

The People First Connection

The Voice of Self-Advocacy in Oregon

Published by Self Advocates As Leaders



Having a Say in Policy

There are many ways to make your voice heard. You can make a difference in the laws and the policies that affect your life. This month we share stories from self-advocates who have done it. How they make their voices heard is very different. From voting, to testifying at the legislature, to taking an advocacy class; from talking to your governor, to serving on a local board - it's up to you!

**YOU MAKE A
DIFFERENCE!**

Voices in Oregon are
getting stronger.
Be a part of it.

Our Address:

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Vote For President, By Ron Bell, Portland

I talk about politics a lot with my Toastmasters group. A friend of mine at Toastmasters volunteers with the Democratic political party. We talk about politics all the time when we get together. I was originally a Republican but have changed to an Independent in the last eight years. I like talking to my friends about politics even if they are not in the same political party. Friends are friends no matter where they come from.

I vote every time there is a presidential election. I think that voting for your president is the most important thing in the world. You are voting for a person that is going to be in office for the next 4-8 years. I vote because I want my vote to count. Sometimes I vote to get a person I like into office and sometimes I vote to keep someone I don't like out of office. I started to vote when I was 18. Some-

times I vote Republican, sometimes I vote Democrat, and sometimes I vote Independent. No one tells me how to vote (not even the President of the United States).

Be a Leader



By Eddie Plourde, Salem

It is a good experience being Chair of Self-Advocates As Leaders (SAAL). It is fun being Chair. I like making the agenda for the Operations Committee meetings. I like working with Cindy, the Executive Director of SAAL, and Hannah, the Support Staff for Operations. I helped move our office when our Salem office moved to OTAC. OTAC is the Oregon Technical Assistance Corporation. OTAC wants me to serve on their board.

There are opportunities for me to go to different meetings. I sit, listen, and participate in the meetings. I get to help make big decisions about SAAL. Big decisions are things like moving SAAL from OHSU to PSU. I got to help decide whether or not SAAL should move. I get to do training with Marcie, SAAL staff, Ann (Chair of SAAL's Outreach and Training Committee), and Judy Cunio, our link to SAAL from the DD Council. I get to go to big conferences, like the Mega-conference in Bend, to help with training, such as violence awareness and other different SAAL trainings.

We are looking for more leaders to get involved. Contact me if you are interested in joining SAAL. I am looking for a new At-Large member. We

especially need members from the coast and southern Oregon. My email is: racedane@uci.net 503-589-1664, or toll-free 1-888-589-1664.

National Update

Self Advocates Becoming Empowered (SABE) is working on its legislative priority for 2008, the Developmental Disabilities Act (DD Act) reauthorization. For the past several years SABE has worked with the Administration on Developmental Disabilities and other national organizations to promote the inclusion of a new title to the DD Act for Self Advocacy Information and Training Centers.

The potential new grants that would be authorized from this new title would provide federal funds to support and expand self-advocacy activities that are going on, with little financial support, in local communities and states throughout the nation. For more information and ideas about how self-advocates and their supporters can get involved, read the DD Act action alert at www.sabeusa.org.

To learn more about SABE and what is going on in self-advocacy nationally, read the Self Advocacy Nation bulletin at: <http://www.sabeusa.org/documents/SABEnewsletter2008.pdf>



Get Involved:

Serve on a Board!

By Rita Beckett, Portland

I am on four boards. I have been very busy these days - it never ends. I am on the Independence NW board and the boards of DSI and SDRI (they are brokerages) and I am on Ridewise, too. Ridewise is looking for people who would like to work with them. They will tell you more; you can call them and ask them. The ages are from 16 through 21 years in high school. If you would like to know a little bit more you can call Christina Turner or Mike @ 503-528-1748.

These days I am still making home made soaps. I will be at the fair on Alberta Street (Portland) between NE 28th and 33rd, at the end of each month, on Thursday.

So, I am having fun these days with everybody. I am doing lots of sport with Special Olympics. I am a coach and I play, too: I play volleyball and basketball. Because I help out on my own time my coach said, "Rita, you are my second coach."

I said, "Sure, I was glad." Basketball started in January. I have lots of things to do these days.

Calendar

Mega Conference, Bend, May 30-31, 2008. A coalition of organizations are coming together for Oregon's first statewide disability MegaConference. www.arcoregon.org

National Self-Advocacy Conference Indianapolis, Indiana, Sept. 3-7, 2008. Information online at: www.sabe2008.org



My Term is Done

By Charlie Hammett, Pendleton



As I look back on my eight years, all I can say is, "Wow!" I thank all of my friends at the Oregon Council on Developmental Disabilities. I have learned many things in the years I served as a representative on the OCDD. One thing I learned is how to be a better self-advocate. Helping people has always been a lot of fun for me, and because of the Council, I feel I am a better self-advocate.

I also learned how some of the state government works. I know more about how agencies fit together and how advocates speak up for themselves within government.

As a Council member, I had to read through the agenda and informa-

tion packets before meetings. I traveled to meetings in Salem, our capital. If the DD Council was coming to my area to do training, they would call on me to help get a place for the training, and to get people to come. I served on the Self-Advocacy Committee for eight years. A person who is aware of other people's needs might want to think about becoming a member of the Oregon Council on Developmental Disabilities.

The most important thing to me is the wonderful friends I have made there. Thank you for letting me be a part of it.

Training

Want to learn more about changing public policy?

Self-Advocates As Leaders can help you set-up training in your town.

Voting: find out why voting is important, register to vote, and get information about issues and candidates

Talking with policymakers: learn who your legislator is, how to make a meeting with them, and what you should say

Testifying: learn the in's and out's of testifying for an issue

Writing a letter or email to your legislator: learn how to write a letter or email about an issue, what you could say, and where to send it

For more information, call Hannah Bowen at 1-866-835-0659.



Testifying at the Capital

By Ross Ryan, Mount Angel

My provider, Rick, told me about a bill that would change the law so that I wouldn't lose part of my paycheck to pay for my support services. I felt that it was unfair for people who don't have much money to pay out of their own pocket for their services.

I had never testified before and I was a little nervous. I had taken some classes from Self-Advocates As Leaders and the Victory Alliance about testifying so I felt brave enough to testify in front of a big group of legislators.

Rick helped me to do everything that I needed to do. He said to know exactly what I was going to say, be polite to the legislators, and don't get intimidated. He helped me to write my story and he supported me by staying next to me when I testified. I was really nervous.

The legislators asked me questions and I got to share my view of the situation. I was glad that I testified and I was honored that I had the chance to speak my views.



SAAL-Sponsored Bill Passes into Law By Marci Alvarez

"The Respectful Language Bill" (HB3047) was sponsored by Self Advocates As Leaders and carried forward by former Representative Billy Dalto (R-Salem). Caleb Arnold, Judy Cunio, Cindy Helvington and Gayle Berniece Gardner all testified in 2005.

The June 2005 signing ceremony was held at the Governor's office in Salem. The "Where's Molly?" bill was also signed during that ceremony.

When Gayle met the Governor that day, he asked for her name, and she said, "Gayle Berniece Gardner, and don't you forget it!"

He laughed and laughed, and she asked me later if she shouldn't have said that to him. I told her he probably never would forget her - what a great way to leave a lasting impression on your Governor!



Change in Parking: Wheelchair Users A Notice Submitted by Mark Knecht, Salem

(Published courtesy of Oregon Department of Veteran's Affairs.)

The Oregon Legislature passed laws relating to parking spaces for citizens with disabilities. Beginning in January 2008, all parking facilities with more than 100 spaces must have at least one space dedicated to drivers that use wheelchairs.

This space must provide an area for loading and unloading the wheelchair from the vehicle. Signs will be required for "Van Accessible" and "Wheelchair User Only" for each accessible parking space. Van Accessible applies to all parking facilities, while Wheelchair User applies only to parking facilities with 100 or more parking spaces.

Senate Bill 716 from the 2007 Oregon legislative session directs the Oregon Department of Transportation (ODOT) to provide citizens that

qualify with new wheelchair-only parking placards. This includes a person who uses a wheelchair or similar low-powered motorized or mechanically propelled vehicle designed specifically for use by a person with a physical disability.

The new law took effect on January 1, but facilities have flexibility with regards to construction or repainting. Parking in any of the new designation spaces using the old placard will result in fines.

Accessible parking spaces and signs have been designed in compliance with the standards set forth by the Oregon Transportation Commission and the Oregon Disabilities Commission. The Committee On Health Policy and Public Affairs carried the new law at the request of Oregon Paralyzed Veterans of America. For more information contact the Oregon Department of Motor Vehicles at 503-945-5000.

What do you think about this? Tell us!



ADVOCATE'S CORNER

What Can I Do to Help Stop Abuse?

By Judy Cunio,

Self-Advocacy Coordinator, Oregon Council on Developmental Disabilities

There is nothing new about abuse. Right now it is on everyone's mind because of recent articles that have been in The Oregonian. Over the past few months, they have covered abuse that happened in group homes and foster homes.

This has brought the subject of abuse to everyone's attention and people are wondering what they can do about it. Everyone can do something. Even if you only suspect that someone may be experiencing abuse, you need to tell someone. It's always better to be safe.

Here is a number you can call if you or somebody you know needs help. The Office of Investigations & Training: 1-866-406-4287.

Just Like You

By Theda Tawney,
a parent from Dallas

I am a person just like you
With a heart that beats
And loves and breaks.

My world is simple and sometimes
small
When others greet me
I brighten and smile.

Sometimes people avoid me
They think I'm different
Or weird.

I am a person just like you
Only I have developmental disabilities
That's true.

So please get to know me
Before you judge
For I have feelings too.

I cannot do what you can do
But I do all I can
Whatever it takes.

It makes me want to stand up tall
And I feel valued
For a little while.

But I'm a person just like you
Who wants to be included
Not feared.

And just like you
I have strengths and frailties
Who knew?

I want to live the best life I can
I am a person who matters
Just like you.

Talk to Your Legislator

By Trent Minor, Stayton

I talked to my legislator at the capitol about the need for more transportation. I let him know there is a need for more regularly scheduled rural transportation. We do have some weekday transportation, but we also need evenings and weekends. We have events we want to attend that happen in the evening and on weekends. I will continue to keep him informed about our needs and encourage him to support transportation bills.



My Annoying Cat

By Anne-Sophie, Dallas

Barney is always meowing if I forget to wear Barney's favorite T-shirt. Barney likes his wet cat food. He is an annoying cat. I love my cat Barney.

I am voting because of Anne Frank and because of the war in Iraq. I want the troops home and I want healthcare. I want to stop teen pregnancies. I want to stop the dying in Africa.

New SAAL Address

Self-Advocates As Leaders
3886 Beverly Avenue NE, Suite I-21
Salem OR 97305-1373

Phone: 503-589-166
 Toll-Free Number: 1-888-589-1664

www.asksaal.org

Long Journey to a Good Place

By Jen Phillips, Salem

When I was a kid, I had a couple of stays at the Albertina Kerr residential facility. Then I lived in foster care, on a horse farm outside of Lebanon. I attended Lebanon High School in ninth grade. When I was there, my doctor prescribed too much medication for me. It caused a chemical imbalance, so I saw hallucinations, and always felt cold, so I wore layers of clothes. This caused family problems because the family was not trained to help me with those things.

I went to a hospital in Albany, because my levels were out of whack. I was transferred to Providence Hospital. We waited several hours before I was admitted to the hospital. They gave me medicine to fall asleep because my other medications have been keeping me awake. Another doctor prescribed me anti-psychotics.

Since 2005, I have lived in adult group foster care in Salem. I have great staff now, they are great people and we are like one big, happy family. We go swimming at the pool, take trips to the library and go to The Arc dances.

I work at Mount Angel Center. I experience some PTSD (Post Traumatic Stress Disorder), anxiety and anger. Counseling and group support helps, as well as Bible study and Sunday School.

I love music. I love to sing. I attend Judson Baptist Church and sing on the worship team. Singing is my passion!

Helping Out By Rusty Hubbard, The Dalles

Wanted you to know that I care for you truthfully
Do not do anything to make life harder on you honestly
Trying my best to help you realize that you have to make a choice
You have your own mind and your own voice

What you decide is your decision, don't allow anyone to badger you
I know you know what is true
My heart is right, and I only do things to help you
So I hope you can see what I say, I mean and I do

Careful about what and how I say things about you
I don't want to offend you
Your life and how you want to live it is your choice
You don't need to be afraid to have your own voice

I want to offer you a better life
Where people don't cut you with cruel and vicious words like a knife
Just have the courage to seek hope and a better day
You can find a better way

When you're ready make up your mind
However, we don't have an endless amount of time
So, for yourself and I you should make a choice and know
Love and respect is there, you can choose to find it and it will grow

You're not going to find it where you are now
It is what you must figure out somehow
My heart and soul are yours if you can fight for it
For your life to be better I would put myself on the line for it

Are you able to make that kind of dedication and commitment?
Is your life the way you really like it to be
Cause, see you are the one that has to decide how it's going to be
Take action on what your true feelings are about what is right for you

I sincerely care, and love you more than I could ever say
Please don't run away
Stick up for yourself, you're the only one that can
So many can help -- take that jump and don't look back.



A Model Strong Woman

By Jeanne Petshow, Mount Angel

Every day I like to read the Bible. I like the story about Ruth and how she became a very nice lady. Her story makes me very powerful and strong in my life. Sometimes she is sad in her life and that makes me strong, too. Ruth lived in the days when the Judges ruled. She was a woman from Moab. Her husband died, so did her two sons. She was left with her two daughters-in-law. They decided to go back to the land of Judah. They were strong women looking for security.



Painting with Words

By Julie Powers, Dallas

I have a girlfriend who is going to school. She wants to be a doctor. She wanted to be a doctor all her life. But she never graduated, so she still thinks about it.

I am studying for my G.E.D. The teacher gives me books to study. I want my G.E.D. to be sure I have education. It would make me happy to have it. My brother Pat thought I should try. I am glad to do it.

I want to fall in love and have a husband and be a good mother some day. I like to paint with words. I have a job sorting clothes at Downtown Trends in Monmouth.



Learn To Advocate

By Glenda Coombs, White City

I learned about self-advocacy through my former husband Bruce. He was active in different meetings in the state. Soon he had me going too. At first, I was his PA (personal assistant) and driver to Self-Advocates As Leaders meetings and to the board meetings for the new brokerage system in the state. Later, I became a member of the SAAL Public Policy Committee, secretary-treasurer of our local People First chapter, and still his PA at the Brokerage Board meetings.

I was learning so much and making new friends. At the People First meetings I was learning to keep the minutes of the meeting, serving on committees like fundraising and public service projects, and helping SAAL teach people about voting and how to be a self-advocate. At brokerage meetings as Bruce's PA, I sat in on the start-up of a Brokerage, the choosing of an Executive Director, and all the in's and out's of how a brokerage works and how the brokerage will help us as a group of people. At SAAL I learned how to help write white papers and went to a group of lessons called Capitol Connections that teaches about the legislature and how it works and how we can talk to our representatives and senators about our interests and what we want in the laws.

That brings us to now. I am still active with SAAL and now I have been

working with my other committee members on a new White Paper on the marriage penalty. What is the marriage penalty? If two people who are both on SSI marry, they lose around \$300-\$350 dollars a month. If you just live together (without filing a marriage license) then you both keep your full SSI-SSDI checks. There are a few other penalties in food stamps and HUD housing (HUD means Housing and Urban Development). While working on this paper I have talked with several of our legislators, especially the ones from Southern Oregon. I learned that we can work with SSI because Oregon contributes to our federal social security.

This has been so interesting and I have learned so much over my last 10 years to help me become a better advocate for all of us and for me.



Do Something New

By Jonathan Tripp, Corvallis

I was born in Denver, Colorado and have lived in Corvallis since I was three years old. I have lived on my own since I was 19. Now I'm 48 and I like to keep busy. I'm active in a lot of things in my community, some I do for myself, some for others.

I was a Special Olympics athlete for many years; my favorite sport was basketball, but I did some soccer and volleyball. When I was younger, I competed in track; I liked running most. My mother thought I had a lot of potential

as a runner. I competed in the 1995 World Games in New Haven, Connecticut.

These days, I stay active doing swim aerobics weekly. I am active at the Calvary Chapel of Corvallis, a church I've gone to for nine years. I do Bible study and other activities there. I am involved in the mental health alcohol and drug group.

If you want to do something new, you need to learn how to do it. I am trying to get a new computer. I want to be ready when I get it, so I am taking keyboard classes at Linn-Benton Community College.

I also have grown more active in advocacy issues. I graduated from Partners in Policymaking class in 2006. In taking that 9-month class, I learned a lot about disabilities and policy making. When I graduated from the class I decided to get involved with the SAAL Public Policy Committee. I had to get approved by all the committee members before I was accepted as a new member. I have been going to the SAAL Public Policy committee meeting for one year now. Every two months Hannah sends me a bus ticket so I can get up to Salem to attend meetings. I wait at the SAAL office. Hannah takes me and two other people to meetings and drives me back to the bus station when we are done.

I am connected to The Arc of Benton County and People First of Corvallis. I attend Integrated Services Network meetings, ISN is the brokerage in my area.



Advocacy Is Fun

By **Scott Korte, Mount Angel**

My name is Scott Korte. I live in Mt. Angel, Oregon, at the Schwab house. I live with other people. I work at Mt. Angel Developmental Programs. I do hospital kits. I work with my girlfriend, Jeanne. I live close to my brother, Dan. He lives in Mt. Angel. My brother and my girlfriend are important to me.

I have been to many rallies at the state capitol. I have marched with Victory Alliance. We were there to support staff wages and more funding for DD services. This is important to me. It was cold, but worth it.

Victory Alliance is a group of advocates. We provide leadership training. The training teaches skills to all who want to advocates for their rights. Plus, it is fun!



The Book on Advocacy

By **Pete Bowen, La Grande**

In second grade, I went up to Governor Kitzhaber and told him we need more staff to help people with disabilities. I only got to talk to him for two minutes, but it was really cool to be able to stand up and speak up for myself and others.

If I had the chance to talk to the governor now, here are a few things I would want to talk about:

1. I don't like feeling like the state is jumping into people's love lives. I had a girlfriend, but my case manager kept telling me he didn't think she was good for me. I hated it, it made me feel like I was not capable enough to make my own decisions. I am not stupid, but it felt like that's how I was being treated. In the end, she wasn't great for me. I appreciated the warnings, but I still don't like the way it made me feel.
2. Money issues. They say "later" you can have your own checking account. I think I could do that now, hold on to my own check-book. Sure, speakers for the car would be nice, but rent comes first, then fixing the radiator. I know that.
3. Sometimes it feels like providers try to run our lives. I would like to tell them, even get friends to stand in rows and show them physically, that we are future generations. Don't control us, but teach us how to do things. If we can't do it, it will be a mess later.

I carry this label "disability" – but am I really disabled? I wonder. My friends tell me, "You can't judge a book by its cover." I agree. You have to open it up and look at what is inside.



Changes and Life

By Bertha Spinning,
Portland

I was reading in a recent People First Connection about the closing of the small institution in Pendleton for people with developmental disabilities. What bothered me about this article and what was proposed was that the timelines for the closure were not stated. You need to know about when and how this “institution” is to be closed. I think this is the last institution for people with developmental disabilities in Oregon.

I think the advocacy movement is very important. Being a member of People First for so many years, my thoughts went different ways from many others. I still think that all of us as leaders and self-advocates can work together. We can put our plans into action with help from everyone. The years I was able to work with

the leaders in self-advocacy – if my memory doesn’t fail me—we had a plan. Our friend from Partners in Policymaking (she lives in Georgia and does this for her clients) helped us write a plan and she helped us with goals. That plan is our future to work together. The plan was to see where we can go as our future leads us into different areas, to learn to be a “self-advocate” and to help people that need it, to understand their future and independence. I’ve learned many things from being a President of People First and The Arc of Multnomah County.

I think the self-advocacy movement has been very good for Oregon. There is one thing though: for self-advocates to have a better understanding of the issues, we must continue to talk about the plans and our changes in the future. I see a lot of things that can get in the way of self-advocacy and what it can do. One thing that has been a problem is that we have not – all of us- had an opportunity to go to

the legislature and to see our representatives and say how we really feel about the things that are important to us. Our independence, our programs and the services that we have now are all having a very big change. I feel the changes from being in a Semi-Independent Program in Portland. I’m still there- but it is now called Supported Living. The old SILP programs went away and Supported Living became the new thing. I went through a lot of things, it took a lot of time but it didn’t really change that much. I still have my support system.

The big changes in services and in the lives of people with disabilities in Oregon are something we have to live with like I had to. Last year was pretty hard on me and my family, we lost a good friend – and a good advocate for me – my sister Mary Elizabeth Kelley. Some changes are good, some changes are not too much but some changes can be very hard on us.



People First

By Tim Molin, Mount Angel

My name is Tim. I'm 58 years old and I work at the Mt. Angel Developmental Programs in my hometown of Mt. Angel, Oregon. I have been a part of this place for almost 22 years.

PEOPLE FIRST is a small group that is a part of a bigger group that meets all over the world. The group that I belong to gives me the chance to plan, work out problems, and speak for myself. We work hard to earn money and plan things like camping trips. We never take a break from the ideas of PEOPLE FIRST.

One place that I can practice what I have learned at PEOPLE FIRST is at the Mt. Angel Fire Department. One of my favorite things to do is stand by with my brother firefighters. When the whistle blows and I'm not at work I go to the fire station and stand by. I even go to drills on Wednesday nights. We have meetings and I tell the firemen what I think about things. Sometimes they listen and sometimes they don't. I don't like it when they don't do what I say but that is life in a fire station. I don't always get my way, but it is good practice in sharing what I think. Firemen are stubborn and fun and I am a good fireman.

Being a part of the fire department and PEOPLE FIRST is good. We have meetings and it's always good getting together and planning more

things to do. I like listening to other people talk. I like going to the convention and meeting new people. I want us to work together and get involved with more projects in our town. I think it would be good to help people that need help doing yard work. I am the co-president of our group and Jeanne is the secretary. She likes being with people. She also likes to express herself and she thinks going on trips is a lot of fun too.

PEOPLE FIRST is great. Look out, here we come!
(Reprinted with permission from Tim Molin and the Mount Angel Developmental Programs)

Websites Check These Out!

Self-Advocates As Leaders (SAAL):
www.asksaal.org

Self-Advocates Becoming Empowered (SABE):
www.sabeusa.org

The Riot!
an e-newsletter for self-advocates
www.hsri.org/leaders/theriot

The Oregon Council on Developmental Disabilities: information on advocacy and issues facing all people with DD in Oregon. www.ocdd.org