

the Independent

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What's in a Name

by Mark Bourdon, program director

So what's in a name? Many people will say, "it depends." So, what about the names for newsletters? Some of you may have noticed that Freedom Resource Center has changed the name of our newsletter from Freedom Focus to the Independent. Why the change? What was wrong with Freedom Focus? Isn't that what Freedom Resource Center is all about? Freedom? Freedom from what? Freedom from segregation, from exclusion, from barriers. Freedom to experience equal opportunity. With so much emphasis on freedom, why change to the Independent? Maybe the term Freedom Focus made it sound like it was about us. It's not.

When we talk about independence we talk about inclusion and equal opportunity—the right to move about freely in

this society. Independence doesn't mean doing everything for yourself, it means you control what is done for you – you make the decisions. Independence isn't asking for charity. It means demanding your rights! Independence means opening up more doors, creating choices for people, not the choice of segregation. We want this to be an "independent" voice for disability issues. We want to inform people with disabilities and others.

Our mission is to work toward equality and inclusion for people with disabilities through programs of empowerment, community education, and systems change. We are committed to preserve, enhance, and enrich the quality of life for all people with disabilities. In partnership with others, we work to empower people with disabilities to become fully integrated into society. The core values by which we base our decisions on are: consumer control, equal and full access, independence, and individual and systems advocacy.

In other words, Freedom Resource Center is committed to independence for people with disabilities. And now you know the rest of the story... ■

Minnesota 2005 Legislative Update

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The Minnesota Consortium of Citizens with Disabilities (CCD), of which Freedom Resource Center is a member, is pleased to report the outcome of the 2005 Minnesota legislative session.

Dental Services

Eliminates the annual \$500 cap on dental services for Medical Assistance, GAMC, and MinnesotaCare enrollees. This cap has significantly limited access to dental services and resulted in increased hospital emergency room utilization.

Lower Drug Co-pays

People enrolled in Medical Assistance will pay a maximum of \$12 per month regardless of their prescription needs. Currently, the cap is at \$20.

More Pocket Money

Individuals receiving subsidized housing in licensed group residential settings can keep more of their money before turning it over to the state to pay for room and board. The proposal lets them keep an extra \$20 per month. (Current law allows them to keep about \$77 each month.)

Parental Fees

The proposal moderates monthly premium costs that parents of children with severe disabilities must pay to access needed medical services. Some increases implemented in 2003 have created tremendous hardships for middle-income families.

What's Wrong With This Picture?



The building pictured was constructed after the ADA took effect, granting equal access for people with disabilities. Anyone who can't go up steps has to enter at the side. Is that OK?

Increased Choice for People with Disabilities Leaving Nursing Homes

Allows for individuals to choose the targeted case management provider to help in moving out of a nursing home. Currently, counties choose to provide this service or contract with a qualified organization. Counties would retain administrative duties and approve service plans. Private agencies would coordinate the services to make sure the transition goes smoothly. More than 3,000 non-elderly individuals with disabilities languish in nursing homes today.

Transitional Support Grant

To assist individuals with disabilities in relocating from a nursing home to a more independent, community-based setting, a one-time payment up to \$3,000 would be available to pay for lease or rent deposits,

essential furnishings, or other transition expenses. (No net cost. Funds come from existing waiver allocations.)

Community-based Provider Rate Increases

Boosts by 2.26 percent in each of the next two fiscal years the MA rates paid to agencies delivering community-based services to people with disabilities. Most of the increase must be used to increase the compensation of direct care workers providing assistance and support to Minnesotans with disabilities. Home and community-based service providers and ICFs/MR would receive a rate increase.

Home Care Provider Rate Increases

Boosts by 5 percent the MA rates paid for in-home delivery of skilled nursing, home health aide, or physical, occupational or speech

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From Where I Sit

by Nate Aalgaard, executive director

Well, for those of you who remember my life insurance saga, it finally reached the conclusion. Over a year ago I applied for life insurance. I was subsequently denied due to “quadriplegia and related conditions.” After calling around to a few different enforcement agencies, the only one I found that would look at the situation was the Minnesota Department of Commerce. The others basically said, “Not much of a chance,” or “We’ve never seen a successful case.”

After a few weeks I received a letter from them which says, “The Department of Commerce only has the authority to initiate administrative procedures against a licensed insurance company should a violation of Minnesota insurance law be found. In order for this department to initiate such action, we must establish, through legally admissible evidence, that the respondent has engaged in specific activities prohibited by Minnesota insurance law. Based on the explanation including the documents provided to justify the company’s position on the subject matter, it appears that the company resolved your complaint in compliance with Minnesota insurance law...”

So the bottom line is this: insurance companies are free to deny coverage to people they feel are an uninsurable risk. No enforcement agency that I found

can do anything about that. I guess the more you need life insurance the less likely you are to get it. One thing I will say, the Minnesota Department of Commerce at least looked into the matter. The other agencies I called seem to be resigned to the fact that there’s nothing to be done.

So in the previous case, delving into an issue provided an unsatisfactory conclusion. In another, however, the result will hopefully be better. Several months ago my wife told me that she noticed I stopped breathing during the night. At first I resisted the whole idea. After all, I’ve got enough equipment and other things I have to deal with already. Besides, I don’t want to get old.

I did, eventually, mention this to my doctor. He said I should probably get it checked out at the sleep clinic, so I did. To make a long story short, I now have my very own “plastic lung” or C-PAP machine. It pushes air into my airway at night through the use of nose piece attached to a hose, which runs from the machine.

An interesting point here is that earlier this year someone sent me an e-mail link to a spinal cord injury rehabilitation center’s web site. Information highlighted indicated that respiratory problems are the leading cause of death for people with spinal cord injuries, like myself. One shocking statistic was that up to 40% of people with quadriplegia have sleep apnea. This is 10 times the rate for the general



population. The strange part about this is that no one in my 28 years of having a spinal cord injury had ever mentioned anything about this. Maybe people don’t learn this stuff in medical or nursing school, but they should. But the best bet is to be your own advocate and seek out answers. Since getting diagnosed with sleep apnea, I have heard several stories of people who had huge health problems and two of whom even died from it.

So here’s the bright side. Maybe this whole saga will prolong my life. Maybe I would have thrown all that premium money for life insurance away anyhow, because I plan on living for awhile. So any information that I can gather to help do that is well worth the time and effort to find. I would highly recommend it. And if you have questions about your own disability, maybe we can help you. Please give us a call. It might save you a lot of money, or something else. ■

Broken Wheels

By Chuck Stebbins, systems change advocate

This is a story of a gimper, a broken wheelchair and the people who broke it. I haven't traveled by air since I got my new power chair four years ago, so I had a certain amount of anxiety about it. Well, actually I had A LOT of anxiety about it. I had this very profound feeling that something bad was going to happen and things were not going to go smoothly.

The first leg of the journey brought us to the Minneapolis airport, where I immediately noticed that my joy stick was broken clean off, leaving just a bit of a nub to drive with. My fears were starting to be realized.

The next stop was Washington DC. Outside of the joy stick, I didn't notice anything else out of place, but it didn't seem to be responding normally; lights were blinking and there was a strange delay before the thing would respond. It was when the chair started to

turn in a circle with my hand off of the joy stick that I knew things were just not right. I was waiting for it to slip into mode 5 and slam me straight into the nearest unforgiving wall.

I then began to freak out about making it through a week of tooling around DC, chasing down our delegates and various other conference goings on. Of course being in DC for the first time, we had to see some of the sights. We must have put on ten miles the third day, but it did make it through the week.

On the return trip, Northwest Airlines took the liberty to finish the demolition they had started just six days prior. I saw my chair come out of the baggage hold in Minneapolis on its side. I shook my head and wondered if it would work. I didn't have to wonder long, after I saw a rather large man dragging it through the front of the cabin. I saw no life in the wheels as he was pulling it, and was convinced at that point that it was not going work. And of course, it didn't. We must have plugged the joy stick in a dozen times hoping for some miracle that it would connect and I would be off to the next gate. Didn't happen! So, like

any other irrational man, I got upset. I totally stepped outside of who I was and became a cursing machine. It actually was a thing of beauty that only I had come to appreciate. I continued this cursing rampage throughout the terminal until we reached the next gate, where I continued to share my displeasure with the friends I had traveled with. Then I saw the child a couple of seats over. I realized then that I was no where to be found, and that if I don't want to scar this young man for life, I'd better get it under control. So I did...until I got back to Fargo and the reality of the situation hit yet again.

There is a point to all this and that is; airline personnel need to understand the difference between a bag and a wheelchair. You carry a bag, but a wheelchair carries YOU! If your power chair does not work, you CANNOT carry the bag. Although this was not a case of discrimination, it was a case of blatant disregard for very personal property. We would like to take a moment to remind people of The Air Carriers Access Act of 1986. See adjacent box.

The Air Carrier Access Act (ACAA) prevents airlines from discriminating directly or through a contractual arrangement against people with disabilities. Under the law, new and renovated terminals must be designed to be accessible by people with disabilities. Fully accessible services must also be provided in all existing airport facilities that air carriers own, lease, or control. The ACAA affects all domestic air carriers and all airport facilities within the United States and its territories, possessions, and commonwealths. As of September 1, 2000, the ACAA was amended to cover foreign air carriers operating in the United States.

It took four weeks before I got the chair fixed, and I am still of the mindset, "If I can't drive there, I am not going." There will come a time when I will have to fly again, but this time I'm going make sure that the airline understands that my chair is not just another piece of luggage. It should be treated with more respect. It is in their best interest to do so. It would have saved them almost \$10,000 when things are all said and done. In the case of Northwest and their current situation, they could probably stand to save the money. ■

Continued from page 2

therapy. Minnesota lags behind most Upper Midwest states in payment rates for these services. Effective 10/1/05.

Disability Services Interagency Work Group

Requires the Department of Human Services, the Minnesota Housing Finance Agency, and the Minnesota State Council on Disability to convene an interagency work group to make planning and policy recommendations relating to persons with disabilities who are attempting to relocate from or avoid placement in institutional settings. Requires the group to report to each participating state agency and the chairs of legislative health and human services policy and finance committees by October 15, 2006.

Case Management Redesign

Requires the Department of Human Services to examine case management services to improve access, quality, and cost-effectiveness of delivering these services to Minnesotans with disabilities. A similar 2003 legislative mandate did not result in the policy and draft legislation recommendations called for in the report. This ensures that the 2006 legislature will revisit this issue after careful study by the department and all stakeholders.

Managed Care

The state is instructed to seek federal approval to expand the current voluntary managed care program for individuals with disabilities enrolled in Medical Assistance - called the Minnesota Disability Health Options (MnDHO) program — beginning with regional population centers throughout Minnesota. Currently, almost 500 high-cost, medically complex individuals are enrolled in this innovative care coordination program. ■

The ACAA prohibits airlines from requiring a person with a disability to accept special services, such as preboarding, that the passenger did not request. Similarly, air carriers cannot segregate passengers with disabilities, even if separate or different services are available to them.

For more information on the Air Carriers Access Act and people with disabilities, go to: <http://airconsumer.ost.dot.gov/ACAAComplaint.htm>
You can find Part 382 of the Air Carriers Access Act here:
http://www.access.gpo.gov/nara/cfr/waisidx_99/14cfr382_99.html

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.

Funding for this publication was provided by the Minnesota Department of Employment and Economic Development, Rehabilitation Services from the state's general fund and The Federal Department of Education.

Alternate formats available upon request.

Leave a Legacy

By including Freedom Resource Center in your will, your commitment toward equality and inclusion for people with disabilities lives on. In recent years, donors have included a gift to Freedom Resource Center in their wills or other estate plans. These gifts will have a tremendous impact on our ability to create a society where ALL individuals with disabilities are valued, respected, and have equal opportunity, access, responsibility, and freedom of choice in all aspects of their lives. We appreciate your support. Thank you.

If you would like information on how to include Freedom Resource Center in your will, please contact us.

16th Annual Meeting was a success

On September 15, a group of almost sixty people met for Bobby Silverstein's workshop "How to be an Effective Policy Change Agent" and Freedom Resource Center's 16th Annual meeting. Bobby Silverstein is the director of The Center for the Study and Advancement of Disability Policy. At the Center; Mr. Silverstein conducts action-oriented policy research; conducts advocacy training; gives keynote speeches; and assists disability groups, and federal, state and local agencies draft disability policy. His areas of focus include civil rights, education, work incentives, workforce investment and welfare reform 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.

Both events were held at the Courtyard by Marriott in Moorhead, MN. At the annual meeting, Sue Pederson and Larry Chial were elected to the board. After fine dining, Brad Arett, board president and Nate Aalgaard, executive director talked about the strength of Freedom Resource Center and our direction for this next year. Bobby Silverstein was the keynote speaker and the evening ended with awards and a special recognition. The Volunteer of the Year award was given to Gregg Palmer, a mentor from Fergus Falls. The Advocate of the Year award was given to Mark Boatman from Jamestown.

Fargo Mayor Bruce Furness was also given an award to recognize what he has done for the disability community. Bruce Furness is serving his third term as Fargo mayor, after starting the job in April 1994. His current term expires in June 2006 and he has decided not to run for another term. Bobbi Franks and Scott Burlingame were also recognized for five years of service. ■



Keynote Speaker
Bobby Silverstein



Tom Thompson, MC
with Julie Dotzenrod
presenting award



Mayor Bruce Furness



Gregg Palmer,
Volunteer of the Year



Chuck Stebbins presenting Mark Boatman
Advocate of the Year Award

Gift Card

Name: _____ Phone: _____

Address: _____

Please Check if you are interested in:

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

I would like my contribution:

- To be used wherever needed
- Endowment
- In memory/honor of

Your thoughtful gift will be acknowledged to the person(s) indicated:

Name: _____

Address: _____

Please check if you do not want your name published as a contributor

Enclosed is my tax deductible donation:

- \$100
- \$50
- \$25
- \$10
- Other

Thank you for supporting Freedom Resource Center

DC Update

by Chuck Stebbins, systems change advocate

On a recent trip to Washington DC for the National Council on Independent Living conference, we had a chance to meet with three Senators and two Representatives. Phone calls were placed well in advance of the trip, and times were set to have a sit down. We had scheduled meetings with the offices of Norm Coleman, Collin Peterson, Kent Conrad, Bryon Dorgan, and Earl Pomeroy. The operative words here are, "the offices!" We actually got to sit down with "the staff" of five of the above, which was fine considering how much stuff can be on their plate. What was not fine was, when we mentioned specific legislation like the Medicaid Community Attendant Services and Support Act (MiCASSA), and the Money Follows the Person Act. Coleman, and Peterson's offices were not really sure what we were talking about. Dorgan and Conrad's offices acknowledged them and stated that their position was in support of anything that would allow more choice for people with disabilities...Byron Dorgan did pop in for a few minutes and a photo op, and we did get to sit down with Earl Pomeroy for about a half hour where he actually said he would sign on as a co-sponsor. Norm Coleman's office nodded in agreement to most of what we said about eliminating the institutional bias, and the stated concerns about the cuts to Medicaid, to which she responded by saying we have to wait and let the recently named Medicaid Commission do its work to see where we're at.

Now I understand that sitting down with staff is about as close as some get, and I do appreciate the time that was given to us, but I could not shake the thought of them not knowing about the legislation. It told me that disability policy issues are still not on the radar with some of these people. And those that say they support the disability community do not show that support by signing on to legislation that profoundly affects our choices. Collin Peterson and Mark Dayton are listed as co-sponsors of MiCASSA, and the others are no where to be found.

So, I have to wonder if they ever think about the 58 million plus people with disabilities out there. They may say they do, but they don't much. So as we plug away at this antiquated system, we must keep in mind that we are still not on their minds, so we must continue to get our message to our elected officials...because if we don't...well, you know what they say about history repeating itself? ■

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Return Service Requested

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.

Calendar of Events

October

October 10-11

Upper Great Plains
Technology Conference-
Fargo Dome

Chamber of Commerce
of Fargo Moorhead

October 12

Self Employment
Workshop

Doublewood, Fargo

Sponsored by NDCPD

October 15

Fargo Recreation Group
Cobbers Game

October 27 -28

Human Rights Colalition
Conference

Ramada Plaza Suites -
Fargo

November

November 8

City Elections -
Moorhead

December

December 2

MN Human Rights Day