

There are very few people even with the most severe disabilities who can't take control of their own life. The problem is that people around us don't expect us to. We built a system, a political system, and a system of public policy based on old attitudes that actually allow us off the hook, to have no expectations, that believe that we will not work or participate in our communities when in fact we've discovered that the reality is just the opposite. ~ Ed Roberts

January 23, 2019
Testimony on H.3

Good afternoon. My name is Sarah Launderville, and I'm the executive director of the Vermont Center for Independent Living (VCIL) and the president of the Vermont Coalition for Disability Rights (VCDR).

Thank you so much for inviting me to testify today regarding H.3.

The Vermont Center for Independent Living is a nonprofit organization directed and staffed by individuals with disabilities and those who are Deaf. We work with people with disabilities and Deaf individuals in the community to provide support and advocacy as they move through their goals of independent living. (www.vcil.org)

The Vermont Coalition for Disability Rights is a coalition made up of organizations throughout Vermont that serve and advocate for individuals with disabilities. (www.vcdr.org)

We are in support of H.3 and believe it is the right time to move forward on this important legislation by bringing together an advisory group to develop ethnic and social equity studies standards as well as reviewing and making recommendations to the State Board of Education.

Passing this bill will make a strong statement about the commitment from political leaders in our state in addressing systematic policy issues of racism, sexism, ableism, homophobia and other systematic discrimination of social and ethnic groups.

The bill goes further, as well, and is inclusive of groups most affected by these systems and who are eager and willing to work on these issues. It will allow for a statewide eye toward understanding our full history, conversations of our full cultural heritage and learning from individuals who have systematically been left out, cast aside and harmed by the current system.

Most excitingly it will address and give credit to more individuals who have done great things in our society for our children to learn from and aspire to.

This ultimately will lead to adults who are not just following a systematic policy but are thriving, aware of their biases and working to create a stronger society.

We support the intersectionality of this bill as well. As groups come together we hope this will rise up and address issues of people from multiply marginalized communities.

According to Cornell University's 2017 Disability Status Report for Vermont, 14.5 percent of all Vermonters have a disability. This number *does not* include those in institutions, including jails and nursing homes. VCIL estimates that about 1 in 5 people living in Vermont have a disability.

In 2017, the prevalence of disability among persons of all ages of Hispanic or Latino origin in VT was 14.4 percent.

In VT in 2017, the prevalence of disability working-age people (ages 21 to 64) was

- 11.6 percent among whites
- 22.9 percent among Black/African Americans
- 13.1 percent among Asians
- 48.0 percent among Native Americans
- 18.6 percent among persons of some other race(s)

Our state has an awful history of oppression and torture of individuals with disabilities. As a leader in the eugenics movement, Vermont sterilized and institutionalized individuals with disabilities and other ethnic, social and racial groups in hopes for "good Vermont stock."¹

There is a rich history of warehousing individuals with developmental and psychiatric disabilities as well. These important parts of our history are largely underplayed but are the basis for policy decisions and systems set up in our state. The context of history is important in terms of what those of us who have disabilities and work on policy issues believe need to change to encourage a world that is accessible to people with disabilities.²

You can see it within the education system, in which accommodations for youth with disabilities are within "special education" as if it is something different and not within the norm.

Disability is a natural part of life. It can happen to anyone at any time. But we treat it in our society as something different.

We appreciate that the bill goes beyond curriculum and looks to school policies and the school environment as a whole.

¹ <http://www.uvm.edu/~eugenics/>

While many things have gotten better systematically, our federal and state laws still pit schools against families with disabilities when it comes to funding education. I've heard from families who were working to make access changes in their school that they were outcast in the papers and social media by their very own communities because putting in an elevator for that one child was too much money.

Of course, we don't often think of all the "accommodations" we make for able-bodied individuals—lights, stairs, chairs at a table. Shifting perspectives of society can be very difficult when you are in the minority.

Our law in Vermont sends a letter to new parents of Deaf children telling them about their options around Cochlear Implants, but does not lay out the options for consideration of a life without medical intervention. One that is based on a strong, thriving community of Deaf individuals and has a rich Deaf culture of its own. Simply put, the doctors and society of people who are not Deaf are afraid to live that way so there is biased information sent to families.

We still have in place ways to restrain and seclude children with disabilities in school settings and we know from the 2015 report [Kicked Out! Unfair and Unequal Student Discipline in Vermont's Public Schools](#) that "students with disabilities were nearly three times more likely to be suspended than students without disabilities." ³

We are very supportive of the section of the bill which lays out the advisory working group that includes stakeholders with lived experience.

As I mentioned, the Vermont Center for Independent Living is directed and staffed by individuals with disabilities and who are

³ <https://www.vtlegalaid.org/sites/default/files/Kicked%20Out%20-%20Unfair%20and%20Unequal%20Student%20Discipline%20in%20Vermont%27s%20Public%20Schools%20-%20print%20version.pdf>

Deaf. When we were founded in 1979, that was a very new concept. Up until then then, it was parents of people with disabilities who typically fought for disability rights. And the people who were most revered around disabilities were medical professionals.

That was a problem for those of us in the disability community, because most medical professionals saw us somehow as broken or needing to be fixed. So, a group of people with disabilities came together, and drawing upon their own lived experience with disability, created our organization. Almost forty years later we are still working to dismantle ableism, so we know this work takes time.

Ableism has been defined by author Leah Smith as a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be 'fixed' in one form or the other.⁴

Well intending people who don't have disabilities often set the tone in education around disability and present to young people a set of ideas that perpetuates the idea that people with disabilities are either devalued or to another extreme inspirational. Both extremes set the tone for young people with disabilities as well as their non-disabled peers.

The AMA Journal of Ethics article [Three Things Clinicians Should Know About Disability](#) highlights this point:

As disability activists and disability scholars have argued for decades, people with disabilities, on the whole, flourish in all sorts of bodies and in all sorts of ways. What many people with disabilities do report as diminishing quality of life is often less the direct effect of their physical or psychological

⁴ <http://cdrnys.org/blog/uncategorized/ableism/>

impairments than the effects of living in a society that is designed for and supportive of abled-bodied people alone.⁵

The most common example of teaching about disability in schools is through simulation. This is when a teacher takes out a bunch of blindfolds and asks students to try and walk the halls or participate in class, or brings in a wheelchair and students take turns trying to push themselves along.

These activities, though well-intentioned, seem to have a couple of responses, including students who wish they could use the wheelchair because it's fun or the students saying to themselves that they hope they never get a disability.

This approach is to help nondisabled students become empathetic to the disability experience. But students only get a small glimpse into some limitations and barriers and, more importantly, some students go away with a stronger sense of pity towards those with disabilities. It is especially harmful if the person running the exercise does not have a disability themselves and can share from personal experiences.

Another commonality in schools are the study of individuals with disabilities who have led extraordinary lives. Helen Keller and Stephen Hawking come to mind. The lessons usually are unbalanced and create an atmosphere of "in spite of their disabilities, they were able to do these important things." While it is important and vital to acknowledge and raise up contributions of people with disabilities in the lessons it needs to be done in a careful and intentional way that highlights achievement but does not cross the line of inspirational or patronizing.

These are subtle but important pieces in teaching about disability.

We appreciate the collection of data asked for in H.3.

⁵ https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-11/msoc3-1812_1.pdf

When we see people as “other” and not part of the makeup of our communities we see more incidences of bullying. According to PACER’s National Bullying Prevention Center, “there have been ten U.S. studies done on the connection between bullying and developmental disabilities. They all found that children with disabilities were two to three times more likely to be bullied than their nondisabled peers” and according to Davis and Nixon, 2010 “when reporting bullying youth in special education were told not to tattle almost twice as often as youth not in special education”⁶

This was one of the reasons the Vermont Statewide Independent Living Council has put together a curriculum called Include! in which you can “explore disability rights and the social history of the disability experience through the voices and experiences of those who lived it”⁷ The curriculum is web based and each year additional content is added. This year, the council is focusing on social justice and general inclusion.

Going through the language of the bill:

- We appreciate that the working group will select a chair from among its members. This is an important part of the legislation.
- We appreciate the commitment to compensate members of the group for their contributions.
- We are hoping that independent schools are included in this bill. Since a number of independent schools in Vermont specifically serve individuals with disabilities we believe it is vital for this work to extend to those schools.
- Page 9 of 12 (C): We would like to see the following change: challenge racist, sexist, gender or ~~ability-based bias~~ abelist or bias based on socioeconomic status when it occurs, using principles aligned with restorative practice.

⁶ <https://www.pacer.org/bullying/resources/students-with-disabilities/>

⁷ <http://www.includevt.org/>

Ability refers to “possession of the mean or skill to do something” while “ableist” is “discrimination and social prejudice of people with disabilities” and aligns with the intent of the rest of the sentence.

Today is Ed Roberts’ birthday. I wonder if children in our classrooms are studying him today. He is considered the father of the Independent Living movement. Not the co-opted language of independent living facilities, but that of disability rights. A man who had polio and using his lived experiences created with others the philosophy and world of independent living in which individuals with disabilities would be able to live as they chose and that individuals with disabilities must be part of the systematic solutions.

We’re going to develop leadership that has a fundamental difference.

That is, it’s inclusive.

It believes in people, and in our strengths together.

And, we are going to change our society. ~Ed Roberts

Thank you for this opportunity to testify today.