

# SELF-ADVOCACY NATION

## BY SELF ADVOCATES BECOMING EMPOWERED

Spring 2010



SABE is your national self- advocacy organization. Self advocates are people with disabilities who speak up for themselves.

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Region 9 Nancy Ward, Oklahoma



For an update on SABE's 2010 National Self Advocacy Conference, see page 8!

### The President Speaks

By Chester Finn

What has Self Advocates Becoming Empowered been working on?

SABE spent the last months of 2009 working with the Obama Administration and Justice for All on health care legislation. We advocated for the Community First Choice option and the CLASS Act to be included in health care reform legislation. This includes self-directed services, people being supported in the community, and insurance coverage for people with disabilities who do not qualify for Medicaid. We need to keep up the pressure for Health Care for All and not accept it not being approved by Congress.



In 2010, we have been working on an employment initiative to hire people with disability at the federal, state and local levels. The unemployment rate for people without disabilities is around 9%; however the unemployment rate for people with disabilities is 14%. So watch for new initiatives that will provide opportunities for people with disabilities to work. Also, make sure that you work with your Alliance of Full Participation State Teams on employment. The Alliance of Full Participation has opportunities for webinars on employment. ([www.allianceforfullparticipation.org](http://www.allianceforfullparticipation.org))

With Easter Seals, we have sponsored four conference calls on family support and self advocacy. We encourage self advocacy groups and other organizations to participate. Conference call topics to date have included: family support, employment, being a part of the community, and inclusive and generic supports for individuals for individuals with autism. Our self determination committee members attended the conference on family support held in Detroit February 19th and 20th. The focus of the conference was family support navigation with self advocacy being a major component. (More info on page 5)

We also filmed stories on self-determination at our board meeting in Decatur, Georgia in October 2009. Thanks for all of the help from our board members, People First of Georgia, and the University of Georgia. Stories will be on our website and the self-determination website soon.

We are working with People First of Missouri and the University of Missouri-Kansas City Institute for Human Development in planning for the National Conference September 23-26, 2010. The theme is *Jazz It Up in Kansas City-Feeling the Music of Self Advocacy*. The conference will be SABE's 20th Anniversary. See [www.sabekc2010.org](http://www.sabekc2010.org) for more information.

We are working with the Justice for All Network on the ADA celebration in July. Also, remember to Get Out and Vote in your local, state and national elections. It is important that our VOTES be counted.

**SABE USA**

A message from SABE to the Alliance  
The Founding groups are looking for priorities for the future

Our answer is:  
**JUST DO IT!**

Many have listened, some have taken action and we thank you.  
But we have talked enough and waited too long!!!

We have told you what is important to us  
Get rid of the infamous and hurtful “r” word, do not label us  
We will not put up with the “r” word continuing  
as part of an organization’s name even as initials

If you are working with me and for me  
then do not disrespect me

We have been prepared enough,  
**ASK** the people who are living in institutions  
Would you trade places

Close institutions

Get us real jobs. Close sheltered workshops

Give US the money to live OUR lives  
Money follows the person means it is OURS not programs

We have the right to make our own decisions  
with or without the support from others  
**WE CAN RUN OUR LIVES**

Support our movement,  
**IT IS OURS**

You receive millions of dollars in our name  
We want to control this money as we are the **EXPERTS**

You must change,  
we have changed,

we are taking the power

**Walk the Walk, Respect Us or We will go on without you!**

**WHAT IS HAPPENING WITH RESPECTFUL LANGUAGE, GETTING RID OF THE “R” WORD AND CLOSING INSTITUTIONS?**

**Current list of states that have passed respectful language bills:**

1. Alabama
2. Alaska
3. Arkansas
4. Connecticut
5. Indiana
6. Louisiana
7. Maine
8. Maryland
9. Massachusetts
10. Minnesota
11. New York
12. New Hampshire
13. North Carolina
14. Ohio
15. Oklahoma
16. Oregon
17. Pennsylvania
18. South Dakota
19. Vermont
20. Wyoming
21. Washington
22. Washington DC
23. Utah

**Current list of states that still have NOT changed the name of the state agency from the “R” word**

1. Kentucky
2. New York
3. Tennessee



How did your state change their agency’s name??? Let us know at: [sabenation@gmail.com](mailto:sabenation@gmail.com)

**Current states with no institutions**

1. Alaska
2. DC
3. Hawaii
4. Indiana
5. Maine
6. New Hampshire
7. New Mexico
8. Rhode Island
9. Vermont
10. West Virginia
11. Oregon

**Let’s make it all 50 states! Educate your legislators and policymakers about why institutions need to be closed and people BELONG IN THE COMMUNITY!**

**Julie Petty Meets with White House on “R” Word**

**Joint Statement of Disability Leaders:**

We came here today to meet with Rahm Emanuel and share with him our view on the importance and impact of language. We wanted to invite Mr. Emanuel and all of America to understand the collective efforts of our community to remove the words “retard” and “retarded” from everyday speech.

The R-word is polluting our language. Every day our community hears this word – in schools and workplaces, in print and in movies, on radio and television. And every day they suffer its dehumanizing effects – mockery, stigma, ridicule. This is a word that is incredibly damaging – not only to the seven million people with intellectual disabilities in the United States, but also their friends, family and to all of us.

We are thankful to Mr. Emanuel for meeting with us today and hearing our concerns. He sincerely apologized for his mistake and the pain it caused in our community.

We are happy that he will join more than 76,000 people who have pledged to end the use of the R-word at [www.r-word.org](http://www.r-word.org), and that he committed that the administration would continue to look for ways to partner with us, including examining pending legislation in Congress to remove the R word from federal law.

Our community has earned the right to be respected instead of ridiculed. We have suffered injustice for generations and we are demanding that it end.

This is another small step on the road to a country that accepts the gifts of all.



*From left: Julie Petty (SABE Past President), Rahm Emanuel (White House Chief of Staff), and Ricardo Thorton (Self-Advocate and Special Olympics Athlete)*

**R-WORD UPDATE FROM DOWN SOUTH**

After joining together to do the Tropic Thunder protests in Georgia, People First of Georgia and the Arc of Georgia have been collaborating to get legislation passed that will remove the R-word. People First of Georgia organized a meeting to educate people on the issue. The president of People First of Georgia, Cheri Mitchell, asked the SABE Board to speak about the work

they have done nationally on this issue. The meeting started with the People First of GA explaining why they wanted to have the meeting and an update from a representative from the Arc of Georgia on getting legislation passed in Georgia. The SABE board led a discussion on why Removing the R-word is important. Tia Nelis, the vice president of SABE, told the audience that it

is about respect. Words hurt! Different members of the SABE board shared what worked and what did not work in their state on removing the R-word. People left the meeting with a better understanding on the issue. They were fired up and ready to speak to their state representatives! —Cherie Mitchell, People First of Georgia

## PARTNERSHIPS FOR THE FUTURE AND BEYOND

Partnerships for the Future will only be successful if they focus on common issues of access that face our nation, and develop strategies and solutions that can benefit ALL. Issues that face our country such as employment, housing, transportation, and education are important to all in our communities. Organizations and advocacy groups for people with disabilities need to reach out to other groups in our communities who are also struggling for strategies to address these issues. Self advocates bring a unique perspective to the table with their experience of having experienced discrimination and lack of access to employment, housing, transportation and education.

Examples of Partnerships for the Future may include:

- Self advocates working with direct support professionals to have them recognized as true professionals, just like doctors, nurses, social workers and lawyers - these professionals can offer supports and services to people with disabilities and the elderly in more cost effective ways than our current systems of home health care.
- Self advocates and organizations supporting people with disabilities become involved with community economic development groups addressing the issues of education, workforce issues and employment opportunities.
- Self advocates and organizations that support us may partner with AARP to eliminate the marriage penalty under the Social Security Act.

In our future, our partnerships must embrace self advocacy groups as unique and equal partners, and recognize that others cannot speak for us or become us.

—*Chester Finn*

## UPDATE ON SABE SELF-DETERMINATION COMMITTEE

The SABE Self-Determination Committee has been working with a project funded by the Administration on Developmental Disabilities called “A National Training Initiative to Scale-Up Self-Determination in the United States”. We filmed several self-advocates in Atlanta last October telling stories about how self-determination improved their lives and helped them live the life they want to live. These will be on the project website soon- we will let you know when the website is up! If you have stories about self-determination in your life, email them to Laura Walker Jackson at [walkerla@umkc.edu](mailto:walkerla@umkc.edu). Also, we have put together a survey for state and local self-advocacy organizations to let us know what is happening in self-determination in their self-advocacy efforts. Go to [www.SABEUSA.org](http://www.SABEUSA.org) to fill out this survey or email Laura Walker if you want a survey sent to you.



**Have you visited our website yet? <http://www.sabeusa.org!>**

## SABE A PARTNER ON A FAMILY SUPPORT PROJECT

### Who are the partners?

We have 6 partners:

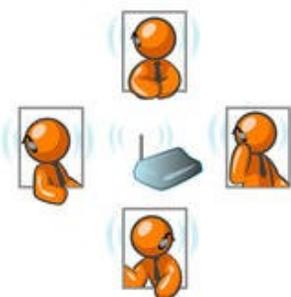
- Easter Seals
- National Association of Councils on Developmental Disabilities (NACDD)
- National Disability Rights Network (NDRN)
- The Association of University Centers on Disabilities (AUCD)
- The Arc of the United States
- Family Support Center on Disabilities: Knowledge & Involvement Network (KIN)

### What are you trying to do?

The goal is for SABE to share information about becoming a strong self-advocate with parents of children with disabilities. This includes encouraging and supporting their children to develop leadership and self-advocacy skills. These skills support a person to find their own voice and become active in the self-advocacy movement.

### How are you doing this?

Through September 2010 SABE is holding monthly conference calls. SABE picks the topics to talk about and invites self-advocates and family members to speak on the call. This is a great opportunity for members of local and state self-advocacy groups to connect with SABE on important issues.



### When are the FREE conference calls?

The 3<sup>rd</sup> Wednesday of each month at:

- 3:00 Eastern Time
- 2:00 Central Time
- 1:00 Mountain Time
- 12:00 Pacific Time

Most of the calls last one hour.

### Are you doing anything else?

Yes, we are helping to train people who work with families. We are making sure they understand self-advocacy. We want them to keep our issues in mind when they work with families.

### How do I get more information?

Check the website each month to find out how to sign up for the conference calls. You can also email [topper@sover.net](mailto:topper@sover.net) if you have any questions.



From left: John Britton, self advocate from Phoenix, AZ; Diana Mairose a self advocate from Cincinnati, OH; Bill Story, SABE Board Member (Region 4-KS). Diana speaks to the SABE board at their meeting in Phoenix about the Family Support conference calls.

## The Top Ten Reasons You Should Call In!

1. It's free!
2. All you need is a telephone!
3. It's a way for your voice to be heard.
4. It's an opportunity to hear the truth coming from us.
5. Because Chester said so!
6. It is a chance to know each other and learn about each other.
7. Be part of self-advocacy.
8. We will send your input to Obama.
9. Be included. Join the discussion about what is happening with our lives.
10. If you call your email address will be put in a raffle and in July we will pick a winner who gets a free registration to the SABE national conference!



# SABE CALLS FOR ENDING SUB-MINIMUM WAGE IN 2012

**“We have been prepared enough.  
Get us real jobs. Close sheltered workshops.”**

Position on Employment

October 31, 2009

## **Reasons why SABE is calling for an end to sub-minimum wage:**

- Inclusion is a birthright and work is a civil right. Every American has the right to work in their community without discrimination for any reason.
- Slavery still exists today even though it was banned in 1865 through the US Constitution. There are over 400,000 people with disabilities working in sheltered workshops. There is a rule called 14(c) certificate from the US Department of Labor that says people with disabilities can get paid “sub-minimum wage.” It is not sub-minimum wage; it is hardly any wage at all.
- People 30, 40 and 50 years old are just sitting in sheltered workshops, looking at the wall. It is babysitting grown men and women, not getting them in the community or giving them training to be independent. It is wasting their time.
- Some people earn 45 cents an hour or less in a sheltered workshop. This is “chicken feed.” They really use you and take advantage of your disability. Basically more training in a sheltered workshop means the same training. They should teach people how to do a job on the job.
- Legislators have no problem giving money to institutions and sheltered workshops but they have a lot of problems funding transportation and supports to get people to work. When people work, they put money back in the system.
- People with disabilities can work and handle a job. They know what they are doing and how to speak up for themselves.
- US law says agencies need to believe that people with disabilities can work. The Rehabilitation Act says people can work regardless of the severity of disability, if the right services and supports are provided.

## **Therefore, be it resolved...**

- SABE calls for equal employment opportunities and for equal pay for all people.
- SABE calls for immediately, no new people can go into sheltered workshops.
- SABE calls for immediately, no new people can go join an enclave.
- SABE calls for ending sub minimum wage in 2012.
- SABE calls for ending enclaves in 2014.

*Position on Employment, CONTINUED***Issues to consider:**

- Start with people who feel trapped and want to get out of the workshop. Avoid focusing on the people who you think it will be the easiest to find jobs for. If a person is motivated to make a change, even if they have fears, they are the ones who will lead the way.
- Get benefit counselors to show people how much money you can earn over 10 years. Educate self-advocates on benefits and Medicaid.
- Self-advocates need to talk more about closing sheltered workshops to each other. We need to boldly put out why sheltered workshops must close. There are not enough people speaking up. We must have equal employment opportunities for all people.
- Be sensitive. Do not create a feeling that you are going to shove people out and abandon them. Give them options and support. Even those who are really afraid will have a complete turnaround once they see everybody else working. They will say, “I can do this let me have a chance.”
- People should not lose their home if they do not have a job or place to go during the day.
- It is not acceptable to close a sheltered workshop by moving people into day programs. The goal is to support people to work in real jobs.
- People do not miss the “work” at the workshop; they miss hanging out with their friends. Do not forget to focus on helping the person to get more friends. If you have money in your pocket you can socialize
- Get families on board. When family members are scared about the workshop closing, their fear spills over to their son or daughter. Families are still stopping people from working because they are afraid a person will lose their social security or Medicaid benefits.
- You need to keep people in jobs not just find them. You need to be there for people who lose their jobs and help them find another job. But unemployment is a fact of life!
- Provide peer-operated employment support groups. We have been out in the workforce as a person with a disability. We want the truth. Sometimes agency staff “sugar coat” the information. And depending on the staff person, they can talk for hours when it could have been said in a few words. We are better at knowing how to deal with discrimination and problems of people not accepting us for who we are.
- Provide flexible job support. A person may need support on weekends, evenings, or on a schedule that varies from week to week.
- The agencies with the best success have customized supported employment. They avoid just responding to want ads. Design it around the person: be customer-focused.
- Think outside of the food and filth box – find jobs that involve something other than cleaning, carts and dishes.
- Provide support for people to start their own businesses.
- Improve collaboration between Departments of Labor, Vocational Rehabilitation and other agencies that support people with disabilities.
- Create opportunities for jobs in public speaking and teaching for people with disabilities, their families, and support staff.
- Seek out all types of jobs, including government jobs. Push for employment at their developmental disabilities agencies.

## MESSAGE FROM THE PRESIDENT ON EMPLOYMENT

This statement is my personal opinion and not necessarily the opinion of the SABE board. I am writing this to go with SABE Position Statement on Employment.

It is important for people to understand that employment is important for people with intellectual and developed disabilities no matter what the disability or circumstance. I have friends who are still in sheltered employment and day programs that want an opportunity to get out. They want to have a job and contribute in whatever way that is.

The most important thing is giving a person an opportunity. I would not be where I am without those opportunities and self-advocacy, knowing how to speak for myself. I was given different types of training opportunities through the Commission for the Blind and Visually Handicapped (those words should be changed), and asking for an opportunity from the Commissioner of OMRDD (working to change that name too).

I asked for an opportunity and got it. Here I am 13 years later making progress. This is why I believe other people need opportunities.

When I first went to a sheltered workshop I did not want to go. I took it as an opportunity to learn something I didn't know. I was determined to stay there for a short period of time, get some experience and leave. Most people never get that opportunity to leave. I have never heard from my friends or other people I know say, "I want to be in a sheltered workshop or a day program."

They are there because they were told by an agency or other people that is where they should be. On the other hand the people I know that got an opportunity to have a real job are successful when they got support.

In 2005, at the meeting of the Alliance For Full Participation, I had conversations with Martin Luther King III. One of his questions for me was, "How are we going to get the community to know who we are and get information about us?" I thought about this. And my belief is that we have to be out there in the community for people to see us and get to know us and work with us. The laws of the US Congress give the right to work to people with intellectual and development disabilities as well as people without disabilities. Other groups fighting for their civil rights would not stand for separate places. Neither should we!

As a person that is blind and visually impaired I have a better opportunity for employment then I do as a person with a developmental disability. There is something wrong with that!

So I challenge developmental disabilities agencies, family members and self-advocates to do a better job for fighting for our civil rights to work.



*Chester Finn*  
January 31, 2010

**SELF  
ADVOCATES  
BECOMING  
EMPOWERED**

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**SABE 2010 NATIONAL SELF ADVOCACY CONFERENCE**

**Mark your calendars! The 2010 National SABE Conference, Jazz It Up: Feeling the Music of Self Advocacy will be in Kansas City at the Westin Crown Center September 23 -26.**



Proposals for breakout sessions are currently being accepted and can be submitted at <http://www.surveymonkey.com/s/sabekc2010>. A list of potential keynote speakers is being compiled.

Check the website (<http://www.sabekc2010.org>) often for updates on presenters and hotel information!

There has been a lot of interest in this conference! Over 200 people have signed up for e-mail updates from the conference website!

**See you there!!**

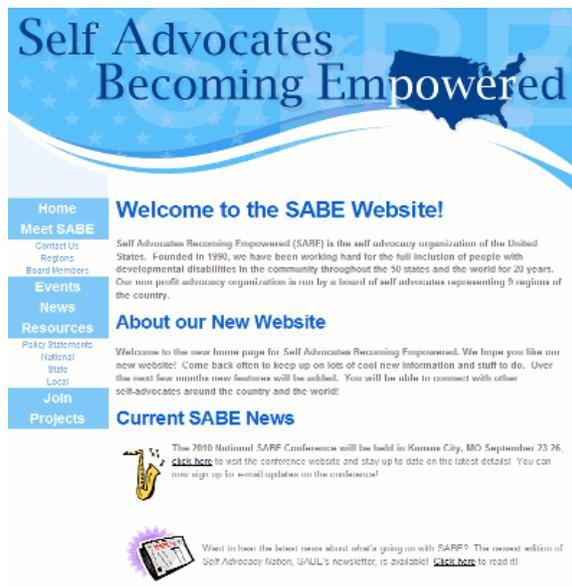


**Visit us online  
[www.sabeusa.org](http://www.sabeusa.org)**

**HAVE YOU VISITED OUR NEW WEBSITE YET?**

Have you visited SABE's new website yet? Sabeusa.org is now live!

While accessing the website, people can look up their regional board member. The website has many cool features, including the latest news about SABE and upcoming events. There is a section describing all of the different projects in which SABE is involved (Projects). There is a resource section where people can read SABE's policy statements and get information to start or support their local and state chapters (Resources). The website also includes an online membership form (Join), so if people visit the website and want to get involved, they can join!



The front page is updated often with 'Hot Topics,' which are stories or pieces of information about what's currently going on with SABE.

networking website for people with developmental disabilities. People who access this site can learn how to create a facebook page, an email advocate, and other important skills related to social networking. People will also be able to ask questions of a different self advocate every month and more! Stay tuned for Our SABE USA!

**Coming soon:** Our SABE USA — a social

**Self-Advocacy Nation**

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