of people we support have significant and chronic health issues. Our services keep health care costs down, help people live longer, healthier, typical lives, and allow them to work and participate in our communities.

People with I/DD in Vermont are working hard in workplaces near you. CCS specializes in supported employment and our partnerships with over 50 Vermont businesses demonstrate how we, like other providers, keep people active, working and engaged. Over 76 percent of the people supported by CCS have jobs, are contributing to our state economy, paying taxes and reducing dependence on social security.

These are tremendous outcomes for a service system where the per-person costs have remained stable – or decreased – in recent years.

But life as a Vermonter with intellectual disability can be difficult. People face exclusion, abuse, bias and fear. In a 2012 national study more than 70 percent of people with I/DD reported that they have been victims of abuse (<http://www.disabilityandabuse.org/survey/findings.pdf>) - a striking data point all too familiar to my Vermont colleagues and me. Many people we serve have been neglected and exploited and have challenging or unique behaviors that make relationships especially difficult. Life in the community can be scary for people with complex needs. Recently I heard one man ask, "What does it feel like to feel comfortable in the community?"

Over the past year service providers, advocates, families and the state have begun working together to redesign the Vermont Developmental Services System to better demonstrate our successes, outcomes, data and service delivery while also reforming our payment structure. I'm concerned with how the redesign will affect people in services, and our statewide network. It will be critical to maintain the commitment to a robust, person-centered, community-based network as we design a system that's sustainable for Vermont.

As we work to increase awareness of our friends and colleagues in developmental services – we must also commit to providing livable wages, robust training and supportive workplaces to our staff. Maintaining a strong workforce is a necessary part of our commitment to people with I/DD.

Our service system evolved from the closing of Brandon Training School – the State's former institution that shut its doors in the late 1990's. In the current system people are involved in the direction of their care, have individualized goals and are increasingly a part of their communities. Plus, it costs far less than institutions (nearly two-thirds less, by current estimates) – with greater health, happiness and social outcomes. Currently here is a Vermont Bill (H.332) that seeks to establish a Developmental Disabilities Independence Day. It is important for Vermonters to remember the closing of Brandon Training School and show that we value *true* inclusion and equal opportunities.

Recent positive and person-centered interactions with health care providers, students and law enforcement demonstrate that people with I/DD are seen more and more as individuals who have community interests, presence and agency.

How are you working to make the community welcoming for people with diverse needs? What kind of community do you envision when you think about diversity?

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