



**Council Connections** brings the latest news on disability rights, resources that promote inclusion, and opportunities for advocacy to individuals with developmental disabilities and their family members living in the heart of Vermont Communities.



Electric shock can have serious side effects such as burns, scarring, seizures, and other serious physical and mental health ailments.

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## ELECTRIC SHOCK THERAPY STILL ALLOWED... BUT NOT FOR MUCH LONGER

The [Food and Drug Administration](#) will finalize regulations they began outlining in 2016 to ban electrical stimulation devices from being used to influence the behavior of people with developmental disabilities.

The [Judge Rotenberg Educational Center](#) in Canton, Mass., which serves children and adults with developmental disabilities as well as those with behavioral and emotional problems, is the only facility in the country where the electrical stimulation devices are known to be used.

Electrodes attached to the skin deliver electric shocks in response to an unwanted behavior such as an aggressive outburst or self-injury. In a 2018 ruling, a Massachusetts judge upheld the use of this technique despite evidence of significant side effects including burns, seizures, and increased anxiety.

Disability rights activists from [ADAPT](#) and other groups have followed this issue very closely to end the practice. Former patient of the Rotenberg Center, Jennifer Msumba, came forward and [shared her experience on social media](#).

In a press release following the FDA announcement, ADAPT urged continued advocacy. "We must continue to press the FDA to move forward as quickly as possible with this ban because – everyday – disabled people are being tortured in the name of "treatment".

The Food and Drug Administration says they would like to establish regulations by the end of this year.

For more information [read the article by Disability Scoop](#).



**"The shocks hurt a lot -- They try to make it secret when they shock you. They don't really want you to know when it's coming."  
- Jennifer Msumba**



The majority of Vermonters who receive SSDI also have to work to try and stay above the federal poverty threshold.

## DYING TO WAIT: APPEALING THE DENIAL OF FEDERAL DISABILITY INSURANCE

**As baby boomers enter their golden years, they are applying for more financial assistance from the federal government because of a disability or financial hardship. In 2017, ten-thousand people died waiting for that help - over a thousand more people than the previous year.**

The budget for the [Social Security Administration](#) has not kept pace with increased need and employees are stretched thin by the demands of file processing and follow-up. If approved the average benefit is about \$1,200 a month - similar to rent for a 2-bedroom home in Vermont.

How is eligibility for Social Security Disability Insurance decided? Adults may qualify if they have one or multiple ailments that meet predetermined definitions as laid out by the administration. Within those groups are subgroups, definitions, and diagnostic and documentation requirements. Children are in a separate category.

When people are denied coverage they may appeal the decision and request a hearing with a federally appointed judge. Over 800,000 Americans are on the appeals wait-list after being denied coverage, and the average wait time is about a year and a half.

For more information [read the article by USA Today](#)



Vermont is only one of four states that follow a "opt-in" model to a statewide health information exchange.

## YOUR HEALTH HISTORY MAY BECOME AVAILABLE TO ALL MEDICAL PROVIDERS

**The Vermont Department of Health Access (DVHA) has recently recommended that the [Vermont health information exchange \(VHIE\)](#) change its approach to how Vermonters consent to sharing their health information with the medical staff that use the exchange.**

Currently, Vermonters must agree to have their information shared across the exchange, an approach known as "opt-in." DVHA is advocating that the Green Mountain Care Board adopt an "opt-out" policy, where health information is automatically available to medical providers using the VHIE unless a patient specifically requests that it not be shared.

The health information exchange is a statewide platform that collects and shares medical information about patients between medical providers. It is hosted by Vermont Information Technology Leaders (VITL), which reports that [they take patient consent very seriously.](#)

Only 38% of Vermonters have willingly enrolled since the programs launch in 2005, in large part because providers often fail to ask patients about opting-in. When asked, 95%

agree to make their information available across providers so their care can be better coordinated.

State officials argue that an “opt-in” system is too burdensome to providers and that the VHIE will not reach its full potential as a tool for improving healthcare delivery unless the consent structure changes. Among States that have a consent policy, most use an “opt-out” approach.

Stakeholders and professionals who oppose the switch are concerned about protecting patient privacy and the right to choose how one’s health information is used. Advocates from the mental health community, for example, have long argued that it should be easy for patients to keep their mental health history private if that’s what they want.

At last week’s presentation, Kirsten Murphy, Executive Director of the Vermont Developmental Disabilities Council, voiced her concern that the change would degrade patient privacy. “Soliciting patient consent is part of delivering fully integrated care, an opportunity to engage individual Vermonters in our State’s new approach to healthcare,” she said.

For more information [read the article by Vermont Digger.](#)

## WHAT'S UP, UNDER THE BIG DOME?

**VTDDC is at the State House closely monitoring policy that could impact Vermonters with developmental disabilities...**



The new legislative session started with a bang on January 9<sup>th</sup>. The Vermont Center for Independent Living and Green Mountain Self Advocates joined other groups for opening day events where they announced their agenda and platforms.

**Save these dates:**

Mental Health Advocacy Day January 30<sup>th</sup> and Disability Awareness Day February 27<sup>th</sup>.

Come to the Statehouse! Who’s House? Our House!

Contact VTDDC for more details at [Susan.Aranoff@Vermont.gov](mailto:Susan.Aranoff@Vermont.gov)

## SAVE THE DATE for the next Quarterly Meeting

**When: Thursday, March 28, 2018**

**Where: Capitol Plaza, Montpelier, Vermont**



**Council members work together** to increase awareness about the needs of Vermonters with disabilities and encourage systems change. They are expected to attend four day-long meetings each year and to be active participants on a committee or work group.

The mission of VTDDC is to help build connections and supports that bring people with developmental disabilities, and their families, into the heart of Vermont Communities.