

The People First Connection

The Voice of Self-Advocacy in Oregon

Published by Self Advocates As Leaders



Policy Matters

You can make your voice heard! In this edition are stories from self-advocates who are being heard. They each have their own way of having a say. They each have their own issues they feel strongly about, from Presidential leadership, to personal care issues, to learning to speak up, to joining a committee. You can make a difference, too! Here's your chance to learn from what others are doing.

**YOU MAKE A
DIFFERENCE!**

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

Our Address:

People First Connection
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PSU-RR1
PO Box 751
Portland OR 97207



Making History, By Matthew Kiele, Monmouth

I would like to talk about Black History and how it affected me. I had a hand in making history by voting and electing the first black president of the United States of America. I felt like my prayer was answered and I felt like Barack Obama can make my dream of real health care and I also felt like my voice mattered. It felt like the change that Barack Obama was talking about is going to be action and not just a powerful speech and nothing happens.

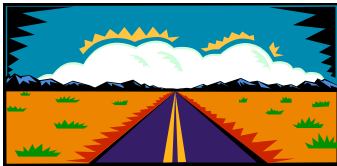
I would also like to talk about my experience with being witness to Martin Luther King III and his legendary speeches. First off, I was at the at the Alliance for Full Participation in Washington D.C. This was my first chance of a lifetime to speak on the behalf of Oregon and SPARC (Self-Protection Advocacy & Rights Council). The things that I learned there were how people with developmental

disabilities were in the same boat that I was in and I felt like this was my chance to make a impact on the things that mattered in my community.

Martin Luther King III talked about how many people with developmental disabilities are still living in poverty and some are being exploited for other people's personal gain or governmental gain.

I also watched the "Yes We Can" speech on YouTube. The speech inspired me to follow my dreams and when I fail, just pick myself off the ground and pursue my destiny of being a self advocate and not feel sorry for myself and help make a difference in my life and others. The main goal of the speech was that yes you can pursue your dream and never give up hope. I'm happy that I helped make the first step in the right direction for change and never looked back on the past and am moving on.

Sally's Opinion



By Sally Kramer, Portland

I want to express my opinion about Barack Obama becoming President. I want to know that he will support people with special needs, especially because I have a niece with special needs. I hope in the future I can go to Washington D.C. I'd like to take my husband, Steven, with me. It is important to go to the White House and visit with Barack Obama. I didn't vote for him, but there is hope for us.

I fear he will cut money from special programs that help people with disabilities and things that are important to me like Self-Advocates As

Leaders (SAAL).

I look forward to seeing where we go with this new President. I hope this story inspires others to express their political opinions. I hope my story helps Obama think about the outcome of people with special needs and our future. It's important to me that my story is read by him, and I hope he writes me! I would say to Barack Obama, "Thanks and I hope we have your support!"

Self-Advocates Becoming Empowered (SABE)

SABE is a national organization for self-advocates. Learn about their mission and goals!

www.sabeusa.org



A Letter from SABE

By Chester Finn, New York City
President of Self-Advocates
Becoming Empowered

Hello to everybody,

Thanks for the support from all your organizations and groups for electing me again. I wanted to send out a message to update everyone on what has been happening and what I have been working on since taking of-
fice and how you can play a part.

I want to let you know we have a voice. Even though there are budget crunches in the states, there is a way to figure it out with the federal government.

I have been networking with the Obama Transition Team. We had a meeting on December 17 to talk about our top two issues. The first issue is talking about the Self-Advocacy Information and Training Centers and funding for state self-advocacy organizations across the country to continue to do the work that we do.

The message that the Obama Transition Team wants all self-advocates to know is they are concerned with our issues and they will

be listening to us. To make sure that all organizations are heard, SABE will be the network that gets this information to the Transition Team. I will be the liaison to help carry that message.

When it is time, sending letters and messages to Congress will help to get the DD Act passed with the language in there for Self-Advocacy Information and Training Centers and for family support.

The second issue will be employment. The Transition Team and Obama Administration will be working on that. And actually they will be talking to Governor Paterson on some of the employment issues for people with disabilities. I will be able to help on both of those levels. Give them information on a state level and national level, so the states can duplicate these employment initiatives.

They want states to organize health forums around the country so we can send the information back to the Secretary of Health & Human Services. You can find out how your self-advocacy group can organize a health forum on www.change.gov

I look forward to updating the states on what they can do and any information you want to relay to the White House, let me know. I will be connecting frequently with the Transition Team for now, and then with the Obama Administration.



Calendar

Mega Conference, Portland, June 25, 26 & 27. Oregon's statewide disability Mega Conference. Contact Angie Solis: angie.solis@arcoregon.org & website: www.oregonmegaconference.org

NWDSA All Born 'IN' Inclusion Conference, Portland, April 18th. Contact Angela Jarvis-Holland: sholl2000@aol.com

Life Stories Workshops
SAAL is hosting **Life Stories Workshops** in Linn, Marion, and Yamhill counties this spring. If you are interested in attending a free workshop in your town, please call Marcie Alvarez at 503-725-8129 or toll-free 1-888-589-1664, or email alvarezm@pdx.edu

Storm Watching

By Clayton Evens, Hood River

I like thunderstorms during the summer. Every season, we get them here. I like the light and the bang. I live in a house where I can watch storms from my room.



Training

Want to learn more about changing public policy?

Self-Advocates As Leaders can help you set-up a 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 legislators are, 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

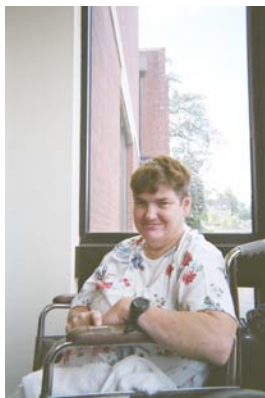
Writing a letter or email to your legislators: learn how to write a letter or email about an issue, what you could say, and where to send it

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

Winter

By Jose Montez, Cascade Locks

Winter is my favorite season. I play outside in the snow. I look forward to the snowy season in the gorge. I grew up in Lyle and live in Cascade Locks. I live with other people there.



ADVOCATE'S CORNER

The 2009
Legislative Session
Has Begun!

By Judy Cunio,
Self-Advocacy
Coordinator, Oregon
Council on Developmental
Disabilities

For all of the United States, it is a time of history-making. We now have our first African American president in the White House and he is already making changes for the better.

One issue that the Oregon Legislature is working on this session is trying to make it easier to find out if a caregiver has a history of being abusive.

That way people can feel safer in their homes.

As most of you know, the whole country is in a budget crisis and that means big cuts in Oregon everywhere. We don't know what all is going to be cut but we do know that everyone will be affected.

To find out more information about what is going on or how you can help, go to the DD Coalition website at

www.Oregonddcoalition.org

The DD Coalition will be having monthly briefings at the Capitol. They will be as follows:

April 23, 2009
9:30 - 11:30 In room 350

May 21, 2009
9:30 - 11:30 In room 350

Hope to see you there!!

Self-Advocacy
By Kristin Nichols,
Lincoln City

Self-advocacy means speaking out for yourself. It means speaking about your own rights. These rights include the right to get educated, the right to vote, the right to work, and the right to live independently. Another very important right is the right to go out into the community. We have the right to have fun. We have the right to travel. We have the right to learn about the world around us. When we are out in the world, we need to be able to do things without worrying about people making jokes, laughing, and staring at us.

We have the right to dream in our lives. To make our dreams come true we have to take action. If we put our minds into it and work hard we can make it happen. A friend told me, "Dreams are the spirit of expressing yourself."

We need to deal with issues and get involved with activities about standing up for our rights in the world. We can't be afraid of getting up and talking about our experiences in life and what we need to have better lives. People need to know who we are and what we do best. If people only think about our disabilities, they are only seeing one part of us. We need to have self-confidence and positive thinking to help people know the rest of us. To help people know who we are and what we can do, we need to join committees that work on rights for people with disabilities. We need to join organizations that have activities for us and get us involved more in our world.

We are human beings and not just people with disabilities. Self-advocacy means that as people with disabilities, we should stand up for ourselves and for our rights.



SAAL Public Policy Committee

By Trent Minor, Stayton

The Public Policy Committee is sponsoring Capitol Connections. We are training about 15 people on learning how to talk to their legislators.

We are working on two White Papers. One is about the marriage penalty. The second one is about how to join transportation boards. Transportation seems to be an issue for most of us.

We are working on ways to "Spread Knowledge" about us to policymakers. We can do this by emailing, calling or visiting our legislators about important issues such as transportation, affordable housing, abuse registry, and bullying. We will get talking points to our members so that they can talk with their legislators.

We are also working on ways to spread knowledge to the general public about us. This means we would get information out to everyone in the

community to change how the world looks at us. We might write letters to the editor or hand out informational cards to people who use disrespectful language.

We will watch the legislature for bills that affect us. We will support the good ones and fight the bad ones. This is what the Public Policy Committee does.

Capitol Connection is going on now, so it is too late for anyone to sign up this year. We will plan more, so people can email me or Hannah and we can put them on a list. That would help us know when and where to hold a training.

If people want to read our White Papers, we have them in a small booklet. They can email Hannah bowenh@pdx.edu or call the office at 503-589-1664 or 1-888-589-1664. The Handbook is on the website. Go to www.asksaal.org, click on Policy/Advocacy, then click on Information Sheets, and then White Papers Handbook 2005.

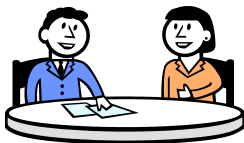


A WELCOMING MEETING

This SAAL White Paper was developed by Rosella Samuelson, Hannah Bowen, and the SAAL Public Policy Committee 10/2007

Someone invites you to a meeting. They say “We would really like you to join our committee.” Do they ask you for your phone number and address? Do they offer to pick you up?

It is important for everyone to be able to participate in meetings. All new committee members need support to learn about the group and how they can best help with the work to be done. Support does not have to be a paid staff person. Support can come from anyone. We should all work together!



Things you can DO to support new members on your committee

Offer support: Make sure that everyone has the support they need to fully participate. Ask about transportation and how you can support them during the meeting.



Clarify the rules: Give clear details about the rules and what is required of the new member. Clarify what the member needs to pay for and what the committee will pay for.

Make people comfortable: Take the time to show the new member around and introduce them to people.

Clarify the roles: What is the meeting about and what is the role of each of the members.

Make materials accessible: Large print, audio, Braille and translated on request.



Contact members: Contact people by phone, email, and postal mail with meeting information. Remind people about the meeting date, time, and location. Talk about what is on the agenda before the meeting.

More information on this can be found in the Oregon Council on Developmental Disabilities publication “Not Another Board Meeting” which costs \$10 and can be purchased at www.ocdd.org.

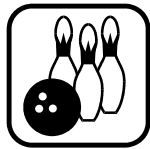
Magic Words

By Lady Goodman, The Dalles

My name is Lady. I was born in France 50 years ago. My parents taught me magic words which are please and thank you.

Charlie, please help me get a glass from the shelf so I can have a drink of water from the sink. Lee, thank you for getting the glass down for me.

I was taught these words were magic words that we should use every day of our lives.



Special Olympics

By Mariah Langer, Hood River

I am a Special Olympics athlete and I am in bowling. I am going to regionals and also state. I am very excited about being a part of going to regionals and state competition this year. My mom is the coach of my bowling team in Hood River county.

Cracker Jack

By Meredith Mitchell, Cascade Locks

I have a dog named Cracker Jack. She is so funny. She is also very well-behaved. She sits when I tell her to sit and lays down when I tell her to lay down. She also knows how to shake when I tell her to shake. She also can heel when I tell her to.

She has one toy out of all of her toys that she likes the best. It's a pink little bone. It's so funny when I think she's lost her toy and we always find it. It's a pain, but she hides it all the time and forgets where she hid it. I have to find it all the time.

She is very smart, too. The park is her favorite spot because she loves to play on the little kid slide. She can slide down the slide. She climbs up the stairs by herself and goes down the slide by herself. She can even swing in the baby swing. She loves it, which is amazing! But she doesn't mind at all. I love my dog and believe we have a lot of fun together.

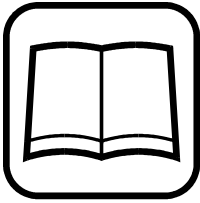


Estrella

By Armesha Jackson, Cascade Locks

I have a dog named Estrella. Estrella is 5 years old and is a Chihuahua /Dachshund. He has a friend named Miles who is a Deermouse Chihuahua and is 3 years old.

I have three nephews, one is 11 years old, one is 12 years old and one is 3 years old. The older ones already wear size 11 shoes, in men's sizes!



Read

By Jeff Lowry, Hillsboro

Little kids learn how to read. Their moms are there to help them learn how to read. My mom helped me through the years to learn how to read.

I hired a tutor about 3 years ago to help me learn how to read. I can now read 82 sight words. I learned to read so I could look up words inside books. If you want to learn how to read you have to work hard. You have to concentrate and focus hard.

I am very proud of myself. I would like you to be able to meet your goals too. Soon, I will advance to harder words. You shouldn't watch so much TV but focus on your words. You will thank me for this advice. You can find a tutor in your area and learn how to read, too.

SAAL Address

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3886 Beverly Avenue NE, Suite I-21
Salem OR 97305-1373

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

www.asksaal.org

How You Get Denied

By Rosella Samuelson, Portland

I have been denied some things in my past, like having my catheter changed. This is important, as they tried to deny me the change of my catheter, which I need to use. My use of the catheter means that I don't need to get on and off the seat like before. That's good because my arthritis in my knees is getting worse. I need the catheter all the time now. They changed my catheter once a month.

Many of us have the same problems. If you don't have the right insurance, the system will screw you over. I may be "in" the system, but I am not "of" the system. My use of the catheter, my use of my wheelchair, all the things I need to keep me alive are all subject to the insurance company. When my chair has a problem, they (the insurance company) deny me getting it fixed. This is unfair because an outside problem, an outside person, makes a decision about my life when they don't even know me. We are not just numbers, we are people with individual health needs. It's not right that someone else makes decisions about me and for me without me being there.

Whoever works with a person who has a disability, they have to talk to the person face-to-face. They have to recognize us all as individuals, as a whole person, which means everything to the interests of the person. They need to

quit lumping us people with disabilities or any and all of us, together.

How would someone else like it if they could not make decisions about their own lives? People with disabilities must have the right to say how their health will be treated and to be treated fairly. Right now we cannot help this. Many of us have disabilities from birth, like my Cerebral Palsy. But this denying of what we need must be changed. I feel good about my doctors; I have for all of my life. I want us all to have control over our health care. I don't want to be denied. This may work for other people, but it doesn't work for me. I need to make my own decisions. I need to get good information on my level, so I can understand it. People can talk over our heads and they need to talk in a way we'll understand it, using People First language.



What's Wrong With This Picture?
Photo of Eastleigh Advocacy Project
from Ann Blackburn, England



Airplane Accessibility

By Sally O'Neill, Portland

I am 17 years old. Like most girls my age, I love animals, going to the theatre with my friends on the weekend, and skiing in the winter. I dream of traveling after high school. I want to see places like Ireland, Italy, and India. Unfortunately, an accessible airplane ride is not an option for me.

I believe the airline industry should have to comply with the mandates of the Americans with Disabilities Act of 1990. I have cerebral palsy. That means, although I have a normal mind, I still have uncontrollable spastic limb movement. I cannot talk, or hold my own body upright. I need my wheelchair to keep me in the right posture, and to restrain my arms and legs. The problem is the airline companies make all people with disabilities check their wheelchairs with other baggage. I have visited my grandparents in Ohio and Florida many times. My parents have spent up to 7 hours trying to keep me seated between them. I don't have the motor function to sit upright on my own. The airplane chairs are not big enough for a seat insert and do not support my upper body. When my shoulders are not in front of my hips, I go into an extension

pattern. Due to my spastic limb movement, my parents have to physically restrain my arms and legs. I have strong tone so this is not easy. None of us can eat, drink, read, or make ourselves comfortable in any other way. As I get older and bigger, each flight gets more difficult.

People with other disabilities have this same need for different reasons. I don't think it makes sense that all other places open to the public are made accessible to every person with a disability, especially transportation companies, but the airline industry is allowed to force every person with a disability into "able-bodied" standards or medical transport. I've heard of an airline removing a whole row of seats to accommodate a Sumo wrestler. If they can do for a special athlete, why can't they do it for a person with special needs? Have you ever wondered why you see so few people with cerebral palsy on airplanes? It's because the airlines do so little to accommodate their needs to ensure their comfort. It's discrimination. I looked up online how easy it is to remove any seat on the plane. I am not asking for the bathrooms to be made accessible.

I am proposing that the first seat in the first row of the airplane be removable and tie downs be inserted. These tie downs are used in automobiles to keep the chair in place during crashes. They are as strong as anything on a plane.

I really believe with some small modifications airplane transportation can be made accessible to everyone. I hope you see the need and join me in this cause for change.

Here is my petition: We petition that the airline industry should have to comply with the mandates of the Americans with Disabilities Act, and propose that the first seat in the first row of the airplane be removable with the capability to have tie downs inserted when needed to accommodate someone who uses a wheelchair.

To sign onto Sally's petition, contact: Susan Blanchard, UCP of Oregon & SW Washington: 503-777-4166 x232.

Websites

SAAL: www.asksaal.org

Europe for Us!

A Newsletter of the European Platform of Self-Advocates
www.inclusion-europe.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