

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.

From where I sit

The freedom to live, or die

By Nate Aalgaard, executive director

There are two notable disability-related stories in the news lately, one real, one fictional. They both are eliciting strong emotions on all sides, and both involve the ultimate decision—life, or death. One is Clint Eastwood's Oscar-winning movie Million Dollar Baby, and the other is the long-running battle over the life of Terry Schiavo.

I could easily fill this entire newsletter and then some with the information that I found in just a couple hours of research on the Internet regarding this subject. But I just want to get a little food for thought going here and maybe bring up a perspective that often gets missed by the mainstream media. That is the perspective of people with disabilities themselves.

Those who have weighed in against this movie range from Rush Limbaugh to the pro-life movement. Those who weighed in for the movie include most all movie critics and the industry itself. Free-speech advocates say that Eastwood has the right to make any kind of movie he wants. I agree.

The group that is noticeably absent from this discussion is the disability movement. All kinds of groups, from the American Association of Persons with Disabilities to the Association of Programs for Rural Independent Living and many others, have weighed in against it. While there are a few in the disability community who think the subject matter of this movie is just fine, the vast majority of opinion seems to be opposed to the whole notion. Some call assisted suicide the ultimate form of discrimination.

The case of Terry Schiavo has been much longer and far more emotional, because it is real. Court battles have been waged for years between her parents and her husband for the right to make a decision on whether she should continue to live in her semi-comatose state, or be allowed to die naturally by removing nutrition. This particular situation has prompted legislation by the Florida Legislature and Governor and the US Congress. It now appears that the husband has won and Schiavo will have her nutrition pulled from her in a few days.

Continued on page 3

What's Inside....

- **What's Wrong with this picture?**
- **From where I sit...**
- **Transition Corner**
- **Fergus News**
- **Legislative updates**



What's Wrong With This Picture?

What IS wrong with this picture? This looks like a nice home that is not completed

yet. Probably, when it is done, a nice couple or family will move into it. So what is wrong with it?

What is wrong is that certain people and families will not be able to live in this house. This particular group of people will undoubtedly think it is lovely and would like to be able to buy it, but it will not be an option for them.

The reason it is not an option for individuals and families in this group is that it has steps, narrow doors and small spaces. It probably will have hard-to-turn door handles and faucets, and probably the wall sockets will be too low and the closet bars too high. This house would work for most of the people, but not all the people.

People with certain disabilities will not be able to purchase this home because the builder, the architect, or the developer didn't concern themselves with design elements that would allow ALL persons the ability to live in and enjoy this home.

If the professionals involved in building this home had used some or all of the specifications of Universal Design (UD) they would have opened up this home to many more buyers - and not only persons with disabilities, but people who have small children in strollers, people who hate trying to fit a large couch

through a small door when they are moving, people who have to haul groceries, or any people who like larger spaces to move around.

The second unfortunate part of the story of this house is that someday someone with a mobility impairment may live there. Then these accessibility barriers will require remodeling, or force individuals to move - maybe to a nursing home. The remodel will be incredibly expensive, and moving to a restricted living situation may result in loss of quality of life, loss of dignity and loss of hope.

The National Association of Home Builders Remodelers Council has created the program Certified Aging-in-Place Specialist, who are trained to remodel for barrier-free living environments. So, if you can afford it, there are people who can redo your current home to suit your needs.

It is the hope of Freedom Resource Center and Centers for Independent Living all over the nation that the building industry will use Universal Design when they build homes and save that remodeling cost.

Thoughts From My World

By Shirley Robideau

Recently, I have had the privilege of experiencing both sides of Freedom Resource Center's Peer Mentor Program. As a mentor, I am finding it inspirational to work with a client who is finding a new place in their life as a college student. Changes can be difficult to work through and fortunately we do not have to deal with them alone. It is a choice experience to watch someone's countenance change as they overcome one obstacle after another. Knowing that we can help someone from our experiences gives us feelings of satisfaction. This client gave me the courage I needed to step to the other side of the fence and find help with challenges I am facing as a low-vision student.

When I mentioned my struggle as a low-vision student to Julie, the Peer Mentoring Specialist, she asked if I would be interested in having a mentor who had faced similar obstacles. I immediately took advantage of this opportunity and while working with my mentor found myself eager to learn. When I first met with my mentor I felt confident that he was sincere in his desires to help me find solutions to my visual difficulties. He had first hand knowledge of several resources available to help me continue in my educational goals.

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Continued from page 1

I mainly want people to think about these issues and do some research on their own. This is very complicated stuff, obviously greatly affected by a person's own belief system. Here's where I come down on it: if you look at the history of people with disabilities it is one of being devalued. People with disabilities have been segregated, sterilized, brutalized and murdered. Sometimes they have been made to feel inferior for so long that they believe it. They are apt to go along with the idea that maybe they would be better off dead. Some of this kind of treatment is not too far into the past. We need to do whatever we can right now and in the future to help people with disabilities become valued, important, and productive people, and provide the best support services that we can.

I looked up a couple of studies that have been done on the satisfaction level that people with significant disabilities feel about their lives. What I saw indicated that there is not a significant difference between the people with disabilities and without, and any difference is related to environmental factors, not the disability itself. Given the past history and portrayals that are still prevalent in the media, I think that the whole idea of assisted suicide or allowing people to die who we think may have wanted to because of the severity of their disability is not a good thing. This is a dilemma, though, for those of us who believe strongly in the right of everybody to choose their own destiny.

For more information on the subject, I would recommend looking for these sites on the Internet:

Not Dead Yet

Roger Ebert.com

Hardball, archives from an interview with Clint Eastwood on March 15

An editorial by John Hockenberry

Million Dollar Baby and Values

February, 2005

From Andrew Imparato, President and CEO American Association of People with Disabilities:

"When movie directors like Clint Eastwood incorporate a gratuitous plot twist that reinforces the shallow notion that life with a spinal cord injury is a fate worse than death—as in 'Million Dollar Baby'—we must speak out. When people have their lives stolen because the only choice the State Medicaid program is willing to give them is isolation in a nursing home or other institution, we must question the values underlying that program. When our public policy expects disabled youth to retire onto Supplemental Security Income benefits upon turning 18, swearing to the government that their disability prevents them from working, we have no choice but to question the morality of such a system.

"Any policy that deters or prevents full participation of people with disabilities in the economic, political, social, and religious lives of their communities is inherently suspect. It is my hope that, by reframing our agenda as a question of basic values, the disability rights movement will gain new allies, persuade more policymakers and voters, and ultimately reinforce the core tenet of many faiths and of American culture that all people are created equal and that every life has value and dignity. To use Dr. Martin Luther King, Jr.'s language, 'Everybody can be great because anybody can serve.' "

In an attempt to reduce the cost of mailings please send us your e-mail addresses to freedom@freedomrc.org.

Or

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

Come Join Us!

Crafts Group

1:00 pm -4:30 pm

Every Thursday

Freedom Resource Center - Fargo

In the Eyes of Youth!

By Bobbi Jo Sailor, IL advocate

The grammar and spelling has been left exactly as the students submitted it.

Over the past school year I have been working with youth from an area high school. I asked them the question, "What is your disability and how does it affect you?" These are a few of the responses I received:

"I really don't know what my disability is but I know if I don't have help I would probably be a D student. So if I could find out what my disability is then I could find out how to beat it and prove everyone wrong in the whole world when I was younger I always took the easy way out of everything because I was different. They always treated me like a failure so I think the only way I can get respect is by pretending that it is not there."

"My disability is in math there will some troubles in the future even though I don't see my disability my self but people say that I have it, it might affect me it might not."

"My disability is reading and spelling. The challenges that I see in class is when we have to read out loud I might not know what the words are so then I feel not bad but I should know what the words, and when we have to write I don't know how to spell some of the words so I have to use smaller words so that I can spell them right. This doesn't make me feel any way because I just joke around and laugh at it and other people laugh with me. My disability might affect me later but I'll be more of a hands on person and won't need to read that much in what I am going to do."

"My disability is reading and it makes it harder for me to do my homework because of my disability. It affects my school like with my homework that makes me not want to go to school. My dad has the reading level of a 3rd grader I see but I see his problem then I see it in me to but he dropped out I am not going to do that. I am going to work past that I am slowly getting better every day. It affects me in my job if I am a mechanics if I have to read a manual I affect my math to and I might be a carpenter."

"Well what can I say; there are a lot of things that I struggle with. I have a problem with math. I am really bad when it comes to doing math in my head. When my dad or my family ext, ask me a question that

involves math, I hesitate for a minute I think it through and then I grab a calculator to help me out. That is really the thing that I have a problem with. The ways I can fix it is by not giving up or doing it and just keep trying. I am not afraid of doing bills or taxes. It's just that I have a problem with doing math in my head."

"I have a disability that I need help with, and the school has been wonderful with helping me. My disabilities include math, study skills, transition work, and social skills. Right now with my disabilities I have trouble with remembering things for tests because I get nervous when the test is put in front of me, it's like everything I studied goes away. My toughest class is math it just doesn't click in my head. Math really frustrates me. I think that in the future some things will be hard for me because I am really bad at math and you need math in your everyday life. I don't like to have a disability because I feel different from the other kids. I don't like when people ask me my classes because 3 of them are in a Special Ed room."

"I have a lot of disabilities but I feel the one that causes me the most problems is that I have oppositional defiant disorder. It gets me into a lot of trouble very often. The effect is that I don't like getting told what to do. But I do listen when people say it nicely. It is not as bad anymore but I do stop listening occasionally. P.S I don't do it intentionally it is a bad habit because of the disorder."

I have been teaching youth to advocate for themselves and letting them know that having a disability is nothing to be ashamed of. Youth today are faced with a lot of things, for example, just growing up. So too many youth are put down and ignored because they are "different", it is our job as parents, teachers, advocates to help them find their voice and place in the world. Here are some interesting statistics:

- 7 percent of boys and 4 percent of girls ages 5 to 15 have disabilities.
- 20 percent of men and 18 percent of women ages 16 to 64 have disabilities.
- 43 percent of women and 40 percent of men 65 or older have disabilities.

PROTECTION AND ADVOCACY FOR BENEFICIARIES OF SOCIAL SECURITY

Article published in the Employment Quarterly newsletter through the ND Medicaid Infrastructure Grant Project

The Protection and Advocacy for Beneficiaries of Social Security (PABSS) program is an initiative funded by the Social Security Administration (SSA) through the "Ticket to Work and Work Incentives Improvement Act" of 1999. The intent of this program is to address employment-related barriers facing SSI/SSDI beneficiaries.

To be eligible for Individual Representation a person must be an SSI/SSDI beneficiary who is receiving cash payments from the SSA, and believe their legal rights have been violated. Assistance is also available to beneficiaries who are facing barriers that may not be a rights violation, still prevent the person from working.

Eligibility for information, referral, technical assistance or training is available to any provider of employment-support services, employer, advocacy organization, or other individual involved in a beneficiary's return to work effort.

The advocacy priorities set forth by the Social Security Administration include:

- ◆ Investigation and review improper or/inadequate services by service providers, employers or other entity involved in the beneficiaries return to work effort.
- ◆ Information and referral to beneficiaries about work incentives and about employment rights, services, and incentives;
- ◆ Consultation and legal representation to protect the rights of beneficiaries;
- ◆ Assist beneficiaries in disputes before SSA involving work-related program decisions and benefits overpayments that are clearly a barrier to obtaining employment.
- ◆ Provide information and technical assistance on work incentives to governmental agencies, employment networks and other service and advocacy organizations.

- ◆ Advocacy to identify and correct deficiencies in entities providing vocational rehabilitation, employment, and other services.

For more information about the Protection and Advocacy for Beneficiaries of Social Security contact the:

Protection and Advocacy Project
400 E. Broadway, Suite 409
Bismarck, ND 58501
www.panda.org
vgross@state.nd.us
701-328-2950
1-800-472-2670
ND TTY Relay 711

Avoiding Social Security Overpayments, How to return to work without paying thousands to the Social Security Administration.

By Scott Burlingame, assistant program director

Imagine this, you are a person receiving Social Security Disability (SSDI). You return to work, first part time, then full time. You earn \$8 an hour on your full time job. Each pay period you turn in your pay stubs to the local Social Security office. You continue to get your full paycheck and your Social Security for a year, then 2 years. Finally you get a letter from Social Security stating that you have used up your trial work period; you are currently earning over Substantial Gainful Activity (SGA), you are no longer eligible for SSDI and you need to repay \$15,000 for overpayment.

And there is really nothing you can do, other than find a way to pay it back.

The fact is this: If you are a person on SSDI and you return to work, it is your responsibility to manage your benefits. You need to know about such things as SGA, Trial Work periods, extended periods of eligibility, work subsidies and employment-related work expenses.

If you don't understand all of this, it is OK. Social Security wants you to stay employed, and they don't want to deal with you paying back these large payments. The key to your successful transition to work is effective benefits management. The important thing is to give us a call at Freedom Resource Center or to contact the appropriate number below and have a benefits management plan set up. Do this if you are thinking about becoming employed or if you are currently employed and receiving Social Security Benefits. The Minnesota Work Incentives Connection Toll-Free: 1-800-976-6728
Or in North Dakota, Rehab Services Inc. Toll-Free 1-800-258-8132

On the Road

by Chuck Stebbins, systems change advocate

We took a windy trip out to Bismarck March 10th to give testimony on HB 1012 for raising the Qualified Service Provider (QSP) rate and add funding to the Centers for Independent Living . After seeing the semi, that was at least as high and as long as the bus we were riding, on it's side just outside of Valley City, I wondered if it was a good idea to go. But, we made it with time to spare and loaded up the room with 24 of the 75 people that attended the hearing. We had it arranged to go on first with testimony. Richard Schneider lead it off, yes he is the older brother of all them lawyers. Speaking through his pathfinder, Richard set the stage for what we had to say. Jack was up next, then Geoff, Donna, and Tami. Gyle was up after Tami, and proceeded to pull no punches when it came to the Long Term Care Association and its influence over the legislature. I flinched a bit, but it really was a thing of beauty.

Somewhere during our testimony the chair, Senator Fischer, was called out, and we were left with Senators Krauter, Kilzer, Thane, Mathern, and Bowman. Although they seemed attentive and interested in hearing what we had to say, not being aware of any clairvoyants in the room, we really couldn't know for sure what was on their minds. My feeling was, we had support from Senators Bowman, Krauter, Mathern, and I think Thane, but again, we won't really know till the fat lady sings.

We hope they were truly impacted, and understood what we were talking about. We also hope they left with a further realization of the importance of home and community based services and what that means to those who spent the time and energy to testify, most of whom had never been in front of a legislative committee before.

By the time you read this blurb, we may know for sure the impact of our efforts. Where's those clairvoyants when you need them? All and all, it was a gas; we've GOT to do that again!



President's Bush's Proposed Budget

by Mark Bourdon, program director

There are so many numbers, and they are so big! How do we know what we need to be concerned about? Let's see if I can help you understand President Bush's budget proposals and what impact the projected housing cuts will have on the disability community.

In 2005, North Dakota housing agencies will receive \$1,044,208 less funding (Minnesota \$8,013,748 less funding) than it needs to support its vouchers, causing an estimated 295 low-income families in North Dakota (Minnesota 1,198) to go without housing assistance. Under the Administration's budget for 2006, the funding gap confronting housing agencies will drop to -\$536,201 (Minnesota \$4,209,282 less funding), allowing it them to restore temporarily 146 (Minnesota - 590) of the vouchers that were cut in the 2005. But estimates based on available information from the Administration's budget plans through 2010 show the shortfall widening to approximately -\$6,484,843 (Minnesota -\$50,907,317), eliminating all of the vouchers restored in 2006 and cutting the number of families assisted by a further 1,309 (Minnesota -5,423). It should be noted that even in 2004 the demand for vouchers far exceeds the supply: only about one in every four low-income families eligible for vouchers receives any type of federal housing assistance.

So in 2005, vouchers in North Dakota and Minnesota will be cut; in 2006 vouchers will be restored but there will still be cuts; and in 2010 vouchers will be cut again. And this is just one area. Low-income energy assistance cuts have been proposed, as well as Medicaid (Medical Assistance), employment, education, child care, WIC (Women, Infant, Children nutrition funding), Head Start, and many other cuts.

So what can you do? First of all, you need to get involved. The easiest way to do this is to send a letter to your congressional representatives, your state representatives, and your state governors. Let them know what impact cuts in housing assistance will have on you. If they don't hear from you... well, in all honesty, I don't know if you want to take that risk. If you send a letter please let Freedom Resource Center know so we can make further decisions on what grassroots efforts may be needed. If you need help, call Freedom Resource Center. We will help you write your letter and organize grassroots efforts to bring fairness, compassion, integrity and justice to the budget process.

ASK BOB...

Dear Bob,

It seems as though every state in America has its own unique way of administering all of its social service programs (social security, housing, food stamps, medical insurance, caregiver programs, etc.). I have heard through the grapevine that, if an individual relocates to a different state, he or she must be re-evaluated by Social Security in that state to determine if benefits will be approved. Is this rumor true?

Also, is there a web site or book that gives a state-by-state comparison of social service programs? It seems as though each state has a different attitude toward disability and/or assistance programs. I hope you can help me out. There is a lot of misinformation out there. Thanks a lot!

Anonymous

Dear Anonymous,

Hopefully we answered some of these questions in our last issue. We wanted to discuss the subjective side of these questions this time. Even though these programs are set up with rules and eligibility criteria, they are administered by humans. Humans make mistakes. Humans get burned-out. Humans make assumptions before listening to the entire story.

The best thing that you can do is to educate yourself about these programs, their rules and responsibilities. Be cool and collected when applying and interviewing for any type of assistance. Never assume that any worker you are assigned to cares about your situation. Maintain the responsibility yourself. This will give you more control.

Wherever a program exists, so does an appeal process. Use it. Some programs accept a very small percent of first time applications, then they accept more after one or two appeals. For example, 60% of initial SSI/SSDI applications are denied, only 4% are approved after one appeal, and 63% of those who actually appeal to an Administrative Law Judge are approved!

Now, let's talk attitudes. Ideally, each person who applies for assistance would be considered equally.

Unfortunately, that doesn't happen. Individuals are discriminated against for a variety of reasons. The best way to prevent this from happening to yourself and others is to keep notes. Write down that name and title of the person you are working with. Present yourself in a professional and respectful manner. Use the grievance procedure if you feel that you have not been treated fairly.

If you have any questions for Bob, send them to "Ask Bob", c/o Freedom Resource Center, 2701 9th Avenue S, Fargo, ND 58103.

**Take a look at our Website at
www.freedomrc.org**

Fergus Falls office doubles employees & doubles the office space!

By Keri Stenstrom, IL advocate

Exciting things are happening at Freedom Resource Center's satellite office in Fergus Falls. Not only have we been fortunate enough to acquire a new independent living advocate, but we have a new place to call home as well. We didn't go very far. We moved to the office that adjoined our old space the first week in February.

Some things have stayed the same. Conveniently our address has not changed, my desk is still messy, and there are still no windows. But if you come to visit our new office you will notice many improvements. First of all, there is more than twice as much space. There is a reception and waiting area, two large offices for the advocates, and a small room for storage. We have new carpet and some lovely new office furniture. You will also notice that there is more space for displaying resource materials. So if you are visiting and see something that interests you, don't hesitate to check it out!

We hope to schedule an Open House soon, but until then, we welcome you to come in and visit any time. We'd be happy to show you around!

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.

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Randy Stetson joins Fergus Falls office



My name is Randy Stetson; I am the new independent living advocate in the Fergus Falls office. I graduated from Western Washington University 1991 with a major in Human Development and Counseling Processes. I also attended the Seattle University Addiction Studies Program, completing that program in 1992. I worked as a Chemical Dependency Professional (CDP) in Washington for 13 years; at West Sound Treatment Center in Port Orchard, WA; Serenity Counseling Services in Fife, WA, and Inland Professional Services in Seattle/Bremerton, Washington. I moved here in 2003, and I currently live in the country south of Fergus Falls with my

partner, and we have two dogs, and several cats. I have a son, 14, and a daughter age 9, who live in Washington. I like to spend my spare time in the summer at Ten Mile Lake, swimming and playing Scrabble. I also enjoy playing with power-tools in the woodshop, and this year's project is restoring an old grain shed into a new woodshop and storage space.

I will be involved with the nursing home relocation project in MN and advocacy.

Mark the Date!
Freedom Resource Center's
Annual Meeting September 15, 2005.
More details to come.