



In October, the IRS had requested feedback on their proposed rules for the Achieving a Better Life Experience Act (ABLE Act). After a lot of pushback from disability advocates and state officials, the IRS will be easing up on the rules for these new accounts.

The IRS said they plan to issue final regulations with less stringent reporting requirements. Specifically, individuals opening ABLE accounts will not need to submit medical documentation, but will have to certify under penalty of perjury that they have a qualifying diagnosis.

The IRS also indicated that ABLE programs will not be required to request taxpayer identification numbers from contributors to ABLE accounts except in limited circumstances and program administrators will not have to categorize how money in the account is spent.

Despite federal passage of the ABLE Act last year, each state must establish regulations of their own in order to make the accounts available. So far, 34 states have approved legislation, including North Dakota.

**Mission Statement:**

The Dakota Center for Independent Living believes in self-determination for people with disabilities and helps to create the environment in which it is achieved.

“The contents of this newsletter were developed under a grant from the Department of Human Services. However, those contents do not necessarily represent the policy of the Department of Human Services, and you should not assume endorsement by the Federal Government.”

This newsletter is available in alternative format—upon request.

These states are still working out the details and need to know the IRS rules before moving forward. ABLE accounts are expected to start becoming available next year, but the timetable for each state will vary.

With these new accounts, people with disabilities will be able to accrue up to \$100,000 without losing access to Social Security and other government benefits. Medicaid coverage will remain intact no matter how much money is in the individual's ABLE account.

These accounts were modeled after the 529 college savings plans and funds in the account can be used to pay for education, health care, transportation, housing, and other expenses. Interest that is earned on these accounts will be tax-free. Individuals with disabilities acquired before the age of 26 will be eligible for the new accounts.

### Loan Equipment Available at DCIL



Wheelchair

Shower Bench

Walker

Grab Bars

Hoyer Lift-one without sling



Quad Cane

Door Knob Opener

**No Charge for Rentals**

**Call Jeannie at 701-222-3636 if you are in need of any  
equipment**

## New Advisory Group at DCIL



Dakota Center for Independent Living kicked off their new advisory group on November 19, 2015 at the Bismarck Veterans Memorial Library. This advisory group is just in its beginning stages, but the focus of this group is going to be community involvement and volunteering. All

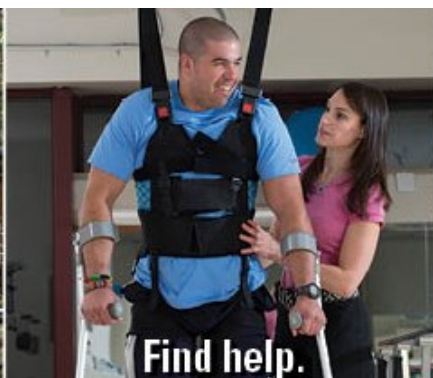
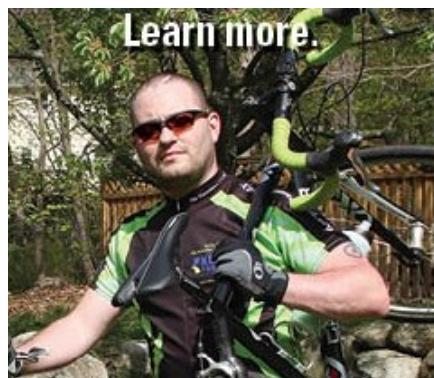
consumers are invited to attend. The next meeting will take place on January 20, 2016. The time for this event has not been decided. If you are interested in joining this new advisory group or would like more information, call DCIL at (701) 222-3636 and ask for Kathy or Ardeen.

## March is Brain Injury Awareness Month

March is brain injury awareness month. This year, the theme is Not Alone. More than 3.5 million children and adults sustain an acquired brain injury each year. An acquired brain injury is any injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma. More than 12 million Americans live with the impact of an acquired brain injury.

Brain injury is unpredictable in its consequences. Brain injury affects who a person is, how they act, think, and feel. The effects of a brain injury are complex and vary greatly from person to person. The effects also depend on factors such as cause, location, and severity.

It is important to make people aware of brain injuries and its impact. Awareness helps people gain an understanding of brain injuries, as well as helping to prevent brain injuries in the future by promoting safety.



## My Life with Neurofibromatosis by: Kristy Thorkelson



Neurofibromatosis (NF) is hard to say, hard to spell, and hard to understand. It is a genetic disorder of the nervous system that causes tumors to form on nerves anywhere in the body. There are two types of Neurofibromatosis. NF1 is common, affecting about 1 in 3,000 people. One of the most obvious signs of NF1 are café au lait spots. While anyone may have these, people with NF1 have at least six measuring 5 mm in diameter. Other signs and symptoms are scoliosis, disfigurement, short stature, precocious puberty, optic glioma, vision loss, and pain. NF2 is

more rare, affecting 1 in 100,000 people. Tumors develop in auditory nerves which leads to hearing loss and deafness. Most café au lait spots are not apparent in NF2. The tumors are usually benign in both types of Neurofibromatosis. The rate at which they grow varies. Surgery, chemotherapy, radiation, and many different drugs are used, depending on the complications.

I was born with café au lait spots. None of the pediatricians that treated me as an infant or toddler ever mentioned café au lait spots being associated with NF. When I was four years old, my left eye started to bulge. My eye lid couldn't shut over my eye when I was sleeping. My parents took me to an ophthalmologist who found a mass entwined around the optic nerve of my left eye and part of my right eye. On March 20, 1990, I was diagnosed with neurofibromatosis with optic nerve glioma. At the U of M in Minneapolis, I went through genetic testing and MRIs of my entire body.

I underwent a brain biopsy to make sure the tumors weren't cancerous. The tumors were entwined with the optic nerve of my left eye, part of my right eye, through the optic chiasm and into the brain. Because the tumors were so entwined around my optic nerves, they were inoperable. However, I was given a mild form of chemo to try and shrink the tumors before I was given radiation for two months. While the tumors did shrink, I am blind in my left eye.

For most kids, puberty is embarrassing; for me, puberty was so much more. Kids with NF go through what is known as precocious puberty. This means that puberty starts early. My growth plates were closing, but I couldn't have growth hormones because it would make my tumors grow. I was seven years old, 4' 3" tall. I had to have injections of Lupron once a month to stop puberty and, hopefully, grow some more. However, I had an allergic reaction and had to stop taking it. I was then put on a nose spray that I used twice a day for three years. I grew almost three inches, but that was all I would ever grow. I was 4'6".

I have many health issues. I have congenital bowing on the leg bones below my knees, my left leg is shorter than my right, I have hypothyroidism, and I have learning disabilities. I was put on a drug called cylert for attention deficit disorder. After being on it for about four years, my neurologist wanted my mom to sign a release form to stop taking it. Cylert causes irreversible liver damage resulting in death. Because of Cylert, I have to have liver function tests every six months.

My parents have always told me that having Neurofibromatosis is a reason for my disabilities and I've had to realize my limitations. It's not an excuse or a copout. My family is my main support. I talk to my Mom and Dad about things that bother me and they try to help me work through it. I don't know anyone else who has NF. My mom always tells me that the only person that can stop me from doing and being who I want to be is me. My biggest obstacle is other people.

Some teachers have helped me a lot, but others get frustrated with me. They think I'm not trying hard enough or that I'm not paying attention. They make judgments about me without knowing anything about my disorder. In my IEP, it doesn't say anything about the tumor in my hypothalamus or how that affects me; it just says "medical: other." What is that? I can't expect other people to understand me.

I don't want people to feel sorry for me or pity me. My mom says people can drown in sympathy. I just want to be accepted for who and what I am. That's no different than any other person.

Kristy is currently working on a book about her disability.

## Crazy Winter Heating Costs: How to Save Money and Find Help



Winters in North Dakota have a dramatic effect on home heating costs. Here are a few tips to help ease heating costs this winter:

- Turn down your thermostat to 68 degrees. Wearing warmer clothing at home and keeping the thermostat down can help save up to 5 percent in heating costs.
- Open drapes during the day to let the sun heat your home for free. Close them before sundown to help insulate.
- Rearrange your rooms. If possible, move your furniture so you are sitting near interior walls. Exterior walls tend to feel colder.
- Cover drafty windows with plastic. Cover drafty windows with plastic from the hardware store and secure it to help keep the warmth in your home.

If you've tried lowering your heating costs and are still struggling to pay the high winter heating costs, you may qualify for help. The ND Department of Human Services is reminding low-income individuals and families that help is available through the Low Income Home Energy Assistance Program (LIHEAP). Applications are now being accepted at county social services in North Dakota.

The program is federally funded and helps qualifying households in need of assistance pay a portion of their home heating costs. This includes natural gas, electricity, propane, coal, fuel oil, wood, or kerosene. The program also covers the repairs of furnaces and weatherization services.

There are income and asset limits to qualify for the program. This ensures that the program helps those most in need. To qualify, a household can earn up to 60 percent of the state median income, which for a family of three, is about \$43,430 per year before taxes. Applications are now being accepted.

For more information, visit

[www.nd.gov/dhs/services/financialhelp/energyassist.html](http://www.nd.gov/dhs/services/financialhelp/energyassist.html)

## The Voice of Royce



Snow has fallen across the North Dakota plains, roads, parking lots, and sidewalks. With snow and ice covering the ground, homeowners and businesses have a few more things they're responsible for.

Snow and ice can be huge barriers in the community for people with disabilities. It is important to make sure your sidewalks are clear of

snow and ice. This prevents people with mobility impairments from getting stuck in the snow with their wheelchair, or having difficulty navigating with their walker. This also prevents people from slipping and falling.

During the winter season, many people forget about clearing curb cuts. It doesn't take much snow or ice on a sidewalk or a curb cut for someone to get stuck who uses a scooter or a wheelchair.

The last thing I wanted to address is the importance of businesses keeping accessible parking spots clear of snow and ice. I have run into this more than once where they will push the snow into the accessible parking spots making these spots unusable.

If anyone runs into a problem with a business where they have pushed snow into the accessible parking spot, please call us at 701-222-3636 and we will talk to the business and try to resolve the situation.

### Are You Looking For A Peer Mentor?

Peer Mentor is one person with a disability offering to share his/her life experience and knowledge with another person with a similar disability.

Peer Mentoring is a goal-oriented process with the outcome or results remaining in the hands of the consumer. The mentor's responsibility is to assist the consumer with increasing their self-confidence or their ability to access community resources.

If you are looking for a Peer Mentor, or would like to train in becoming a Peer Mentor, contact Jeannie at 701-222-3636.

Dakota Center for Independent Living  
3111 East Broadway Ave.  
Bismarck, ND 58501

Phone: 701-222-3636  
Toll Free: 1-800-489-5013  
Fax: 701-222-0511

Web address: [dakotacil.org](http://dakotacil.org)

DCIL has a satellite office in  
Dickinson, ND. They can be  
Reached at: 1-701-483-4363

## Winter 2015



**RECREATION:** Events are a great way to meet new people and make new friends. Come out and join us for a wonderful time. **For more information contact Jeannie at 222-3636.**



**Check out our blog:**

[dakotachallenger.wordpress.com](http://dakotachallenger.wordpress.com)

**If you would like to receive the newsletter by e-mail,  
please contact**

**Lauren at DCIL by calling (701) 222-3636**