Testimony House Human Services Definition of Disability Sarah Launderville Executive Director, Vermont Center for Independent Living

Good morning my name is Sarah Launderville and I'm the Executive Director of the Vermont Center for Independent Living. VCIL is a statewide disability rights organization. If you're not familiar with VCIL, we work with people with disabilities and offer different programs to help people meet their Independent Living Goals, which more often includes working with people experiencing homelessness. A few of our programs include Peer Advocacy Counseling where we have staff with disabilities working with peers in the community on goals related to independent living, Home Access Program providing grants for bathroom and entrance modifications, Meals on Wheels for people with disabilities under the age of sixty as well as grants for assistive technology. We provide technical assistance on the Americans with Disabilities Act to businesses, organizations as well as people experiencing discrimination and more recently, we've taken the lead in the state by responding to people with disabilities who didn't have access to safe vaccines by offering an in-home vaccine program for COVID, Flu and RSV. In addition, we have a person dedicated to supporting the many Vermonters experiencing Long-COVID.

I reached out to Chair Wood this past summer as VCIL saw an increase in the amount of people coming to us who were also experiencing homelessness. This was not only an increase in people, but the increase included many more people who have significant disabilities who were calling in crisis over not having their basic needs met and most importantly needing shelter.

Many had been in the motel program and were confused as they were told they would be exited and our staff was left trying to hold space with people and not having any resources to turn to. We found support from End Homelessness Vermont who was able to provide some technical assistance. Ultimately the support from your statewide Independent Living center has turned to focus on where we believe the state has dropped people with disabilities including sheltering, access to reasonable accommodations and in response to the ongoing pandemic. The work has been difficult and we've hit barriers like we hadn't in the past. That's why I'm very grateful to your committee and for the invitation today to share some reactions and information that we have around people with disabilities experiencing homelessness. I will also focus on what I think is an outdated practice of using the threshold of social security benefits as a way to define disability for being on programs.

Recommendations

I want to begin by clearly laying out our recommendations for a GA Program that would adequately meet the intent for people with disabilities as laid out for them under the American With Disabilities Act and most importantly would make these benefits accessible.

Recommendations as they relate to disability:

- 1. Eliminate Categorical Eligibility. We believe that the best thing this committee could do for people with disabilities is to make the experience of homelessness the qualifying factor for access to GA housing. It eliminates added hurdles and barriers and prevents people from experiencing trauma that often leads to a prolonged experience of living with a disability.
- 2. Expand the definition of disability. Use the ADA definition of disability which I will outline more in a moment. And include people with medical vulnerabilities and temporary disabilities. This can be verified by the form already previously used by the Department of Children and Families following a settlement on this issue with Vermont Legal Aid. I have attached this form to my testimony. It is

important that not only doctors, but providers be allowed to fill out this form, because equity and accessibility are critical. Non medical providers usually have intimate knowledge of a disability and they generally fill out verifications for other programs including ones at VCIL. We find that asking for a doctors note increases barriers to people with disabilities. I also want to note that I take issue with the DCF's assertion that providers medical or non medical would falsify a document to assert a disability that did not exist. That is very insulting to all of us who work in the field.

- **3.** Provide Easy to Access Reasonable Accommodations. When an individual asks for a reasonable accommodation or when it becomes clear that someone needs additional support or when it is suspected that someone needs support, they should be supported through the process of accessing benefits. This is how a reasonable accommodation is meant to work, according to the ADA. The process should be communicated in plain language at all stages of applying for benefits.
- 4. **Simplify the Application and Recertification Process**. The complexities of this process are a burden for individuals with disabilities and their support networks.
- **5. Eliminate Periods Of Ineligibility** Frequently when people are exited from shelter or hotels, it is due to issues related to a disability. Therefore, periods of ineligibility, in addition to being inhumane, penalize people for their disability. People should instead be supported in a transition to a hotel or shelter that may be more successful.
- **6. Use Housing First Principles in Shelter Access** meaning services should be available, but not required. Required services do not allow people choice and are known not to help.
- 7. Invest in non congregate shelter and move away from congregate shelter. For everyone, but particularly for individuals with trauma and disabilities, congregate shelter is not conducive to good or positive outcomes.
- 8. Eliminate Income Contributions and Verification. For people on social security or working in low wage or limited

hour jobs, this prevents people from being able to meet their other basic needs, pushing them into a perpetual cycle that exacerbates their experience of homelessness and poverty.

History Of Definition Of Disability

VCIL is a cross disability justice organization, meaning we work with anyone who has a disability. When providing services we look at "an individual with a disability is a person who has a physical or mental impairment that substantially limits one or more major life activities". While there is no specific list of disabilities, this might mean someone with a physical disability, an intellectual or developmental disability, a psychiatric disability or what some refer to as a mental illness, or a sensory disability which includes people who are Deaf or blind.

Rehabilitation Act Of 1973

The definition we use comes out of the Rehabilitation Act of 1973 in which Centers for Independent Living as well as State Vocational Rehabilitation services, and other programs were originally funded. The definition of disability there is "persons with a physical or mental impairment which substantially limits one or more major life activities".

The term "major life activities" are typically defined as things like (and this is not an exhausted list) breathing, walking, hearing, seeing, learning, concentrating, thinking, talking, caring for oneself, sleeping.

It's important to remember that this is inclusive to all types of disabilities. We know that some types of disabilities are stigmatized and discriminated against more than others. We see that more often people with psychiatric and other non-apparent disabilities. An example of how a major life activities can affect someone with a psychiatric disability may include someone with a diagnosis of depression; it can affect concentration, sleeping and learning.

Americans With Disabilities Act

In 1990 the <u>Americans with Disabilities Act</u> passed and language around disability remained similar and added additional protections. It also expanded where someone with a disability is protected.

To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered.

Vermont Public Accommodation Law

In Vermont, we have the <u>Vermont Public Accommodation</u> law refers to disability as

- A. a physical or mental impairment that limits one or more major life activities;
- B. a history of such an impairment; or
- C. being regarded as having such an impairment

ADA Amendment Act of 2008

In 2008, an amendment to the ADA passed that updated and clarified language. This amendment is important because it clarified intent and gave examples of functional limitations that are often associated with disabilities that are not seen but affect major life activities. It gave examples of functions of the immune system, digestive, bowel, bladder, nerves, neurological, brain and respiratory. There are programs in Vermont that use this language when referring to disability and from VCIL's point of view we prefer language that captures all people who have disabilities when referring to services and supports.

One reason for a common definition is that when state programs report on the services they provide they are not capturing the true story of disability, and that is harmful. Not everyone with a disability will need all services and programs, and there can be other thresholds developed if there needs to be limits set, but disability itself has a common legal definition and is recognized and we believe it is a good one to use.

Other state programs use a definition that is broader than being on social security benefits, including HireAbility.

Social Security

Social Security has a similar definition but is related entirely to the ability to work. While work is a major life activity, there are underlying conditions of major life activity "impairments" that keep someone from the ability to work.

To meet the definition of disability for the purpose of SSI and SSDI and therefore currently also, the General Assistance Hotel Programs, you must not be able to engage in any substantial gainful activity (SGA) because of a medically determinable physical or mental impairment(s) that is either:

- Expected to result in death.
- Has lasted or is expected to last for a continuous period of at least 12 months.

But this is particularly related to work, not someone's ability to survive without shelter. So, inherently, there is a problem with this definition for the purpose of emergency shelter.

There are competing issues at play that we as a state need to decide when it comes to definitions around disability and program policies. On one hand we as a state say we want to expand and

encourage people with disabilities to be in an inclusive world where there is strong accessibility and barriers to the physical environment, communication access and biases are gone. That we see people fully for who they are. The mission of the VT Dept. of Disabilities, Aging and Independent Living is to "make Vermont the best state in which to grow old or to live with a disabilitywith dignity, respect and independence".

On the other side we develop programs that keep some in and some out because we dedicate limited resources to those and so we develop restrictive definitions that keep people with disabilities living in poverty and not fully acknowledge the over 93,688 Vermonters living with disabilities.

This keeps us from telling the full story of people with disabilities and perpetuates stereotypes that lead to more discrimination. It also, prevents people with disabilities from accessing support, benefits and reasonable accommodations when needed.

We also have conflicting messages to people with disabilities who need shelter and other basic need programs. On one hand we say you're only considered a person with a disability if social security has deemed you eligible for that program and on the other hand we say that we want people with disabilities to be working and put work requirements on people that are in direct conflict with becoming eligible for social security benefits.

Work requirements in and of themselves cause barriers for people when accessing benefits so we do not support them. There is an added burden for people with disabilities and then even further for those experiencing homelessness who must focus on meeting their basic needs and finding permanent housing.

In 2021, VCIL in partnership with HireAbility, Vermont Developmental Disabilities Council, Vermont State Independent Living Council, and the Vermont Division for the Blind and Visually Impaired published the report researched and written by the Vermont Public Assets Institute, <u>Our Time is Now</u>. It's a report highlighting the opportunity our state has with employing the potential 44,000 working aged residents with disabilities.

For years, VCIL has prioritized employment of people with disabilities and worked to increase awareness and opportunity to the business community and to people with disabilities helping them understand their rights under the Americans with Disabilities Act and seeking employment.

This report is important in this conversation because as a state we tend to jump to work requirements or SSI/SSDI in order to be eligible or keep benefits, when this is not a determining factor of disability. This report while highlighting areas of accessibility and inclusion to help benefit workers and businesses starts with a recommendation that is often overlooked and that is *Access to Basic Needs*. The report defines basic needs as access to food, shelter, clothing, health care and other basic needs.

This is connected to my own story. In 1995, I was moved to a group home in Vermont. I live with a psychiatric disability called Dissociative Identity Disorder, and was in and out of the hospital system for years. I was sent to live in a group home after my family felt there were no other options for me. I spent time there and eventually was able to move into an apartment. I wanted to work, but each time I got a job I would come in and out of my ability to hold down a position longer than a month or so at a time. As that went on, I wasn't able to pay my rent consistently and my case manager worked with me to apply for social security disability benefits. I was granted benefits in six months which is unheard of in most cases. I had a support system to help make sure my basic needs were met but ended up in an eviction process which was devastating. I was lucky though, as my case manager had also put me on waiting lists for subsidized housing and as I was moving through an eviction process a unit opened up, and I received a call from the Barre Housing Authority. I was able to move into a unit that was affordable and not back into an institution or on the street. I then had benefits and stable housing that allowed me to be secure and focus on what I needed to focus

on. I really wanted to work. I eventually answered an ad working for where I work now at VCIL. The job was initially eight hours a week. I was able to gain skills and having stability I was able to hold down this job longer than the other ones that I had tried. I had the safety net of affordable housing, so was able to take the leap and move into more hours when I was able to and eventually came off of social security benefits. I would not have been able to do that without an affordable housing unit because initially I was making less money per month by working than on benefits. That's not because benefits are a lot of money, it's because I had a very low paying job and limited hours. Eventually that shifted and I was able to move into a higher paying position and into other housing. Often when I tell people my journey I talk about how VCIL and employment saved my life, but while it was a huge factor in my life moving in a whole different direction I needed stable housing and support. I needed the basic needs met before I was able to be in a space to work and thrive independently.

I've discovered over time and my experience in the disability justice field for almost 27 years that my story is not unique and there wasn't anything special about me or my abilities. I was able to thrive because I wasn't exacerbating my disability in fight or flight mode to have my basic needs met daily.

We believe that everyone should be sheltered regardless of disability status, or other status. You're not more or less worthy of housing because you do/don't have a disability or you have a child or are a child. If you are experiencing homelessness you are in need of shelter.

If though, disability itself is a point of where someone is able to access a program, being on social security disability benefits should not be the threshold at all. It's problematic for a few reasons. Number one is most people who are homeless at this moment are not people who have applied or have yet been found eligible for social security benefits. Applying for benefits is a long process and for many people takes years to go through the process. You need access and ability to work through that systems and many people with disabilities who are experiencing homelessness don't have that capacity or resources to move through that system. What is needed is stable basic need of housing and shelter.

Secondly, if someone wants to continue to work and can work but still has a disability this forces them into a system in which you are initially not able to work. Some people who were working with want to keep working but the day to day survival of living homeless is a full time job in itself and if provided with safe shelter they can continue to work and not have to go on additional benefits instead.

The majority of people with disabilities coming to VCIL who are experiencing homelessness are receiving services and support from us because our definition of disability is not limiting, and it is obvious and apparent to us that these people have a disability that meets the definition under the ADA. Which is the definition that our state should be using.

Some examples include:

- A single Deaf woman with health issues facing eviction despite paying rent to her landlord. May be homeless in a month.
- A mother with early onset dementia and her daughter who are facing eviction from hotel that no longer wants to participate in the homeless voucher program due to the rate caps. They lost their home when an elderly relative died and they couldn't afford to continue to pay the rent.
- A mother with severe health issues in a hotel with teen daughter. Recently diagnosed with Diabetes and her doctor has said that being unhoused is worsening her health
- A single man with amputated leg and kidney disease facing possible eviction from rental housing; worried about being able to recover from a kidney transplant if he doesn't have a place to live

- A single woman who is exiting surgery to recover in a motel
 we hear this story often
- A young man with Autism living in a hotel who has been going to the Emergency Department for food and services
- A couple who has intellectual disabilities will be exited on 03/01 and have no place to go if the hotel does not participate.
- Young woman who recently broke her foot. Is in and out of shelters because she felt unsafe and her foot is worse because she is unable to follow doctor orders. She is mostly living on the street.
- Woman with dementia moved in and out of several motels and has not been able to find housing.
- Older man with Cerebral Palsy homeless in hotels and unable to get into assisted living facility due to criminal record from 30 years ago
- Young man in 20s, double amputee from diabetes complications. Moved in and out of hotels due to "behavioral" issues.
- Middle aged man with memory problems, homeless and trying to apply for SSDI without a phone or a place to live

The services:

I'd like to share that VCIL is a disability organization so we see this as a disability issue. Having said that, we have a limited staff which includes one Information and Referral Specialist and nine Peer Advocate Counselors (many of them part time) serving the entire state and supporting people with disabilities on an array of independent living goals. When I looked yesterday there were thirty active people working with our PAC program who are experiencing homelessness. That's just a snapshot and doesn't show the people we've worked with over the past year or the one-time calls our Information and Referral person receives. We have many more stories that I didn't include in the testimony. I'm grateful for End Homelessness Vermont that has provided technical assistance and, in some situations, has helped individuals navigate the system or obtain a voucher, along with ongoing needs, where our peer advocate counselors don't have that level of experience or particular expertise. We've also received support from Vermont Legal Aid.

In addition, the other pressures on systems including lack of personal attendant services is forcing people with disabilities into nursing homes where in the past they would have lived in their own homes. I feel like working at VCIL for almost 27 years. I've come full circle and where we were cutting edge as a state we are now moving swiftly back years to a time pre-American with Disabilities Act. At the end of the day our staff are receiving regular intense calls and people with disabilities experiencing homelessness have run out of options.

Additionally, the process for applying for and keeping up with services is not accessible to many. Many of our peers tell us the communication is awful. That they wait hours on the phone just to speak to a live person and that the system is difficult to maneuver. We speak to people all the time that talk about applying for services is a full-time job. We should make these programs streamlined, and have easier to understand plain language appeal and reasonable accommodation processes that individuals and providers as well as workers at the state understand. Along with providing a simple guide that allows individuals to know clearly the rules and their rights.

I want to name a few other concerns that I have. The practice of moving people to specialized shelters has to have individual choice and dignity. It is ok for people who want and choose that, so long as it is a real and clear choice. The practice of moving people in poverty or who have a psychiatric disability to isolated settings has a poor history in Vermont and across the country and the ADA protects people from being forced to live in institutions including nursing facilities or psychiatric care settings against their will.

Available but not required services work. As soon as services become required or forced, it begins to infringe upon an individual's dignity and ultimately their ability to succeed. I would strongly recommend against any system that forces people into treatment or care facilities. I want there to be robustly available settings and services, but would like to see caution when setting up these systems so that it does not quickly revert us back to times where poor farms and asylums were acceptable practices. That caused a lot of damage and allowed for a lot of abuse and the ADA is supposed to protect against such things.

Finally, in June we will be celebrating the twenty-fifth anniversary of the Olmstead decision, which was a decision that upheld the integration mandate of the Americans with Disabilities Act. VCIL's number one issue that we receive calls about is the need for accessible, integrated and affordable housing. This is across the board. The overall housing crisis has made this mandate more challenging than ever and we must continue to address it. People with disabilities and their families are screaming for help with actual housing, support services and Personal Attendants. We cannot rest on nursing homes or other institutions as the answer. That is not housing. It is not the promise of the Americans with Disabilities Act.

The current system has shifted people who had lived in institutions to the streets instead. So many people worked so hard to make that not happen initially but now the crisis of housing and workforce shortages calls for a new commitment and new solutions and if we don't work to update these systems now we will continue to fail people with disabilities.

I appreciate the ability to share our thoughts today and we're very willing to work alongside to offer suggestions as we move to a more just system of sheltering people.