

The People First Connection

The Voice of Self-Advocacy in Oregon

Published by Self Advocates As Leaders



Relationships and Independence

Stories are rolling in to us about ways people strive for independence in their lives. Yet people are sending us stories about the people that matter to them. We think that both of these points are important. How do people maintain their independence and go for goals while keeping people they care about close? See what you can learn from these authors!

**YOUR WORDS
CAN MAKE A
DIFFERENCE!**

Voices in Oregon are
getting stronger.

Be a part of it.

Our Address:

People First Connection

c/o Marcie Alvarez

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OR 97207



Meaningful Connections

By Jefta (Norman) Koljonen, Astoria

I am 60 years old and was born near Christmas. I like to say I was my mother's early Christmas present. I was close to my mom. She was from Minnesota and my dad was a German Finnish man who lived in this area.

I lived in a state institution, Fairview, for 10 years. I was nine years old when I moved there. I started at

Holman Cottage, then Lane, then West Deal, then to Long Cottage, where I got ready to move out.

I met my best friend there, Paul Charles Wood, and I have been TV Guide friends for 47 years. Paul was looking at his TV Guide and I asked if I could look at his TV Guide. He said, "No!" because he didn't know me yet.

We met the same year my Dad died. I am still good friends with Paul, but he lives in Portland. 47 wonderful years - when I make connections, I keep them.

I work five days a week for Coast Rehabilitation Center in Astoria. I work in the thrift store, where I'm in charge of vacuuming the store and emptying garbage cans - I guess I'm a janitor part of the time. I also make rags that the janitorial service sells. They like the ones I make. I also can run the cash register, but sometimes I mix up big numbers and need some help.

My wife Beth works there, too. Beth and I have been married for 21 years. I let my wife do whatever she wants to do and she lets me do whatever I want. We get along really well.

I like to attend People First meetings here in Astoria. I like to let people out in the community know that people with disabilities can hold steady jobs, too. I have worked at the store for eight years. My wife has worked there even longer. People First keeps me in touch with people all over Oregon.

**Life Stories Workshops
Come share your story!**

Cottage Grove:
Nov. 10th, South Lane Wheels

Dallas:
MLK Jr. Day, January 21, 2008

To attend call Marcie at 503-725-8129 (Portland) or 1-888-589-1664.



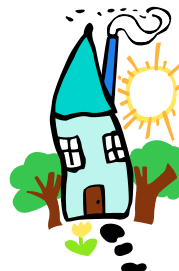
My Life

By Rocky Lafazio, Hermiston

My name is Rocky Joe Lafazio. I live in Hermiston Oregon. I have an apartment and I work for Horizon Projects, Inc. doing janitorial work. I do the dirty work.

I have two sisters and Mom and a step dad. My grandmom is still alive. I like going to church every Sunday, God is in my life 24/7. I love church music.

I have many friends. A lot of people in town know me. I like meeting new people. I am a member of People First.



My Apartment At Last
By Ashley Rose Johnson,
The Dalles

I had a dream when I was growing up. I wanted to be independent in my life. I have lived in many foster homes in my growing up years and was not allowed to do things on my own. So when I turned twenty-one, I set a goal with a case manager that I worked with through DD services. My goal was to

“have my own apartment” when I was able to fill out all of the paperwork. It took a lot of months.

In May, 2007, I got word that I was accepted to move into my own apartment! I love my apartment since I moved in and am able to be on my own independently.

I hate it when people tell me “no” when I want to cook on my own. They are scared that I would catch my apartment on fire. I hope one day I will be trusted to be able to cook my own food instead of pre-heated dinners. That gets really boring!



Home and My Life

By Liz Bowens, Hermiston

I have my own home in Hermiston, Oregon, where I have lived for 16 years. I have 2 cats. Their names are Sunny and Twilight. A contractor comes to my home. I like my home because I live with myself.

I work at the Horizon office in Hermiston, answering phones, taking messages, making copies, doing paperwork. I talk to people and I have a great coordinator for supported living. Her name is Anita M. She helps me.

I went to Hawaii three years ago. We went to the county fair and we had fun. All of us came who are in supported living. I had an ISP meeting with Horizon.

Calendar

TASH Conference

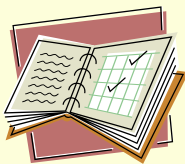
Seattle, Washington, Dec. 5-8. Information online at: www.tash.org/2007tash

Oregon Legislative session starts!

Salem, February 2008.

National Self-Advocacy Conference

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



“Ask Saaly”

NEXT Question:

What does Legislation mean?

Why is it important to us?

Do YOU have a good answer? Share it with us, we just might print it here in the People First Connection!

Thank you to SAAL's chairperson, Eddie Plourde, for making us think about different topics. Talk about them with your friends.

For answers to Last Month's Question, see page 4.

What Is Self-Determination?

We asked you in the SAAL newsletter, here are your answers:

To the SAAL Editorial Board:
This question went around at our work site and here are some of the answers:

Brian Havlick said, "When you are determined to do something and no one can tell you otherwise."

Jennifer Yancey said, "Self-Determination is when you are ready for something."

Jeff Glaser said, "Determined to do something."

Howard Godwin said, "Doing what I want to and no one saying I can't."

Jennifer Phillips responded, "Striving to direct my own life."

Janet Smith said, "I have a say in what goes on in my life."

Amy Quest, "I can direct my supports."

Sincerely,
Fellow advocates at **Mt. Angel** Developmental Programs.



Dear Eddie Plourde:

I learned this at a SAAL training called Self-Determination is for Everyone. Self-Determination means that a person makes his or her own decisions, plans his or her own future, determines how money is spent for his or her own supports, and takes responsibility for the decisions he or she makes.

There are four main principles:

- Freedom
- Authority and control
- Responsibility
- Support.

Freedom means:

- To live a meaningful life in the community
- To live how we want and to decide what is best for our own lives.
- To be able to make decisions (and mistakes) for ourselves.

Authority and Control

Control over the support we need and the dollars needed for that support.

Control of our own lives: having the right to direct our lives and live the way we want... Just like anyone else.

There is a great saying, "Nothing about us, without us!"

Responsibility

Take responsibility for our own actions. Accept the consequences, good or bad. Take responsibility for the use of public dollars. (Don't waste money.)

Take responsibility for our own lives and do what we should as citizens.

Support

Have the support to organize resources that make your life better and meaningful for you.

Have the support to live your life the way you want and do the things you want.

Self-Determination can mean having the drive to do things for your self, setting personal goals, or knowing when to ask for help. Have the courage to dream big and go after your dreams.

Learn who you are, what you want and how to get it (a life-long process).

Self-Determination looks at the big picture of your life. Self-Advocacy is a way to bring these big ideas into your life by making it personal. You can bring the four points of Self-Determination together by practicing Self-Advocacy.

Sincerely, Ashley Rose Johnson,
The Dalles

(Note: Materials adapted from My Voice, My Choice training for SAAL use.)

A Good Life

**By Carl Smouse,
Hermiston**

I live in Hermiston. I deliver newspapers for the Hermiston newspaper. I like to draw. I have my mom, and my sister and brother. They live in lone and have nine cats. I belong to People First. I like to go to church on Sundays.

I play piano and I like to travel. I live in my two-bedroom apartment and Horizon Project, Inc. supports me.



Progress!

**By Buddy Caveness,
Baker City**

When I was growing up back in the "60's" I was picked on by others. I was called four-eyes, MR and stupid all through high school. I got involved with Vocational Rehabilitation and they sent me to Salem when I was 18. I met a lot of nice people at the Voc Rehab center. I had new experiences learning how to get along with other people with disabilities for one year. I was then sent down to Eugene and worked for Goodwill for five years. I met more people with disabilities in the same

boat I was in.

I was living in a group home in Eugene for five years. We had meetings, then I came up with the name People First. The reason I came up with People First was that I was sick and tired of people picking on others with disabilities. They went through the same conditions that I went through.

Other groups asked to start their own People First groups in the surrounding area. We told our story: that they went through the same things I did. This is a little bit about the start of People First.



ADVOCATE'S CORNER

Journey Through the Changes in Self-Advocacy: Just How Far HAVE We Come?

**By Judy Cunio,
Self-Advocacy Coordi-
nator,
Oregon Council on De-
velopmental
Disabilities**

Today most people know what Self Advocacy is. Over the past several years, it has changed many lives of people with developmental disabilities. In many cases it has moved from self-advocacy to systems advocacy. There are quite a few people with disabilities who sit on many state policy boards that have to do with issues that effect people's lives. But it took a long time to get to that point.

I have been involved in the Self-Advocacy movement in some way since 1973 and I have seen many changes in the movement over the years.

I got involved in Self-Advocacy about two years before I left Fairview (Oregon's largest institution). The Superintendent of Fairview began having meetings once a month with two representatives from each cottage and I was one of them. Our job was to see how Fairview could be better. Things began to improve a little at a time. We made small steps and things began to change.

People First also began at Fairview after some people went to a conference in British Columbia that was for people with disabilities (but it was put on by professionals). When they got back they said that it was a good conference but if they had one here that it should be put on by the people with disabilities. A group got together to talk about what they could do to make it happen. They knew that they needed

some help but they wanted to be the ones that would be in charge. It would take a lot of work but they knew that they could do it with the right support.

It took some time because up until that time people with disabilities never spoke up for themselves. So at the very beginning all some did was to get up and say their name. They were really encouraged to do that because it was a big deal.

The group needed to find a name that let people know what we stood for. People wanted to be known as people before their disabilities. Someone came up with the name People First and everyone agreed that it was the message that they wanted to send out.

They had the first People First Convention in 1975 at the coast. There were about 500 people. That was the first gathering of that kind that was run by people with disabilities. There was a lot of support but all of the decisions were made by the people themselves.

The convention was a complete success. People were able to get up and speak in front of everyone in the room and they talked about what was important to them. And that was a huge step for all people with disabilities. And for about the next 30 years there was a Convention every year in Oregon. This was the beginning of the Self-Advocacy movement in Oregon. People First soon grew to become a worldwide organization; it has taken on a life of its own in many states and countries and has moved in many directions.

In Oregon, Self-Advocacy has played a big part in system change, including the closure of Fairview in 2000. In this state, self-advocates are at most decision-making tables that have to do with issues that effect people with developmental disabilities.

Recently, one major accomplishment that self-advocates (through Self Advocates as Leaders) had was the passage of "The Respectful Lan-

guage Bill". This makes it so all of the laws have to be in rewritten in language that recognizes people before their disabilities.

Many lives have been changed because of the work that has been done through the Self-Advocacy movement. People are taking control of their own lives. We have made much progress. But we still have a long way to go. Never stop working for what you believe in.



Cecelia's Camp Adventures

Cecelia Campbell, La Grande

I like being out here at Wallowa Lake. I like to help people and I help out here. I like to help out in the kitchen with serving meals. I like to help people with disabilities. I like to camp. I had a good time with the people here. We had a good time dancing. I got to make some new friends. I would like to see the deer at the lake. I haven't seen them yet. We had a good time going to the movie.

We went to a class today where we talked about voting for our People First officers. I would like to be voted for.

We talked a lot about camp for next year. We stayed in a cabin. It is fun. I hope I can come back again!

The next issue of The People First Connection will be about Laws and Legislation!

If you have a story about making a difference or having your say, let us know!



Mt. Saint Helens

By Chris Bolte, The Dalles

Mount Saint Helens is a large volcano sitting seemingly by itself, steam coming from the center.

I heard recently people are allowed to hike up this mountain after being closed due to a possible eruption. I am concerned for these people and their safety. 100 people per day are going up these slopes with this mountain still steaming and rumbling from earthquakes. The dome is still growing and people can see it from afar.

I know one day it will blow. Oh please, have no one on this mountain when it does.

Special Olympics

By Lindsay Stephens, La Grande

I am in Special Olympics and I do track and field and bowling. It is one of my best sports that I enjoy doing. I get a chance to meet new friends and see all of the friends you don't see all of the time. Whether you win or don't win, there is a lot to do during the events. Whether I get a medal or not, I can go do something and buy things there and I enjoy it a lot. There is a dance, as well. I really enjoy doing Special Olympics a lot.

When I am all done with sports of one month, I go on to the sport that comes next. Other sports in Special Olympics include swimming, golf, track and field, bowling and skiing as well.



Soap Making Business

By Rita Beckett, Portland

I have my own business. I started making home-made soap in 2005. I work out of my home. People call me for it and I take it to them and I get paid to deliver it to them. Every last Thursday, I sold my home-made soap at a fair.

How do I make soap? It takes about 45 minutes to an hour to get done. The price runs from one dollar to \$4.75. It is a lot of work for one person and I teach a class on how to make some homemade soap. The class costs \$4.00 and you take your soap home with you. I get the supplies and stuff to put in the soaps. My favorite is grapefruit. I've got a lot of molds: a car, turtle, frog bear, seashell and football. All of them take time to make. You can put in toys like a snake or any kind of animal if you like. However, it turns out great. I can put bugs in them for fun.

The name of my business is Squeaky Clean Time Soap. I can do some soap without scents in them for those who are allergic. I can do different colors if people like that, or leave it clear. I am open from 9 a.m. to 5 p.m. Monday through Saturday. I am closed Sunday. Please leave me your last name, and your first name, too. You see "Rocky" on my email, that's okay. Rocky is my nickname.

etnrocky@yahoo.com

Be A Self-Advocate: Get Your Freedom and Power

By Gayle B. Gardner, Portland

You wouldn't believe what my life was like before Pat wised me up to an organization that could help me become my own self-advocate and escape from Dipsy Doodle. As I was to learn, there are a lot of organizations for people with disabilities that can educate you and help you make huge changes in your life. One of them is called SABE, or Self-Advocates Becoming Empowered. But I'm getting ahead of myself. Here's what happened to me.

About 20 years ago, I was living at Dipsy Doodle. "Dipsy Doodle" is my name for the group home where I wound up after my mother died. Aunt Lulu was my guardian. She controlled the finances and everything else. She felt that a group home would be just the thing for me. She told me I couldn't move out of Dipsy. The skill trainers agreed with her. Everybody thought it was a great idea. They meant well, but they didn't realize I wasn't group home material.

I hated it. I felt hurt because I thought my family could have taken me in rather than just throwing me in a group home. I think if they had known how miserable I was, they might have changed their minds. I was so distraught that I hurt myself physically. Even that didn't change my situation. I felt like everything I did wasn't good

enough. I was stuck at Dipsy. And I was clueless. Anybody could tell me anything: "Wash my dishes for me." And I'd do it.

They put me in a program called SILP. "SIL" stood for "Semi-Independent Living." I don't remember what the "P" stood for, but it might as well have been "Prison." I had an apartment but I had to live with two roommates who were total strangers, and I was still under peoples' thumb. Skill trainers helped with cooking, laundry and cleaning. They came and went all the time, I never had any peace. It was confusing to have one skill trainer one day and then they would leave. That was great if you didn't like the person. You got to know some of them but most of them were strangers. They didn't listen to me and understand that I wasn't group home material; the ones who did, left. It was frazzling. It almost turned me into a turnip.



You had to take classes like Street Safety, or go to stupid picnics whether you wanted to or not. You had to turn off the television at a certain hour. You had to work, or what they called work. They thought a job doing piecework in a sheltered workshop would be dandy for me. We stuffed envelopes, made doormats, stuffed paper

into purses, stuck labels on envelopes, counted screws and put them in little packages – by the end of the shift I would be a miserable wreck. And then I had to go back to Dipsy.

I wanted to escape but I didn't know how. Then a friend who also lived at Dipsy got me started going to meetings of a group called People First. They met at The Arc. They were all people with disabilities. That was the first time I had been with a group like that. We discussed what we wanted to, though most of the time we heard about political topics. They were working on getting the Americans with Disabilities Act (ADA) passed in the national Congress. It felt really good, being some place where people couldn't push me around. I was amazed to learn that I had the right to speak up for myself. Getting out, socializing, learning about subjects other than how to count screws and cross the street safely was kind of scary. It was a challenge to make that first little step.



It got me ready to make the next step. I didn't know it, but I was becoming my own self-advocate. When a lady named Pat told me there was another organization that might help me escape from what felt like jail to me, I was prepared to take an even bigger step. The group was called Oregon Advocacy Center. They're lawyers. They taught

me that I could get my own guardianship. The skill trainer who started working with me at about this time agreed that I needed to live independently. She went to bat for me along with the lawyers at Oregon Advocacy Center. They sent a letter to my Aunt Lulu, informing her that I had become my own guardian.

Aunt Lulu called me on the phone, and oh boy, was she upset. By the time she got through bawling me out, I was in tears. She got into cahoots with the Dipsy director and they both tried to convince me to stay at that lovely place. But it was too late. Being exposed to organizations that showed me how to be my own advocate had changed my life forever. Aunt Lulu and the director were still treating me like a turnip. They didn't seem to be able to hear me. I don't miss them at all.

I've had my own apartment for years now. No roommates! Skill trainers still have a part in my life. But now I tell them what I want and don't want. I wanted to learn how to use a computer so I could email my friends and keep in touch with my organizations, so my Personal Agent found me someone to help me learn the computer. I choose where I live. I can come and go freely to shopping or Starbuck's, or any place else. I choose what I want to eat and I don't eat food I don't like. I feel independent. I can go to a movie or out to get my hair done. I can choose to travel by bus or I can take the Lift. I can go for a walk without checking in and out with somebody. I can watch anything I want

to on TV, any time I want. I owe this to organizations like People First, Oregon Advocacy Center, Self-Advocates As Leaders (SAAL) and Self-Advocates Becoming Empowered (SABE).



I'm still very active in SABE.

SABE holds meetings several times a year in different parts of the country. At the meetings, they have keynote speakers, social hours and workshops. You meet other people with disabilities from all over the country. You learn what other people are doing in their communities. You learn about different topics like what's going on in the news and controversial subjects like parents stunting the growth of their children with disabilities to make the children easier to handle. You have fun. You get to eat in restaurants, go shopping and take tours. You have your picture taken. You can be on panels and teach workshops.

You too can join SABE, SAAL or other organizations for people with disabilities. Like me, you can learn how to be a self-advocate, find the courage to do it, and connect with other people who will support your efforts. You don't have to feel like a turnip. You can make changes in your life that give you more independence and dignity. Then you can help others who have disabilities to do the same in their lives. Maybe you don't live at a Dipsy Doodle, but I bet you'd like to have more fun and more independence!

More Family to Love

By Jolynn Smutz, Hermiston



In November, I flew to Baltimore because my brother's wife, Kim, was going to have a baby. When I got there, I met the new nephew. He was so cute and I even got to hold him, with someone helping me. I got to hold him by myself. I got to put his binky in his mouth. And he kept spitting it out. I was so excited to meet my new family member. And it was so good to see Kim and my other sister while I was on vacation. I hope you like my story.

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