

the Independent

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Freedom Advocates take St Paul Road Trip



Clockwise from left: Sue Curfman,
Seth Bachman, Gin Ohnstad,
Katherine Pike, Chuck Stebbins

By Chuck Stebbins, systems change
advocate

Following are the legislative priorities as set forth by Freedom Resource Center for the Minnesota 2006 legislative session. The session started in early March and is scheduled to run until May. On a recent trip to St. Paul **sponsored by the MS**

Society, advocates visited with Rep. Morrie Lanning and Sen. Keith Langseth regarding some of the following issues. Both were generally supportive, and did not disagree with anything we brought forward in our time with them.

First up is **EMPLOYMENT**. Freedom supports all efforts that will create new opportunities for people with disabilities to become employed. Freedom will support the Minnesota Work Incentives Connection by working to simplify state work incentives for people with disabilities. Freedom will support training and education efforts on disability-related discrimination in the Minnesota Dept. of Labor and the Minnesota Dept. of Human Rights.

Next we have **HOUSING**. As always, Freedom will support all efforts that will increase accessible/affordable housing for people with disabilities in our service area. Freedom will work to increase the Bridges Program,

which provides stable, decent, affordable housing for people with mental illness, to all Minnesota counties (currently only 50). Freedom will support stronger enforcement of the state's current visitability law requiring that all new housing developments built using public funds be built with one zero-step entrance, an accessible half bathroom on the main floor, and 32 inch clearance through doorways.

Here's a fun one; **HOME AND COMMUNITY BASED SERVICES**. Freedom supports all efforts to provide services for people with disabilities in the most integrated community setting possible. Freedom supports any increase to wages for direct care

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What's Inside

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What's Wrong with this Picture?



Ever been to a place that has all those trendy high tables people can stand by? The law says that features of businesses must be useable by people with disabilities, including those using wheelchairs. Is this? Not really.

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workers providing services in the home.

TRANSPORTATION is a difficult and never-ending issue for the disability community. Some counties in west central Minnesota have little or no public transportation. Freedom supports all efforts to increase rural transportation for people with disabilities. Currently there is some federal money coming available for the state to improve the availability of accessible transportation in greater Minnesota. Legislators from District 9 are now aware of that pending revenue source, and hopefully will work to ensure that those dollars get to where they are intended.

ACCESS TO MEDICAL TREATMENT is always an important priority. Freedom supports the availability of appropriate healthcare for all citizens,

regardless of their income, age, or condition. A recent needs assessment indicated that access to healthcare is a concern for people in our service area. The latest from the federal 2007 budget indicated Minnesota will receive an increase in the Medicaid reimbursement dollars that come to the state. Freedom believes that part of this increase is due to Minnesota being proactive in improving the home based system. There are fewer nursing homes in Minnesota since 2000, so now we can see the benefits of that shift. Granted there is a lot of bad stuff in the federal 2007 budget, but this is one bit of shining light.

That's about it. North Dakota's legislative session will start in January of 2007. The fall edition of *the Independent* will list those priorities. So stay tuned, the fun never ends. ■



Gina M. Powers was hired in February 2006 as an independent living advocate specializing in Minnesota Nursing Home Relocation. Born in San Francisco, California, Gina eventually came to reside in the Fargo-Moorhead area after extensive travel within the United States and Mexico. Gina was in the United States Coast Guard as a young adult where she was part of Search and Rescue and Law Enforcement boat crews in South Florida. She returned to Fargo after her military service and eventually became involved with social justice issues in the Fargo-Moorhead community. She has worked in the areas of homelessness; domestic violence; Gay, Lesbian, Bisexual and Transgender (GLBT) equality; poverty; anti racism and disability rights. She is a volunteer with the American Red Cross and is involved with a number of other community groups. Gina currently lives in Fargo with her spouse of eight years and their children.

From Where I Sit

By Nate Aalgaard, executive director

Milestones in our lives give us the opportunity to look back and reflect. My milestone is that I've now been at my job at Freedom Resource Center for 10 years. I sometimes joke that if I had known then what I know now, there's no way I would have taken this job. Who knows? I guess there's something to be said for ignorant bliss.

I looked at Freedom's annual report from 1995. Here are some of the things that jumped out of me. First of all, the board president and acting directors made mention of a few programs that they were proud of, as well as moving to new office space. The particular programs were the rural transit program in Clay County, and representative payee. There was also mention made of outreach efforts in Jamestown, Valley City, Wahpeton, and Morris.

As far as the office space, that was one of the very first things I was determined to change. Back then I pushed a manual wheelchair. My interview had taken place in early February. It was cold, there was a lot of snow, and I had to trudge on an uphill grade across the parking lot for quite a ways before I got to the door. After that I encountered a long ramp, which led to an elevator. Freedom was on the second floor, not very visible to anyone looking for it. In addition, one of our board members could not even get into the bathroom, because it was not accessible enough.

The transit program, now that was interesting. Knowing absolutely nothing about it before I got here, I really didn't know where to start. One thing I learned quickly, though, was that there is no way you can make money on this kind of venture. Any funds you bring in through advertising or farebox revenue has to go right back in to subsidize your grant. In addition, managing something you knew nothing about, which is being run by a person who does not want to take direction, is a nightmare. I will be forever thankful to the Clay County commission for taking this program off our hands.

I know some Centers for Independent Living provide representative payee services. It didn't fit in with my vision of Independent Living, so I gradually worked to eliminate the program and assist someone else in providing it to those who needed someone to manage their money. I think that helping another person start her own business doing this service was one of the best community capacity building activities we have ever done.

As far as outreach, we just recently started providing some services in the Valley City and Morris areas and have only done some direct service in Wahpeton the last couple of years. My feeling when I got to Freedom was that we needed to make sure and serve our own backyard, our own communities where we had offices, before driving an hour or more to the break new ground. It is taken many years for us to get to this point.



Some of the most interesting things I found in the 1995 annual report were financial. At the end of that year Freedom had a grand total of \$869 in cash. In looking at the balance sheet, current assets were \$21,970, and current liabilities were \$21,865. I'm no financial genius, but an organization that is worth somewhere around \$105 could possibly be in trouble. Good thing I was naïve.

Not that everything was bad back then. There were certainly a lot of good things the Center had done. It was visible in the community. It was trusted by its consumers, and it was filling an important need. Back then, the budget was about a third of our current \$645,000. The Center served 60 people with direct service, over 1,000 with information and referral, and provided 695 hours of community services. In 2005, the Center provided direct service to 543 people, did 4,273 hours of community services and

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Consumer story

Following is the second part to Amanda's story:

4 My disease has progressed a lot. I became in need of total care after a recent spinal fusion surgery, and needed a lot of equipment and staff in order to come home. Thankfully, I did not know about a lot of what was going on till the end, but the short story is, that the county, state and others wanted me to go into a nursing home instead of coming home. The worst thing that they could have done was put my name and the word nursing home in the same sentence. My mom went off like a bomb. She again called Freedom Resource Center, the Minnesota Disability Law Center, and our state and local representatives.

I remember the day in the hospital when my mom told me what was happening. After telling me, she said there was a meeting and that she invited Freedom Resource Center again. This time my advocate plus two others came to that meeting. They were going to arrange a press conference. I was completely overwhelmed because I did not know I had so many people behind me. Sometimes I felt really alone and thought maybe it would be better to give up. But, with so many good people behind me I was able to come home. I got the new wheelchair that had been denied, I got an electric Hoyer lift. I got a hospital bed, plus 24-hour staff, and all of it at home.

Transition from high school to whatever I am going to do has been really scary. My disease is considered terminal, and the whole

team, with the exception of my mom and my advocate, wanted me to go to a group home and a day activity center for people with disabilities. This, after my mom said no. They just assumed I would go to a certain town and set myself up in these places. I want to go to college, I've wanted a job for three years, and I want to live on my own. I want to be married some day and my mom even thinks that is possible. Sometimes, I just want to give up. To be honest, I have in many ways. I just get so tired of the system. I do not understand it, and it feels as if they are always hiding something from me. DRS has canceled two meetings. My counselor never talked to me; always my mom, my social worker, or my teacher. In fact, when he came to school, he didn't even come to introduce himself to me.

Without my mom and my advocate, I know nothing would be accomplished. Now, because of them I am going to another place to be evaluated for services- a place that is familiar with my type of disability and who specializes in finding the truth. I am excited about that and yet scared. My mom says that is a normal feeling for anyone my age. I am happy that it is "normal." To imagine such a feeling as normal, and to think I about missed out on it.

She also told me recently that she was ready for me to leave. At first, I was hurt, but then, that is normal. Most seniors who graduate from high school do leave home. I know I can live here if I want to, but I also know she expects me to take



Amanda Krause

advantage of what is available even if we have to go to the end of the world to find it. I do want to die at home and I know I can do that, but till that time, my mom said it is time for me to get out and get a life.

The place that will be doing my evals said I can live there for up to a year, so I will look into that. If I decide to do that, I expect a battle, because it needs to be approved. Too many over the years have taken their time in providing services; they wait till it is necessary. Like when I was in a chair and they didn't think they needed a bus with a lift, and then I fell under it when they dropped me off. They got a bus with a lift now. Even though they would deny it, I know they were waiting to see if I would die, because then there would be no need to provide the service.

Even though I have wanted to give up during those times, I am just stubborn enough NOT to die. If I had not had the support of my mom and the other people who did believe that I have rights, I would have given up. Because the system is just too hard to fight on your own. ■

The Institutional Bias

An editorial by Chuck Stebbins, systems change advocate

Some call the institutional bias a myth...the Voices of the Retarded (VOR) would be that some (they really need to reconsider the name). Some would say we have a 70/30 split between funding for nursing homes and Home and Community Based Services (HCBS) respectively...that some would be advocates working in Independent Living. Currently in North Dakota we have a 90/10 split, while Minnesota is moving toward a 50/50 split.

When I Googled "institutional bias," up popped the VOR's website and the "myth of institutional bias." VOR says that globally this is true. GLOBALLY!? It seems to me that by saying that, they negated any argument stated after that, because globally indicates the big picture, the broad example, the big numbers, the aggregate. According to VOR's rationale; "The answer lies in the fact that the Medicaid program covers more than people with MR/DD (mental retardation/developmental disability); it also covers people who reside in nursing facilities (NF), most of whom are elderly. The so-called institutional bias in the numbers occurs because Medicaid defines 'institutional care' to include all Medicaid-eligible populations, the vast majority of whom reside in NF's. The facts are far different when one separates the MR/DD and elderly populations."

Now, is it just me, or did they just spin institutional bias into institutional care? According to VOR, when defining 'institutional care' Medicaid includes all Medicaid-

eligible populations, and if indeed the vast majority of those people reside in a nursing facility, and part of that group are people who have MR/DD, you can separate out all you want, but when you add it all up, there is a large majority of people in nursing homes. Given that, there has to be a significant amount of money involved to keep them there. It smacks of institutional bias. By the way, Intermediate Care Facilities for the Mentally Retarded (ICF/MR's) are institutions.

Now, what we know about the ratio of dollars to HCBS and nursing homes in both states could fill a one page fact sheet. Let's see, it's around here somewhere, ahhhh, here it is...nope, that's the sheet on the shortcomings of the Medicare Part D drug program. Ahh, nope, that's not it either, that's the new proposed budget for 07 from the White with black trim house....I know it's around here somewhere...ahhhh, screw it, just take my word for it, North Dakota is at 90/10, and Minnesota is at approximately 60/40.

Working in the aggregate, in my feeble little mind, is the only way to look at the massive amount of money we are talking about. I am coming more and more to believe that the long term care institutional system has gotten complicated for one reason, to confuse the decision makers appropriating the dollars. "Let's see, OT, PT, Medications, three squares a day, and room and board...man that's a lot of stuff for \$5.15 an hour, must be getting a

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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, Mark Bourdon, Deane Feland, DeAnn LaFond, Chuck Stebbins

Matt Solin Wins Civil Rights Complaint

By Joyce Wolter, independent living advocate



Matt Solin

Matt Solin is now 19 years old. Being a student who needed special education services, there were some bumpy roads, but Matt has kept his sense of humor and a sense of himself all along the way. He felt he was mistreated by the Fergus Falls school district, so he decided to do something about it, and he won.

In May of 2004 Matt was not allowed to attend the junior/senior trip to New York. This was not because Matt did not follow the rules or did not raise the money to go. Far from that. The school stated it was due to "safety and liability issues." Wouldn't that pertain to all students regardless of a label? You get a group of juniors and seniors together in New York City and you are going to have "safety and liability issues." After "careful consideration," ALSO KNOWN AS a couple of calls made by Freedom staff to the Office of Civil Rights, a heated meeting with Freedom staff, school personnel and

a very upset mom, the school changed their mind...hmmmm? Matt did too, he chose not to go. Wonder why?

Graduating in 2005 was a great accomplishment for Matt. There were many special moments and activities planned. Among those planned activities was a final concert for the year in which the senior members of the choir perform a special farewell song and are given a carnation to recognize them for their participation in choir. What a proud moment for those seniors and their parents—except for the three students who happen to need special education services. Those students, including Matt, were not asked to participate in the song nor were they recognized with a carnation for their contribution to choir. What should have been a very proud moment for all of the senior choir families turned into moments of frustration and shame for the families and students who use special education.

Matt's mom had had enough. She called Freedom Resource Center in Fergus Falls and started to inquire as to what to do. In Freedom's philosophy, we needed to bring Matt on board with us before we could proceed. He was reluctant at first, but ended up deciding to take action. We filed a complaint with the Office of Civil Rights in Chicago (OCR) on numerous complaints. The main complaint was the senior concert. After negotiation with the school district through OCR, they first came

up with a solution that: 1) The school district will develop a procedure to ensure that all senior special education students involved in high school choir are included in the senior song at the "Spring Pops" Concert, and; 2) By no later than the beginning of fall of 2006, the district will ensure that all the teaching staff receives special education awareness training, and that such training will specifically address the rights of students with disabilities. Such training will be provided annually.

It looks good on paper, but there was no monitoring of the actual training and that it would get done. So the Freedom advocate working on the case asked Matt if he would like to be the monitor in this case. Matt sat straight up in his chair and being a man of few words said "sure" with a very big grin on his face. He knew exactly what this would mean. So back to OCR this went. The worker on the complaint was not sure if they would accept it at the school district level. They did accept it. It now reads in addition: For the period of the 2006-2007 and the 2007-2008 school years, the district will notify Matthew Solin of the completion of training, in writing.

Matt states that this complaint being filed will, "Help other kids so that they don't have to go through this." He said that if he is discriminated against again, he knows exactly what to do. "I will come to Freedom and see you." The best part of this story is not only did Matt have the courage to go up against his school and fight what he

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- Have a Freedom Resource Center staff member speak to your group

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- \$25
- \$10
- Other

Thank you for supporting Freedom Resource Center

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responded to 1,515 information and referral requests. We now have over \$200,000 in reserve.

The thing that struck me the most about reading that annual report was the optimism. You could just feel it in the way they were writing. They believed in the future. They believed in the mission of Independent Living, and they believed in each other. A lot has changed around here and last 10 years, but that has not. In the time I've been at Freedom, I have stuck to the theme, "This is an advocacy organization." We have not been concerned about providing a wide variety of services, but have concentrated on helping people become advocates; and working to eliminate barriers in our community, states, and country. I feel very fortunate to have such a great job. It perfectly matches my personal belief system. I am optimistic that together we will continue to create a positive change for people with disabilities. ■

Bias: From Page 5

hell-of-a deal!" Instead of, "wait a minute, \$250 bucks a day in the nursing home, and \$150 bucks a day for the same services outside the nursing home?"

If we are ever to get a handle on this monster called Medicaid, we have to look at all groups, all disability types, and the whole pot o'money. As soon as you start breaking it down it blurs the reality of how the dollars are distributed. ■

Matt: From Page 6

knew was an injustice, Matt went up against his employer. You see, Matt is also an employee of the school district. He is a janitor's assistant and his boss had to sign off on the very complaint that Matt also had to sign. That's where the big grin came in; his boss used to be his principal! That takes guts and courage. Matt states that he likes that they (meaning his boss and former teachers) have to tell him when they have been to class. Congratulations Matt for doing your part in changing "The System." You have made life easier for those who will follow in your footsteps.

If your civil rights have been violated and you need to file a complaint with the Office of Civil Rights, the procedure is relatively simple. You can even do it online by going to this website: <http://www.ed.gov/about/offices/list/ocr/complaintprocess.html>. or if you choose, contact Freedom Resource Center and we can assist you. ■



2701 9th Ave. S • Fargo, ND 58103

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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.

Upcoming Events

April 1-2: Annual Parent Retreat - Windmill Project-
Ottetail Power Building - Morris

April 13: Mayors Committee Awards Luncheon - Ramada Plaza Suites - Fargo
for information call Tom @298-4400

April 13: Assitive Technology Expo - Ramada Plaza Suites- Fargo
for more information call 1-800-895-4728

What some people say..

"Blindness must be a terrible handicap, and I would applaud any genius who comes up with a device to make it less burdensome," *Columnist William Raspberry in a Nov. 16 anti-disability rights screed in the Washington Post. He's angry with any disability accommodation that, in his words, is "arguably less attractive for the rest of us."*