People First members have been working hard with advocates from the Missouri Planning Council, the Missouri Arc and many others, fighting segregation! People First of Missouri is part of a coalition united to address a plan for rebuilding the Nevada Habilitation Center, one of six institutions open in Missouri.

Advocacy began in April with the announcement of plans to close the habilitation center. Advocates across the state rejoiced at this news. The coalition educated legislators about the plan. They told legislators that people would have a chance at a real life in the community and that the plan had their support! Advocates from all over Missouri called their legislators and the Governor’s office to announce their support for the transition of people with disabilities to the community.

Soon after the announcement, the Missouri Department of Mental Health flip-flopped the plan by announcing a new proposal to build nine 8-bed group homes on Nevada’s campus. It was like a cruel April Fool’s joke and advocates from across the state were gravely disappointed.

This new plan promotes the segregation of people with disabilities from the community and supports a model of living that has been out of demand since the 1980s. People First and its allies on the coalition joined together to testify at the Mental Health Commission, the governor-appointed group that oversees DMH, in May. PFMO testified at this meeting during open comment, explaining to the Commission that people with disabilities want to live real lives in the community!
My name is Kelly Ray and I am the president of People First of Missouri, which represents over 1,000 people with developmental disabilities and is the only self advocacy organization in the state created by, run by, and run for people with developmental disabilities. I’m here today to talk to you about the new plan to build a cluster of group homes on the campus of the Nevada Habilitation Center. People First of Missouri would like to encourage you to return to the original plan to transition people to the community and close the Nevada Habilitation Center.

Our members believe that all people have the right to live in the community. All of our members live in the community. Living in the community means being around all types of people and the opportunity to have a real job, including real friends, and a real home. We imagine that’s what everyone wants.

Building group homes on the grounds of an institution because a small number of people are afraid of what might happen to their loved ones or because the jobs of a few may be lost is not fair to the majority of us who believe in being full participants in the community. The plan to build group homes will still promote the unnecessary segregation of people with disabilities.

In a time where money is tight, we believe that it is not a wise use of money to invest in a model that is not in demand, hasn’t been since the 1980s, and that the majority of people with developmental disabilities would never even dream of using.

Thank you for your time and consideration.

Sincerely,
Kelly Ray
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).
People First of Missouri sent a letter to the governor explaining our view on the plan to build the group home campus. PFMO also signed onto letters expressing our support for transition to the community. People First met with Governor Jay Nixon’s staff asking them not to support this outdated model of service and educating them on the positive aspects of living in the community for people with disabilities.

Building the group homes would reinforce the wrongful segregation of people with developmental disabilities who want to live real lives in the community.

One thing still needs to happen to allow Missouri to rebuild this institution:

Although, Governor Jay Nixon signed the bill to convey the land to build the group homes on the campus of Nevada on July 12, 2010, CMS still has to decide whether they will approve these proposed group homes through the Medicaid waiver. People First of Missouri believes that a cluster of group homes on the campus of an institution is not HOME AND COMMUNITY BASED SERVICES. We also wonder why CMS would allow home and community based waivers to be used in a segregated, institutional setting! CMS will make a decision by August 1. We think they should say “NO!”

Advocates, if the waiver is approved to fund services on the campus of the Nevada Habilitation Center in Missouri, what does that mean for the country? Soon little “group home campus institutions” (funded by the home and community based waivers, no less!) may start popping up all over the country, erasing all of the advocacy efforts advocacy groups have accomplished to get services in the community. Do YOU want to live on an institutional campus with eight other people just because you all happen to have a disability? Separate from the rest of society? Should state and federal money intended to get people out of institutions be used to fund services in a segregated institutional setting???

If you believe that people are best supported in the community and deserve the chance to live real lives, now is the time to act! Call Cindy Mann, Director of the Center for Medicaid & State Operations (CMSO) at 877-696-6775 or e-mail her at Cynthia.Mann@CMS.hhs.gov and ask that CMS not allow the approval of the waiver for the purpose of building group homes campuses on the grounds of institutions!

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Investing in institutions
is like buying an 8 TRACK TAPE
when we’re downloading mp3s to our iPods!
What is an Institution?

Usually, when you hear People First members talking about “institutions,” they’re referring to buildings with lots of beds for people with disabilities. They’re usually talking about habilitation centers, but they could also be talking about nursing homes or other group living situations. An institution isn’t always one big facility, but may be a campus, where there are many facilities.

The picture on the front cover is of the Nevada Habilitation Center in Nevada, Missouri. This habilitation center opened its doors in 1887. The current NHC has been in existence since 1973 and serves 88 people.

You’ve probably heard People First members express their feeling that institutions should be closed. They have reasons for feeling this way. People First believes that people with disabilities belong in the community -- believes they should be able to live and be supported in typical neighborhoods, in typical homes. If you’ve ever met a person who used to live in an institution and now lives in a community residence, ask them if they would return to the institution if given a choice. You’ll hear that people thrive when they’re supported in the community. You’ll hear common themes like, “I’d never go back” and “My life is much better.”

Eleven states have closed their large institutions and moved the residents to community settings like the ones in which most PFMO members live. Missouri still has several large institutions. Many of the residents in the institutions were placed there by their parents. Their parents said it’s because they want their sons and daughters to be safe. But community programs are required to look after the health and safety of the people they serve. Do you feel safe where you live?

From the Code of Federal Regulations, the rules established for the agencies of the federal government to follow:

“Institution means an establishment that furnishes (in single or multiple facilities) food, shelter, and some treatment or services to four or more persons unrelated to the proprietor.”

Definitions relating to institutional status, 42 Sec. 435.1009 (2004)

POWER TO CHOOSE

In a recent testimony to the Mental Health Commission, People First member Patty Goss said, “If you ask a person currently living in an institution if they want to move, they might say “No.” But if a person hasn’t been shown all of the opportunities they have to live in the community, how are they able to make an informed decision? I know members of People First that have lived in institutions and they would never go back. We feel that.... people with disabilities have an informed choice about where they live and be shown all of their options.”
Profiles in Freedom

Each quarter, People First of Missouri takes the opportunity to highlight how our members are working toward freedom and independence. Do you know a People First member who should be featured in Profiles in Freedom? Email your suggestion to missouripeoplefirst@gmail.com!

Gary Stevens

The following is an excerpt from the Mental Health Foundation recognizing Gary for his advocacy efforts!

Gary Stevens is well known to everyone connected with the field of development disabilities in Missouri. And he should be, because there is a good chance that anyone connected with the DD community is able to do something better or have access to something better because of the many years of advocacy by Gary Stevens.

For many years, Gary has been a leading advocate and key participant in decision making as it affects persons with disabilities. He is there at the table to ask the important questions and demand the answers. There is a very long list of statewide and local boards, commission and work groups that Gary has been part of over the years, including the second longest serving member ever in a Governor appointed position on the Missouri Planning Council for Developmental Disabilities. Likewise, the list of initiatives Gary has helped to advance is very long. It includes increasing self-determination; helping persons reduce or eliminate guardianship; find a home of their own; and live, work and play in the community of their choice.

Glenda Cherry

Glenda Cherry is a resident of Sikeston, MO. She used to live in a group home for 15 years, but now she has her own apartment. She has been a member of People First of Sikeston for 15 years. A friend of hers told her about the Foster Grandparents program through SeniorCorps with the Sikeston public schools. She made a call to talk about the program and later they selected her! Now, she helps the teacher with 13 children in Head Start. Glenda says she works with both preschoolers and kindergarteners. She says she loves being a foster grandparent because the kids are so sweet and they call her “grandma!” She said she also gives support to the kids that need special help.

If you would like more info about SeniorCorps, a division of the Corporation for National Service for people over 55, visit seniorcorps.gov!

Patty Goss

Patty Goss, a strong advocate and a member of People First (Springfield chapter), has worked hard on many things. One thing Patty has been very proud of lately is she went and talked to her senate 40 board, which used to be called Green County Board for the Developmentally Disabled, to convince them to change their name because it wasn’t People First friendly.

The new name of her county board is Abilities First, Green County Resource Board for People with Developmental Disabilities, which is PF friendly; in fact, it puts the person’s abilities first. Patty said she likes that fact!!!! I agree with her. I asked if she thinks other chapters should become active and do the same, and she said that would be good! By Bobby O’Dell
Chapter Updates

These updates highlight some of the awesome self advocacy activities in our local chapters!

**Boone County**  The Boone County chapter recently met with a professor from the “Cross-Cultural Journalism” department at the University of Missouri. We showed him our PowerPoint about People First language. He gave us ideas about how to make it better. The best thing is that he invited us to share it with his class. We have already shared it at the University with some students, but this is a bigger class with 250 students! We are a little nervous but we will use our voice. His students are studying to become reporters, for newspapers and TV. We talked to the professor about the “R” word. He understood. It was great! We feel like we are giving some good information to reporters about people first language. It was so nice to meet with a University professor who understood what we were saying. He told us this is a good thing for his students to know.

We are getting ready for a parade and party in Columbia celebrating the Americans With Disabilities Act. The ADA is so important!

**Independence**  Independence People First has been holding regular monthly meetings which have included a business meeting with education topics and discussions of current issues which affect people with disabilities both locally and nationwide.

In March several of our members took advantage of free bus transportation provided by the Metropolitan Council on Developmental Disabilities to attend the Disability Rights Legislative Day on March 23 at the Capitol in Jefferson City.

The meetings in April, May and June focused on discussions about the SABE National Conference and also on what parts of the Health Care Reform Bill will specifically help people with disabilities and when different parts of the Bill go into effect. We have also had some good discussions about the current situation at the Nevada Hab Center. There has been a lot of good discussion and helpful information provided by and for our members at these meetings.

**Joplin**  The Joplin chapter presented our 5th Annual Mini-Conference on June 19, 2010. The theme this year was "Dancing with the Stars." We had 30 self-advocates, 10 staff members and helpers in attendance. At the beginning, we were explained what People First was all about and what it can do to help with our daily lives. Throughout the day we had breakout sessions and learned from presenters about self-advocacy and self-determination, how to be prepared for disasters with disaster preparedness and how to protect ourselves with abuse and neglect training. Afterwards we had a very nice dinner and dance. The conference gave self-advocates the opportunity to go one-on-one with the presenters and fellow Self-advocates and learn about different things that will help them and

**Grundy County**  Mary Brill, a member of People First of Grundy County, made the beautiful red, white and blue quilt for her chapter to raffle off. The members sold $359 worth of free will donation tickets. The members of People First of Grundy County know how lucky they are to have such a gifted and generous member to help raise money for the members of her chapter who wish to go to the SABE National Conference. We give Mary a huge THANK YOU.

**Booneslick**  We have been working on fundraising for the SABE Conference. In May we had the 1st Annual Boonslick People First Softball Tournament. It was a coed tournament with teams from local businesses and organizations. We got a lot of rain and had to play a few make up games. A few teams canceled because of the rain. Still, we made a lot of money and we hope to do the tournament every year. In July we will be having a bake sale. We are hoping to raise enough money to send 8 members and an advisor to the Conference.

**Kansas City**  We are busy at work recruiting members and collaborating with other programs and organizations to bring trainings and resources to our members. In March, we hosted the Alternatives to Guardianship Training for folks in Kansas City. We also rode the bus down to the Capitol for rally day! In May we held a pilot training for People Planning Together, which will teach self advocates
Chapter Updates

to be in the driver’s seat of their planning meetings. PFKC members hosted a bake sale at the Troost Festival May 22 to raise funds for the SABE conference!

Our chapter experienced a great loss in May when John Scroggham, our chapter secretary, passed away. John graduated Partners in Policymaking and never hesitated to help our chapter advocate, whether it was here in KC or down at the Capitol. He was a very important part of our chapter, a great self-advocate, and we will miss him very much!

**Kirkville**  The People First chapter in Kirkville wants to say “hi” to all the other chapters throughout Missouri and give a little update on what we’ve been up to the last few months! On March 1 we presented a proclamation to the Kirkville City Council declaring “March Disability Awareness Month.” With the help of a fraternity from Truman State University, we celebrated the month by having a dance on campus. It was a great way for the chapter to make new friends within the community. On March 17 the chapter participated in the local St. Patty’s Day Parade that was sponsored by several businesses.

Last year the chapter adopted a street in Kirkville to pick up trash. We continue to come together to show our community that we care and appreciate the area we live. In May our featured speaker was from the Kirkville Fire Department, and they discussed disaster preparedness and what to do in case of a tornado, flood or fire.

This summer we plan on having a couple of cookie fundraisers at a local farmers market to raise money for the Second Annual Kirkville’s Disability Awareness Day. The Kirkville People First chapter co-sponsors this event with the Kirkville Regional Office and several other agencies.

**Lebanon**  Greetings from Lebanon’s People First! We’ve had several bowling nights. It seems Scott Howe and Ronnie Mullins have a competition going on, but we do have fun. In fact at our last bowling night, Ronnie beat every one.

We’ve had a picnic to invite new people and the weather was gorgeous. Unfortunately we didn’t have any prospective new members come. We had a game/pizza night, and that’s always a good time. Charles finally won in our ongoing poker tournament.

We did have an Avon fundraiser that we did well on. We will be having another one soon. We’re always open for new fundraising ideas.

We’re preparing for our annual dinner to honor one of the citizens in the area that has helped our chapter in August.

**Macon**  People First of Macon/Shelby County is working on getting their feet off the ground. Biggest news for the chapter is that we held our first fundraiser by participating in the Macon City Wide Garage Sale on May 15. It was a huge success. We are still in the process of completing the paperwork for becoming an official chapter and hope to have it all completed very soon.

**WE LEARNED A LOT FROM YOU.**

84% OF YOU BELIEVE CHILDREN WITH AND WITHOUT DEVELOPMENTAL DISABILITIES SHOULD BE EDUCATED TOGETHER.

The evidence is clear. In a recent poll by Missouri State University, an overwhelming majority of Missourians supports inclusive education and believes that, together, all children benefit. Thanks to your support we’re doing everything we can to make it happen. For more information, visit www.mpcdd.com
Chapter Updates

**Madison County**  People First of Madison County went through an organizational change: Kit Stahlberg is back on as a steering committee rep. Katie Lawler is back as an advisor and Wendy Crome is an advisor also. Roger Crome is the president, Kit Stahlberg is the secretary, Sylvia Cartee is the treasurer and sergeant at arms. We will be bringing 6 people to the SABE conference.

**Rolla**  People First of Rolla begin the new year with a new member, Joey. The search for new membership is an ongoing task. The possibility of leasing an accessible van to pickup those that are mobile by wheelchair may help to increase our membership, is being explored.

At the March meeting, Angela Gourley spoke to the chapter about starting an ARC of MO Chapter in Rolla. A vote was taken and all agreed. The Rolla chapter agreed that the rally was the best and everyone is looking forward to the National Conference. In April, our treasurer, Gary Stevens, was honored with a banquet at the Capitol Plaza Hotel in Jefferson City as the Mental Health Champion of 2010.

**Sikeston**  Our People First Chapter has been very busy this spring. In March, there was a presentation about Abuse & Neglect Training on March 11. We also had 11 members from our chapter attend the Legislative Day conference held in Jefferson City in March! We had an Easter party on April 8.

We have 5 car washes scheduled for the spring/summer months: April 17, May 15, June 12, July 10, & August 14.

Our ADA Picnic is scheduled for July 24, 2010 in the Rotary Park in Sikeston.

**Springfield**  Springfield continues to hold monthly meetings. Membership is up and we have an enthusiastic group. We attended the rally in Jefferson city in March and that was a first time experience for some members; they got an opportunity to listen to the House while they were in session and meet with a few of our representatives. Charlie Dennison was very supportive to our group.

Springfield wrote letters to Governor Nixon’s office in support of closing Nevada Hab Center. Will had an abuse and neglect training last week which was very good. Springfield is electing new officers, inviting people from Bolivar to our meeting and are in helping start a new chapter in the Branson area.

We heard you. In a recent poll by Missouri State University, you expressed your belief that most people with disabilities can be very productive workers. So you know that ability is far more important than disability in the business world. Thanks to your support we’re increasing our efforts to get more of those with disabilities into the workplace. For more information, visit www.mpddd.com
St. Charles  With the support of their DDRB, People First of St. Charles spent the month of March educating all of the towns in their county about Developmental Disability Awareness Month with Clean Up Your Language, an awareness campaign developed by the Missouri Planning Council and People First of Missouri. We got signed proclamations from all the mayors in our county. We presented each town with a poster, bookmarks, and a silver ribbon pin to wear to show their support. We let them know how we are people with developmental disabilities should be seen as people like everyone else, our disabilities do not define us. The St. Charles chapter is also growing in membership as well! We are up to 34 self advocates who enjoy going out to community events and making sure they are all accessible for everyone. We are also focusing on personal health issues and one of our members started a walking group that meets every week to walk in a different area of the county to stay fit and socialize at the same time.

St. Joseph  People First members, Gary Clouser and Chris Fagan, met with the MERIL Executive Team in April. They presented the information about the upcoming conference in September in Kansas City and asked for financial support from MERIL to assist with the costs of registration so that members could take advantage of this great opportunity for training. The MERIL team agreed to sponsor six member’s registrations to attend the conference in September. The group is looking forward to meeting new people, making new friends, showing what our chapter is all about and getting new ideas from other groups. Our local chapter has been working to raise money to help offset the cost of the conference. They have had a successful Bingo night and are selling rice bag warmers to make extra money for the group.

Chapter Updates

Tell us what your chapter has been up to! If your chapter wants to be highlighted in this section of the newsletter, please submit your chapter updates to missouripeoplefirst@gmail.com!

Congress on Disability Policy

SELF ADVOCATES TAKE THE LEAD IN STATEWIDE ADVOCACY COALITION!

Becky Dickey, who represents People First of Missouri on the Congress on Disability Policy will soon be the leader of that Coalition!! She was nominated and elected chair last year. She assumes her chairwomanship this summer.

The Congress on Disability Policy is a broad-based, cross-disability coalition of Missouri associations and councils that represent people with disabilities, their families, community providers, and others. Membership consists of 11 statewide organizations with thousands of individual or organizational members who provide services and supports to over 100,000 Missourians with disabilities. The purpose is to “advocate for an enhanced quality of life for Missourians with disabilities and their families by identifying common values that drive shared policy positions.” We are committed to bringing about positive change for Missourians with disabilities through education, advocacy, and action.

The CDP, as it’s called, has been around since 2003. They have taken positions on legislation, advocated, testified before House and Senate Committees, held a statewide candidates forum on disability issues and written papers on policy positions. The CDP will get together in the fall, under the leadership of Becky, to talk about each organizations legislative priorities and decide which of those they want to support as a group. Have ideas? Want to know more about legislative advocacy? Talk to your representatives on the Congress on Disability Policy: Becky Dickey, Gary Stevens, and Cathy Enfield!
Registration for the conference is now open! The registration fee for self advocates, family members, and professionals is $375. Registration for PCAs is $300. Don’t hesitate—register today and make your reservations directly with the hotel! Any information you need about registration, lodging, and transportation as well as conference activities can be found on the conference website at http://sabekc2010.org.

The opening ceremony this year will consist of a huge celebration of the self advocacy movement and the ADA. We will highlight personal stories and testimonies of the leaders of the movement. Sharon Lewis, the new ADD Commissioner, and Jim Gardner, the president and CEO of the Council on Quality & Leadership will present keynote speakers for the Friday morning general session. The SABE board will present a skit about how they envision Self Determination in 2020 and host a World Cafe activity where you will have a chance to help SABE to what self determination will look like in 2020! Sunday morning, the conference will send you off with a call to arms from the youth of the self advocacy movement!

SABE KC 2010 will have over 75 breakout sessions for you to learn about what speaks to you, including sessions on self advocacy, sexuality, and employment. In addition, the SABE KC 2010 Self Determination Showcase will allow you to visit with pioneers from across the country about the innovative projects they have created to highlight self determination in the lives of people with developmental disabilities! Don’t miss the No Talent Show on Friday night, where you will see self advocates from all over the country shine!

SABE has had a busy spring. We were active in working to keep both the Class Act and Community First Choice Acts as part of the Health Care Reform Bill and we were successful!

SABE has been active in working to eliminate Section 14c of the Rehabilitation Act of 1973 which allows the payment of subminimum wages to people working in sheltered workshops, however it is not likely that the Reauthorization of the Rehab Act of 1973 will come up for a vote during this session.

SABE is getting more opportunities to work with other groups to get rid of the “R” word and to promote the use of People First Language. They are also working hard to get all institutions closed. Closing institutions and getting rid of the ‘R’ word are so important to SABE that we have established a committee that deals only with these two issues at the national level.

SABE has a more prominent role at the national level under the Obama administration than we have had. SABE President Chester Finn was recently appointed by President Obama to be a member of the National Council on Disabilities. As part of this group Chester will help advise President Obama on all national and international disability issues. Chester also represents SABE on Justice for All. This group is a coalition of organizations that works closely with the White House and with other groups primarily on civil rights issues for people with disabilities.

Several SABE Board members have been organizing and facilitating monthly conference calls on various topics that concern self advocates including family supports, employment, health care reform and social security issues. This is part of a grant project that SABE is doing in partnership with the Easter Seals Foundation.

SABE has participated in the Project Vote grant for several years and is applying for the grant as the lead agency!

SABE is looking forward to seeing all of their Missouri friends at the National Conference in Kansas City in September.

By Cathy Enfield, SABE secretary & Region 4 Rep
The Patient Protection and Affordable Care Act was signed into law on March 23, 2010. Congratulations advocates for staying tride and true! Now millions of Americans have access to quality, affordable healthcare.

The comprehensive health care reform legislation passed by Congress will significantly improve health care. The new law will make health care more affordable for working people, cover millions of Americans without insurance, and strengthen Medicare and Medicaid.

The health reform builds on the current system to increase access and choice in health care and long term care for people with disabilities.

- **Insurance reform:** National Health reform will end discrimination by insurance companies against people with disabilities and people with pre-existing conditions. You won’t be denied and there will be caps on out of pocket costs.

- **Coverage of medically necessary benefits:** Required benefits provided by health plans will include durable medical equipment, rehabilitation, habilitation, mental health and substance abuse treatment. You will be able to access a range of disability-related services you need to live independently.

- **Affordable health care:** People in the two-year waiting period for Medicare and other low and mid-income uninsured individuals with disabilities can get affordable health care using premium credits and cost-sharing subsidies. You won’t have to go into medical debt trying to pay for COBRA or for high premiums in the individual market.

- **Medicaid coverage:** Low-income people with disabilities will be covered in the new Medicaid expansion, increasing access to health care and long term services and supports. You won’t have to pay such large out of pocket costs to qualify for Medicaid. The healthcare reform legislation passed in March raises Medicaid eligibility to 133%

- **Access to home and community-based services:** The 90% of Americans with no long term care coverage will be able to enroll in a voluntary long term care insurance program that guarantees benefits and does not discriminate against people with pre-existing conditions. If you pay into the program for 5 years, you will be able to access supports necessary to stay in your own home without having to spend your life savings to qualify for Medicaid attendant services.

For more detailed information on what healthcare reform means to you, please visit DCHR’s website: [http://missouriDCHR.org](http://missouriDCHR.org)
What’s Happening

Real Choices, Real Voices Conference
August 22-24, 2010
http://dmh.mo.gov/diroffice/consaff/ConsumerConference.htm

SABE KC 2010: Jazz It Up!
September 23-26, 2010
Westin Crown Center - Kansas City, MO
http://sabekc2010.org