

# Self-Advocacy Nation

## By Self-Advocates Becoming Empowered

September 2010

20th Anniversary Issue

### Interview with Chester Finn A Vision of SABE's Future

**Max Barrows:** *How do you see SABE going forward?*

**Chester Finn:** I would say that SABE is at the next level, putting strategies together to having an office. We will be having a couple of staff members working, rather than relying on the Board to do everything. That is important especially now that a lot of grants are coming in. And I think networking will continue to promote SABE as a major player.

**Max:** *What will be in SABE's future?*



**Chester Finn:** The direction of SABE is up to the future leaders. You can't just rely on the past. Everything has been set in place to move to the next level.

The next ideas on disability services coming out of the government have been shaped by us. There is a move to change employment, housing and Medicaid. The Affordable Health Care Law has

initiatives to support people with disabilities. They will help move people from institutions and out of nursing homes to community settings. People won't need to rely on guardianship and the other things that have kept people from living productive lives. So I think the attitudes and directions have to change.

**Max -** *What has SABE done well?*

**Chester Finn:** I think pushing the issues that we really feel strongly about, like closing institutions, pushing for respectful language and name changes (getting rid

of the "r" word). The whole idea of funding for self-advocacy is going to be a reality soon. As

people change and get more freedom, their life style will change and you have to adapt the ADA and its rules to the new life style. It is up to future generations to determine it. SABE can't give up its goals or compromise our principals. If you give up those you lose everything.

**Max:** *What is your advice to new leaders?*

**Chester Finn:** You can't forget your history and where you came from. Even though you may have not lived in or experienced sheltered work and institutions – there is always a threat to go backwards. Things can be reversed and you can go back to it if you don't pay attention to it. You have to continue to educate.

**Max -** *How can members of SABE stay strong – without going our separate ways?*

**Chester Finn:** You have to remember what is best for the organization – not what is better for you personally. That is where people can go wrong. Keep in mind what is good for people all over the country. Sometime you can get caught up in the moment. You need to have goals and purpose. It is not just about working together as a team – you need a mission like closing institutions, eliminating guardianship and closing workshops. But, we need to offer suggestions about what to do to replace those things. Beyond strategies you need the ideas of alternatives. And you have to have a path of where you want to go and a strategy on how to get people to work with you to get there. Always have a plan and a strategy.





## ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

**1990**

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- Self-advocates from around the country met in Atlanta, Georgia. They wanted their own national organization. They decided to bring up the idea during the first national People First conference.
- In September, the first national conference was held in Estes Park, Colorado. The People First conference attendees voted to start a national organization and a steering committee was formed. They decided to divide the country into regions and elected representatives from each region to be a part of the steering committee.

**1991**

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- In May, the steering committee met in Chicago, Illinois. They made 14 recommendations on how a national organization of self-advocates could work. They made an easy to understand booklet and a sample ballot to mail to self-advocates before the next conference.
- In September, the second national People First conference was held in Nashville, Tennessee. All self-advocates who attended the conference accepted the recommendations of the steering committee. One of the representatives said, "The idea was conceived in Colorado, it was born in Nashville, and now we have a toddler on our hands."

**1991**

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- In December, the first board meeting was held in Nashville, Tennessee. The representatives decided on the organization's name, SABE (Self-Advocates Becoming Empowered). They created sub-committees, published their first national newsletter, and made a video about the organization to record what self-advocacy means to them and to the advisors. (Advisors are typically people without disabilities chosen by self-advocates to be their allies.)



# ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

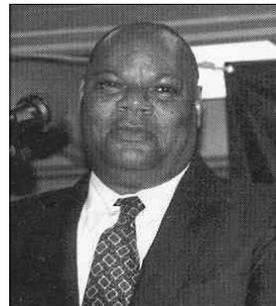


- In April, SABE met at Wingspread Conference Center in Wisconsin. Representatives received a President's Pioneer Spirit Award. Justin Dart, father of the ADA, the Americans with Disabilities Act, and a renowned human rights activist spoke with SABE representatives.
- An international People First conference was held in July in Canada. Representatives worked on team building skills that helped them to accept differences of people from other countries and build more trust between representatives.

**1993**

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- SABE met at Highlander in Tennessee. They discussed the history of the Civil Rights Movement and how it connects with the self-advocacy movement. They completed their bylaws and logo.
- SABE gave the keynote to the President's Committee on Mental Retardation in Washington, DC. 800 people attended the national conference held in Virginia. SABE sent out our first position paper, *Taking Place: Standing Up and Speaking Out About Living In our Communities*.
- SABE celebrated the life of Roland Johnson. He was often heard in speeches to shout, "Who's in control? Are you in control or is the staff in control?" This was also directed at the human service workers, a real wake-up call.



**1994**

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- In April, SABE met at Wingspread Conference Center in Racine, Wisconsin to organize the *Close the Doors Campaign* to put pressure on state governments to close down institutions and better support individuals who live in institutions. It included ways to educate policymakers, professionals, parents and others who live in our communities about the horrors of living in institutions.
- SABE completed our *Community Living Leadership Training* package. This training was developed for regional representatives to educate self-advocates and professionals about the importance of helping people move into and be a part of the community.

**1995**

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# ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

1996

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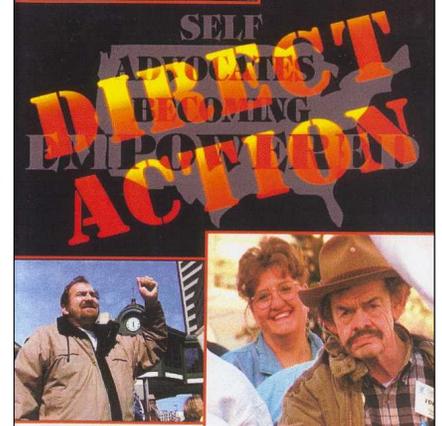
- SABE received its non-profit status 501(C)3 and officially became a Board of Directors.
- Close The Doors Campaign was launched at the National Conference in Tulsa, Oklahoma. This campaign of national significance supports the efforts to close the institution doors across the country.
- The Board defined "self-determination" in their own words.  
*Open The Doors: The Nuts and Bolts of Building Supports For Each Other*, a new booklet.



1997

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- The Close the Doors Committee begins work with four states to develop plans to close institutions in their states.
- A toll-free number with a voice mail message was established to help share information about the Close The Doors Campaign.
- Produced a new video, *Self-Advocates Becoming Empowered*, with national leaders talking about how self-advocacy is part of the civil rights movement.



Because actions speak louder than words.

1998

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- SABE learned about direct action by attending an ADAPT demonstration.
- SABE co-sponsored the Fourth International Self-Advocacy Conference in Anchorage, Alaska. Released the RESPECT recording became a candidate for a Grammy nomination in the Best Contemporary Folk category in 1998. *RESPECT: Songs of the Self-Advocacy Movement* was written and performed by Karl Williams with Self-Advocates Becoming Empowered (SABE) to show that self-advocates need and want RESPECT!
- SABE wrote new definition of institutions: "An institution is any place, facility, or program where people don't have control over their lives."

# ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED



- SABE joined Olmstead amicus brief for the Olmstead case in the Supreme Court. The Olmstead Decision requires all states to create a way for people to live in the most integrated setting.
- SABE produced a Direct Action video.
- SABE was awarded a grant from the Administration on Developmental Disabilities, along with three other partners. Project Leadership project brought key self-advocates and parent/family leaders to Washington D.C. to gain knowledge and skills that they could use to advance the goals of self-determination through policymaking at the federal level and to create a nationwide Leadership Network.

**1999**

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- Eighteen self-advocates and eighteen parent leaders participated in Project Leadership. The goal of the two weeklong training sessions was to shape and guide the implementation of federal and state policies, practices, and approaches that enhance self-determination.
- One thousand people attended the 5<sup>th</sup> national conference, Ride the Wave, hosted by Advocates in Action in Providence, Rhode Island.
- Freedom Rallies to “free our brothers and sisters still living in institutions” were organized on April 26 in 11 states. Thousands marched and listened to the testimony about people's institutional experiences. One woman talked about the "scars that will never heal".

**2000**

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- ADAPT, NCIL and SABE signed a statement of solidarity to reaffirm their commitment to cross-disability cooperation.
- Project Leadership graduated another class of self-advocate and parent leaders and held a meeting in Alabama with 11 southern states to discuss self-determination, grassroots advocacy, and coalition building.
- SABE received a new grant: Everyone Can Serve! The goal was to include people with cognitive disabilities in national service programs.
- SABE representatives presented at the International Self-Advocacy Leadership Meeting held in England.



**2001**

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# ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED



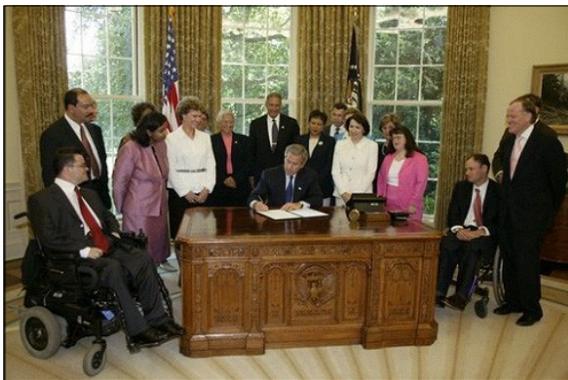
**2002**

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- Project Leadership graduated its 3rd and final class. Project Leadership amplified the distinct voice of parents and self-advocates which results in an enhanced choice, direction, and self-determination.
- 1200 people attended the 6<sup>th</sup> national self-advocacy conference, Share the Spirit, hosted by Self-Advocacy Association of New York in Buffalo.
- The SABE Everyone Can Serve team presented to directors from VISTA , Ameri Corp , and Learn and Serve. The training provided common sense ideas on how to include people with cognitive disabilities in National Service.

**2003**

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SABE testified to push President Bush's committee to change their name. Everybody said it could not be done. It is no longer called the President's Committee on MR. They voted to change their name to the President's Committee for People with Intellectual Disabilities. Not perfect, but much better.

- The Everyone Can Serve project developed a toolkit for AmeriCorps on effective practices for including people with intellectual disabilities.

**2004**

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- SABE met with ADAPT in Seattle and participated in a direct action at the National Governor's Association meeting. SABE also joined ADAPT for their "Stolen Lives" march on Washington DC.
- SABE wrote a Position Statement on MiCASSA saying all people have the right to choose where they live.
- SABE and Project Vote produced a video showing how to register to vote and cast a ballot, and to show how to overcome barriers to voting.



# ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED



- Over two thousand people attended the Summit: *Many Voices, One Vision*, organized by the Alliance for Full Participation. SABE was one of the founding organizations. It was the first time all of those committed to making the promises inherent in the Developmental Disabilities Act came together to dream, plan and organize around a common vision, and to create a proactive and responsive action plan for the future.
- The Project Vote team of SABE used a peer-to-peer model to provide training and technical assistance to promote voter participation among people with developmental disabilities in 8 states.

**2005**

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- Project Vote team of SABE developed videotapes, public service announcements, training materials and provided training on voting and cognitive access for people with developmental disabilities to national Protection & Advocacies.



**2006**

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- SABE wrote a position statement condemning the use of aversives. We believe that aversives are neither treatment nor education. They are merely procedures that restrict freedom of choice and adversely affect the human development of people with disabilities. We believe the use of aversives should be considered a failure in treatment.

- SABE created a YouTube channel of video protests against doctors who stunted the growth of a child named Ashley. Self-advocates said that just because someone has a disability it does not mean he or she should be denied the basic human right to grow and mature as everyone else. To all people with disabilities and people who believe in human rights, SABE calls you to action. Don't let what happen to Ashley happen to others. We hold the medical profession accountable for not upholding their oath "to do no harm."

**2007**

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# ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

**2008**

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- SABE co-sponsored two Presidential Forums in 2008, one in New Hampshire and the other in Ohio. These were the first disability specific forums held for presidential candidates.
- In 2008 SABE made a Voter Registration Public Service Announcement with their partners in the National TA Center for Voting and Cognitive Access. Go see the public service announcement at [www.govoter.org](http://www.govoter.org)



**2009**

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- SABE president traveled with Vice President Joe Biden on Air force II to attend the World Games in Idaho.
- SABE partnered University of Missouri , Beach Center, University of Illinois and the Valhalla UCEDD on the National Gateway to Self Determination Project. SABE serves on the Advisory Committee; and, as a direct liaison to Self Advocacy groups around the country to collect information they consider to be the most effective from a self advocate and family members perspective to help them lead self determined lives.
- SABE wrote a Position Statement on Hate Crimes. We believe that no one, whether they have a disability or not; should be the victim of a crime of hatred.

**2010**

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- SABE joined Easter Seals, Wayne State University, AUCD, Arc USA, and National Disability Rights Network to work together on a Family Support Navigation Training grant. This project educated families and adults with developmental disabilities on specific issues (i.e. employment, housing, guardianship, living in the community, health care, etc.) and ways and importance of their partnerships during monthly national interactive information sharing conference calls.



# Love: Not Just for Some, But for Everyone!

By Max Barrows



## ***What did you learn in high school about sexuality?***

Like most people, I got my first messages about sexuality from my fellow students. All I seemed to hear about was “intercourse”! Everybody wanted to get to the Promised Land! But, nobody seemed to know practically how to get there. My first source of official information came from a mainstream health class. This was very disappointing. We talked mostly about how to be protected from Sexuality Transmitted Infections (STI’s). The message I got was: “Sexuality is Dangerous”! Later, I was fortunate to take an alternative sexuality class designed for students with disabilities. This was much

more open and detailed. We learned that sexuality was a lot more than just intercourse. Sexuality is also about pleasure and relationships. The message I got here was: sexuality is a part of life for everybody! I wish I had learned this sooner in life.

Learning this made me feel less scared of sexuality. Before, I thought that sexuality was only for the “popular” students, not me. Now, I felt that sexuality was possible for me! I became more comfortable talking about sexuality. For example, I helped present workshops on



***Carrie and Sujeet from New York on their wedding day.***

Self-Pleasure and Flirty Dancing at a sexuality conference for people with disabilities. This experience made me more confident. Sexuality is now something to be celebrated, not to be afraid of!

How can high school students get their needs met in this area? You can advocate for more open and detailed health classes at your school. Another new approach is Peer Sexuality Education. This is when persons with disabilities teach sexuality workshops. These are not classes taught by teachers or staff. It’s more comfortable when peers educate each other. Check with your local self-advocacy group about what’s happening. Remember, sexuality is for everybody. You can learn what you need to know. There is nothing to be afraid of!

# Are You Prepared?

Have you given any thought on what you would do if a disaster occurred? Here in the U.S, we have our share of natural and man-made disasters.

Natural disasters include hurricanes (Katrina), tornadoes, flash floods, and ice storms. Man-made events have been terrorist attacks (9/11), nuclear power plants (3 Mile Island), and bridge collapses (Minnesota).

When disasters strike, there are two basic possibilities. First, you may have to stay put (shelter in place) for an inconvenient period of



time. Or, you may have to get out in a hurry (evacuate). In either case, you need to prepare! So, what do you need to be thinking about?

When you have to shelter in place, what are your basic needs? If the power is out for several days, would

you be able to stay warm, have enough food and water, or be able to communicate with others?

You should have an emergency bag ready. This might include matches, candles, flashlights, batteries, blankets, water, medications, can food, a cell phone, and a battery powered radio.

## Emergency Supplies When You're Stuck At Home

Supplies are expensive! Just buy a few things at a time and put them away in a dry place.

### Food and Water

- Water: 1 gallon per person per day
- Ready-to-eat canned meats, fruits and vegetables, juices and soups
- High energy foods—peanut butter, jelly, crackers, granola bars, trail mix
- Comfort foods: Cookies, hard candy, instant coffee, tea bags
- Special diet foods if needed

### Tools

- Flashlight and extra batteries
- Battery operated radio or TV
- Manual can opener
- ABC-type fire extinguisher
- Shut-off wrench to turn off household gas or water if necessary
- Matches in waterproof container

### Other Important Items

- Books, cards, games (*to keep you busy & calm*)
- Extra eyeglasses

### Supply List (as needed)

- Extra batteries for wheelchair, medical equipment, hearing aids, etc.
- Wheelchair patch kit
- Gloves for manual wheelchair
- Cards listing key phrases you would use in an emergency
- Extra medical supplies like dressing materials, catheters, syringes

### Sanitation Supplies

- Toilet paper and feminine hygiene products
- Soap, hand sanitizer, disinfectant
- Plastic garbage bags and plastic bucket with tight lid

### First Aid Kit and Medicines

- Non-prescription medicines like pain relievers, stomach remedies, etc.
- Extra prescription medicines
- First Aid Kit and manual

Getting the real information about what's going on can be challenging when you are stuck in one place. Feelings of isolation can kick in, and not knowing what's going on can be frightening. For example, when 9/11 occurred, some people with disabilities in Vermont were afraid that New York City was much closer than it actually is. They needed accurate information so they wouldn't feel as scared!



Before disasters occur, it would be a great idea for local self-advocacy groups to meet with emergency first responders. This would be helpful in educating first responders to know how to assist persons with disabilities respectfully.

What if suddenly someone came to your house, and told you to evacuate? I, for one, would deeply appreciate them taking the time to accurately explain what is going on. It might take a little bit of patience to let my mind process this information!

If you had to get out in a hurry (evacuate), what would you need to think about? One thing to consider is having a backpack ready to go. It might contain ID and insurance cards, medications for several days, contact numbers for family and friends, money, flashlights, food, and bottled water. Another tool to include might be a pre-written plan about where to meet in case you get separated from your supports, and where your nearest shelter is located.

There are a lot of States that have been working on emergency preparedness for persons with disabilities. Check with your local and state self-advocacy organizations to see what's been done already. For a national resource, you can visit: [www.disabilitypreparedness.gov](http://www.disabilitypreparedness.gov). Hopefully, we can all be better prepared and be more in charge of ourselves in the event of a disaster!

## Pack A Bag To Go With You In An Emergency

Put these things in a bag but don't make it too heavy.

- Change of clothing and shoes
- Personal care products (toothbrush, etc.)
- Cash
- Towel
- Prepaid phone card
- Blanket or sleeping bag
- Extra eyeglasses
- Flashlight and batteries
- Copies of *Emergency Information Sheet and Emergency Contact List*
- Copies of important documents like (birth certificate, driver's license, passports, bank account and insurance information, etc.)

Make a note *that says "Don't Forget Your Medications!"*

Pin the sign on the outside of your bag.



Checklists adapted from:

<http://dail.vermont.gov/dail-resources/emergency-preparedness-assistance/view?searchterm=emergency%20preparedness>

# Bullying Is No Fun For Anyone

By Maisie Lajeunesse

*Maisie LaJeunesse is a junior at Spaulding High School in Barre, Vermont. During the summer of 2010, she worked as an intern at Green Mountain Self-Advocates writing articles about self-advocacy.*



Everyone in their lifetime has seen or heard someone being called names, or being picked on. Others have experienced it first hand. Unfortunately it seems as though people with disabilities are faced with the challenge of being made fun of more than the average person probably does. Some people are not aware when they are being cruel or hurtful towards people with disabilities. In our society, we are exposed to movies

and media poking fun at those who may be different. One of the most common things that is said is the word “r#tard”. The ‘R’ word is used more often than it should be, and it seems as though people feel it is an appropriate term; however, it is not. This is a very offensive word to those like myself and others. Using this word makes people not only sound

ignorant, but genuinely mean. As a person with a disability, and who is surrounded by many friends with disabilities, I have seen my fair share of people being picked on. It hurts to see the people I care about being made to feel bad for how they are. I would like for people to walk a day in any of our shoes and see how it feels. Maybe it would make them think twice before saying or doing something hurtful.



## Introducing Self-Advocacy to Youth

1. When you meet with students, begin by asking them what they think self-advocacy is. Get their perspective first. This gets them thinking.
2. Take time to explain how a self-advocacy group is run. Set up group agreements. They should include reminding teachers to talk as little as possible. Self-advocates make the decisions, not the teachers. Teachers provide support but they are not in charge.



3. A self-advocacy meeting may be new to students, so remember to take your time and not go too fast.
4. Ask students if they want you to talk about your experience moving beyond high school. This could give them a preview of what to expect in the future. It might be the first time they have talked about growing up with peers. The truth comes from us and it is not sugarcoated.

5. Self-advocacy can give you the courage to listen to your voice. A peer atmosphere helps you to say what is on your mind. Be careful not to shut down another person's dreams. Try to make everyone feel listened to.



6. Support students to make their own decisions. Give them a chance to take control. Do not judge them. Tell them their opinions are important.
7. Talk to them about guardianship alternatives.
8. Make the meeting fun with lots of hands-on activities. Find meaningful ways for students to get involved. For example: attending a statewide self-advocacy conference; working with you on a community service project; helping teach a workshop.
9. Sometimes students are reluctant to speak up with teachers in the room. They may need to be encouraged. Be careful not to interrupt a young person. Give them time to share their ideas. When an adult interrupts it sometimes can shut the person down and they stop talking.

10. Create an atmosphere that says it is okay to make mistakes. No question is a silly question.
11. Be laid back. Listen. Don't jump in with an answer. Give space for students to come up with their own answers and ideas.



12. Remember students have busy lives. They may choose to hang out with their friends instead of meeting with you. Respect their choices.

# SABE Representatives Joined President Obama at the White House to Celebrate the 20th Anniversary of the ADA: Americans with Disabilities Act



Victor Robinson from DC joined his friends from SABE to hear President Obama speak.



Julie and Brian Petty dancing the night away after a fun day at the White House.



President Obama shaking hands with advocates from across the country.



Chester Finn dancing up a storm at the ADA Gala celebration.



Topper and Chester hanging out on the South Lawn.



Kareem Dale dancing at the ADA Gala.



Nathaniel Ayers performed at the White House. His life story was portrayed in the movie, "The Soloist".



Patty Labelle sang and told stories of strength.



Senator Harkins' Hearing on how ADA was passed!



Chester & Jonathan Young from NCD

# Max's Vision of SABE's Future



I want SABE to be strong enough to be a role

model and take the lead on true inclusion. We should be a real role model for team work. For example, team work is when everyone is involved in the process of moving forward, not just a

few leaders. Important issues will continue to be eliminating institutions, closing sheltered workshops, and getting the word out about respectful language.

The golden key to this strategy is to reach out to the younger generation and high school graduates.

Young people bring enthusiasm and energy to

self-advocacy! They also bring new ideas to the table. Building a strong connection with state and federal legislators will be

very important. In my experience, personal contact with legislators really makes a HUGE difference!

We need to

continue to believe in ourselves. We can do this!



## Action Alert:

Pennhurst turned into Haunted House!



Pennhurst is the institution that brought national attention to the fact that many of our brothers and sisters were living in horrible conditions and being abused. As a result of legal efforts the institution was closed. Now this institution is to be used as a Haunted House. [http://www.hauntworld.com/featured\\_article/haunted\\_house\\_in\\_philadelphia\\_pennsylvania](http://www.hauntworld.com/featured_article/haunted_house_in_philadelphia_pennsylvania) We know it is a scary place, but this should not be the way people who lived and died there should be remembered. It is an insult to Roland Johnson who lived there and fought to have it closed.

Visit the Preserve Pennhurst website [www.preservepennhurst.org](http://www.preservepennhurst.org) to sign a petition against the use of Pennhurst as a Haunted House. The Preserve Pennhurst group is working to establish a Museum on the site. Remember that SABE wants all institutions closed!

**Welcome to the 20<sup>th</sup> anniversary of the ADA and Self-Advocates Becoming Empowered.**

We have had a lot of accomplishments in the past. But we are ready to explode into the future. It is a new day for Self-Advocacy and People First. So put away the old and welcome the new.

We can look forward to establishing self-advocacy as a political powerhouse which we stated as one of our goals. We will have funding for self-advocacy in every state as we strengthen our partnerships with the DD Councils, Protection and Advocacy and the University Centers as well as DD agencies. There will be more

networking with governors and state governments to have self-advocates push the agenda. We can help with budget cuts how to do things like individual services, self-determination and create better lives for people in the community.



SABE will continue to help people learn who they are. Have marriages, families and teach people about sexuality so we can avoid people being locked up in facilities and accused of being monsters.



**Self Advocates Becoming Empowered Celebrates their 20th Anniversary**

- Celebrate at your state conference.
- Have a party with your local group and show videos or make a scrapbook of your groups accomplishments.
- Talk with your Newspaper about the Anniversary and about your group's accomplishments.



Those are our challenges and we welcome youth leaders to work with us and we will be there as mentors. As our forefathers understood in building this great country, there is nothing like experience.

Our next challenge will be employment: getting real jobs and creating opportunities for all types of employment. Also keeping people out of institutions and building a life in the community. We must take from the examples around the country. Free our people!

I have a dream that self-advocates will take our rightful place in the community and be accepted by society and we can fulfill our hope and dreams.

Thanks—Chester Finn, President of SABE