

Message from the People

People First of Missouri

Self-Advocates Determined to be All for One and One for All

Summer 2009

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People First

of Missouri

People First is a
self-advocacy
organization formed by,
run by, and which exists for
people with disabilities.

Celebrate Good Times!!!

This summer we remember landmarks in civil rights history, and honor pioneers in advocacy who have helped pave the way to a brighter future for people with disabilities. We celebrate new steps in a worldwide effort to raise awareness that we are people first, and part of our communities. Our core value in this issue reflects our dedication to a dream that will come true: inclusive communities.

•In Missouri, self-advocates came together to continue learning about how to make changes in their own lives and for others with disabilities at the 14th annual People First Missouri conference, April 24-26 at Tan-Tar-A Resort in Lake of the Ozarks. The theme was "Feel the Winds of Change." It was a very busy and fun filled weekend! Check out more on page 4.

•June 22nd was the 10 year anniversary of the Olmstead decision, which recognized the right of people with disabilities to live and be supported in the community. Inclusion in the community is important to everyone

and this landmark decision helped to make it a reality for many who had previously been living in institutions.

•On July 24th, President Obama announced the signing of the United Nations Convention on the Rights of Persons with Disabilities. This treaty seeks to increase opportunities for life and work in the community and improve the standard of living for the 650 million people with disabilities across the world. It has been signed by 140 nations since May 2008. SABE president Chester Finn was at the White House for this historic announcement. Read about his experience on page 11.

•July 26th was the 19th anniversary of the ADA (Americans with Disabilities Act). Over the past 19 years this law has done a lot to improve the rights of people with disabilities. To learn more go to page 5.



Message from the President

As highlighted in this issue, we are proud to be celebrating the 10th anniversary of the Olmstead Decision and the 19th anniversary of the Americans With Disabilities Act (ADA). These events are an important aspect of the changes we have seen and will continue to fight for.

People of all abilities can and should live among one another and benefit from each other's strengths. An inclusive community is the ultimate goal. Imagine a world where curb cuts and no step entries are automatically considered. Imagine a world that offers opportunity for all of its citizens because every person is considered a valuable asset. This is a world that I dream of and work for.

I hope that one day, accommodations will not be something based on the potential for legal ramifications but a universal design of equality based solely on the principle that we are all equal. Many use the fact that we have not achieved inclusion to promote institutional

bias. The reality is that people will not learn compassion and empathy by remaining separate from one another. It is through work and play that we learn to see the value in one another. It is through this enlightenment of values that we begin to see the strengths and develop empathy for the challenges. It is only then that we may find cooperation and begin to build a community that is made for all of us.

So, let's continue to struggle against institutional bias and work to enhance community options.



Thank you,

Roger Crome
President, People First of Missouri

Mission

People First of Missouri is a statewide organization that promotes equality for people with disabilities so they can live the life they want in the community. People First members:

- Teach and empower people to understand their rights and responsibilities and to speak up for themselves (self-advocacy);
- Stand up for one another to help people live the life they want with the supports they need (advocacy for one another);
- Advocate for community services that allow people to have choices and control over their supports and lives (advocacy at the systems level);
- Create change in communities to ensure opportunity and full, meaningful participation for all people (advocacy within the community).

PF Core Value: Inclusive Communities

WHAT INCLUSION MEANS TO ME

by *Patty Goss, Member of People First Springfield*



Twelve years ago after I had a stroke, I wound up in a nursing home. Believe me; a 31-year-old woman doesn't belong in a nursing home. There, I was excluded from the community. I couldn't come and go as I pleased. I had a bedtime – 10 o'clock. On New Year's Eve I had to beg them to let me stay up till midnight. I had a wake up time – 5 o'clock they'd barge into my room. I had no choice over my meals, and I was required to eat what they served me. I don't have anything against people who are declining, but at 31 I felt like I was on death row. Many of my neighbors were waiting out the end of their lives, waiting to die, and I only wanted to live.

I had to take initiative and advocate for myself and my independence. I wanted inclusion in the community. I wanted a life. And thank God I got one. I've been living on my own for 12 years since I left the nursing home. I live in a home I own – I've been there for five years. I come and go as I please. I decide when to go to bed and when to get up. I decide whether or not to eat, what to eat and when to eat. I have a social life – there's more to life than Bingo on Saturday morning. My neighbors are also my friends. And – no offense, but – they don't have dementia, don't wear diapers, and don't rummage through my things.

We have a right to be included in our communities. Life in the community and life in institutions is like day and night.

Profiles in Freedom

IT'S MY LIFE

by *Melanie Nau, Member of People First Boonslick*

My name is Melanie. I grew up living with my mom, my dad, and my sisters. When I graduated from high school, I decided to move out. A long time ago grown ups who had disabilities and needed a little bit of help had to stay with their families or move to institutions. I got to choose. I chose to live in my own home in the community and receive some help when I need it. I'm not a little girl. I'm a woman. I don't want to be treated like a little girl and live in someone else's house with someone else's rules.



Thanks to Olmstead, other grown up women like me get to choose too. We don't have to live in institutions. We can be in charge of our own lives.

14th Annual PF Self-Advocacy Conference

THE STATEWIDE PEOPLE FIRST CONFERENCE

by Sandi H. and Lizi B., Members of People First St. Charles

On Friday, April 24th, over 300 people from all over the state made their way to Tan-Tar-A Hotel and Resort at the Lake of the Ozarks for the 2009 People First Self-Advocacy Conference. The theme, “Feel the Winds of Change,” was chosen to celebrate the many changes People First has successfully advocated in the past two years and to recognize the growing momentum of positive change in institutions and legislation affecting people living with disabilities.

The event began with karaoke and dancing on Friday night while chapters from across the state were arriving. On Saturday morning, a flag ceremony signaled the official opening and was followed by an informational and inspiring key note address by Rebecca Cokely, Coordinator for the National Consortium on Leadership and Disability for Youth. The rest of the day consisted of break-out sessions and exhibit hours with an occasional break for a bite to eat. When the attendees weren't engaged in one of the educational activities they were able to enjoy some of the resort amenities, especially the indoor swimming pool and hot tub.

People may have been exhausted after a busy day, but there was still much excitement for the banquet, awards ceremony, and dance. The room was beautifully decorated, dinner was delicious, and the surprise slide show highlighting friends, family, and People First activities from the last two years was a big hit. The music started once the awards were handed out and the dinner plates were cleared. There was not an empty spot on the dance floor all night!

The activities concluded on Sunday morning with a breakfast buffet, another guest speaker Bryan Murphy, and a drawing for attendance prizes.

Award Winners at this year's conference: Kit Stahlberg – Anita Carroll Self Advocate of the Year; Roger Dickey, Advisor of the Year; Sandy Morton, Support Person of the Year; Madison County Council for the Developmentally Disabled, Agency of the Year; Kevin Engler, Legislator of the Year; Carol Utterback, Long Time Commitment and Dedication.



What is the Americans with Disabilities Act?

The ADA first became a law on July 26, 1990. This piece of civil rights legislation has done a lot to benefit the lives of people with disabilities. It has made public transportation, streets, and buildings more accessible than ever. It also allows those with disabilities to participate in various programs and services that they had previously not been able to be a part of, and it helps to provide equal employment opportunities.

The 19th anniversary of the ADA happened just recently and Senator Tom Harkin of Iowa, who was the author of the ADA, said, "Nineteen years ago, we changed the rules, we changed the law and we opened the public's eyes to the struggles of those living with disabilities. The progress we've made since that time is all around us and it is so integrated into our daily lives that it is sometimes hard to remember how the world was before."

What is "Olmstead"?

by Shelly Shetley, Chairperson of the Missouri Planning Council



June 22 marked the 10 year anniversary of a landmark Supreme Court decision that admonished segregation, sought to put an end to discrimination, and opened the door to freedom for thousands of people in the United States. This decision was not about race or gender. This was about freedom for our fellow citizens who happen to have a disability. The court ruled that, "the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability."

Years ago, it was common practice for people with disabilities to be segregated in institutions... locked away and forgotten about. Today, our brothers, sisters, classmates, co-workers, friends, aunts, uncles, moms, and dads who happen to have a disability have the opportunity to live the life they want in the community because of two brave women in Georgia, living in an institution, who wanted to leave. However, for many of our brothers and sisters, the struggle continues.

Missouri has six institutions for people with developmental disabilities. Ten other states have none. Medicaid is required to pay for more expensive nursing home and institutional care and yet people are forced to wait to get services in their home. There is not a demand for segregated, institutional caretaking. People with disabilities and their families demand home and community-based services as evidenced by a wait list that rose to more than 5,000 people in Missouri this year.

Will this be the year that Missouri's citizens cry out against the injustice that is occurring for our brothers and sisters locked away in institutions?

Will this be the year that true policy is passed reflecting what every citizen has a right to — a real life in the community?

Chapter Updates!!!

Take the time to read about the wonderful work of our local People First chapters. These are GREAT examples of People First chapters making opportunities!

Boone County is working on two new projects. One is to advocate for better public transportation services. Those of us who depend on the city bus have real lives and schedules. Many of us have jobs. It's not cool to arrive an hour late for work. Some of us who depend on the city bus routinely show up late for work. And that's just the tip of the iceberg. We really appreciate having a public transit system in Columbia, but there's room for improvement, and we're going after it.

We're also working on a PowerPoint presentation for newspaper, radio and TV editors on "people first language." We elected new officers – Jason Mize is our new president. "We" planted flowers in an Adopt a Spot for the Friends of Boone County Family Resources. Jason, thanks for taking on the project and giving us the credit! Another one of our members represented us with the Columbia Community Garden Coalition. Thanks Arnold!

We're having a hard time selling People First polo shirts. We put a lot of money in them for a fundraiser and we need to sell them for \$17 each. They're nice shirts; they come in red, blue, or white. If you'd like to order one, call Greg at 573-474-2779.



Boonslick People First has had a lot of changes. The biggest change is that Yvonne Kempf retired. Yvonne has been our advisor since the group was

first started. We will really miss her, but we know she can't stay away for very long. Her husband, Bud, has always done whatever he can to help us. We will miss him as much as Yvonne.

We also decided to change the time we meet in order to serve snacks instead of a full meal. It was costing too much. Some of us went to the Spring Conference and had a great time. We really want to thank the Cooper County Board of Sheltered Services because they gave scholarship money to two of our members. We also want to thank the Marshall group for helping us out with the decorations.

Grundy County is celebrating with member Charles Gash, who wanted to get a job in the community, and got one. Here's his story: I contacted Experience Work, an organization that helped me set up an interview with the Trenton Police Department. I interviewed with the Chief of Police. He asked me several questions. Then he told me when to report to work. My job is keeping everything clean, including the building and the police cars. I also water the plants. Working at the police station makes me feel really good; they tell me I do a good job.

Independence People First continues to hold meetings as we search for a new advisor for the chapter. At our April meeting we held elections to fill vacant officer positions and to vote on our representatives for the Steering Committee. Our Officers are: Mary Seigfreid; President, Bob Nelson; Vice President, Debbie Schoonover; Secretary, Joe Wrinkle; Treasurer, and David Wills; Sergeant-at-Arms. Our Steering Committee Representatives will continue to be Cathy Enfield and Joe Wrinkle. Our attendance has been down, but we have a dedicated group of members that continue to stay involved and are working to keep the chapter going.

Iron County had a program on "How to Recognize Abuse & Neglect" presented by Linda Roberts, Executive Director of Ozark Valley Community Service, Inc., Ironton, MO, a local provider of services. We are continuing to plant and take care of flowers in the community. This makes us feel like we are a part of this community.

We started a program in support of our troops called, "Care Package Project." We all bring something that our troops can use. We are starting out small and providing things for two soldiers at this time and hope to increase this number next year. We will send all of the things we have collected to these soldiers in Iraq for Christmas along with special cards, letters and pictures. We are also going to make a craft project to send to them.

Jefferson City has been thinking of ways to recruit new members. We recently had a barbecue which drew five new people to us. Our advisor, Roger Dickey, was awarded "Advisor of the Year" at the statewide conference. He deserves it.

Chapter Updates Continued!!!

Kirksville has been working on ways to have and do more trainings in our area. We are also thinking of ways we can help out in the community. We are going to do an Adopt a Spot in Kirksville. We feel like we can make things look better by picking up trash and planting flowers and trees. We also had Self-Directed Services training and Alternatives to Guardianship training.

Lake Area has been busy, as we always have something going on. We had a speaker about hand washing. We thought this would be good due to the swine flu problem. We have had several members go to the State Special Olympics and also had several members at the conference at Tan-Tar-A. We're making plans for a hayride this fall, plus a dance and a cookout.

Lebanon had a carwash fundraiser. We held an awards dinner. We elected officers. A new person is coming to our meetings. We're looking forward to the retreat in September.

Madison is thinking of fundraising ideas. We're thinking of selling combo meals at a picnic, like a hot dog and chips. We're thinking of having a yard sale. We had a great time at the conference and we're looking forward to camp.

Marshall continues to be busy since the conference with projects like the membership drive. We are trying to focus on individuals who have recently left the Habilitation Center to live in the community. The Officers and members feel that they would fit in well with our chapter. Since the weather has improved, we have worked on our Adopt-A-Highway project. It may not seem like a lot of work, but when you start picking up all the trash that people throw out it fills many bags. It sure has taught our chapter why NOT to litter because someone has to pick it up and it is



much easier to put trash in a trash can than bending over and picking up a ton of it along the highway. Again we would like to thank everyone who helped make the People First Conference so

successful. We have lots of pictures of the wonderful event. So much can be accomplished when you work together for a common cause.

Sikeston had 15 chapter members and advisors/support staff attend the conference in April and everyone really enjoyed the conference. We shared our experiences and what we learned at our May chapter meeting.



We have been very busy so far this summer, with a bowling activity, car wash, and a 50/50 raffle to raise money for The House of Refuge in Sikeston, which is a place for family members who experience domestic violence. We will also have our annual ADA Picnic with a guest speaker from the MO National Guard to talk about the war in Iraq. We will be presenting the raffle money to the House of Refuge at the picnic too. We attended the Steering Committee meeting July 11 & 12th in Kansas City and members are looking forward to Camp Wonderland again this year.

St. Charles: Every month People First of St. Charles plans an activity for our members. We decide what activity to do at our monthly meetings. This month we are planning a swimming party and BBQ at the YMCA in O'Fallon, Sandi said, "I cannot wait. This is going to be so much fun." Lizzie chimed in, "This is going to be the best pool party ever! We are very excited about it.

St. Joseph members have been busy. The last meeting hosted a Bingo Night and members were invited to bring guests and perspective new members. There were 13 members and 5 guests. The group will have representatives attend the People First Missouri State Steering Committee meeting on July 11-12, 2009 in Kansas City. The local group will hold their next meeting on July 13, 2009 at 5:00 p.m. here at MERIL. Jackie Allenbrand and Kristy the PHARM dog will be doing a demonstration at 5:30 p.m. PHARM stands for Pets Helping Agriculture in Rural Missouri. Kristy is a trained demonstration dog able to assist farmers with disabilities to maintain independence on their farm. This is provided by a grant through University of Missouri Agribility. PHARM is the first program in the nation to offer these service animals. More information available at www.meril.org.

Signing the UN Treaty

On July 24, 2009, President Obama invited disability advocates to the White House to celebrate the 19th anniversary of the ADA (Americans with Disabilities Act). Chester Finn was there representing SABE, Self-Advocates Becoming Empowered. During the celebration, President Obama announced that the United States was signing the United Nations Treaty on Rights for People with Disabilities. "Disability rights aren't just civil rights to be enforced here at home; they're universal rights to be recognized and promoted around the world," President Obama said. "And that's why I'm proud to announce that next week, the United States of America will join 140 other nations in signing the United Nations Convention on the Rights of Persons with Disabilities -- the first new human rights convention of the 21st century."

Here are Chester Finn's comments about being there for this historic event:

It was fun talking to all the people outside the gate of the White House. Once inside, I met with Paul Marchand, director of the Disability Policy Collaboration, who gave me a tour of all the different rooms: the red room, the blue room, and the dining room. I spoke with Hillary Clinton and my governor, David Paterson. These two, plus President Obama, are political figures I look up to as far as making things happen. We were showing the President and all the politically powerful people that people with disabilities and the elderly should not be left out of the healthcare reform.

I think by signing the treaty it means more freedom for people with disabilities. It will strengthen our advocating on guardianship issues. Also, it will put a focus on getting people out of institutions. This new treaty will strengthen some older UN decisions against aversives and people with disabilities being sterilized against their will. This should inspire us and give us more incentive to work harder in our advocacy. However, without us making it work in the community and speaking out, signing the treaty won't mean anything. It won't be getting anything done for people. We have to stop thinking about just what it is we can get out of something, and instead consider what it means for the overall disability community.

Before SABE was not included in events like this and now we are. It is because of our partnerships. Down the road we must work harder with some of the agencies like Health and Human Services (HHS). We have to report on the things that are happening in our lives. We need to set the example of how to work together and how to use respectful language.



People First Members In Action



Cathy Enfield of Independence attended the Disability Policy Seminar in Washington D.C. in April 2009. Cathy is a statewide officer for People First of Missouri and a national officer for SABE. She had the opportunity to meet U.S. Senator Claire McCaskill and is pictured with her.

She also attended the International Conference on Self-Determination which was held in Winston-Salem, North Carolina in May 2009.

Cathy reports that there were many good sessions that provided valuable information on personal freedom, community inclusion, Medicaid issues, guardianship, microboards, and differences between self-direction and self-determination.

Cathy said: “On this Tenth Anniversary of the Olmstead decision it was really good to meet people from all over the world who are working to make self-determined lives possible for people with disabilities.”

Mission Accomplished

I am happy to report that the project I undertook when I was elected, which was to get the financial records for People First of Missouri transferred into a computer data base, has been completed.

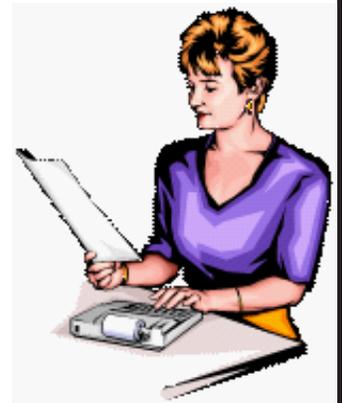
All of our Commerce Bank transactions beginning with July, 2004 (which was the date of our incorporation as a 501c3) up to the present have been entered on QuickBooks and the account has been reconciled through the last bank statement which was for the month of May 2009.

I want to express my thanks to Ms. Sharon Groom, who is one of my support staff and Ms. Dana Arth, CPA with the Julia E. Hampton accounting firm for all of their support and hard work. Their assistance and dedication made this project possible.

Paper copies of all records will continue to be kept and archived. As we become more familiar with the system we will plan to generate our future reports using QuickBooks.

I would like to thank People First of Missouri for giving me the opportunity to work on this project. I think it will be beneficial to us as we continue to grow as an organization.

Cathy Enfield
Treasurer



Is Self-Determination Right for You?

by Tonda Lain, Self Directed Services Coordinator, and Chuck Comstock, Self Advocate, Kirksville Regional Office

Ask yourself the following questions: Would you like to have more authority to plan your supports based on the lifestyle you choose? Do you want to be more involved in your community in regards to the activities that interest you? Would you like to hire the staff of your choice and have more say in how your budgeted dollars are spent? If you are saying “yes” to any of these questions, then the Division of Developmental Disabilities in Missouri has a Self-Directed Service option for you.

Self-Determination can begin for you when you make the choice to find out what options are available through Self-Directed Services. For more information on Self-Directed Services, talk to your service coordinator at your local regional office.

Chuck Comstock started asking questions and made the choice to self-direct his supports as you will see through the personal story he is about to share with you.

A little over 16 years ago I suffered a spinal cord injury that left me with quadriplegia. After living with my parents in their home for five years, I found myself asking these very questions: What did I want out of life? How could I have more control and be more independent?

I just wanted and needed more freedom. Then I heard about self-directed services through the local independent living center and made the choice to self-direct my supports and take charge of my life. That decision changed my life.

By self-directing, I am able to completely manage the care I receive. One aspect of this is the hiring and firing of staff. Self-direction allows me to choose who is going to work for me, so I'm not stuck with a personal assistant that doesn't quite get along with me. Over the past several years I've made a few mistakes with my hiring choices, but luckily, through the self-directed program, I had the authority to replace those people with staff who are much more in tune with who I am. Each of my current staff has worked for me for more than two years and I am very satisfied with all of them.

Through self-direction, I also have the opportunity to train my own staff. That way, my care is tailored to my individual needs. For example, I have an accessible van and I've trained a number of staff and friends to operate it in order to get me

where I want to go. Each of us has different requirements and should have the right to train our own staff.

Another feature of self-directing that I really appreciate is being able to adjust the time of day my staff works. If I need to go shopping at 2 p.m. on Saturday or go to church at 10 a.m. on Sunday, I can adjust my staff's schedule to match my own. I'm not stuck at home staring at the walls. I can go out and have fun with friends and family when I choose.

Thanks to self-directed supports and self-determination, I was able to attend classes on campus at Truman State University and I earned my Bachelor's degree in English in 2006, graduating with a B average. Taking charge of my own life has enabled me to get a good job and be a part of the community where I live. It is a decision I am glad to have made.



Update from the DMH DD Division

DD Systems Transformation Initiative

A training program on Positive Behavior Supports was launched in October of 2008. This advanced level PBS course is for direct support professionals, family members, and anyone who provide supports and services. Participants learn how to treat people with respect and dignity, how behavior is a form of communication, and how to support people in a more positive way that helps them build skills and become more independent. As of the end of June, there were nearly 40 trainers statewide, and over 300 people had completed the 3-day training. For more information about the training, go to <http://www.dmh.mo.gov/mrdd/new/pbs1.htm>.

The Olmstead Supreme Court decision in 1999 mandated that public programs with limited funds and waiting lists must have a fair and equitable way to prioritize access to services. The Division of Developmental Disabilities has a method for managing the waiting list and determining access to services called "prioritization of need" or PON, which assigns a score ranging from 1 to 12 depending upon the needs of the individual. Some people also call this the UR process, which stands for "Utilization Review." A workgroup was formed in early 2009 to make improvements on the PON assessment tool to assure that it is fair, equitable, reliable, and valid. A new PON tool was field tested during May and June, and the results are being analyzed by Dr. Cynthia Gruman who works for a company called The Lewin Group. The workgroup will review the results from the field testing and will then make recommendations to the division about whether to implement the new form. The state regulation will have to be amended before the new tool can be used. For more information about the waiting list workgroup, go to <http://www.dmh.mo.gov/mrdd/issues/waitlist/waitlist.htm>.

On July 21st, People First of Joplin will hold a train the trainer on abuse and neglect for Advocacy Specialists at each regional office. The training covers what people should do if they are abused or neglected, rights of individuals supported by the Division of Developmental Disabilities, and how people can protect themselves. The Advocacy Specialists will be available to train people in their area, especially people living in habilitation centers.

Kyla Eversman, the Director of Community Services for the Division of DD is working on several projects to help people take control of their lives. The Division wants more people to be able to direct their own services and develop their own person-centered plan. More information about self-direction can be found at: <http://www.dmh.mo.gov/mrdd/selfdirect.htm>. The Division will be adding a new person-centered planning webpage to their site soon.



"Share our similarities, celebrate our differences."
--(Morgan Scott Peck)

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Very Important Reminders!

- *PFMO Self-Advocacy Training Retreat Friday September 18-20, 2009 at Camp Wonderland in Rocky Mount, MO*
- *Steering Committee November 14-15 at Stoney Creek Inn in Columbia, MO*
- *SABE National Conference in Missouri Fall 2010*

People First: Self-Advocates Determined to be All for One and One for All

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