

The People First Connection

The Voice of Self-Advocacy in Oregon
Published by Self Advocates As Leaders



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EVERY PERSON DESERVES A HOME

March was Developmental Disabilities awareness month in Oregon. This year's poster theme: "It doesn't take a wizard to know... There's no place like HOME for kids with disabilities."

There is something powerful in living where you want to live, with people you care about, doing the things you want to do. Sound easy? Not for everyone... Here are stories from people living their lives in ways that make sense for them.

Am I Disabled or Do I Have a Disability? Is There a Difference?

By Ann Blackburn, Portland

Working as a Training Specialist in the Disability Rights and Self-Advocacy movements in Oregon over the last seven years, I have become used to seeing Self-Determination and hearing People First Language. It has become a norm for me. I have even

begun to notice businesses are starting to use terms like "people with disabilities" instead of "disabled people."

I hear you asking, "What exactly is **People First Language** (also known as Respectful Language) and why is it even an issue?" Well, it's a respectful

way of talking about people with disabilities, focusing on a person and their strengths instead of what they can't do. It puts the person first before their disability, not describing anybody by their disability or medical diagnosis. When we describe a person by their weaknesses, disabilities or conditions, we are devaluing them and forgetting about the individual, not to mention their skills and strengths.

So many of the words used to describe people with disabilities have evolved into something negative and demeaning. For example, we use the word "disabled" to describe something that has broken down or is no longer working ... like "a disabled vehicle." People with disabilities are not broken or defective, we just have bodies that work differently.

It is much more than the language we use, it's the way people with disabilities are perceived and valued in society... strong and capable of contributing versus weak and vulnerable or needing to be taken care of. This can play a role in how people feel about themselves and their disability. There are many schools of thought on this. I have had people say, "What difference does it make, the words are insignificant and mean the same thing?" They argue that I can't walk or dress myself, therefore I'm "disabled." I disagree. To me, the word "disabled" means the whole package, whereas "disability" may only refer to specific abilities. *My disability is only one small part of who I am and I only*

have certain things I need assistance with, but I have many other abilities. I don't know about anybody else, but I want people to think of me by my many capabilities and contributions, not by what disability, or needs, I may have. If it was up to me, I would change the term to "people with different abilities!"

There was a bill passed in the Oregon Legislature, "The Respectful Language Bill" that ensures all laws are written in a way that is more respectful towards people with disabilities. If you want to get more information about this topic, there's a great article by Kathie Snow that can be found at:

www.disabilityisnatural.com

I used to live in England and now go back each year to see family and friends. The differences in societal attitudes toward people with disabilities is very interesting. Both countries have their positive and negative aspects and things they can learn from each other.



From what I have seen and experienced, even though Self-Advocacy seems to be a growing concept in the United Kingdom, Respectful Language is a brand new idea and non-existent. I can tell you that it's strange and even irritating for me, to see and hear people being referred to as "disabled people," "the disabled," or even "the handicapped." To me, this implies that people with disabilities are lumped together and looked down

upon, seen as something to be pitied and a burden on society, reinforcing other negative ideas about people with disabilities. This is exactly opposite from what the Self-Advocacy movement is all about and what I've been trying to do my entire life. Yes, I sometimes see this attitude in Oregon, but it's far more common in England. I even saw it among so-called disability organizations, and that shocked me.

I once heard a great quote from a colleague, **“Language has a powerful influence on public attitudes. We must do everything possible to promote respectful language that acknowledges the value and uniqueness of each person with disabilities.”** - Bill Lynch, Executive Director, Oregon Council on Developmental Disabilities.

I have been thinking about moving back to England as most of my family lives there and I miss the British and European culture. However, I really don't want to be made to feel that I'm not a valued and capable member of society. I know that if I do end up moving back to England, I'll continue working to spread the message of Self-Determination and the fact that *people with disabilities are just as capable!*

I always say: **Disability is an attitude and you are only as 'disabled' as you think you are.** By the way, I'm in NO WAY whatsoever disabled -- I just happen to have a disability.

Correction

Mistakes were made in listing the Editorial Board on the last page of the Winter 2007 People First Connection. The errors have been corrected on the final page of this issue.



A Story About Me

By Shana Stubbs, Beaverton

I'm glad I'm on my own and I'm glad I'm independent. I have someone living with me and that is Sunshine, my parakeet.

I'm going to be a new customer in the brokerage*. I like it, it keeps me independent. But I still talk to my mother every day. I do not have a father - he died last year in April. My Dad's spirit came to me and asked me if I am helping my mother. I said, "Yes, I am." At first, it was very scary. Then I got better. I cried at first, but then I felt better. I don't have those dreams any more about my daddy.

I hope that the brokerage will help me be more independent, like going on trips or something. I'd like to go on the Love Boat cruise. I'd like to meet people like me.

(*If a person is eligible, a brokerage is an agency where a person can get services based on Self-Determination, on what they need and want.)

All About Beverly

By Beverly Francis Powell, Corvallis

I am a member of my church, Zion Lutheran. I like being there. I got christened with holy water. I like being in the Christmas pageant. I want to be Mary in the play next year. I would like to be a preacher, like Linda.

I am an artist. I went to a tea party at a new place. It was cold inside.

We got a new piano. Some people donated it to our house. I donated my clothes, and some of my toys to kids. I am on a list to donate more presents.

I look forward to going to Goodwill with Chad. I am going to Dollywood in April and I will take small trips with Dennis. I want to meet Dolly Parton!

I am moving to COHO House. I will have a roommate and new staff. I can make new friends. I can go shopping. I will invite my friends to visit me. I like to have sleep-overs.

I got a new chair. It doesn't have wheels on it. We took them off for safety.

I work at Packaging Plus. I am proud of my pay checks. I changed jobs. I am getting ready to retire in the Spring. I don't want to wait until June, it is too far away.



Community Membership

By Ashley Johnson, The Dalles

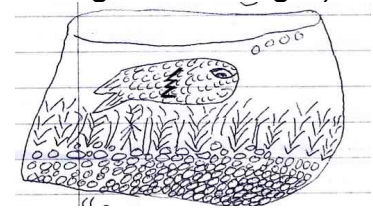
I am a member of The Arc of the Mid-Columbia. They are trying to get people to join their chapter. It would be nice to see more people join. They need more volunteers for the work they do. They set up a clothing bin drop-off site for donated clothing in Mosier. The sacks of clothes are sent to Multnomah County Value Village and profits are sent back to our Arc chapter.

I was once a client of The Eastern Oregon Support Services Brokerage but that changed and I do not get support from them now. I still keep in touch with my Personal Agent, we built a strong relationship.

My education is important to me because I am a strong and willing person. I want to learn new things every day. I currently attend the Columbia Gorge Center in The Dalles five days a week.

I am saving my money to get a place of my own soon. I am on the HUD waiting list and a waiting list for energy assistance. That will help. I live in The Dalles and would like to stay here forever. I want to say thanks to everyone who is supporting me and who has supported me.

(Ashley's picture of her goldfish, Sugar):



Thinking Ahead

By Theresa White, Aloha

I live in Aloha, Oregon. My subject today is a home of my own, some day. I will need lots of help along the way. Right now, my Mom is living with me, but I'm worried how much longer she will be able to do that. I do have a brother in Boise, Idaho, who would come if something happened.

I have always lived with my Mom. I am visually impaired and she has helped me with things I need help with. I'm worried that if someone else moves in and she moves out, that we won't click as much as mom and I do, and the person won't help as much as Mom does.

I want to live on my own, with friends and family and people from work helping me along the way.

I am worried about how to ask my friends and co-workers for help. I don't know who to ask for what and how to ask them. I want to get started now, rather than waiting until later. I would need to ask them for the help I need.

This is different for me because *Mom knows what I need. I'm nervous asking people for specific help, in the way I like it to be done.* I know I have friends and co-workers and church friends. I know I have people in my world who care about me. I guess I will need to ask them for help some day, but I don't want to ask the wrong people because I might be rejected.

I would worry about asking people to do too much, especially people who have families to take care of. Some might say yes. If they do, I would say, "Thank you" for their help.

I want to learn how to teach people how to help me best. That would be hard.

I don't want to move to Idaho with my brother because I have friends here. I'm thinking this story might help me because I can show it to friends. This might be an easier way for me to help recruit people.



My Neighbor's Cat

By Chris Bolte, The Dalles

We are not allowed to have animals at our home - landlord's rules - but every day my neighbor's cat named "Talsler" comes over to visit me.

Talsler is a large, soft, purring cat that lives to eat tuna fish and lay on my lap. My Dad enjoys our short term cat also, gives it treats when I'm not looking.

Talsler belongs to my neighbor across the street and waits for me to come home, all day sometimes. The cat enjoys jumping onto my lap. Talsler never asks for anything, and always gives his love.



DD Awareness Day

ADVOCATE'S CORNER

By Judy Cunio, OCDD

Self-Advocacy Coordinator

March was Developmental Disabilities Awareness Month. On March 12, 2007, the DD awareness celebration took place at the Barbara Roberts Human Services Building. The celebration included the re-dedication of a sculpture that stood in front of the administration office at Fairview Training Center for many years. The sculpture was first dedicated to a Superintendent of Fairview who passed away while serving in that role.

On March 12, the sculpture of a circle of kids holding hands was moved to its new permanent home in the lobby of the Barbara Roberts

Human Services building. It was re-dedicated to the over 9,100 people who lived at Fairview over the 92 years it was open. The sculpture's new plaque reads:

"This exhibit is dedicated to the more than 9,100 children and adults who lived at Fairview Training Center (1908 -2000) Oregon's largest institution for people with developmental disabilities.

To those who suffered, I say, The people of Oregon are sorry. Our hearts are heavy for the pain that you endured. And it is in honor to you that I declare December 10 hereafter to be Human Rights Day in Oregon.

-Governor John A. Kitzhaber. December 2, 2003, on the occasion of a state apology for the inhumane treatment and involuntary sterilizations of Oregonians in state institutions."

Some people may wonder why we would want a reminder of Fairview. There are a number of reasons.

- It shows just how far people with developmental disabilities have come. Even though institutions are not good, Fairview is a very important part of our history.

- It's important that people know where we came from so that no one with a developmental disability will ever have to go through what so many others before them went through.



Although Oregon's largest institution, Fairview, is now closed, it is not our only one. The Eastern Oregon Training Center in Pendleton is still open, with about 40 people still living there.

Eastern Oregon Training Center

Melinda Kristovich,
Beaverton

I think the institution should be shut down. The people should be sent out where there is more socializing and activities.

I think the people there should get the money for supports in the community. **I think people with disabilities should be treated fairly.**



Close It Down By Jeff Lowry, Hillsboro

The institution is a bad place to live. They don't let the people out very much. The people don't get out and the doors are locked. We need to let the people out.

If we get more services out in the community and dedication to help people with disabilities out... if we had more money in the community, we could close it down.

I am a person who lives and works in the community.

Fight for All

By Judy Atkinson,
Beaverton

We need to get the people out of Eastern Oregon Training Center. We need to help them find homes, meet new people, teach them new skills and have more money available for services outside.

Other people should have more chances and fight to get out.

News Update:

In April, the Governor said Eastern Oregon Training Center will stay open. His first plan was to close it.

The Story:

http://blog.oregonlive.com/politics/2007/04/inside_the_capitol_gov_does_ab.html

Services and Home By Paula Novak, Corvallis

I was born in 1967 and raised in Corvallis. My parents George and Kay, my sister Christine and my brother, Dan live

here. My extended family includes my grandma Thelma, my brother-in-law Scott and my sister-in-law Tahnya. I have six nephews and nieces: Drew, Thomas, Barrett, Garrett, Gracie and Julia.

I have cerebral palsy, a hearing impairment and learning disabilities. I earned a certificate of achievement when I graduated from Corvallis High School in 1987. With the help of my physical therapist, I was a member of the high school swim team.

After graduating, I got some support through Work Unlimited and Voc Rehab to find a good job. In April 1988, I started working my first job at Siuslaw National Forest by volunteering for two months. That June, I started working for pay. I file and copy. I work a second job for O'Brien Dental Lab where I clean and label lids. Before that, I worked in Albany City Hall seven years, delivering mail to all departments.

I ride my bicycle for transportation. I need help when it is dark or icy.

I volunteered to give a bike safety talk to other persons with disabilities in my town.

I moved out of my parents' home to live in a duplex owned by The Arc of Benton County for a year before my parents bought me a condo. I moved to my condo on October 1, 1997 when I was 30 years young.

I live on my own with some help from my parents. I'm employed and pay my bills with the support of Work Unlimited, Social Security and Medicare. If these services were cut, I couldn't work my two jobs. I would lose my independence and have to move back home to my parents. I really don't want that to happen! My independence at my condo and my two jobs are important to me. I want these services to be safe from being cut.

A Sister-like Bond By Hannah Williamson, Lyons

I moved into the Granger's home six years ago. I wasn't sure what to think, but I knew my life

was about to change. What I didn't expect, was that one of the little girls they were caring for would make such a difference in my life, and I would never be the same again!

I lived with them for a couple months when I started to notice something about Jenaya. Driving by her in my chair, I saw her sitting just as content as could be watching TV. I sat next to her and talked to her for a while, instead of the "hi" and "bye" as she came and went from school.

When I sat next to her and started talking to her, she got so excited. As I just sat there and kept talking to her, I noticed a spark in her eyes. It was as if she was living trapped in this box. She was excited to have me talking to her, but she couldn't communicate verbally what she wanted to say. I saw the spark in her eyes and knew she was communicating in her own special way.

From that moment, I knew we would be best friends and have a sister-like bond that would last

forever. She inspired me to get involved with Rett Syndrome. Over the last six years I have met many individuals with Rett Syndrome who have inspired me and changed my life. I enjoyed getting to know you, Jenaya. Thank you for letting me come along on one of the most exciting adventures of my life. I look forward to plenty more.

2007 Calendar

Arc of Oregon Convention

Pendleton, May 4 & 5.

1-877-581-2726

www.arcoregon.org

Building Futures: Transition Conference

Tigard, May 15-16.

1-888-505-2673

Oregon PTI Conference

Seaside, May 18-19.

1-888-505-2673

Life Stories Workshop

Newport, June 16. 1-3pm.

1-888-589-1664,

Oregon Conference on Direct Supports

Corvallis, July 24 - 26

www.directsupports.com

Finding Home

By Daniel McKinney,
Newport



I enjoyed working at Shangri-La for the last four years, since right after I moved from the Florida Panhandle. That's where my family came from. I grew up in different places. I was born in San Angelo, Texas and during my childhood years, I grew up overseas where my family was stationed at Ramstein Air Force Base (AFB) in Germany. I lived there for 10 years. Then, my dad was assigned to Eglin AFB, Florida in the Gulf Coast of the Panhandle of west Florida. I graduated from Niceville High School and the mainstreaming education program at Okaloosa County. I attended a program called Choice First. I had a Support Coordinator who helped me and my family, to get me in the Independent Skills Pro-

gram of the Adult Enrichment Program.

I had to work hard at home to learn how to be independent and do what my parents wanted me to do. In high school, they tested my IQ. The results said I was smart, but I wasn't ready to be independent yet. It took me seven years. My biological mom died from cancer in March 2002. Life made me move on. My dad and I moved to Pensacola and he got married. I have a stepmom and she is so good to me.

My parents decided to take a vacation trip to the Pacific during the summer of 2003, around my 24th birthday. We traveled from Washington, through Oregon and California. We stopped on the Oregon Coast and decided to explore. We moved to Oregon.

My parents found a good rehabilitation program on the coast in South Beach. I participate in the adult programs and I like getting to know people and being a part of the party activities. I started living in my own

apartment about a year ago, semi-independently. I really like taking care of myself and learning how to cook, to serve others, and do nice things for other people. I like going to movies, partying, going out to eat, and going to church every Sunday. I work in Coastal Ceramics and Coastal Firewood. It is a very good place to make money for a living. The program I work for is called Shangri-La.



Spring is Here

By Bertha Spinning,
Portland

The sun is taking over the sky now. The flowers are coming out.

I am a long-time member of People First. It is nice to have heard new stories. And YES we all can live strong and independent lives!

I am from Portland, Oregon. Our self-advocacy is very strong.

The SAAL Newsletter asks readers for ideas. Here is one response to an "Ask Saaly" question:

**What is a Self-Advocate?
By Ashley Johnson,
The Dalles**

A self-advocate is someone who stands up for themselves or others who cannot stand up and defend themselves in their communities, work or relationships.

A self-advocate can try to help a person access help through agencies, plus they can ask what is best to help this person out in the community.

A self-advocate can defend people who cannot say things for themselves or help others.

**My Favorite Things
By Andy Owens,
Portland**

As the song goes in The Sound of Music, so goes one of my favorite things, the movies. Ebert and Ropert (movie reviewers) have nothing on me!

Not just any type of movie works for me, it has to be a comedy or a love story with a happy ending. Almost any Tim Allen, Tom Hanks, and Jim Carey movie is good. I like some animated movies, romantic comedies, physical humor or slapstick, some dramas, holiday movies are some of my favorite, especially Christmas (Santa Clause 1, 2 & 3).

I would rather go to the theater to see a movie, versus home rental and I love to use my Regal Card!! When you go to the movies, you get to see previews for more movies to come!

I buy some of my favorite movies in DVD. I buy gift cards for others to go to movies, too.

Another favorite thing for me is Karaoke. I get together with friends from "Job club" and we will have a Karaoke night. I love it. Elvis songs really get me rockin. They even kid me and say, "Elvis has entered (or left) the building" when I come and go.

I also like bowling. I know, I know, bowling, you say! But it is one

thing I can do even from a wheelchair. My grandma, years ago, was on a bowling league and gave me her old bowling ball. My dad and I get together with some guys from our church and we have bowling tournaments. We had one named after me in the end of March! I also have my own team, made up of my Dad, my older brother Aaron, my friend Darren, my sister Krystyna and her boyfriend Michael.

So these are just a few of my favorite things!



More Fun

**By Pat McGhee,
Corvallis**

I went on a weekend to Albany. We stayed all night. We watched movies (The Lone Ranger and The Dukes of Hazard.) I don't like scary movies. We ate popcorn.

We read The Christmas Story. We had a sleep over in bunk beds and went to bed early. We drove in a car. For my birthday, I want a new wristband.

My Friend and Love

By Rusty Hubbard, The Dalles

My Friend, I think of you every day
 You are in my heart, and it will always
 be that way
 I remember you coming to visit that win-
 ter morning
 To see if there was any work, or if I had
 heard any inclement weather warning

How you spent the evening at my
 apartment
 And you just kicked back and had a
 drink with me
 We just sat and talked, as well as
 watched a movie
 You grew close to me

That night, you saved my life; I had too
 much to drink
 In a wink I had passed out, and you
 asked if I was all right
 I will always be grateful you saved my
 life

When you hugged me next to you
 I felt so at ease that if the sky was fal-
 ling, I would not care
 Nothing feels as good as being with you
 I love no one else the way I love you

I vividly remember watching music vid-
 eos on TV
 And you were joking with me
 How we made each other laugh
 I watched wrestling with you

Do not give up on fighting for what you
 love
 No matter how hard it may seem to
 you, you can get above
 All that criticism, just believe in yourself
 No matter what happens, I want you to
 know

I love you very much
 And I will always love you, no matter
 what
 I will stand behind you and there are
 others who will
 Until this life is through and forever



My Nephew

By Armesha Jackson,
 Cascade Locks

My ten-year old nephew William
 read more than 50 books, so he gets to
 go to a real Trail Blazer game. It is
 really cool. My ten-year old nephew
 William will be 11 at the end of this
 month. He is starting to speak up more.

Have you signed up?

If you or your friend want to
 have **The People First Connection**
 mailed to you at home, **Sign up!**
 CALL THE OREGON COUNCIL ON DD
 AND ASK! 1-800-292-4154. TRY
 ONLINE AT THE OREGON NETWORK:
WWW.OREGONNETWORK.ORG AND
 FILL OUT THE FORM.