



To the Senate Appropriations Committee

I regret that I cannot be there to testify in person today.

My name is Sarah Launderville and I'm the executive director of the Vermont Center for Independent Living and submitting written comments today as the president of the Vermont Coalition for Disability Rights which is a membership coalition of over twenty disability rights organizations throughout the state.

I've provided with my testimony a full listing of all our VCDR legislative priorities for the year and will highlight only a few in my testimony today.

We are asking for an increase in state funding of \$100,000 to the Vermont Association for the Blind and Visually Impaired for the continuation and expansion of needed services. Due to limited resources, VABVI has not been able to provide adequate technology training for people who are blind or visually impaired and who come to the organization looking for training on technology. This funding will allow for more people who are blind to be trained and expand their level of independence and quality of life.

Once again, VCDR asks that you support a repeal on the law that now counts \$125 of adult Supplemental Security Income (SSI) against a households Reach Up benefit which continues to effect parents who have disabilities. The reduction has targeted Vermont families who by the Social Security Administrations definition are unable to work as a result of their unique disabilities. Over 800 families continue to be affected by this reduction.

We request an increase in both Medicaid Global Commitment and general fund dollars that support Children Integrated Services to allow the agencies delivering these essential services to increase capacity to meet the increased demand.

We ask that you fund an Agency of Human Services Deaf, Hard of Hearing, DeafBlind Services Director position. This position will cost \$89,347 and will be responsible for coordinating services within AHS and taking the recommendations of the Deaf, Hard of Hearing, DeafBlind Council who have come together to make policy recommendations that promote diversity, equity, awareness and access. This position would begin to address the system gaps reported by the council.

We ask that you support unfreezing the Participant Directed Attendant Care (PDAC) program. This vitally important program, which is funded by Vermont's general fund revenues, needs to be opened up to accept new applicants. The program can mean the difference between Vermonters having to impoverish themselves so as to be eligible for other attendant services programs, or retaining employment and thus maintaining their independence. We believe that unfreezing the program will give opportunity to youth who depend on attendant services to have the same access to employment opportunities as those who were able to access the program before it was frozen four years ago.

We are asking that the full funding to the Copeland Center for Wellness Recovery Action Plan (WRAP) trainings be restored. We are shocked that this evidence-based practice that has demonstrated overall positive outcomes was eliminated in the administration's budget. In a time where we should be, and need to be, as a state investing in mental health services we ask that this funding be reinstated in the budget.

A full list of the VCDR priorities are included below. Thank you for your time and commitment to Vermonters with disabilities.

Sarah Launderville slaunderville@vcil.org

VCDR's 2019 Legislative Platform

Budget and Policy Priorities

BUDGET

Budget Gap: VCDR believes that the perennial imbalance between state revenues and the funding needed to meet very basic needs may well be "structural". We do not believe that this can be addressed by simply denying needs and cutting programs which ultimately help people live independently. Adapting our tax structure to current economic realities may well be the best way to avoid greater future expenditures.

Unfreeze the waiting list for the Participant Directed Attendant Care (PDAC) Program: Unfreeze the wait list for the PDAC Program. This vitally important program, which is funded by Vermont's general fund revenues, needs to accept new applications. The program can mean the difference between Vermonters having to impoverish themselves so as to be eligible for other attendant services programs, or retaining employment and thus maintaining their independence.

Rehabilitation Services for the Blind and Visually Impaired: Seeking an increase in State funding of \$100,000, for the continuation and expansion of our services and the addition of technology assistance. Due to limited resources, VABVI has not been able to provide adequate technology training for the visually impaired. Smartphones, iPhones, and the Internet have significantly improved the quality of life for adults with disabilities, and VABVI clients have asked for training on using these devices. A six-month pilot project funded by some one-time donations provided training to some clients (and yielded very good outcomes), but more training is needed so that additional clients can be helped.

Request Increased Funding to Children Integrated Services (CIS) to Prevent Adverse Childhood Experiences. Increase both the Medicaid Global Commitment and general fund dollars that support CIS to allow the agencies delivering essential CIS to increase capacity to meet the increased demand for services. By fully funding CIS now, the state of Vermont will save 7 to 10 times that amount as a return on investing in preventing to high cost of trauma in adults such as: incarceration, chronic medical conditions, substance use disorders and suicide.

Early Periodic Screening Diagnosis and Treatment (EPSDT) Requests the review of funding levels and program management to ensure access to home health specifically in children needing pediatric high tech care. This is an EPSDT mandated service for Vermont's Medicaid eligible children, but children with high tech medical needs are often unable to access staff to support them at home. VCDR requests that home health high tech nursing services be adequately funded and administered in a way that ensures that each individual child gets the medically necessary services to which he/she is entitled.

Repeal the "tax" on low-income families with children: A recent law counting \$125 of adult Supplemental Security Income (SSI) income against a household's temporary cash assistance (or "Reach Up") benefits every single month is driving adults with disabilities and their children deeper into poverty—as much as 10 percent farther below the federal poverty level in some cases. The reduction targets Vermont parents who, by Social Security Administration definition, are unable to work as a result of their unique disabilities. These parents need their SSI income to meet their needs related to disability, yet they are being "taxed" in order to reduce the Reach Up benefits designed to support other members of their household. Over 800 Vermont families are affected by the reduction.

Denture Coverage: Dentures make adequate nutrition possible and are important for the overall health of individuals with disabilities. They are not adequately covered by the Affordable Care Act and other insurance providers, including Medicaid.

Health Care Reform

VCDR will continue to monitor these efforts and advocate for the following:

- Health reform efforts – including the Medicaid Next Generation pilot – must preserve and strengthen Vermont’s person-centered and person-directed services and its community-based, disability long-term care system.
- The implementation of Vermont’s all-payer waiver, updated global commitment waiver, and the statutory requirement to align Medicaid long-term services and supports with these agreements must be informed by robust engagement with individuals with the lived experience of disability, their families, and other allies.
- Resources and planning for population-based approaches within health reform should prioritize the needs of groups that experience poor health outcomes disproportionately to the general population, including Vermonters with disabilities.
- Policies and procedures adopted in the service of health reform must ensure the continued protection of patient rights, including freedom from coercion, the security of protected health information, and access to health information in an easy-to-understand format delivered in a patient’s preferred means of communication.
- The use of Medicaid investment dollars must be delivered in a transparent public process that seeks the greatest benefit for medically underserved Vermonters.

EDUCATION

Legal Assistance for Families with Education Needs:

Requests resources for legal assistance to families of children with disabilities who are eligible for or on a Section 504 plan or an Individualized Education Program (IEP) at school in order to place families on a more level playing field with schools when there is a difference in opinion over educational services for a child with a disability. This plan could be a fully funded full-time special education attorney position at the Disability Law Project (DLP) or sustaining a bank of pro-bono attorneys trained by DLP in special education law.

Ethnic and Social Equity Standards: VCIL supports the creation of an Ethnic and Social Equity Standards Advisory Working Group to advise the State Board of Education on the adoption of ethnic and social equity studies standards into statewide educational standards. VCIL also supports requiring the State Board of Education to publish data on student performance and hazing, harassment, or bullying incidents disaggregated by student groups, including ethnic and racial groups, poverty status, disability status, English language learner status, and gender.

Inclusive Sex Education Reform: VCIL advocates for students across the state of Vermont having access to health education that is representative of the varieties of human experience. In order for these curricula to be truly inclusive for all students, they must be culturally diverse, include disabled students and content, and discuss sexual orientation and gender identity. Students need education that focuses not merely on sexually transmitted infection prevention but that also teaches them how to navigate consent, body positivity, and healthy relationships.

CIVIL RIGHTS

Safeguarding Civil Rights and Protections: VCDR will monitor and oppose legislative proposals that may diminish the civil rights of people with disabilities and mental health issues. Vermont has created the country's least institutional system of care but issues of access, accommodations, and involuntary treatment are still important in an era of budget constraints and misplaced fear of people who seem "other."

People with Disabilities in Prison. VCDR advocates for change in the way people with serious disability and mental health issues are treated in Vermont's prisons.

- People ordered by courts to a hospital for psychiatric evaluation should in-fact be admitted to psychiatric units where they can receive appropriate care, not to prison.
- Segregation is not treatment. Vermont should reduce or eliminate the holding of people with mental health issues or serious functional impairments in settings so restrictive that they exacerbate individuals' mental health conditions. In order to make this possible the State needs to develop the capacity envisioned in Act 78 for inpatient level of care.
- Individuals who have served their minimum sentences without incident are generally released from our prisons. Prisoners with disabilities should be supported to attain safe, supported, community placements so that timely release is an equal option.

Use of Force in Emergency Departments: When force is used to prevent an injury on a psychiatric unit, the Department of Mental Health (DMH) collects data. That data is shared with the "Emergency Involuntary Procedures (EIP) Review Committee" and the Mental Health Care Ombudsman. VCDR advocates that the Legislature also require hospitals to report these uses of seclusion and restraint to the DMH when they occur in Emergency Departments where many people in crisis are held for considerable lengths of time. Patient specific use of force should be reported to the Mental Health Care Ombudsman and aggregate data to the EIP Review Committee.

Expand Protections for Crime Victims with Disabilities:

Currently, the Vermont Rules of Evidence allow “hearsay evidence” from a child or person with a psychiatric, intellectual, or developmental disability who is a victim of a crime in cases of sexual abuse (VRE 804a). VCDR believes, along with the Vermont Network Against Domestic and Sexual Violence (The Network), that this should be expanded to include crimes involving serious bodily injury. The rules should also prohibit taking the deposition of a child who is a victim of a physical assault except by agreement of the parties or after court approval and further, to require a hearing before a court may issue a subpoena for a victim’s personal records (VRE 807).

Prevent Economic Harm to Involuntary Psychiatric

Patients: People held involuntary through no choice of their own can be powerless to prevent the impounding of their motor vehicle while they are ostensibly held for the purpose of receiving health care. Burdensome car impound bills may accumulate and upon discharge the individual may find that they will be unable to regain their only form of transportation due to bill they were powerless to avoid. We propose a bill that would allow impound fees to be paid by the DMH for people held involuntarily for psychiatric care in an effort not to over-burden people working on recovery.

Alternatives for people in crisis: Other jurisdictions have created alternative models for assisting individuals in crisis. VCDR believes that setting up facilities, largely staffed with peers, whose primary function would be to de-escalate and attend to an individual’s human needs would reduce the pressure on Vermont hospitals and reinforce the community basis of our mental health system.

Open Captioning Screening Bill: cinemas with more than two screens would have to offer two open caption screenings a week for each film they’re showing.

Support a constitutional amendment on Equal Rights which will provide equal protection under the law shall not be denied or abridged because of race, sex, age, religion, creed, color, familial status, disability, sexual orientation, gender identity or national origin.

SERVICES & NEW INITIATIVES

Home Modification: For Vermont seniors and individuals of any age with disabling health conditions, everyday living environments can interfere with mobility, safety and productivity. Home modification investments can make living independently at home possible, avoiding or delaying costly institutionalization.

VCDR proposes to create a State income tax deduction to mitigate the expense of home modifications required by a disability or physical hardship. The credit would be for a percentage of the expense or \$9,000.00, whichever is less. The percentage of the deduction that may be taken varies depending on the income of the person claiming the deduction

Establish a Vermont **Pilot Program for Professional Support Service Provider** for Persons who are Deaf-Blind. SSP's assist with accomplishing everyday tasks including reading the mail, relaying visual descriptions of the environment, providing transportation to and from locations including grocery stores, medical appointments, and many other personal errands as well as allowing participation in community events.

Pass legislation that creates and funds an AHS Deaf, Hard of Hearing, DeafBlind Services Director position within the Agency of Human Services with a single point of entry as recommended by the Deaf, Hard of Hearing, Deaf-Blind Council (DHHDB) to coordinate services and identify gaps and strengths. The position will cost \$89,347 and will be responsible for coordinating services within the Agency of Human Services, including creating and administering a referral network for services as well as the services recommended by the DHHDB Council and to identify system gaps.

The coordinator must have thorough knowledge of the differing needs, issues, and attitudes among the culturally deaf, the hard of hearing, the late deafened, and the deaf blind communities and have the Ability to communicate proficiently with deaf, hard of hearing, late deafened, and deaf blind persons by using a variety of forms of communication.

Support a Tactile Communications Assistance (TCA): Act No. 118 (H.429) passed last session and directed the VT Dept. of Public Service to study the potential creation of a communication facilitator program for Deaf-Blind individuals in Vermont. The Communication Facilitator (CF) Program would enable Deaf-Blind individuals to access videophones and video relay services through use of tactile interpreters, scheduled ahead of time to meet the individual's needs. The report with findings and recommendations is to be completed by December 15, 2018.

Advisory Boards: VCDR proposes that AHS, including DVHA and the AOE, take stock of their consumer advisories/boards and clarify, for the legislature and the public, **how stakeholder input is being effectively utilized to inform planning, implementation, and evaluation of programs and services for people with disabilities and their families.** There are significant changes proposed in funding and services for people with disabilities and their families, including census-based special education funding, mental health and DS payment reform, electronic verification and more. People with disabilities and families need to be fully included in the change process, moving that process forward and not having it move over them. Meetings need to be more than checking the box of stakeholder inclusion. Necessary accommodations must be provided to ensure robust participation by individuals who experience a disability. We need to be sure that we are making the most of diverse strengths, gifts, and abilities for dynamic decision-making that has lasting impact in Vermont. Example: the Special Education Advisory Council

Support for Peer Initiatives: The state should continue and expand support for Peer initiatives and organizations “of, by and for” people with disabilities. VCDR supports advocacy within the budget process for adequate funding of organizations and projects like: Vermont Psychiatric Survivors, the Green Mountain Self-Advocates, Another Way Drop-in Center, Alyssum, Soteria VT, Pathways VT, Deaf Peer Services, Vermont Family Network, Vermont Federation of Families for Children’s Mental Health, the Wellness Workforce Coalition, and other developing peer-run services. This is particularly important as the state budget “tightens” with the pressure of developing expensive residential and inpatient services.

Hearing Aid Coverage: Private insurance and Medicaid should be required to provide coverage of medically appropriate hearing health care, including hearing aids, their remote microphone devices, and aural rehabilitation. Coverage should have the same copays and cost and frequency limits as other durable medical equipment or other outpatient services. Medically appropriate hearing health care is essential for language development, communication, good health and personal safety.

Peer Navigation for Families with Complex Needs: Vermont should reinstate this program in which people with the lived experience of complex needs in their OWN families assisted other families to find their way through the complex system of social, economic and health programs. Formerly federally funded for 6 years (Family Support 360 Project), peer navigation has a documented record of success in supporting more informed choices and positive outcomes for families with children and/or parents with disabilities.

Vermont Family and Medical Leave Insurance Program: VCDR supports the development of a program that will assist families by providing paid leave at the time of emergencies and major life events. Just as workers comp insurance meets the needs of employers and workers injured on the job, a new system could help stabilize the workforce and assist families. VCDR would support a small tax to support this as long as other, existing supports are not negatively impacted.

Increasing the Minimum Wage: Supports increasing the minimum wage so that it reaches \$15 per hour by Jan. 1, 2022. Any legislation that increases the minimum wage should be careful to avoid the “benefits cliff” that can occur when an increase in a beneficiary’s earnings causes a corresponding decrease in the beneficiary’s public assistance by some greater amount, resulting in a net loss in household resources.