Message from the People

FALLING BACK ON EDUCATION

In September, over 200 people attended the annual self-advocacy training and retreat! This is always a fun time for everyone to get to know each other and see old friends with games to break the ice, boat rides, swimming, and dancing. However, one of the most important reasons why we attend camp is for the education. This year, as in years past, we heard presentations and participated in training workshops that help build our skills for advocacy.

At camp, we heard about all the alternatives to guardianship, which is sponsored by Missouri Protection & Advocacy, the Missouri Planning Council, UMKC Institute for Human Development, and People First of Missouri. The training taught us about guardianship, and all the ways a person might be supported — instead of having a guardian. Inside this newsletter, you will read about one man’s quest for freedom as he works to get his rights restored. He was inspired to do so by the alternatives to guardianship training, which has been presented all across the state.

One session sponsored by the Division of Developmental Disabilities taught us how to start and keep “life books” — scrap books with pictures and memories from our lives. People come in and out of our lives. Keeping a life book is a fun way to keep track of people and events that influence who we are.

Also at camp, we took a poll of members that will help us set our legislative priorities for the year. According to poll results, the most important issues for self-advocates were Medicaid and receiving needed services.

That’s where the other kind of education — the kind we give — comes in. This year we will educate our legislature about how important these things are to us. We will tell them about how spend-down forces many to live below poverty, and basically, if we have Medicaid, we cannot have savings. We will tell them about thousands of people and their families who need services in their homes and communities. While our state is still willing to spend millions and millions of dollars on institutions and nursing homes, taxpayer money would be better spent in the community, and would serve more people.
Steering Committee elections are on November 15th, and a new President will be elected. So, this is my last article as President.

As I think back over the past 4 years, I am amazed at all that we have accomplished. We have finally gotten the “R” word removed from the Division of Developmental Disabilities. A self-advocate is now working in each Regional Office as an Advocacy Specialist. Four years ago, these were dreams of ours, and now, they are reality because of your hard work and persistence.

In addition to these huge tasks, we accomplished a lot within our own organization. We have relooked at our values and redone our mission. We developed an Affiliation Agreement that shows our drive to be a powerful voice.

For these and many other things, I say thank you. Thank you for allowing me to represent you. This has been an experience that I will take with me and look back on proudly. You are all awesome, and I look forward to seeing what other dreams you have come true.

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).
Education is a very important value for People First of Missouri. As an organization, we participate in activities where we learn about what we need to live the lives we want to live. We also educate the community about everybody’s right to belong.

As you can see from the cover article, self-advocates received training at our annual retreat. We also have partnered with Missouri Protection and Advocacy and UMKC-Institute for Human Development to teach self-advocates and their families about the alternatives to guardianship with a grant from the Missouri Planning Council. In this newsletter you will read about the training workshops and you will also hear the story of how one self-advocate who attended the training made a change in his guardianship status. You will also read about how People First is helping The Arc of Missouri to get the word out about the “waiting list” and also how self-advocates are becoming educated about the power of their vote.

We know that informed people make informed decisions and informed decisions will help drive us toward the goals we wish to achieve.

Profiles in Freedom

Mike’s Quest for Freedom

I've been living on my own and looking out for myself since July 9, 1990. I remember the exact date. All that time though, I've had a guardian. Legally, I don't own my life. My guardian does.

My guardian could decide I need to live in a nursing home. If she did, I'd have to go. I want the right to say “yes” or “no” about things in my life. I want to get married some day.

With a guardian, I don’t have rights. Even though I care about elections and political issues, I don't have the right to vote. I’m determined to get back that right and all my other rights as a person. I want to own my life again.

A couple months ago I went to the guardianship alternatives training [co-sponsored by Missouri Protection & Advocacy, Missouri Planning Council for Developmental Disabilities, the Institute for Human Development, and People First]. There I met an attorney, Lisa, who is now helping me get my freedom back. We talked to my guardian, and she agrees; I don't need a guardian. Still, I can't get out from under guardianship unless a doctor writes a letter agreeing I don't need a guardian. That's where we are right now, in the process of getting two letters from two of my doctors.

Then we go to court and we hope the judge agrees.

I'm writing this article to share with you that I'm fighting for my rights. Next newsletter I plan to write another article whether I win or lose. I learned in the training that there are other kinds of support that work just fine, and you don't have to give up your life to someone else.
The goal of the Guardianship Project is to give power to individuals with developmental disabilities, as well as their families, so they can make informed guardianship decisions and get appropriate guardianship status. Those who are involved with the Project want to make sure guardianship does not interfere with a person's right to make his or her own decisions whenever possible.

The Missouri Planning Council for Developmental Disabilities (MPCDD) developed the Guardianship Project. People First, Missouri Protection and Advocacy Services (Mo P&A), and the Institute for Human Development (IHD) have been working together to carry out the Project’s goal for the past year and a half. What has the Guardianship Project accomplished in this time?

Since April 1, 2009, the Project has hosted seventeen (17) Alternatives to Guardianship trainings across the state of Missouri. From St. Louis to Kansas City Mo P&A Staff Attorney Lisa Sutherland, IHD Community Inclusion Specialist Jane St. John, and Attorney Elizabeth Moran have provided people with developmental disabilities, their friends, and families with information on how to safeguard self-determination from the limitations of guardianship.

Elizabeth Moran often leads these trainings. “A Guardianship creates a substitute decision-maker who has the authority to make decisions for you, including such decisions as how to spend your money, where you will live, what kind of medical treatment you will get, what kind of services you will receive, and even decisions about who you will associate with,” Moran says.

“It is important that people understand that guardianship often unnecessarily limits a person's self-determination,” adds Lisa Sutherland. Lisa Sutherland has been involved in many cases in which people are in restrictive guardianship situations. Sutherland and other Guardianship Project attorneys have helped restore the rights of individuals who were under restrictive guardianships.

Participants in the Guardianship Project had their right to vote restored before the 2008 election. At the start of 2009, another client gained not only her voting rights, but the right to determine where she would like to live. Christina Chapman, a recent client served by the Project, was able to completely restore all of her decision making rights by removing herself from guardianship altogether!

The Guardianship Project has affected all the organizations involved in it, and they will continue to promote the value of self-determination far into the future. If you have a developmental disability and have found that guardianship limits your actions, don't hesitate to contact Missouri Protection and Advocacy Services at 1-800-392-8667.
On September 18, 2009 Wonderland Camp came alive! As People First of Missouri members arrived, Judy and Angie (Regional Office Education Coordinators) captured memories of a well deserved retreat by taking photos of members relaxing and enjoying themselves. Judy and Angie explained the photos would be used during a session on creating a Life Book page that would be held the following day for those who wanted to participate. A Life Book is a collection of words, photos, graphics, artwork, and memorabilia that creates a life record. A variety of photos were taken that included meeting new friends, enjoying time with old friends, people playing basketball, volleyball, miniature golf, video games, dancing, eating and just plain old relaxing.

After breakfast on Saturday it was time for the Life Book session to begin. Judy and Angie were pleasantly surprised that even though they only planned for seventy five participants, there were one hundred in attendance. Participants were given supplies and a handout that explained further ideas on creating a life book. Judy and Angie shared some creative ideas and, with the support of staff, assisted members in creating a page that proudly described each member’s time at Wonderland Camp. One member shared her Life Book that she had been working on at home and was excited to add a new page to, which included photos of her friends and what being a member of People First meant to her. As members finished their pages, they were encouraged to present to the group explaining how they would use their life book in planning their lives. One gentleman spoke of his role as a high school assistant basketball coach. He was anxious to get home and create life book pages using pictures and memorabilia that describe his role and responsibilities as an assistant coach. He gave credit to the People First organization for teaching him advocacy skills which resulted in attaining the assistant coach position. Before letting go of the microphone, he put out a challenge to all of his fellow People First members. He challenged them to create Life Book and to bring them to the next retreat.

Life Books can be great fun! The focus of attention is on YOU and building a picture of YOUR story, YOUR special relationships, likes and dislikes, modes of communication and aspirations for the future. In terms of developing person centered planning, Life Books work as the foundation. YOU become more involved in the planning of YOUR services. This is done all year long versus during a meeting that might occur once or twice a year. Life Books help service coordinators, providers and friends get to know YOU; helps plan for YOUR future and self-advocacy. It creates a picture of YOU; it records important events, organizes emergency and medical information, and encourages communication among YOUR circle of support including YOUR family members, friends and professionals. Use a camera to capture people, places and things that have meaning to you. Get together with friends to create theme based pages. Consider having Life Book parties with your friends from your People First chapter. Meet the challenge. Bring your Life Book to next year’s retreat!

People First members teach and empower people to understand their rights and responsibilities and to speak up for themselves.
**Boone County** Members of our chapter and Jeff Johnson, Advocacy Specialist, presented a PowerPoint on People First Language to a class at the University of Missouri. After the PowerPoint we talked to the class about our experiences and feelings about labels and how respectful language is just good old-fashioned manners.

We sent a letter to the transportation manager at the local bus station with a list of concerns people with disabilities have about the transit system. He wrote back to us -- and there have been improvements! Self-advocacy works. We found that they just needed to know about some of the issues. It's important to use our voices!

**Boonslick** People First has been very busy. We're raising money for the national conference next year. Our September fundraiser was a duck pond and food booth. We set up every Thursday night at the Boonville Festival of Lights. Unfortunately, we haven't broken even, but there's still one more night to go.

Some of our members went to camp. We had a great time. We learned about scrapbooking and guardianship. We played games and made new friends.

In October, twelve of our members will be bowling on two teams to raise money for Habitat for Humanity.

Two of our officers (Melanie Nau and Sheila Bader) will be representing us at the steering committee in November. We'll see you there!

**Independence** is still without an advisor but we are continuing to have regular meetings and work on issues that are important to our chapter. Our treasurer, Joe Wrinkle, was among those honored recently for their military service at a reception for Vietnam veterans, which was hosted by Representative Emmanuel Cleaver II on September 12, 2009. Joe received a framed citation and a medallion. The Independence Chapter is proud of Joe and grateful for his service to our country. In October we had a Halloween party and a short business meeting. We enjoyed treats and music and had some great discussions about disability issues.

Cathy Enfield of Independence Chapter has taken on some new responsibilities this fall. In late September Cathy was elected Chair of the Board of Directors of Missouri Protection and Advocacy. In early October she was elected to serve on the Executive Board of the ARC of Missouri. Congratulations Cathy!

**Lake Area** The group is getting ready to have its third annual chili cook off. We never knew that there are so many ways to fix chili! In December, we are going to be having an election for officers. The group planned to have a hay ride, but due to the rain we had to cancel until next year. We have had several of our members sick. We are having a speaker come to talk about Self-Determination and Self-Directed Services. We also had the someone from Camden County Deputies come and talk to us about safety in and out of our homes.

**Marshall** People First of Marshall attended camp, which was held September 18-20 at Wonderland Camp in Rocky Mount. We had 15 members attend. The Marshall chapter provided games which were donated by Sandi Morton. John Ezelle did the DJ for Friday and Saturday nights’ dance. We would like to thank John Ezelle for being the DJ both nights. Sandi Morton also donated the snack items for the camp concession stand hosted by region 1. We also did trainings on how to make your People First chapter run more smoothly when problems arise. We would like to thank Sandi Morton, John Ezelle and Carol Utterback for all their hard work.

We recently held our elections of new officers. We are working on our upcoming awards banquet. We are also working on fundraising ideas to help send our members to the national SABE conference next September in 2010. We are planning on picking up trash with adopt the highway. We would like to congratulate John Burriss and Roger Rose for completing Partners in Policy Making this year.
Rolla  People First members had a chance to listen to a group of guest speakers recently. Lisa Nothaus talked to us about S.A.F.E (Self-Advocates Families for Excellence). Andrea Purdome talked to us about self-directed services and self-determination. Ken Nakinshi and Vince Giacolone talked to us about cyberspace and safety in the community.

We have been holding fundraisers and have had good success with our candy bar sales. We also raised $200.00 at Lemonade Stands for Child Abuse for the Community. In addition to raising money, we have been donating items to Grace local food pantry, two times so far!

We are really looking forward to participating in the Legislative Rally for 2010. Everyone enjoyed the Real Voices- Real Choices Conference and Camp Wonderland was a blast!

Sikeston  People First Chapter has been very busy lately. 16 of our members, support staff and advisors made the trip to Camp Wonderland this year for the annual Missouri People First retreat. Members enjoyed music, dancing, pontoon boat rides, seeing old friends and the game room.

The Cotton Carnival Parade is coming up soon! Joe Fritz of the Eagles Club will provide his truck & trailer for the members who want to ride in the parade. The Halloween party is scheduled for October 30, 2009 at the Shriner’s Club in Sikeston from 7:00-9:30 PM. We will have food, drink and music. There will be prizes for the costumes that are the scariest, funniest, prettiest, most original & best overall. Our Thanksgiving Party will be held at the November chapter meeting. Everyone is encouraged to bring a dish. We are also purchasing a turkey to be given to the House of Refuge, a place for people affected by domestic violence, in Sikeston. The Chapter’s Christmas Party will be held at the Eagles Club sometime in December.

Springfield continues to hold monthly meetings around the community and most recently at a city park where we had a nice picnic and had several new people come. Some of them were from Bolivar Missouri and they will be attending our fall Cookout on Sept. 26th. Barbra McDuffy presented a training for our members this past month on disaster readiness in our homes. She get a lot of good input from our members. We are currently working with Judy Wanko, Education Coordinator at Springfield Regional office. Springfield People First will be hosting a fun workshop on Life Books. We will also be hosting more trainings in areas such as guardianship. We look forward to seeing everyone at the next Steering Committee meeting in November.

St. Charles  Six members of People First St. Charles along with a handful of support staff spent the weekend at Camp Wonderland at the Lake of the Ozarks. Except for a few light sprinkles on Saturday night, the weather was perfect for a fall weekend at the lake. The only complaint heard all weekend was that it was too short!!!

As far as other news, People First of St. Charles now has a new advisor, Susan Newton. Kellie Buehrer now has a permanent place in our chapter helping facilitate the meetings. Kellie has been participating in the People First chapter for a year already, but is now permanently becoming part of the team. She looks forward to being a part of the People First chapter.

St. Louis  People First and College for Living had their 20th anniversary September 17. Bonnie Fiasco and Tom Evans are oldtimers of the group. Jeff Pomaranka was there too and everyone had a real good time. St. Louis People First and College for Living had a picnic and everyone had a good time.

St. Joseph  People First chapter has been busy. We had elections for new officers of the group. Sara Shishler-Chairperson and Kristen Sample-advisor went on the local “Live at 5!” TV show on 9/22/09 and talked about everything that is happening with People First. We are having the Guardianship Project with Missouri P&A, UMKC, and Missouri People First on Oct. 13, 2009. We will also present a training session at the No More Stares conference on Oct. 29th at Holiday Inn in St Joseph. Our topic is: Transition to Independence. Each presenter will share a short speech about how they are independent. We have a volunteer to put a slide show together for us. The group’s big activity for now is preparing for our bingo fundraiser on Nov. 9th at 5:30 PM. The money raised that night will go to help the group attend the national SABE conference in Kansas City, MO.
On October 16th, I had the pleasure of presenting with Jessica Wohler about Self-Directed Supports from an advocate's perspective. Jessica’s story demonstrates the potential of the Division of DD’s redesign of the service delivery system.

The redesign of the service delivery system is meant to fulfill the Department’s vision so that Missourians with developmental disabilities will have the opportunity to pursue their dreams and live their lives as valued members of their communities. The intent of the redesign, outcomes and activities is to provide the right supports and services at the right time so individuals with developmental disabilities have hope, opportunity, and community inclusion.

Missouri’s Road Map to Supports and Services for Person with Developmental Disabilities

A year ago Jessica’s problems isolated her from family and community. Her family did not know what role to play in her life and were told by staff that their visits aggravated her behaviors. Jessica was excluded from her brother’s wedding because of her family’s concerns. Staffing was doubled, new medication was added and a new lengthy behavioral support plan was created. Jessica eventually was arrested and faced charges due to her aggression.

Jessica’s family and staff from the regional office began applying the principles of self-determination and person-centered planning — key elements of the system redesign. This included the importance of people with disabilities having freedom of choice, opportunities to have respected and valued roles in their communities, and to give back to others and not feel constantly dependent upon others for assistance.

Jessica’s team started asking what she really wanted. At first, she didn’t trust them, was uncomfortable with changes, and hated disappointments. She was cautious and guarded in her answers, fearing she was being set up to hope for something unattainable. They persisted and eventually she began to give answers.

During the presentation on Oct 16 Jessica proudly went before a large group and told them about her life now. She showed photographs of her new home, where she lives by herself in a neighborhood close to family and friends. She talked of the “buddies” and “teacher” that come to her house on her own schedule and her own agenda. Jessica is taking her own medication, doing her own hair, and learning to cook for herself. She talked about the dog that she thought she wanted but then later found out it was too much work. The audience saw her busy schedule and the activities with her family and friends, including meeting her niece for the first time! Because of her courage and success, some of her friends are inspired to do what she has done.

I myself became overwhelmed during the presentation thinking what a difference a year makes and how the future of individuals with disabilities in Missouri will be forever changed for the better as a result of “Missouri’s Road Map to Supports and Services for Person with Developmental Disabilities.” I cannot wait to see what the next year brings!

If you are interested in self-directed supports contact the Self-Directed Coordinator at your regional office.

By Kyla Eversman, Department of Mental Health- Division of Developmental Disabilities
Director of Special Community Services
kyla.eversman@dmh.mo.gov
Johanna Wortmann does not want to be institutionalized. Wortmann, 42, has Asperger’s Syndrome and other developmental disabilities. She lives in a St. Charles apartment with a cat as her only roommate. “I prefer to live on my own,” she said. Wortmann receives individualized supportive living services from Willows Way in St. Charles. Willows Way staff visit her for several hours per week and provide 24-hour protective oversight in case of emergency. But most of the time it’s just Wortmann and her cat.

It was not always that way. Wortmann spent years living in a nursing home. She has roomed with other people with disabilities. Families have taken her in, giving her temporary housing. In 2003, Wortmann met Karen Schneider of St. Peters. Both women attended Harvester Christian Church in St. Peters. Schneider, a financial advisor, had a reputation for taking struggling people into her home. “The minister asked me to see what I could find out about a woman with special needs who was always distraught and crying in church,” Schneider said. “I learned the reason she was crying was because people were calling her, saying they were going to take all her stuff.”

Bill collectors were threatening Wortmann for unpaid credit card debt. Schneider said Wortmann thought credit cards were like gift cards. She did not realize she had to pay for her credit purchases. Schneider helped Wortmann solve her financial problems. “She wanted to move in with me,” Schneider said. “But I was afraid I wouldn’t be able to deal with her needs on a daily basis.” The two never became roommates, but they did become friends. Through Willows Way, Wortmann started her own business, Hannah’s Heavenly Mailing Service. Schneider became her client.

Now Wortmann is helping Schneider launch a nonprofit organization to help people with developmental disabilities live independently. Schneider is the founder and chairwoman of Foundations of Love, a startup agency working toward the goal of leasing affordable, traditional housing to people with developmental disabilities in St. Charles County. “The program would offer an alternative to living in large group homes, nursing homes or institutions... We want to integrate these people into the community,” Schneider said.

The Division of Developmental Disabilities Transformation Initiative is offering Home Brokerage Services in some areas of the state that will assist people who are interested in buying their own home. This service will help you find loans or help from things like: Rural Development Loans, Neighborhood Stabilization, or assistance for first time buyers from Missouri Housing Development Commission. The DMH housing broker (the person who will help you with this) will be a part of your person-centered planning. If the contract is with a HUD Housing organization, the housing broker will provide financial counseling or ensure the self-advocate or family receives this service from a qualified HUD housing counselor. They can also help you in exploring all housing financing options by finding everything that is available for you in your region to help you buy a house. They will also assist you in filling out the applications to get the assistance.

Right now there are five areas of the state that have “housing brokers” in place to help you. The places are Kansas City, city of Marshall, city of Nevada, Southeast MO, Audrain County and St Charles County.

Do you write books or poems? DMH needs you! DMH received a grant to help librarians learn how to work with people with disabilities and to help them see the talents of people with disabilities. Right now DMH is looking for people with disabilities who have written books or poems. If you have written something and you want to show it off, go to www.librarian411.org to fill out an application and maybe you will be chosen to be a part of the next training video. Good luck!!!

-by Nancy Nickolaus, Project Coordinator, Division of Developmental Disability Transformation Initiative
Camp Wonderland 2009: Unforgettable Memories
In the past few years, Missouri politics have taught us that the issues are our issues. Our legislators have thought about whether or not to take the MR out of the Division of MR/DD, argued support for community vs. institutional living for people with disabilities, and made big changes to state and federally funded healthcare services. Each of these issues is important to our ability to live the way we choose in our communities. An educated vote has been the key to giving ourselves a voice in Missouri politics. For over 8 years, the Missouri Disability Vote Project has been working with groups of people with disabilities across the state to educate voters.

Groups like People First of Missouri put time and resources into voter registration, get out the vote, and voter education year round. People First members and its partners organize local candidate meetings which allow the candidates to take questions straight from people with disabilities on our issues. This also allows the community to listen to them. Members give out candidate questionnaires on disability issues and use the information they receive to create voter guides to pass out all over the state. A lot of time goes into making phone calls that remind voters with disabilities about election dates. Rides to the polls are also offered. Creating and mailing out information explaining the pros and cons of major issues and important voting suggestions is another use of our time. Members of the Missouri Disability Vote Project are featured at local disability events across the state. They register voters and educate them on their rights at the polls. Staff and volunteers give their time and energy to make sure that large numbers of voters with disabilities turn out at the polls on election day. They also make sure that these voters are ready to cast an educated vote that will support the future of disability rights in Missouri.

Our partnership has grown, and so has the influence of its membership. Today, the project is about more than just educating people with disabilities. It is about educating the politicians themselves about the power of the disability vote. Project leaders teach elected officials about the impact of new legislation on this growing group of voters. They demonstrate just how many people with disabilities are actively participating in politics in Missouri. At the local level, leaders educate election boards and county clerks one-on-one about accessibility, accommodation, and respect that make voting a pleasant, fair and equal process for all voters on election day.

By educating voters with disabilities, legislators, and election authorities, the Missouri Disability Vote Project and People First are creating a more accessible voting process. They are also building a disability voting community that can change the face of Missouri politics. For more information about the Missouri Disability Vote Project and your rights as a voter with a disability, please contact Michelle Bishop at mbishop@paraquad.org or (314) 289-4264.

People with developmental disabilities and their families are well aware of the waiting list for services in Missouri. Many of us can remember when few services were available and the difficulty in navigating the system to receive services. Unfortunately, most people in Missouri are unaware of both the need for services and the size of the waiting list.

The Arc of Missouri is made up of family members and self-advocates whose mission is to advocate for community services for people with developmental disabilities. Recently, the Arc of Missouri received a grant through the Missouri Planning Council to create a campaign to educate people about the “waiting lists for people with developmental disabilities to receive services from the Division of DD.” There is the need to educate families on how to advocate. There is the need to make the general public aware of the situation. There is a need to educate legislators on the problem and how they can help fix it.

The scope of this project goes far beyond the Arc in Missouri. It will require the cooperation and collaboration of strong advocacy groups such as People First of Missouri and others. This is an issue which boils down to individuals. People are being denied the opportunity to a life of dignity and respect. Families are impacted financially and emotionally.

All of us want to be happy in our lives and to live a life which is both satisfying and fulfilling. It is happening for many individuals in Missouri who are receiving appropriate services. It should be happening for all of us. We can make that happen if we are united in our efforts and passionate about our goals. Waiting for concert tickets is acceptable; waiting for needed services is not.
February Newsletter Articles Due: Friday, January 30th

National Self-Advocacy Conference: September 16-19, 2010 at the Westin Crown Center in Kansas City, MO

9th Annual Disability Rights Legislative Day: March 23, 2010 at the Missouri State Capitol in Jefferson City, MO

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