Self Advocates Becoming Empowered SEPTEMBER 2014 FALL EDITION

Self Advocates' Reflections of Marriage and Family at Olmstead Roundtable

On June 24, 2014, Donna and Ricardo Thornton, two leaders in Washington, DC's statewide self-advocacy coalition, Project ACTION!, testified at a roundtable hearing before the U.S. Senate Committee on Health, Education, Labor, and Pensions (HELP). The hear-

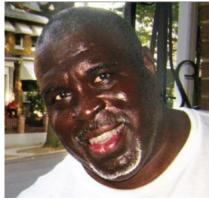


ing was entitled Moving Toward Greater Community Inclusion – Olmstead at 15. The Thornton's grew up in

Forest Haven, a state institution, and their unique story of life and love after transitioning into the community has allowed them to share their experiences around the country and world. They recently celebrated their 30th wedding anniversary, renewing their vows in front of hundreds of family and friends, including their son, daughter-in-law, and three grandchildren.

Donna described Senator Harkin, the Committee's chairman, as, "...polite and friendly. It looks like what we said meant a lot to him. He seemed very understanding and patient. I wanted to tell him the way I feel." She shared with him and the committee's other members about

her prayers as a child to get out of Forest Haven, to one day become a wife and mom, and that all residents of



Forest Haven would be free. When some of the committee members prompted her to talk more about Forest Haven and how she feels about institutions, Donna said, "No. I just want those places closed. I'm just glad me and my husband spoke up and got out of there. I want to look forward, not backwards." Donna's testimony revealed that her prayers were answered.

Story continues on Page 12

SPEAKING UP FOR US OF MAINE

Maine's Self-Advocacy Network

...every time we speak up for ourselves we make Maine a brighter place

Big Changes for Speaking Up For Us of Maine!

Lately the Board of Directors of Speaking Up For Us (SUFU) has been talking a lot about change. At a recent board meeting our new Executive

Director, David Unger, shared a famous quote by ancient philosopher Heraclitus "The only constant is change." SUFU Board meetings have been featuring "Aha moments" at the start of every meeting. These moments have brought new skills to our Directors to be able to make decisions about our organization

and make changes that will benefit all of our members.

SUFU has a whole new website that will be easier for our members to find out updates, news, and training information. The new website will also feature a training video series all about cooking. We formed a partnership with The Art Department and Maine Health to bring healthy cooking tips, tricks, and recipes easily to our members. If you want to check out our new website go to www.sufumaine.org.



SUFU Board of Directors

Growth is another form of change, and SUFU is working to grow our membership. We are meeting with support agencies to sponsor chapters around the state. We are offering members only benefits which will include chances for employment opportunities.

Membership growth is

important to help our organization stay a strong and an important part of our members' lives. We want to get more young people involved so they can learn to become strong community members.

SUFU has even made some changes to our annual conference. The SUFU conference this year is being held in Bangor at the Hilton Garden Inn on September 16 and 17. This year's conference will feature keynote speaker Josh Kennison, a bronze medalist in the Paralympics. We have also invited gubernatorial candidates to speak. For our dance we are having a live band, and we are offering a game room space for members who do not want to dance, but want to socialize with new and old friends. There are sponsorship opportunities and exhibit spaces available in our vendor fair. Our conference registration will be available on our website www.sufumaine.org.

Our Board Chair, Jon McGovern, had this to say about the growth of SUFU: "I like the changes and the direction that we are going in and I would like to see it stay that way. For example I like the new director we hired, he has been teaching us to work as a board. I have been getting the agenda ahead of time and phone calls every week. Our advisor roles have changed too. Board members have all been helping out and everyone is participating now."



Overall, these changes have brought the fun back into SUFU and reminded us that even though the work we do can be

SELF-ADVOCATES BECOMING EMPOWERED ~ FALL 2014 NEWSLETTER ~ WWW.SABEUSA.ORG

serious, it can still be enjoyable. All of these exciting changes have brought a new feeling to SUFU and we will continue on our new path to make a difference in the lives of our members.



SABE Executive Committee

Bryon Murray, President
Utah, Region 3
Cathy Enfield, Vice President
Missouri, Region 4
Betty Williams, Secretary
Indiana, Region 5
Ryan Duncanwood, Treasurer
California, Region 2
Chaqueta Stuckey, Sergeant At Arms
South Carolina, Region 6

SABE Board Members

Region 1

Jason Billehus

Region 2

John Britton

Region 3

Amira Rasheed

Amira Rasheed
Region 4
Bill Story
Region 5
Carrie Varner
Region 6
Bernard Baker

Region 7
Region 8

Clint Perrin & Max Barrows
Region 9
Consuelo Castillo & Samuel Jenkins

Declaration By Coleman Institute

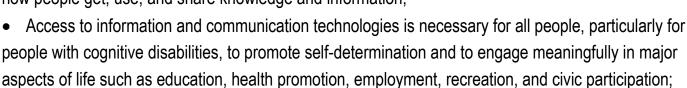
Rights of People with Cognitive Disabilities to Technology and Information Access

Watch a video on the Declaration https://www.youtube.com/watch?v=X0ACjPsndAs

Adapted Version of the Declaration

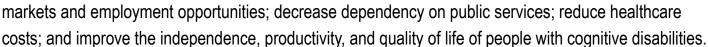
Whereas,

- Twenty-eight million United States citizens have cognitive disabilities.
- People with cognitive disabilities are entitled to inclusion in our society.
- The use of computers and communication technologies has changed how people get, use, and share knowledge and information;





- The vast majority of people with cognitive disabilities have limited or no access to information and usable communication technologies;
- People with cognitive disabilities must have access to devices and software that incorporate principles of universal design such as flexibility and ease of use for all;
- Technology and information access by people with cognitive disabilities must be guided by standards and best-practices, such as personalization and compatibility across devices and platforms including automated and predictive technologies;
- Security and privacy must be assured and managed to protect civil rights and personal dignity of people with cognitive disabilities;
- Enhanced funding is urgently required to allow people with cognitive disabilities to use technology and access information;
- Ensuring access to technology and information for the 28 million people with cognitive disabilities in the United States will create new



Therefore

We hereby affirm our commitment to equal rights of people with cognitive disabilities to technology and information access and we call for implementation of these rights with deliberate speed.

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Technology and Communication Access A Self-Advocate's Perspective



The Coleman Institute's Declaration of the Rights of People with Cognitive
Disabilities to Technology and
Information Access is vital to the future of all Self-Advocates.

Information and communication technologies are commonly used and valuable tools for billions of people worldwide today. This technology includes things such as computers, cell phones and iPads. As common as these tools are, we know that access to these technologies is very limited for people with intellectual and developmental disabilities. As the world continues to change we are seeing that access to education is more and more dependent on these technologies. Our access to participating in many community activities is becoming more dependent on them. It is becoming very difficult to even apply for a job without the ability to get online.

Reducing the barriers to information and communication technologies for individuals with cognitive disabilities is becoming more and more important as these technologies play a larger role in everyday life. Without access to these technologies people with cognitive disabilities will become more and more disconnected from their community and from opportunities to be a part of it. Many

of the gains we have made may be lost. I believe that this declaration and its commitment to obtaining equal rights and opportunities for people with disabilities to technology and information access are vitally important to our future. I also believe that we do not have a great deal of time in which to act.

I am proud to have been one of the 24 members of the work group at the Coleman Institute that developed this declaration. I would ask you to please read it and I hope you will endorse it. If you agree with its commitment to our future please get it distributed to as many organizations and individuals as you can and make them aware of it importance to you and to the self-advocacy movement.

The **Declaration** and its history can be read, copied and endorsed at: <colemaninstitute.org/declaration>. If you

do not have access to a computer please call me and I will mail you a hard copy that can be endorsed and returned to me.

Thank you
Cathy Enfield
816-808-4080



Abuse of Persons with Disabilities: The Silent Epidemic By Kecia Weller and Molly Kennedy



In "Abuse of Persons with Disabilities: The Silent Epidemic," We ask all victims of abuse to join together to stop these crimes in their community. Our video is an easy-to-understand call to action. Educate, Organize and Prevent!

Link: http://youtu.be/yhLsATwO0o4



Kecia Weller has been a disability rights advocate for more than 15 years.

a government agency that helps people with disabilities live the life they want.

I want to break the silence. Too many people fear retaliation when they think about talking with someone or reporting people who hurt others. As a self and peer advocate who sits on boards of directors and councils, I represent my community. I help make public policies that improve our lives. I also want to help people with disabilities break through barriers that abuse brings and become empowered to help break those chains.

Some people tell me that they were told

to **BE QUIET** by their abusers. I feel strongly that we all have to be educated about this. We must have trusted friends who will help us get the courage to report people who take advantage of us - take our money, beat us up, or intimidate us. I have learned abuse comes in different ways, such as:

- Someone taking your ATM card and taking your money
- Uncomfortable, unwanted touch
- Being forced to make important decisions, not understanding what they mean

As a former Consumer Advocate for a California regional center, it was my job to help other advocates stand up for themselves. When the idea of a short



abuse prevention video came along, I realized this is an important way I can continue my advocacy.



Molly Kennedy
has been a
disability rights
advocate for
more than 20
years. She
currently serves
as the vice
chairperson of

the California State Council on Developmental Disabilities.

I became involved in our abuse prevention video because *I do not want to be intimidated*. I don't want other persons with disabilities to be intimidated, neglected or abused. When people have limitations it can make them more vulnerable. It can lead others to control and abuse those individuals. You might have limitations but you don't lose your human rights to live without intimidation and abuse. I'm smart and I know sometimes I express my frustration in inappropriate ways, but it doesn't give anyone the right to abuse me.

Helping to make this video and encouraging others to report offenders (like I have done) makes me feel like a true advocate, by using my own example. It gives me a way to say to others, who are intimidated or shamed

by authority figures, to stand up, share your experience and, most important, report them! **This must stop** –

Unfortunately today research presents a horrific picture. Persons with developmental disabilities are 4 to 10 times more likely to be victims of crime than are others. We are all human beings. We all have a right to a peaceful, safe life. If you like the video, pass it along to others. Most important, if you or someone you know has had an abusive experience – share it with someone you trust and report it to the authorities.

Board Resource Center

Our work centers on advancing human rights by helping people clarify how they want their lives to unfold and how their communities could better serve everyone. Guided by colleagues who have been victims, we are committed to assuring crimes of abuse are confronted.

As self-advocate leaders affiliated with many advocacy organizations, Kecia and Molly recognize that abuse is pervasive and often hidden. They know that the first steps towards prevention are raising awareness of the problem.

North East Advocates Together NEAT!

By Hilary Clark and Skye Peebles



July 18, 2014 - In October 2013, the Administration on Intellectual and Developmental Disabilities awarded a

three-year grant to the North East Advocates Together (NEAT) Peer to Peer Connections Technical Assistance Project as one of the Projects of National Significance. NEAT is one of three groups to receive this Technical Assistance Award.

The other awardees are: Self-Advocates Becoming Empowered (SABE) and Autistic Self-Advocacy Network (ASAN).

The goal of the North East Advocates Together (NEAT) Peer to Peer Project is to build strong peer to peer connections between the Self-Advocacy groups in Maine, New Hampshire, New York, Vermont, Massachusetts and Rhode Island. Starting in October 2014, NEAT hopes to add Connecticut to the project as well.

This project supports self-advocates and teaches each other to organize self-advocacy activities and to share knowledge around building our regional self-advocacy organizations to be stronger. Each of the peers and self-advocacy organizations in the northeast

region have so much experience and knowledge about self-advocacy. The foundation of this project is to have state

self-advocacy organizations identify their organization's needs and then match that organization up with another state in the region that is strong in that area. Peers will provide technical assistance to each other to strengthen needs and share information

and resources. The creative part is that we largely use the internet to communicate and share information. Together six Self-Advocacy Organizations of the northeastern United States came together to design this project.

Peer leaders from each state have been elected to be on the NEAT Regional Advisory Committee. Each state has also identified someone from one of their state Developmental Disability Network programs to be an advisor on the Advisory Group. The group is responsible for directing the project and supporting the project's Outreach and Administration Coordinators.

The NEAT Advisory Group has monthly meetings and one face to face meeting

NORTH EAST ADVOCATES TOGETHER

SELF-ADYOCACY

STRONGER

TOGETHER

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NEAT!

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per year. So far, each state has completed a needs assessment about their self-advocacy strengths and needs. 27 people from the group came together in Manchester, NH for two days in May 2014 and reviewed each other's needs and strengths. The groups had "roundrobin" style meetings with each other to talk about ways their strengths and needs match up. After these meetings. each state made a technical assistance plan to plan out how they will give technical assistance and how they well get technical assistance. People said that some of their favorite parts were, "Learning about what other states are doing to improve how their state organization are running," "Chatting with people I haven't seen in a while," and



"Learning how other states are approaching their challenges which were often similar to ours." We are now in the stage where states give technical assistance and will help each other learn new self-advocacy tools.

Here are a few examples of the types of technical assistance states are going to give each other: how to connect to young



adults through self-advocacy, Board Development, Improvement in technical operation and organization policies, website accessibility and using social media and technology better, school presentations, leadership development, and creating diverse and sustainable fundraising.

During the course of the project, states will learn about technology and new ways to connect with each other. The technology that we are learning right now include Doodle, Dropbox, Google Plus, Google Calendar, Google Hangout, GotoWebinar, GoToMeeting, and Facebook. We are also using these tools to help us stay connected. We are creating a website for NEAT that will have information about the project, project partners, resources about self-advocacy, and will be a place to keep all of the technical assistance tools we develop.

For more information about NEAT, please contact: Hilary Clark, NEAT Project Outreach Coordinator (hilary@gmsavt.org) or Skye Peebles, NEAT Administrative Coordinator (skye@gmsavt.org).



Alabama Arkansas Florida Georgia North Carolina Oklahoma South Carolina Tennesseo

Self Advocacy is like Kudzu, you can't stop it!

Our Community Standing Strong, SABE's Regional Technical Assistance Center for Self Advocacy Grant (OCSS) continues its efforts to spread the word about the power of self advocacy across the South. The states involved in these efforts include: Alabama, Arkansas, Florida, Georgia, North Carolina, Oklahoma, South Carolina, and Tennessee. All states are being supported by partners in their perspective state as well as states sharing and encouraging others to progress.



Advisory Committee Members at the Birmingham Civil Rights Museum

Update on our activities:

- Advisory Board Meeting met in Birmingham, Alabama in May. There were 39 participants and all members had a voice and a stake in activities. Some members joined the meeting through social media outlets. How awesome was that experience! State teams gathered to begin work on their state plans. Alabama DD Council showed tremendous support as a partner and host state of the meeting. Members visited the Civil Rights Museum and Disability Rights Exhibit.
- •7 of 8 states that have completed video blogs. The Vlogs range from various subjects of importance from each state. Every state has different issues that need special attention.

http://goo.gl/8BQKEI

- We have reached our 1200 Survey Goal. Congratulations! Total surveys are nearing 1250. http://goo.gl/KOlklZ
- •4 of 8 states have completed their state technical assistance plans and all will be complete by August.

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Self-Advocate Coalition of Kansas (SACK) has been invited to partner with the Kansas Council on Developmental Disabilities in a program to build leadership among the self-advocate community in Kansas. The program is through the Kansas Leadership Center in Wichita, Kansas

designed to create a sustainable leadership program within our local communities. The project officially began July 18, 2014.

SACK recently held its annual statewide conference on June 27-29 in Topeka,

Dream Big



2014
Self Advocate Coalition of Kansas

Annual Conference Topeka Ramada Inn June 27-29th, 2014 Topeka, KS Kansas. This year's theme was "DREAM BIG" and was attended by over 250 self-advocates, family members and/or support staff. 15 workshops were offered on a variety of topics such as voting rights, sexuality and relationships, healthy eating habits, grassroots advocacy and others. Following a formal dinner, self-advocates attended a DJ dance complete with a Photo Booth which was

the hit of the night! Planning for next year's conference has already begun as expanded workshop offerings have been requested and celebration of the 25th Anniversary of the Americans with Disabilities Act will be included.

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•Monthly Webinars are hosted and conducted by self-advocates and allies. Topics have included: Writing a state technical assistance plan, How to produce Blogs/Vlogs, How to build partnerships, Funding Strategies.

We will be working with People First of Alabama and the DD Partners from Alabama in August with the SABE executive committee on partnerships and Alabama's Technical Assistance Plan.

Our next advisory committee meeting is planned for the National Conference in

Oklahoma City October 9-12, 2014.

OCSS would like to also thank Bryan Murray, President of SABE and the SABE Board for their continued support as well as the many allies and partners joining in this moment of excellence for self-advocacy. The project effort is led by Co- Directors Chaqueta Stuckey and Vicki Hicks Turnage. Other support efforts include Juliana Huerena and Glenda Hyman-Singletary. For more information on the project follow SABE



on Facebook or follow the project at www.sabe.org

Self Advocates' Reflections of Marriage and Family at Olmstead Roundtable ~ continued from page 1

She and Ricardo are married, and they have a son, who is now married and has a family of his own. In closing, Donna shared one final prayer: "I hoped that I could see them grow up and go to college. Because I didn't go to college,

but I want to see them go to college just like everybody else."

Ricardo's testimony before the Committee reflected times of sadness, joy, and hope. His description of



Ricardo and Donna's wedding 30 years ago.

growing up in the institution was "like I was doing time for a crime I didn't commit." It did not sentence him to a life of anger, but rather fueled him with optimism and motivation. He, like his wife, remains focused on what the future holds. When Ricardo was asked how he feels about advocating before politicians, he stated, "It means that – once living in an institution and now living in the community - we live the words, 'Let our voices be heard.' Teamwork makes the dream work! I like telling other people that they can choose, and I like to encourage them to look at disability not as a weakness, but just as part of a person.

We can work, love, and share in each other's happiness. I love changing politicians' concepts. I love changing the concepts of what institutionalization means, and what community living means. Getting married is one way of

showing others we can do things like anybody else! Our anniversary was a celebration of the past, present, and future. We were blessed to have so many people celebrate with us."

Donna and Ricardo Thornton are longtime members and leaders in Project ACTION!, Washington, DC's selfadvocacy coalition, where they continue to inspire and motivate others to dream and advocate for a better life.





This letter to SABE was written before Michael Brown, an unarmed African American teenager, was shot and killed in Ferguson, Missouri by a police officer on August 9, 2014. Our hearts are heavy with sadness and anger because of what is happening to victims of Police Violence throughout our country.

Dear SABE Editor,

My name is Chad Sinanian. I'm a Past Officer of SABE and Vice President of People First of Connecticut.

I am writing this letter because it bothers me that around the United States I hear of stories where the police have taken advantage of persons with disabilities, questioned them and arrested them without a lawyer. There are too many stories of people being manipulated into signing confessions to crimes they're not guilty of, and as a result, there are many persons with disabilities serving life in prison, or worse yet, they're on death row.

I've become personally and emotionally involved with RICHARD LAPOINTE, an individual with disabilities, who has been in prison in the state of Connecticut for over twenty five years for a crime he didn't commit. I've been visiting him in prison for several years, and have done several presentations on his behalf because I know he's innocent.

The crime took place in 1987 in Connecticut. For two years, this crime went unsolved. Then, in July 1989, Police Detectives took RICHARD LAPOINTE in for questioning. He was questioned by police for more than 9 hours. By 1:30 a.m. he had signed three inconsistent confessions. The questioning wasn't recorded. Richard, due to lack of comprehension, didn't know what he was signing. As a result he was tried and convicted and sentenced to life without parole.

The Friends of Richard Lapointe have rallied behind him. We believe he's innocent. I have conducted several fundraisers and I visit him in prison. I tell him to hang in there, not to give up hope, that he'll be set free.

On **September 17, 2013**, the state Appellate Court overturned Richard's convictions and ordered a new trial. There is currently an appeal pending in the Connecticut Supreme Court. We are anxiously waiting for their decision.

None of this would have happened if RICHARD LAPOINTE was given accommodations. Richard should have asked for a lawyer, been told he could have a lawyer, and he shouldn't have signed anything without a lawyer.



I would like to say to persons with disabilities, if you are questioned or arrested by the police, NEVER SIGN ANYTHING OR MAKE ANY STATEMENT WITHOUT A LAWYER. Some police do take advantage of persons with disabilities, and we persons with disabilities need to know and advocate for our rights so there aren't more of us in prison or on death row for crimes we're innocent of committing.



Tammy Mills

People First of New Hampshire

"I felt excited and adventurous when I voted for the first time. When I say adventurous, I mean brave, daring and willing to try strange new things."

Here is what Tammy has been up to this summer!

I love going to Silver Towers Camp every summer. Need I say more? I don't know how many friends I've made at my favorite summer camp that's geared for all ages and ability levels, but I do know that there are plenty of things to do at the camp. Here are some examples of what the camp activities include.

Let's start with music, because that's my favorite subject. It's not just about sitting around or dancing and listening to music. You have to include some fun games you can play that involve music.

I love to play Bingo on Monday nights after supper, because when I get a Bingo and win a prize, I just have to go to the prize room and claim it. I found out this summer that I didn't need prize tickets to cash in before claiming my prize. All it took was a walk into the prize room in order to get it. In my case, the prize I claimed was a Word Search book.

The camp also has a swimming pool for campers. But because I only had a half hour of rest time during the weekdays this

year, I didn't have enough time to take a dip in the pool except for Saturday afternoon. That was the one and only time I got to wear my swim suit and go swim in the water.

Now, I'd like to bring up the subject of indoor and outdoor sports back home in my town. There are plenty of games to play both inside and outside at your local Rec Center. One of them is bowling. I love to bowl. The only problem I have with bowling is the fact that it's not ten pin bowling, but candle pin bowling. And it takes longer to knock all the pins down with the smaller balls. My only wish is that the local car dealers hadn't decided to buy out the local bowling alley where I used to play with the Family Fun Bowling League.

Horseback riding, nature walks, and arts & crafts, are fun to do. I love horseback riding best. It gives me the freedom to ride tall around the outdoor arena and sing as I go along.

But the best part about my two-week stay at Silver Towers Camp, was the award I got. I was awarded for Best Leader, and I'm very PROUD of myself for that award.

My Reflection

By Maleia Darling

Maleia Darling goes to High School in Vermont

I came here as a young wild child, adrift in my own world of sensory stimulation. The concept of school, the idea of learning to read, write and do arithmetic, weren't on my agenda. I was different. I was the beautiful blond little girl with big beautiful eyes. I was also the girl who bolted out the door at any given time. I was the girl who screamed at random, but couldn't speak to tell you what was wrong. I was autistic.

Don't get me wrong. I am still autistic but not as wild as I used to be. I have used my time well at Middle and Elementary School and it is quite evident through my writing. What I have learned here is more than language arts and irrational numbers. I had to learn to cope in a world that is oh so out of my comfort zone. I had to break through my world of autistic jumbled nerves and take on the task of being social.

When I was little, like in first grade, all I heard was "maleia, put with same." I had to match pictures together as if matching items or words was a measure of intelligence. (By the way, it is not.) I knew I was smarter than most of the people I worked with. I am pretty sure they knew that too and matching items was a test of my ability to focus, motor plan and overcome the sensory disturbance common to people with autism. My job as a young student was to learn coping techniques that would enable me to stay in a

noisy, bright class without having a meltdown.

I have some advice for my friends. We all have to cope with stress in our lives. I don't struggle with language arts but fluorescent lighting flickers in front of my eyes and distracts me. You on the other hand don't even notice the lights but can't stand writing poetry. You like to talk a hundred miles an hour but are scared that silence means you are alone. I can't understand what you talk about so fast and I love the calm of silence. What we have in common is wanting to belong, to be wanted and valued. We are all the same, we all need to cope and be patient of ourselves and each other. Coping is the same for all of us, we just have different issues to cope with.

We leave here in the next few months to go to high school. Will we have a whole bunch of stress? Undoubtedly. Our lesson learned at middle school will still apply at high school. We will need to cope and deal with stress, happy or sad events as they may be.





PO Box 12239

Florence, SC. 29504

What's Happening with People First of Eugene and Springfield in Oregon By Cindy Helvington



People First of Eugene/ Springfield is a welcoming place that to make new friends. speak for themselves,

and learn new skills. We enjoy having teen-age guests at the meetings to see how groups work and get inspired to start a group for others their age. We are working on a presentation to help them start a group.

People First members fill our meeting room, run the meetings, vote on and plan activities and outings, elect officers, and practice leaderships skills, inspiring each

other to become leaders. We make our agendas and decide what we want to do and how to make it happen, like our gives everyone a chance annual bowl-a-thon and camping trip and holiday party, as well as day trips and movies.

> People First members serve on community boards of directors and other committees to change how services are offered. People First members learn about what is happening in the state, vote, and write letters to their legislators. People First members spread the word about People First and invite others to join, participate in activities, become leaders, and do things they never thought they would.

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