

# FREEDOM



**Freedom Resource Center for Independent Living, Inc.**

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## **Mission Statement**

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.

## **Vision Statement**

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

## **National Disability Policy Expert Coming to FM Area**

*By Chuck Stebbins, systems change advocate*

There's are two events coming this September that you all should be aware of. No, it's not the annual bake sale to help with the massive federal budget deficit. That's in George's backyard sometime in October. ☺ The Northern Plains Conference on Aging and Disability (NPCAD) September 13<sup>th</sup> through the 15<sup>th</sup> at the Holiday Inn here in Fargo. The second is Freedom's annual meeting. Three fun-filled hours of fine food, drink, and some of the most stimulating conversation you will ever experience in this, or any other lifetime... Well, maybe it's not that stimulating, but it is going to be one of the finer annual meetings we've had around here....at least that's what we're hoping for.

*Continued on page 4*

## **North Dakota legislative session leaves mixed results for disability agenda**

The North Dakota legislative session wrapped up on April 23. After breathing a collective sigh of relief, interested citizens start the process of assessing how the legislature's activities will affect them. As usual, it's a mixed bag. Freedom Resource Center, as part of the 23-member North Dakota Disabilities Advocacy Consortium (NDDAC), worked on several initiatives this past session. In the category where we feel we were successful in getting what we wanted are:

- **Workers With Disabilities Insurance program/Senate Bill 2194** passed with no opposing testimony or votes. It no longer has a sunset clause.
- **Senate Bill 2117** passed with language added that strengthens the requirement for businesses to remove existing barriers to people with disabilities when doing so is

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### What’s Wrong With this Picture?

The blue accessible parking strips are worn and faded with one designated accessible parking sign for six parking spaces. North Dakota law requires that the lines designating reserved parking be painted with 4 inch blue lines on the sides of each parking space (MN does not have specific marking guidelines but require markings). Both states require a sign for each space.

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“readily achievable.” This language is similar to that of the Americans with Disabilities Act.

- In the area of Medicaid waivers, **SB 2395** provided for a micro-waiver for children who meet certain requirements. A study resolution, **HCR 3054**, has been adopted. It will be a discussion about “making your own waiver.” The **HB 1148** legislation provides for a waiver to allow consumers to hire unlicensed people for certain tasks.
- NDDAC has increased the legislature’s knowledge of home and community based services. We are seeing that people are more willing to use home and community based services.

In the category of what we didn’t get;

- The amount of increase in payments to Qualified Service Providers (QSP’s) that we wanted. It ended up at 2 percent one year and 2.65 percent the other. We had been advocating for up to 6 percent each year to help bring the rates for these people, who provide

personal assistance to people in their own homes, to a more equitable level with nursing home workers who do many of the same tasks.

- Language that would have strengthened the Department of Labor’s (DOL) enforcement powers. The NDDAC Civil Rights Task Force argued that once a probable cause determination is made, the position of the DOL should change to an advocacy role for the person with disabilities. But the DOL and Attorney General maintained that they ought to be neutrals, and state law has now been changed to provide that the Attorney General represents only the DOL.
- In an issue that the NDDAC did not officially become involved with, the Centers for Independent Living had been asking for approval of the Optional Adjustment Request submitted by the Department of Human Services to add \$175,000 in state general funds to support the network of Centers across the state. It did not pass. This would have allowed for an expansion of the area that would be adequately served by the state’s four Centers for Independent Living.

In a membership meeting on May 18, participants expressed satisfaction with the progress of the NDDAC and its work during the legislative session and particularly expressed how positive they felt about so many participants getting together so soon after the session. They felt this will keep the momentum going and provide impetus to NDDAC being highly proactive during the interim before the next legislative session.

In addition to those issues left from the past legislative session, things the members thought were important to work on were:

- Social Security reform
- Vocational Rehabilitation issues and potential dismantling of the Rehabilitation Services Administration, related to the US Department of Education
- Housing voucher cuts
- Medicaid cuts and block grants of funds
- Amtrack services

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## From where I sit

by Nate Aalgaard, executive director

Murderball, the award-winning documentary, will soon be released to theaters around the country. It's about something that I have some personal experience with — a wheelchair sport officially called Quad Rugby. There are some local roots to this. The sport, originally called Murderball, was actually invented in Winnipeg, Manitoba in the late seventies by some guys who were in the rehab hospital and wanted something to do. They had quadriplegia, meaning some paralysis in all four limbs. They were tired of watching wheelchair basketball from the sidelines and wanted something of their own. Being originally a Canadian sport, it does have some aspects of hockey. There's a lot of checking, or in this case, smashing of wheelchairs. People who commit fouls have to sit on the sideline, a sort of penalty box.

I don't believe the documentary points this out, but the first team in the United States was actually in Grand Forks, North Dakota. From there it spread to other parts of Canada, the Twin Cities and now it's recognized around the world as a Paralympic sport. This summer's release of Murderball is the ultimate in recognition.

The sport certainly wasn't glamorous or glitzy at the beginning. It was played mostly in the winter months, which of course in North Dakota and Manitoba are six to eight months per year. Many a trip was made across the northern prairies in subzero weather and snow. I wasn't involved with Quad Rugby at beginning, but I did join in about 1981. One of the first trips I ever took with the team, the North Dakota Wallbangers, was to Regina, Saskatchewan. I remember it was probably almost 30 below and to my recollection none of us had anything that would resemble appropriate dress for that kind of weather. Had we encountered a breakdown we would certainly have lost some appendages. But we had no fear in those days.

If you see this movie, you will probably see why we didn't think safety first. We were just being typical young guys. What we were really doing was just real life. This was sports, pure and simple, just like any other. It was just like the high school football, basketball, or any other sport we had played before we became disabled.

I saw many instances, including my own, when people would develop self-confidence by being involved. We traveled to cities all over the country by plane. We competed fiercely (and partied hard too). It was a great feeling to be able to go somewhere with a whole bunch of other guys with disabilities and not only survive, but thrive. Our team in North Dakota, although



from the smallest population area by far of any team, did pretty well. We placed in most tournaments we went to, even finishing second in the Tampa International tournament at one point.

I'm excited to see this movie and hope you do too. It'll really open your eyes to a new aspect of disability. Fair warning: It is rated R for language and some sexual content.

## Health Care Cuts...Are you next?

By Mark Bourdon, program director

By the time you read this newsletter, 323 thousand Tennesseans will have received notices in their mailbox informing them that their publicly funded health insurance, TennCare, will end. Two groups will be the first to lose benefits: a group of 38,000 people who are also on Medicare — most of them seniors — and an additional 121,000 people who had originally qualified for TennCare because they did not have other insurance. An additional 67,000 adults are scheduled to be cut from the rolls by fall. These are people who enrolled in TennCare because they had medical problems that prevented them from obtaining private insurance. There are approximately 100 people among the 323,000 who are on ventilators and will have to go to an institution to survive.

The fight for the health care program isn't just a Tennessee problem. It's a national issue. In California, the Governor has submitted proposals to eliminate health care coverage for nearly 300,000 low-income parents. Deep cuts in Oklahoma's health care programs have been approved and are scheduled to take effect in coming months, including near-elimination of the state's SCHIP program (the State Children's Health Insurance Program). If fully implemented, these cuts will cause approximately 80,000 children, adults, seniors and people with disabilities to be dropped from coverage. Nebraska has implemented a series of Medicaid cuts that will likely result in the loss of health care coverage for an estimated 26,000 children and adults. New Jersey has begun to phase out enrollment of low-income parents in NJ Family Care coverage, the state's joint Medicaid and SCHIP program, which has served more than 100,000 working parents.

States are facing budget gaps of historic proportions. Given that 49 states are required by law to balance their budgets, many will look to institute reductions in programs such as Medicaid. The impact of such cuts is likely to be severe for many poor and near-poor working families insured through Medicaid and SCHIP. It's time to get involved, or you might be next.

## Native American Healing

By Mark Bourdon, program director

Native Americans appear to be at a greater risk for disease, injury, death, and disability than the general population. Native American children have shown the second highest incident of students with disabilities among minority groups in public schools. The most significant disabilities with children include learning disabilities, speech impairments, and multiple disabilities.

Unlike many cultures that shun people with disabilities, Native Americans honor and respect them. They believe that a person weak in body is often blessed by being especially strong in mind and spirit. By reducing our emphasis on the physical, which promotes our view of separation from our fellow man and all that is, a greater sense of connection with the whole is created, the ultimate source of strength.

Spirituality cannot be separated from physical life, because life is considered to be holistic; one part of life cannot be separated from the whole, or the whole will suffer. When a person is experiencing ill health, emotional or physical problems, it is because the spirit is out of balance with the forces of life. Native Americans believe in a spiritual life before and after their earth life. Our spirits come to earth to learn or experience things that our spirits need to understand. In doing so, a spirit chooses to accept the difficulties of life, including disabilities, in order to gain something in the spirit life.

Overall, in treating physical disability, Native-American healers emphasize quality of life, getting more in touch with and honoring inherent gifts, adjusting one's mindset, and learning new tools. By so doing, the individual's humanity is optimized.



On June 10th, Freedom held a Mentor Appreciation Ice Cream Social at Lindenwood Park to thank all of the mentors for thier hard work.

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We were fortunate enough to get Bobby Silverstein as our featured speaker. Some of you may have heard of him; some of you need to hear of him. He is doing some breakout sessions for the NPCAD, so we thought we would nab him for our annual meeting. For those of you involved in disabilities issues, which should be a boatload of you reading this blurb right now, you may want to reconsider any plans you have already made for the evening of September 15<sup>th</sup> and be at the Marriot in Moorhead from 5:30 pm to 8:30 pm.

Here's a short bio:

“Bobby Silverstein is the Director of the Center for the Study and Advancement of Disability Policy (CSADP). In this capacity, Mr. Silverstein has written guides on how to be effective policy change agents and papers analyzing policy issues from a disability perspective. For over 13 years he served on Capitol Hill in various capacities, including staff director and chief counsel of the Senate Subcommittee on Disability Policy, chaired by Senator Tom Harkin. Mr. Silverstein was the behind-the-scenes architect of more than 20 bills enacted into law, including the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and the Rehabilitation Act.”

There are a few significant points here that need to be stressed; the ADA, IDEA, and the Rehabilitation Act, “the advancement of disability policy!!” These laws are the reason some us have a job! Every Voc Rehab counselor and Independent Living dude and dudette within a two state area should take advantage of this opportunity. It's not too often that we here in the hinterlands get to meet and hear someone who actually helped to write that stuff. So please join us.

Here's the website if you want to learn more about the Center for the Advancement of Disability Policy: [www.disabilitypolicycenter.org/about.htm](http://www.disabilitypolicycenter.org/about.htm)

Silverstein is also presenting a workshop on Disability Policy from 9:00 am to 4:00 pm on September 15th. All Center for Independent Living staff and board members and others interested in disability legislation are encouraged to attend. Call us for more information.

## The ADA at 15

*By Scott Burlingame, assistant program director*

On July 26, 1990, President Bush signed the Americans with Disabilities Act (ADA) into law. The bill had recently passed the House and Senate with tremendous support. The ADA promised to guarantee people with disabilities access to employment, public accommodations, transportation, public services and telecommunications.

Early supporters of the ADA felt that this comprehensive civil rights bill would level the playing field for a largely repressed part of society. They felt that this bill would increase the community involvement of people with disabilities in all aspects, including employment, recreation, volunteerism, and much more.

Early critics of the law felt that the cost of the needed accommodations would be harmful to business. I remember reading in a college text book in 1993 that the cost of making all of the busses in our country wheelchair accessible would be so many millions of dollars, that it would make cities choose between providing services to everybody or just to people with disabilities.

Now, 15 years later, look where we are at. The ADA has had some solid points. A vast majority of the public transit systems now provide transportation to both people with and without disabilities. Public accommodations have been made to make buildings more accessible. In the Olmstead decision, the U.S. Supreme Court ruled that it was illegal discrimination under the ADA to only offer services to people in institutional settings.

However, the ADA has also failed to live up to the expectations of its supporters. Time after time the Supreme Court has narrowed the definition of "disabled" for workers' protections. Public buildings continue to be built that do not meet even the most basic needs of people with disabilities. Lack of enforcement and clarity in the law have made some parts of the Act less than effective. Clint Eastwood and his anti-disability rights lawyers have used his star power to attempt to deteriorate disability rights.

As we sit here 15 years later, one thing is very clear. The target of the ADA on July 26, 1990 has not been met. In fact, the ADA was only the beginning legal framework in what is to become the greater disability

rights movement. Now is not the time to reflect. Now is the time for all people with disabilities, all friends and family of people with disabilities, and all other concerned equal rights advocates to step up the fight for real equality and inclusion for all people.

### A Living Wage ... and People with Disabilities

The federal minimum wage, presently \$5.15 an hour, would need to be raised to \$8.20 an hour simply to meet the federal poverty level. In many higher-cost regions, a true living wage is substantially higher (up to \$18 per hour). The national average wage index for 2003 is \$34,064.95; the average income for individuals with disabilities is one-third of the national average (three times as many individuals with disabilities live in poverty with annual household incomes below \$15,000.) Only 35 percent of people with disabilities reported being employed full or part time, compared to 78 percent of those who do not have disabilities. (Resources: Social Security Administration, National Organization on Disability, and Triangle, Inc)

A fifth of Americans have disabilities; almost everyone knows someone who has a disability; and anyone can acquire a disability at any time in their life. Everyone has a stake in this.

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**Take a look at our Website at [www.freedomrc.org](http://www.freedomrc.org)**

## **MANUFACTURED HOMES (alias “trailer” or “mobile home”)**

### **A Home Ownership Option**

*By Val Neilsen, information specialist*

Many people would like to own their own home, but are unable to do so because of the costs involved. Persons with disabilities, who often live on low and/or fixed incomes, may be part of this group. Manufactured homes are an affordable home ownership option.

According to Research Works, a magazine issued by the US Department of Housing and Urban Development (HUD):

- Manufactured homes are a growing segment of the affordable housing market.
- Manufactured homes are costing 10 to 35 percent less per-square-foot than homes built from the ground up.
- Manufacturers are offering a range of Universal Design (accessible) plans for manufactured homes.

A report from HUD shares results of the American Housing Survey (AHS). Between 1993 and 2001 comparisons between manufactured housing, traditional owned housing, and rental housing, for low-income households are reported. The results contradict several preconceived notions about manufactured housing:

- “...owned manufactured housing is ...higher quality than rental units.”
- “...cost of manufactured housing...is much lower than other alternatives including renting.”
- “Owners of manufactured housing have the same concerns over structural quality as owners of traditional homes.”
- The American Planning Association wants “...all levels of government to recognize manufactured homes as an acceptable form of housing and a viable alternative to more costly site-built construction.”

This information should be good news for persons with and without disabilities who want to own their own home but have a limited budget. There are still barriers concerning ownership of a manufactured home:

- Many communities hang on to their view that manufactured homes will negatively impact

property values of site-built homes nearby. Current research shows this is just not the case.

- Chances of finding a mortgage for a manufactured home, while improving, can be difficult.
- Interest rates tend to be quite high for a number of reasons.
- Many government fix -up loans available to owners of site-built homes are not available to persons owning manufactured homes.
- Volunteer organizations that do safety and accessibility fix-ups for persons with disabilities are restricted from working inside manufactured homes. (strange one)
- Some of the necessary service providers refuse to service manufactured homes, ie. plumbers, electricians, banks, etc.

So, while there are still barriers, the manufactured homes industry is on the increase. This type of home provides a great opportunity for persons with disabilities to achieve home ownership. The homes are regulated for safety and quality construction. There are an increased number of styles, many that strongly resemble traditionally built housing. What is needed now is for the services (banking, plumbing, and electricity) to come on board and provide a full array of options for manufactured homes as they do for traditional site built homes.

Freedom Resource Center and/or its Board of Directors do not necessarily endorse or support any of the views expressed within the personal testimonies within this newsletter, with the exception of those specifically so attributed.

## Employment Rights (Yes, you have them)

By Mark Bourdon, program director

Federal and state laws prohibit discrimination on the basis of an applicant's race, color, national origin, religion, sex, age or disability. The ADA makes it unlawful to discriminate in all employment practices such as: recruitment, hiring, job assignments, pay, firing, training, promotions, benefits, leave, lay offs, and all other employment-related activities. Employers may not ask job applicants about the existence, nature or severity of a disability. Applicants may be asked about their ability to perform specific job functions.

The following questions could result in an Americans with Disabilities Act (ADA) lawsuit: Do you experience illness or disability? Have you ever had or been treated for any of these conditions or diseases (followed by a checklist)? How often have you been hospitalized? What for? Have you ever been treated by a psychiatrist or psychologist? Have you had a major illness recently? How many days of work did you miss last year because of illness? Do you have any disabilities or impairments that might affect your performance in this job? Are you taking prescribed drugs? Have you ever been treated for drug addiction or alcoholism?

If you feel you have or are being discriminated against because of a disability, or want to learn more about the ADA and employment rights, contact us.

## News from the Fergus Satellite

By Randy Stetson, IL advocate

Hello to all from the Fergus Falls office of the Freedom Resource Center. Well, the Fergus Falls office is once again in full swing with change and transition. Some of you know Kerian Stenstrom, our wonderful Independent Living Advocate. She has worked here for three years now, and is about to have her second child and will leave to go on to complete her nursing degree. All of us at Freedom will miss her a lot and wish her great success.

A new team member has been added to our office. Her name is Joyce Wolter and she is currently doing a lot of training with Kerian. Stay tuned; there will be more forthcoming about Joyce.

Carol Bangs, our office assistant, is no longer with us. However, she often keeps in touch with us all by phone and visits, and of course on those visits, she reminds us of where things are in the office. Carol is really missed and we all here at Freedom Resource Center wish her well, and appreciate all that she has done for us here at the Fergus Falls office.

Well, I've been here at the Fergus Falls office for three months now and still learning lots of things. I continue to visit the nursing homes and remind folks that there are resources available to live in the community. It's always interesting to meet residents and listen to what they have to say about independent living and their specific situations. It's most always a challenge.

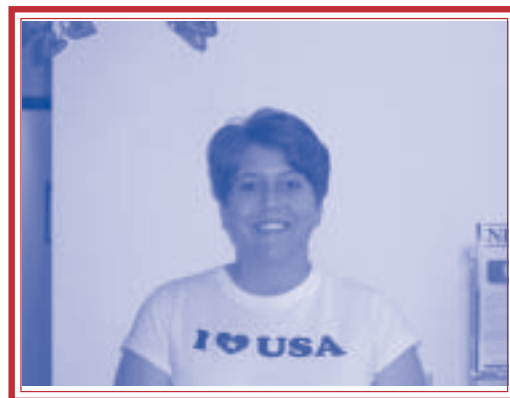
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## New in the Jamestown Office

By Andrea Nelson, IL advocate

I'm Andrea Nelson, a "newby" to the Freedom group. I started my position as an Independent Living Advocate in Jamestown at the end of April. I originally hail from Hankinson, ND and currently reside in Valley City with my husband Darren. I graduated from VCSU with a B.A. in Psychology and special studies in Early Childhood Development. I will be responsible for independent living skills training, general advocacy, transitional services, and nursing home relocation. I find myself spending my spare time shopping, with my family and friends, and going to the races. If you make it out to the Jamestown Speedway be sure to cheer for 19N in the Wisconsin Streets!!

My future goal with Freedom RCIL is to have the Jamestown and Valley City area very familiar with Freedom and utilize the services that are offered. I look forward to empowering those with disabilities and enlightening those who don't see the other side of the fence clearly.



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**Up Coming Events...**

July 12	Freedom Rec – Trip to the Zoo - Fargo	Aug 29-30	North Dakota Disabilities Advocacy Consortium Conference – Bismarck
July 26	Anniversary of the ADA Celebration -Brooklyn Park , MN	Aug 31-Sept 1	Leadership from the Disability Community - Bismarck
Aug 3	Freedom Rec – Redhawks Game – Fargo	Sept 13-15	Northern Plains Conference on Aging and Disability - Fargo
Aug 22-24	2005 Age & Disability Odyssey Building Together – Duluth	Sept 15	Bobby Silverstein workshop and Freedom’s Annual Meeting – Moorhead
Aug 25-26	Anne Carlson School – Designing Programs For Individuals with Autism Spectrum - Jamestown	Oct 12	Self Employment Training – Fargo
Aug 27-28	Lake Cormorant Camping – MN	Oct 27-28	North Dakota Human Rights Coalition Conference - Fargo