

Self Advocates Becoming Empowered

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SPRING EDITION

Self Advocates Becoming Empowered Update

1. What are SABE's priorities?

- *To step up anti-R-word campaigns*
- *Working on bills to phase out sub-minimum wage, institutions and the marriage penalty. Making sure the states are held accountable.*
- *To get better at paying attention to what is going on in the legislature, both nationally and state, and to get the word out.*
- *Advocate for legislation in our states and nationally that requires education of police officers on interacting with people with developmental disabilities.*

2. How is SABE involving members who signed up to be on committees at our conference in Oklahoma City?

Each committee found out who was interested in serving and invited those members to via conference calls, Skype, etc.

3. What makes a good leader?

A good leader is supportive, trustworthy, respectful, a mentor to others, a good

listener, and helps people build up their skills. A trustworthy environment is the key, so that others can come to them with questions and concerns. The leader should also ask others for help when they need it and not try to do everything themselves, it's everyone's group.

4. Where do you see SABE going in five years?

I hope we have a staffed office in DC with lots of people involved. I hope people look to SABE first when they need information about self-advocacy. I hope we have the ability to hire staff to support and that we have the infrastructure in hand to maintain our groups. Have a strong presence and get our voice out there.



Tia Nelis

5. How do you get involved in SABE?

We're making a video to increase awareness of SABE. Board members are also doing presentations about SABE across the USA. Our newsletters, conferences, and projects describe ways to get involved. We have a technology book that teaches ways to connect and our projects, like Project Vote do webinars.



Article Re-Printed From NEAT Winter Newsletter

By Mike Rogers & Sophia Roberts

Self Advocacy Association in NYS

A power lunch is a brief meeting about a topic. We share innovative ways to achieve goals. To host a good power lunch, it is a good idea to have an agenda before hand and plan the details of the call. You need a telephone or computer. We have power lunches once a month.

Self advocates who are involved with a statewide self advocacy organization in one of the Northeast states are on the calls. They are also open to any local self advocacy group or person interested in the topics. In New York, we are able to share information about the Power Lunch call with the self advocacy groups on our email lists. In that way the NEAT project reaches out to self advocates from our grassroots giving them a chance to hear directly from other states about what they are doing. We recently learned that a few self advocacy groups who live in the more



rural locations in New York State tuned in to the last Power Lunch and learned more about state self advocacy conferences.

Hosting a power lunch is empowering and informative. We were able to receive input from multiple states and get different perspectives, which was a unique experience for me as a host. Power Lunches are organized by North East Advocates Together (NEAT), a Peer to Peer Connections Technical Assistance Project which is one of the Projects of National Significance. Members of the statewide self advocacy organizations take turns being hosts of the power lunch.

We use GoToMeeting videoconferencing service to host power lunches. You call in on the phone, and then you can see the presentation on your computer. Everyone

who has a camera on their computer can also be seen, which is pretty cool: you can see people's images in a line across the top of your screen.

One of the "NEAT" things about the NEAT project is learning about how things go in different states. The power

lunches teach us what is possible with technology. The NEAT Power Lunches are a great way for us to connect with other states. Since they are just an hour long and happen once a month, they are a way to spend a short amount of time when you don't have a lot of time, and get a good amount of information.

FOR MORE INFORMATION GO TO [HTTP://WWW.NEAT-PEERS.ORG/](http://www.neat-peers.org/)

Being a “Self-Advocate” ...

What’s in a Name?

This article was reprinted from **Advocates in Action**
Rhode Island Self-Advocacy News You Can Use

Self-Advocacy means finding out what’s important, speaking up about it, and making a difference! Sometimes people use the words “Self-Advocate” when they refer to people who have a developmental disability. That can be confusing. Having a disability doesn’t automatically make you a Self-Advocate.

Being a Self-Advocate is something that a person learns to do and practices doing. A Self-

Advocate may attend Self-Advocacy meetings, classes, presentations and conferences to learn about important issues, including how to speak-up for themselves and

others. A Self-Advocate is also someone who says, “Nothing about me without me,” because they are involved in the conversations, day-to-day decisions and future planning that affects them.

We think the title “Self-Advocate” is very important! In fact, a person who is a Self-Advocate might even want to put that on their business card. Not all of our readers who have a developmental disability may be Self-Advocates, but by learning how to speak-up, connecting with others, and working to make a difference together, you can become one. Get started

today! <http://www.advocatesinaction.org/material/pdf/news/ainanews1.pdf>



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Rights of People with Cognitive Disabilities to Technology and Information Access

Watch a video on the Declaration <https://www.youtube.com/watch?v=X0ACjPsdAs>

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;
- Access to information and communication technologies is necessary for all people, particularly for people with cognitive disabilities, to promote self-determination and to engage meaningfully in major aspects of life such as education, health promotion, employment, recreation, and civic participation;
- 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 markets and employment opportunities; decrease dependency on public services; reduce healthcare costs; and improve the independence, productivity, and quality of life of people with cognitive disabilities.



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.

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 its 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





Our Community Standing Strong

'when self advocacy gets started it is like Kutzu you can't stop it!
Gail Bottoms "Kutzu Summit":2001

Alabama Arkansas Florida Georgia North Carolina Oklahoma South Carolina Tennessee

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

Video Blogging

There are several ways self-advocates can express themselves. I have found that video blogging is one of the most popular ways to communicate. I love how effective it supports the message that self-advocates are trying to present. Video blogging is very important because it shows action, and the passion of communication. If you haven't video blogged, then I challenge you to **try it**.

Let me share some information that might support you in your efforts to try it. My best words in describing a video blog are a way to let people know about your beliefs or situations. It is a fun way to share your personal ideas and feelings about an issue. I was very nervous when I did my first video blog. It also had a good feeling too because I was trying something new. I decided to **choose a topic** that I felt strongly about and express myself



Stirling Peebles—

from the heart. It was a great feeling just to release my message in my own words and own way. At times I needed a script to help me along the way. Using a **script can support you** if you need a little help to explain the issue or just a simple reminder of some **points** you want to be sure to make. The script gave me added confidence because it was there to

support me through this new experience. Next you will want to make sure that you **find a comfortable location**. Make sure your location is neat, and well lit. For example, you can do your video in a formal or informal setting. My best advice is to do it in an area that makes you feel good.

Self-Advocates have a lot to say. However, a video blog should not be too long. It should be short. The video blog should be **no more that 3-5 minutes** long. We want to keep the interest of our listeners and have them remember the points. It is important for us to reach out and have others

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grab our message. When I got started doing a video blog, my equipment was limited. You can do it from your iPhone, smart phone, tablet, computer or with a video camera. You can edit your video with iMovie, window share, movie maker or on YouTube. Some editing software is free, others cost money.

Our stories and issues are so powerful. I never thought that video blogging would add so much to our message. I can tell you that everyone has a story and a choice on what they want to hear. It goes to say that we all are entitled to our opinions. We think for ourselves and we are people with a message for somebody who is struggling with a situation. Video blogging is a great way to make your point. I am a believer in video blogging. **Join** me in becoming a video blogger. It is a fascinating way to **share your ideas**. The more you do, the more you love it! I will be looking for your video blogs.

Go to <http://goo.gl/DSi4yo> to watch 22 Video Blogs by SABLE



The Southwest Alliance Technical Assistance Center (SWATAC), a division of Southwest Institute for Families and Children (SWI), is assisting leaders of disabilities communities in Arizona, Colorado, New Mexico and Texas to strengthen grassroots self-advocacy organizations. These leaders meet monthly

with SWATAC facilitators to discuss creative strategies that improve communication between self advocates, strengthen peer-to-peer support, and link with national programs and technical assistance centers in other regions.

Based on SABLE's successful *Our Community Standing Strong* project, the Grassroots Technical Assistance survey is being done in our four states. To date we have completed 508 surveys, 85% of our goal of 600. From this information, the leadership teams will build individual state plans that reflect the unique needs of each state's self advocates and allies. Finally, the teams will create and share resources across the region. The self advocates will use the resources to train and support new self advocates and to inform communities of the power and skills of their members.

Currently, state leadership teams are learning to create video blogs and lead webinars. We will share progress toward their state plans at the Spring Face-to-Face meeting. Stay tune for more exciting SWATAC information in the SABLE Nation fall 2015 newsletter.



ABLE Act

An Essential Step to True Inclusion!

By Nicole LeBlanc

Green Mountain Self-Advocates



The Steven Beck Jr, Achieve a Better Life Experience Act was signed into law on December 19, 2014. The ABLE Act is a piece of legislation that advocates, families and others alike have been working on for the past 6 years.

So what is the ABLE ACT?

The ABLE Act is a law that will allow people with disabilities and their families to set up tax free savings accounts in order to pay for basic daily living expenses like housing, education, transportation, healthcare, job training, wellness, and personal support services. While at the same time maintain eligibility for Medicaid, and SSI. The people who are going to benefit the most from this law are people with developmental disabilities. These new accounts established under the ABLE Act are similar to a “529” account (college savings account).

In order to set up an account an person must have become disabled before age 26. This law will also increase work incentives for people with disabilities by allowing them to save money, something that we haven't really been able to do because of the \$2,000 asset limit in Medicaid and Supplemental Security Income-SSI. There is also a Medicaid Payback provision which means that

when a person with a developmental disability passes away any money left in the account will go back to the Medicaid program. On March 10, the IRS gave a green light to move forward on establishing tax-free ABLE Act programs. Also each state is going to have to pass a bill in order to set up these accounts that says what department or agency the ABLE Act program will be run. In the long run this is going to hopefully increase the number of people working because it will give parents peace of mind that their son or daughter will be able to maintain state benefits. I often hear stories of businesses and parents limiting their son or daughters work opportunities because they are afraid they will lose their SSI and Medicaid. In the long run I see this bill leading to greater self-sufficiency among people with disabilities. Especially given that there are numerous states that are doing Employment First along with making state government become a model employer for people with disabilities. It's long overdue that we be given equal opportunity to get ahead and be part of the middle class in this society in terms of economic status. For more information go to the National Down Syndrome Society at:

<http://goo.gl/HRQPUX>