

Disability Advocacy Network Members Contact SD's Congressional Delegation Members

On July 2nd, several members of the Disability Advocacy Network sent a letter to the members of South Dakota's Congressional delegation - Senators Thune and Rounds and Congresswoman Noem - in relation to the ABLÉ Age Adjustment Act (S. 817/HR 1874). The Achieving a Better Life Experience (ABLE) Age Adjustment Act would amend Section 529Ae of the Internal Revenue Code to increase the eligibility threshold for ABLÉ accounts for onset of disability from prior to age 26 to prior to age 46. ABLÉ accounts are tax-favored accounts that are designed to enable individuals with disabilities to save for and pay for disability-related expenses. Without the passage of this legislation, the nationwide ABLÉ program faces serious threats to its sustainability.

The Stephen Beck, Jr. Achieving a Better Life Experience (ABLE) Act (PL113-295), signed into law in December of 2014, assists certain individuals with disabilities to secure more financial stability for themselves and their families. Presently, it is limited to individuals whose disability occurred prior to their 26th birthday. Many individuals who could benefit from ABLÉ accounts are left out since their disability can and does occur later in life, including disabilities such as multiple sclerosis, Lou Gehrig's disease, Parkinson's disease, paralysis or traumatic brain injury due to an accident. In addition, veterans who acquire a disability as a result of their service after age 26 are currently ineligible for ABLÉ accounts.

It has been nearly four years since the ABLÉ Act passed, and the disability community is waiting for Congress to fulfill its promise to expand eligibility based on age of onset of disability. There are presently thirty-seven states with ABLÉ programs that empower individuals with disabilities, either in their own states or nationwide, to achieve and maintain health, independence, and quality of life. Yet millions of individuals with disabilities that occurred in their late twenties, thirties and forties, and later in life are unable to take advantage of this important savings tool.

Network members stressed that the passage and enactment of the ABLÉ Age Adjustment Act is an equity issue for those left behind by the final bill, and it is critical to sustainability of all ABLÉ programs nationwide. Without increasing the ABLÉ eligibility criteria for age of disability onset from prior to age 26 to prior to age 46 in order to significantly expand the pool of individuals who can open ABLÉ accounts, the entire ABLÉ program appears to be in jeopardy nationwide.

Signatories were: Community Support Providers of SD; Disability Rights South Dakota; Independent Living Choices; SD Association of the Blind; SD Association of the Deaf; SD Coalition of Citizens with Disabilities; SD Council of Mental Health Centers; and SD United for Hope and Recovery.

Advocates say More Long-term Care Needed for Brain Injuries in SD

Seth Tupper - Journal Staff
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After many months of searching for a place where his brother could receive long-term care for a traumatic brain injury, Francis Cameron was desperate. "I sent out a group email, kind of a Hail Mary pass, to all the people I had talked to," he recalled. "I said, 'Hey, look, I'm down to dropping my brother off at the emergency room and walking away, and that's not acceptable.'"

Soon afterward, he was contacted by Sunrise Villa, which is believed to be the only place in South Dakota with long-term care options designed specifically for people with a traumatic brain injury. Although Sunrise Villa has only eight beds and is in the small far-southeastern South Dakota town of Irene - 400 miles from the Camerons' hometown of Custer - the facility had an opening.

Steele Cameron moved to Sunrise Villa in February, thanks in large part to the advocacy of his brother. "We were fortunate," Francis Cameron said. "But what happens to people that don't have an advocate?"

According to Justine Ashokar, director of clinical services at The Brain Injury Rehabilitation Center in Rapid City, some people with moderate to severe traumatic brain injuries live at home with loved ones, or in nursing homes or specialized out-of-state facilities - or, in worst-case scenarios, on the streets.

The number of people living with a traumatic brain injury in South Dakota is unknown. The number of new traumatic brain injuries suffered in South Dakota is also unknown, although partial statistics

kept by the state Department of Health show there are at least hundreds of traumatic brain injuries suffered each year in the state.

The Rapid City facility that Ashokar directs provides outpatient treatment for traumatic brain injuries and has some off-site apartments where patients may stay while they receive services. But Ashokar would like to expand those services to include longer-term care. She is in talks with state government officials to advocate for a statewide needs assessment and to identify funding sources to establish a 10- to 12-bed, long-term care facility.

A traumatic brain injury is defined by the Centers for Disease Control and Prevention as a disruption in the normal function of the brain caused by a bump, blow or jolt to the head, or penetrating head injury. Causes include falls, assaults and motor vehicle crashes.

There are millions of traumatic brain injuries suffered annually in the United States. In South Dakota, traumatic brain injury numbers are tracked by the state Department of Health, but not all hospitals report, Ashokar said. Among those that do, there were 956 traumatic brain injuries reported in 2017.

The effects of traumatic brain injuries are diverse, and may include impaired attention or memory; poor coordination and balance; loss of sensations such as hearing, vision, perception or touch; and emotional challenges including depression, anxiety, aggression, loss of impulse control or personality changes.

Not all traumatic brain injuries require long-term care. But Ashokar said the injury numbers in South Dakota indicate a

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Your Vote Matters! Your Voice Matters!

The Primary election is over. Next is the General Election on **November 6th**. Between now and November there will be many opportunities to listen and learn, as well as talk with candidates about issues of importance to you.

Through a grant from Disability Rights South Dakota, South Dakota Advocates for Change and the Coalition will be carrying out a variety of activities in the coming months designed to encourage voters from the disability community "to vote!" They will include public meetings, postings on websites and social media, newsletter articles and special editions of newsletters focusing on voting and more.

There is also a survey available for people with disabilities to complete now! There will be one following the general election. It is an effort to see if these grant supported efforts made a difference in getting people out to vote!

In reading a recent publication from AARP, they had four questions for candidates relating to Medicare - questions for candidates running for seats at the federal level. They were:

- 1) Do you believe Medicare should be cut as a way to reduce the budget deficit?
- 2) Do you favor converting Medicare to a voucher program?
- 3) What changes would you make to ensure that individuals continue to get promised benefits?
- 4) Do you support expanding coverage to include hearing, vision and dental care?

They also had four questions for candidates relating to Medicaid - questions for candidates running for positions at both the state and federal level.

They were:

- 1) Will you promise not to cut Medicaid to pay for tax cuts or other spending?
- 2) Would you oppose making Medicaid a block grant program?
- 3) Would you support Medicaid guaranteeing long-term care services at home?
- 4) Should Medicaid recipients be subject to work requirements?

These are examples of how we can prepare for visiting with candidates on issues of importance to us! Formulating questions before we visit with them, helps us to ask about what is most important to us! Knowing which policies they can influence and which ones they cannot is important, too.

The Coalition has also sent our a "Governatorial Candidate Questionnaire" to the three candidates running on the ballot in November - Democratic, Libertarian and Republican. The Coalition will share responses that are received when they are received via their website and social media page.

If you wish to learn more about the voting process in South Dakota, contact C.J. Moit at Disability Rights South Dakota, the Coalition or the Secretary of State office (contact information on last page.)



Absentee Voting (early voting) in South Dakota **begins September 21st**. You don't need a reason!

Advocates say More...

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potential need for more long-term care options, and so does her experience. She has been contacted, she said, by people searching for long-term care for loved ones with traumatic brain injuries in western South Dakota.

Francis Cameron is one of those people. His brother, Steele, suffered a traumatic brain injury at the age of 27 in a 1990 motor vehicle accident near Deadwood. The injury left Steele needing daily assistance, and for many years he received that assistance from a paid, home-based caretaker.

But last year, when the caretaker provided notice of her impending retirement, Francis Cameron, who now lives in Arizona, was forced into an unexpectedly long search to find new long-term care for his now 55-year-old brother.

"I was absolutely blown away by the lack of resources," Francis Cameron said.

After encountering limited options in South Dakota, he researched some out-of-state facilities specializing in long-term care for traumatic brain injuries but learned they had long waiting lists.

He eventually turned to a nursing home in South Dakota and made arrangements for Steele to live there, until the facility's administrator reconsidered because of concerns about Steele's behavior and the nursing home's ability to handle it. Francis Cameron said the situation was representative of the inadequate training and education regarding traumatic brain injuries that some workers receive in the long-term care industry - which is one reason the families of traumatic brain injury patients sometimes end up seeking care in specialized facilities.

Nursing homes and other standard long-term care facilities may also lack adequate therapy opportunities for people with traumatic brain injuries. Ashokar said the right therapy may help improve memory, attention, concentration and other cognitive skills. "If you're challenging the brain to do more work, then they can continue to do better," Ashokar said.

A potential obstacle to expanded long-term care options in South Dakota is funding. Because of the specialized services that traumatic brain injury patients may need, their care can be expensive.

Some states have creative funding solutions. Colorado, for example, imposes a \$20 surcharge on convictions of driving under the influence or driving with impaired ability, and a \$15 surcharge on convictions of speeding and riding a motorcycle without a helmet. The money goes into a Traumatic Brain Injury Trust Fund, and payouts are made at rates of 55% for client services, 25% for research, 15% for program activities and 5% for education.

During 2017 fiscal year, Colorado's fund received \$2.15 million, spent \$20.5 million and had a reserve of \$1.6 million.

Colorado's trust fund was established by its Legislature in 2002. During the following two years, some South Dakota legislators attempted to pass similar legislation. A \$5 surcharge on some traffic violations was proposed in 2003, and a \$25 surcharge on driving under the influence was proposed in 2004. Both of those proposals were rejected.

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Advocates say More...

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Ashokar said she has discussed proposals for new legislation with a local legislator, but no new bill has yet been introduced.

Another obstacle to action in South Dakota could be a lack of adequate data about people living with traumatic brain injuries. State Department of Human Services officials interviewed by the Rapid City Journal said they have no data on the total number of people living with traumatic brain injury in the state.

When asked if there is a need for more long-term care services similar to those offered in Irene, the state officials said there is no waiting list at Irene. That statement conflicted with the Journal's separate interview of the facility's administrator, who said there are three or four people on a waiting list.

To gain a clearer understanding of the needs of traumatic brain injury patients, some states have conducted needs assessments.

Two years ago in neighboring North Dakota, that state's Department of Human Services contracted with Minot State University to conduct a traumatic brain injury needs assessment. The assessment produced an estimated 8,872 to 14,695 people living with traumatic brain injuries in North Dakota, or 22,896 to 28,719 when stroke survivors with symptoms similar to traumatic brain injuries were included.

Despite the prevalence of traumatic brain injuries in North Dakota, the final report from the needs assessment said, "For people with brain injury in North Dakota, services and supports for the condition are few, are disparate, and are disjointed."

Ashokar said the situation may be similar for some people who seek long-term care options for traumatic brain injuries in South Dakota.

"We have so many who walk in looking for services," she said, "and it's just sad to have to say 'no.'"

Voters with Disabilities

We need your help!

Voters with disabilities are registered to vote at rates very similar to voters without disabilities. Yet, they do not vote at the same rate as voters without disabilities. We want to know why.

Please take a few moments and go to the link below to complete a very brief survey on voting in the 2016 General Election.

<https://www.surveymonkey.com/r/YourVoteMattersSD>

If you need assistance in completing it, you may contact the Coalition staff at 605.945.2207 to request a paper copy of the survey or complete the survey over the phone. They will be happy to assist you.

Following the 2018 General Election on November 6th, a similar survey will be circulated again. This is being done to see if efforts to encourage voters with disabilities to vote made a difference.





SOUTH DAKOTA

COALITION

OF CITIZENS WITH DISABILITIES

**Voters with Disabilities
We need your help!**

Please go to:
[https://www.surveymonkey.com/r/
YourVoteMattersSD](https://www.surveymonkey.com/r/YourVoteMattersSD)

and complete our survey. THANK YOU!

Equality



The assumption is that **everyone benefits from the same supports.**
This is equal treatment.

Equity



Everyone gets the supports they need.
This is the concept of affirmative action, thus producing equity.

Justice



All 3 can see the game without supports because **the cause(s) of the inequity was addressed.**
The systemic barrier has been removed.

Contact information to learn more about the election process:

CJ.Moit@DRSDlaw.org or 605.224.8294

shellyp@sd-ccd.org or 605.945.2207

elections@state.sd.us or 605.773.3537