As I write this, I am currently stranded in the airport in Washington, DC, attempting to return to Fargo from the National Council for Independent Living annual conference. In the past few months, the legislative sessions in North Dakota and Minnesota have both wrapped up. On the federal level, the big news is the nomination of Judge Sonia Sotomayor to the United States Supreme Court. Advocates have also begun to move into a post-economic recovery act mode, and have been working on tweaking policy and legislation to make our communities more accepting of full participation by people with disabilities. Below are some summaries of recent happenings.

**Federal**

President Obama has called on Congress to begin to work on Health Care reform. His goal, as of today, is to have a plan for healthcare reform on his desk by October. In order to achieve this, the Senate must begin shaping this bill in early July. Among the three committees who will be forming this program is the Senate Finance Committee, of which North Dakota’s own Kent Conrad is a member.

Nationwide, disability rights advocates are calling for the rights of individuals with disabilities to be upheld in any health care reform. There are three primary ways in which health care reform done right could go a long way towards improving the viability of full community participation for Americans with disabilities.

The first is the inclusion of the principals of the Community Choice Act (H.R. 1670 and S. 683). Currently, every state that receives Medicaid MUST provide nursing home services; however, home and community based services (HCBS) are viewed as optional. This has allowed state governments, in times of budget crises, to cut HCBS services and force people into nursing homes.

The second is the Promoting Wellness for People with Disabilities Act (HR 1983). This bill would ensure that medical examination equipment, central to all preventative health care, is made accessible to individuals with disabilities. This includes such things as examination tables, examination chairs, weight scales, mammography equipment, X-rays and other commonly-used equipment. It would also require that medical and dental schools increase training to improve the competency and clinical skills in providing care to patients with disabilities.

Finally, Ending the Medicare Waiting Period Act (H.R. 1708 and S. 700). This bill would work to eliminate the 24-month wait for Medicare. As it is, many people who become disabled go without medical treatment during those significant first two years with a disability. This bill would eliminate that wait.

None of these bills on their own stand a good chance of passing at this time. However, if disability rights advocates from across the country can rally together and demand they are achieved, the Senate must begin shaping this bill in early July. Among the three committees who will be forming this program is the Senate Finance Committee, of which North Dakota’s own Kent Conrad is a member.

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*Legislative cont. on page 2*
**Legislative con’t from page 1**

included in health care reform, we can finally close a major part of the gap in access to health care that people with disabilities have faced for too long.

One of the buzz words in the fight against health care reform will be that it will decrease the general public’s access to health care. Well, for many people with disabilities, they have never had adequate access to health care, for a number of different reasons.

**Minnesota**

Governor Pawlenty has a constitutional responsibility to balance the state budget this July. Here is what the Minnesota Consortium of Citizens with Disabilities (CCD) recently said concerning the state budget for human services:

The legislature and the Governor were not able to reach a compromise on the overall state budget prior to the end of the legislative session on May 18th 2009. As a result, the Governor will balance budget through the unallotment process which will allow him to make additional cuts not approved by the Legislature. Based on what Governor Pawlenty proposed in his human services budget earlier this session, this could include $250 million more in cuts to health and human services.

A few of the cuts already passed by the state legislature include a 2.58 percent provider rate cut for long term community support services, a $25 million cut in state funding for personal care assistance (PCA) services, and reductions in dental, OT, PT & speech therapy for adults on Medical Assistance. It is important that Minnesotan’s who are concerned about these upcoming cuts call or write Governor Pawlenty. It has been Freedom Resource Center’s and the Minnesota CCD’s position that the state should not to balance the budget disproportionately on the backs of people with disabilities.

**North Dakota**

Among the highlights of bills passed was an across-the-board pay increase for Qualified Service Professionals, Developmental Disabilities Staff and nursing home staff. This one-time pay increase of $1 per hour and annual increases of 6 percent for the next two years will help to ensure that direct care jobs are financially feasible. These increases are significant, because it is the first time that the hard-working folks who provide home and community based services were given the exact same increase as those who provide care in non-home settings.

For people who have been burdened with recipient liability, more good news is on the way. Recipient liability is set by the medically needy level. The Legislature passed the largest increase in the medically needy level in history, increasing it to $720 for individuals and $969 for a family of two. This means more money that they can use to pay for other things besides medical care.

Finally, North Dakota added a third tier to home-based services in the state. It adds two more hours per day to the maximum, which will now be 10 hours. This will lead directly to people who have been living in a nursing home being able to get the services they need to return to independent, community-based living.
By Nate Aalgaard, Executive Director

Our difficulty with the celebrity spokesperson

Many of us people with disabilities have a conflicted view of the celebrity spokesperson. I’m talking about people like Jerry Lewis with muscular dystrophy, Michael J. Fox or Mohammed Ali with Parkinson’s disease, or Christopher Reeve with spinal cord injury. In all these cases, the celebrity spokesperson gets to be the figurehead for that particular disabling condition. Many of them use that popularity and access to the media to raise funds for research to cure whatever particular condition they happen to be most concerned with.

To varying degrees, the celebrity spokesperson uses that condition in order to create an emotion to entice people to open up their checkbook or whip out their credit card. Herein lies the dilemma. On one hand, curing things like ALS, which is fatal, is a great idea. I’ve had a friend who died of it before he reached the age of 40. That’s tragic, and nobody can deny that. Likewise, I have friends who have died at a fairly young age from accidents or infection that they probably would not otherwise have died from if they didn’t already have a spinal cord injury.

On the other hand, I don’t want anybody to think that just because I have a spinal cord injury my life is pitiful or pathetic. But what some people in the disability community objected to when Christopher Reeve started talking about cure for spinal cord injury is that the unspoken but unmistakable message was that life just isn’t worth much unless you can walk. We don’t want pity; we want civil rights. We want equal opportunity to get a good education, a decent job, health care, and to go and live where we want just like anyone else. We don’t want the message that somehow we need to walk, or hear, or see, or breathe without assistance, in order to be a “whole” person.

So what is the alternative to the celebrity spokesperson? How will these different disabling conditions and diseases gain sufficient awareness and notoriety in order to get the funding that is needed for research and treatment? The perfect solution would be that the government, whether state or federal, would spend whatever money is needed to do the best research possible for all types of conditions. In reality, that won’t happen. And donors have a vast array of choices of where to give.

So we are stuck with the celebrity spokesperson. It is our job as disability advocates to also explain that even though research and cure is good, we live in the here and now and that it isn’t that we need to be cured or fixed, it’s the environment that needs to change. That means the elimination of physical barriers, communication barriers, and discriminatory policies and attitudes. That’s why we’re working on disability rights; so that everybody has equal opportunity, whether or not they eventually get “cured.”

Save the Date

Freedom Resource Center
20th Anniversary
Annual Celebration
September 24, 2009
5:00-9:00 pm
Ramada Plaza Suites-Fargo

Only $10: Includes dinner, raffle, awards, and keynote speaker

Keynote speaker: Chad Hymas, Salt Lake City, Utah

On April 3, 2001, Chad was involved in a serious accident leaving him a quadriplegic. Chad’s dreams were not paralyzed that day. Since that fateful event Chad has spent many hours with other injured individuals in therapy, encouraging them to overcome their challenges, focus on dreams and make them a reality, and to love life for all that it has to offer. To achieve the unachievable and to reach for the unreachable. Last year Chad spoke at 160 different events traveling just over 180,000 miles. Chad has shared his personal message and entertained many audiences from organizations such as Wells Fargo, Blue Cross Blue Shields, VastFX, IHC, Coca Cola, and the Utah Jazz.
Historical Perspectives on Disabilities

Scott Burlingame, Assistant Program Director

We at Freedom Resource Center, and our brothers and sisters in our movement, have often faced a seismic challenge when we begin to describe what it is we do. It is not enough for us to say that we serve people with disabilities, because lots of people do that. It is not enough for us to say that we are an advocacy organization, because advocacy can mean different things to different people. In order for people to truly understand what we do, it is first important to understand and be able to identify and tell the difference between the historical perceptions of disability.

The first perception is what is often called the Moral Model of disability. The Moral Model has two forms in which it manifests itself. The first form states that people with disabilities either became disabled because of something they did, or something their parents did, and therefore they are inherently bad and should be avoided. This form is shown in some of the earliest writings of civilization, in which people who were blind or physically disabled were shown to be cast off and viewed as subhuman. They were often only used as objects of pity or called upon to be supernaturally cured.

The second form of the Moral model says that people with disabilities are morally superior. They are special. They are the most precious among us. They are brave. They are viewed as objects that, by the nature of their disability alone deserve and in fact demand our affection and our appreciation.

An example I often give when talking about the moral model is something that happened to me many years ago when I was working as a job coach. I was working with a person with Down’s Syndrome. This person was struggling to learn his job, and I was struggling to teach it to him. At the worst possible time, a passerby walked up and said to me, “Wow, I had a neighbor who had Down’s, and those people are so nice.” This passerby judged this guy from the moral model of disability. She did not know if this person was nice. She did not know that on this particular day, this guy was in fact, sort of a being a “difficult employee.” This passerby was living in the Moral Model of disability.

The second perception of disability is the Professional/Medical Model. This model began as science and took off around the turn of the 19th Century. The Medical Model states that people with disabilities are inherently broken and need to be fixed. They can be fixed by medical science, which will work for a cure, and by well-educated professionals, who will work to manage the lives of those who are incapable of making the decisions for themselves. This view emphasizes the importance of well-educated professionals being put into positions of authority over the untrained and incapable masses.

Today, a majority of the human service field works out of this model. Your level of competency is often seen as synonymous with your level of education. People with Doctorate degrees make rules that are interpreted and implemented by people with Masters degrees and Bachelors degrees. People with titles like Social Worker, Case Managers, QMRP’s and others, as a result of their education, are put into positions to determine aspects of others’ lives. These well-trained professionals create labels for disabilities, and treat people based on their labels.

The final perception is the Civil Rights Model of disability. The Civil Rights Model states that disability is a natural part of life. It believes that the biggest barrier facing people with disabilities is not the medical condition, but rather the barriers to equal access that are faced as a result of their condition. It believes that the biggest issues facing people with disabilities are sociological, political, cultural, and economic and should be dealt with accordingly.

The Disability Rights Model states that if a woman with a physical disability cannot get into a building, it is not her fault, but the fault of the business that fails to provide the access required by law. It states that if a boy with a learning disability cannot access the education he needs, it is not his fault, but the fault of the system that is not providing him his promised free and appropriate education. If an elderly women living with the effects of aging can only get the services she needs in a nursing home; that is not her fault. It is the fault of the system that spends a disproportionate amount on institutional care.

The Disability Rights Movement challenges all of the perceptions of the Moral and Medical models. It challenges the perception that disability is a tragedy or that living with a disability in any way predetermines any part of one’s destiny. It challenges the belief that professionals should be put into positions of power over people with disabilities, and instead shifts the burden of responsibility and control to the individual.

Freedom Resource Center is a disability rights organization. We work from our core values including cross disability, consumer control, peer mentoring, and equal access to our communities. We work to remove the artificial barriers people with disabilities face, and by doing so encourage increased community participation by them.
Staff Profiles

By Mark Bourdon, Program Director

Andrea Nelson is an Independent Living Advocate in our Jamestown satellite office. She specializes in accessibility issues, nursing home relocation and she assists individuals in becoming involved in civic activities. Andrea has been working with Freedom for four years.

Angie Bosch is the Office Coordinator in the Fargo office. She is responsible for the accounting and administrative functions of the organization. Angie is also responsible for updating the Freedom Resource Center webpage. She has been working with Freedom for two years.

Bobbi Mundt is the Peer Mentoring Specialist. She is responsible for recruiting, training, and supervising volunteers for peer mentoring and civic engagement activities. Bobbi recently returned to Freedom after nearly two years with the Social Security Administration. She has been working with Freedom Resource Center for a total of seven years.

Cyndi Collins is an Independent Living Advocate in our Fargo office. Cyndi specializes in nursing home relocation, and assists individuals with independent living skills and general advocacy. She has been working with Freedom for two years.

Joyce Wolter is an Independent Living Advocate in our Fergus Falls office. Joyce specializes in advocacy services provided to children and youth including IEP advocacy, as well as transition services. She also assists individuals with independent living skills and general advocacy, and has been working with Freedom for four years.

Mark Bourdon is the Program Director. Mark is responsible the coordination and management of all individual and community-based service programs. Mark has been working with Freedom Resource Center for five years.

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Information

In an attempt to reduce the cost of mailings please send your email address to freedom@freedomrc.org

If you would like to be removed from our mailing list please call 701-478-0459 or 1-800-450-0459.

Freedom Resource Center and/or its Board of Directors do not necessarily endorse or support any of the views expressed within the personal testimonies contained in this newsletter, unless approval is specifically mentioned.

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Alternate formats available upon request.

Editorial Board: Nate Aalgaard, Scott Burlingame, Cyndi Collins, and Rikki Trageton
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Micara Link is an Information Specialist in our Fargo office. She is responsible for being the first point of contact for assessment, information, assistance and referral for all individuals seeking any type of service or information. She specializes in Social Security, Medicare and health care issues. Micara will soon be leaving Freedom in order to pursue her own business.

Nate Aalgaard is the Executive Director. He is responsible for the day-to-day operations of Freedom at the direction of the Board of Directors. He is also in charge of the public policy agenda for the organization, and collaborates and networks with a variety of individuals and organizations. Nate has been working with Freedom for thirteen years.

Rebecca Waldera is an Independent Living Advocate in Freedom’s Fergus Falls and Detroit Lakes locations. Rebecca specializes in vocational issues; and assisting individuals transitioning from high school to additional schooling, work, and independence. Rebecca has been working with Freedom for one and a half years.

Rikki Trageton is an Independent Living Advocate in our Fargo office. Rikki specializes in advocacy services provided to children and youth, IEP advocacy, and transition services. She also assists individuals with independent living skills and general advocacy, and has been working with Freedom for over three years.

Scott Burlingame is the Assistant Program Director. He is responsible for planning, coordinating, implementing and evaluating Community Education activities, as well as conducting public speaking in the community, service area, and state. He is also the organization’s public policy analyst and works on systems advocacy issues. Scott has been working with Freedom for nine years.

Val Nielsen is the Resource Specialist in our Fargo office. She is responsible for being the first point of contact for assessment, information, assistance and referral for all individuals seeking any type of service or information. She also maintains the Center’s mailing lists and information database. Through two different stints, Val has been working with Freedom for over six years.

Freedom Staff Receives Advocate Award

Rikki Trageton, an Independent Living Advocate in the Freedom Fargo office, received the Advocate of the Year award from the Metro Area Mayors Committee for People with Disabilities at its annual banquet on April 30. Rikki was recognized for her advocacy efforts on behalf of students, and her community work to help organize events that benefit the disability rights movement.

Pictured: Rikki Trageton with children Brittany, Richard and Jacob (front)
For too long, individuals with disabilities have been shut out from the game of golf. This has happened for several reasons. One has been the lack of associations, groups and advocacy by groups for adaptive golf. Another is the lack of properly adapted golf equipment. Golf professionals haven’t had access to the necessary training, tools or club components to actually “fit” clubs to the individual golfer with a disability.

Access North, a Minnesota based Center for Independent Living, has lent Freedom Resource Center adaptive golf clubs for individuals to experience until June 9, in our Fargo office.

From June 10 – September 8, Freedom Resource Center (Fargo office) will have a hand pedal recumbent bicycle available for individuals to try.

**CELEBRATE THE 19th ANNIVERSARY OF THE AMERICANS WITH DISABILITIES ACT**

**Commemorative Walk to Support the ADA**

**Fargo**
Thursday, July 23rd 5:00 to 7:30 pm
Lindenwood Park
For more information call 701-478-0459

**Jamestown**
Thursday, July 23rd 5:00-7:30 pm
National Buffalo Museum
For more information call 701-252-4693

**Fergus Falls**
Tuesday, July 28th 4:30 to 7:00 pm
Grotto Park
For More Information call 218-998-1799

**Detroit Lakes**
Thursday July 30th 11:30 am to 1:00 pm
For more information call 218-849-3988
The Mission of Freedom Resource Center for Independent Living is to work toward equality and inclusion for people with disabilities through programs of empowerment, community education and systems change.

We envision a society where ALL individuals are valued, respected and have equal opportunity, access, responsibility, and freedom of choice in all aspects of life.

Leadership training opportunities

Freedom's leadership trainings are offered to help you gain personal growth and advocacy skills. Learn about your rights as a person with a disability; how to be your own advocate; and connect with others in your community.

Fargo: August 18
Jamestown: August 25
Fergus Falls: September 15
(All sessions run 9:30 a.m. to 3:30 p.m. Lunch provided)

Planting Seeds is a free leadership training for youth with disabilities ages 14-22 to develop self advocacy and leadership skills.

August 6, 2009 from 10-4pm in Wahpeton, North Dakota. Open to both Minnesota and North Dakota residents. Lunch provided.

To register for this fun event or for more information, contact Rikki at 1-800-450-0459 or e-mail rikkit@freedomrc.org.

“You must be the change you wish to see in the world,” by Mahatma Gandhi.