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***The Vermont Coalition for Disability Rights***  
***2020 Legislative Platform***

**VCDR thanks you for your service to ALL Vermonters!**

**VCDR hopes that we can assist you throughout the session as you consider issues that affect the lives of your constituents with disabilities.**

**Please contact us for input and education on disability issues. Learn about our member organizations and the many services they provide at our website: [www.VCDR.org](http://www.VCDR.org)**

**Please contact our VCDR coordinator, Karen Lafayette, at 802-373-3366 or at [kmlafayette@aol.com](mailto:kmlafayette@aol.com) or VCDR President Sarah Launderville at 802-224-1817 or at [slaunderville@vcil.org](mailto:slaunderville@vcil.org) with any questions.**

*VCDR thanks the Vermont Developmental Disabilities Council, VCDR members and friends for their contributions and support of our work. For more information about particular bills and other VCDR advocacy activities, or to share your recommendations and concerns, contact us:*

**VCDR**

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## **Justice and Access for all**

VCDR is pleased to share our legislative and policy priorities for the 2020 legislative session. VCDR members and allies look forward to working with our legislators toward our 2020 goal of “Justice and Access for All”. This theme and our legislative priorities are informed by the experiences and concerns of Vermonters with disabilities and their families and their hopes for this legislative session

People with disabilities in Vermont come from diverse ethnic and social backgrounds. Not all Vermonters with disabilities and their families need services, but all look to our state legislators and other officials for leadership and commitment to programs and policies that promote equity and inclusion. These Vermonters have important stories to tell and expertise to share with state agencies and legislators.

It is time to invest in justice and equal opportunity. We believe that progress is possible but that it requires fiscal strategies that support livable wages and that adequately funds the programs and services that allow individuals with disabilities of all ages and from diverse social and ethnic backgrounds to succeed, thrive and contribute to Vermont.

By working together, we can recreate our state’s ability to renew and preserve the resources and services that make equity, participation and economic success possible for persons with disabilities and their families...and for all Vermonters.

***Deborah Lisi-Baker***

# VCDR's 2020 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 Participant Directed Attendant Care (PDAC) Program:** Unfreeze the PDAC General Fund 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 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.

## **Increase the investment in Children’s Integrated Services (CIS) and stop the historic underfunding of essential early intervention and prevention services:**

VCDR supports an increased investment in CIS, which would ensure continued progress on optimal, healthy child development; family safety and stability and young children’s access to quality early care and education, and meet the requirements of Part C under the Individuals with Disabilities Education Act (IDEA).

Children’s Integrated Services (CIS), maximizes children’s health, development, and learning by providing individualized support to families and specialized childcare programs. Due to inadequate funding over the last 10 years, **Vermont is coming up short in meeting its obligation to its youngest learners, particularly those who are entitled to Early Intervention services mandated by Federal law.** CIS was designed to lessen, if not eliminate, the need for future services that are costlier and less efficient. Yet today, children are unable to access early intervention and prevention services with the timeliness and frequency needed for good outcomes.

## **Repeal the “tax” on low-income families with children:**

Four years ago the State passed legislation to reduce Reach- up the temporary cash benefits for families with an adult member receiving Supplemental Security Income (SSI), by \$125 dollars a month. Three years ago it was reduced to \$115 dollars a month and in the 2019 session it was reduced once again to \$77 dollars a month, but the reduction continues to penalize families because of their disability, keeping them in poverty. Over 800 Vermont families are affected. 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. We continue to advocate for the elimination of this “disability tax”. VCDR advocates for restoration of full Reach-Up benefits for families with disabilities.

**Denture Coverage:** Dentures make adequate nutrition possible and are important for the overall health of individuals with disabilities. Although Medicaid dental services were increased last year dentures are not adequately covered by Medicaid, the Affordable Care Act and other insurance providers.

## **Health Care Reform:**

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

- Medicaid investment funds, including delivery system reform funds, should be directed to shore up Vermont's community-based agency system before any further investments are made in reforming the delivery of traditional medical services.
- If the minimum wage is to be increased, Medicaid funded community based service providers including the designated agencies and home health agencies will need additional revenues to make sure that services will not be cut.
- Medicaid funded services should not be cut due to expenses incurred by the state and service providers when implementing reforms required by law.
- The legislature must lay the groundwork now for potential renewal of the All Payer Accountable Care (ACO) Model Agreement in 2022 by requiring an independent evaluation of the ACO Model in terms of cost, quality of care, and its impact on the health of Vermonters.

## **EDUCATION**

**Legal Assistance for Families with Education Needs:** VCDR 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.

**Inclusive Sex Education Reform:** VCDR 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.

**Restrictive Behavioral Interventions:** VCDR requests that the legislature hold the Agency of Education accountable for monitoring and reporting on the implementation of rule 4500, passed in 2010 regulating the use of restraint and seclusion in Vermont schools.

## **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.

**Bill of Rights for Individuals without Housing:** H.492, introduced in 2019, would establish protections for people who are without housing in order to ensure that individuals without homes are not discriminated against and have the same rights as other Vermont residents, including:

- the right to move freely in public spaces and not be prevented from doing so because they are homeless;
- the right of children to go to school;
- the right to equal treatment by all state and municipal agencies;
- protection from employment discrimination, voting discrimination;
- protection from denial of free emergency health care because of the lack of a permanent mailing address or because someone resides in a shelter or other social service location.
- their right to confidentiality of personal records and information as established by State and federal laws.

**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 emergency departments of 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 that 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**

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.

**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 provide a program in which people with the lived experience of complex needs in their OWN families assist other families to find their way through the complex system of educational, social, economic and health programs. 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. This could be entirely consistent with and complimentary to conflict of interest free case management.

**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. Medicaid funded community based service providers including the designated agencies and home health agencies will need additional revenues should the minimum raise be increased to assure that services will not be cut.

**High Tech Nursing:** Vermont should comply with the Medical necessity standard in children's Medicaid which is Early Periodic Screening Diagnosis and Treatment (EPSDT) provision. Increase funding to support (a) higher wages and benefits for the nurses who provide care to Vermonters eligible for the high tech program (b) aggressive recruitment of nurses to the high tech programs at home health agencies serving these families and (c) increased case management support for families in the program.

**Independent Developmental Services Advocate:** Vermont should create an independent Developmental Services Advocate similar to the Office of the Long-Term Care Ombudsman. The DS Advocate would: receive, track, and address individual complaints; educate recipients of service about their rights; and advocate for administrative and legislative changes that uphold the right of individuals in the DS System to make informed decisions about where and how they will live.

## **OVERSIGHT AND TRANSPARENCY**

### **Membership and State Accountability of Advisory Boards:**

In collaboration with the Secretary of State office the legislature should review collection and responsiveness to stakeholder input and adherence to public meeting law.

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. Adequate notice and necessary timely 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.

**Special Education:** Vermont must adopt legislation requiring that a majority of the members of Vermont’s Special Education Advisory Panel are individuals with disabilities or parents of children with disabilities (ages birth through 26), as required by federal law [Title 34 Sec. 300.168(b)]. The Governor should make appointments in a timely manner.

**Protecting People in Community Placements:**

Vermont can be proud of its community-based services, but are there enough protections from abuse or neglect built into the system? We have seen the vulnerability of people with mental health issues and developmental disabilities who often live in small, isolated settings. The Departments of Mental Health (DMH) and Disability, Aging and Independence (DAIL) should be required to share Critical Incident Reports with Vermont’s Mental Health Care Ombudsman and Protection and Advocacy System - Disability Rights Vermont (DRVT) to assure independent oversight and quality assurance that is currently lacking.

**Prescription Drug Pricing Transparency:**

People facing high prescription costs face the “hidden” consequences they suffer due to the cost and stress of accessing their medications—for example, postponing paying other bills, spending less on groceries, or using a credit card more often. We as advocates need the actual data pharmaceutical companies are required to provide to better understand how much drug pricing affects healthcare spending and insurance premium growth overall. We support measures to make drug pricing transparent, accessible, transparent and affordable.

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