



Self Advocacy

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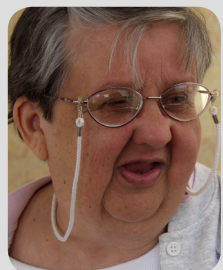
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TASH

CONFERENCE

BALTIMORE, MD

#2020TASHconf

DEC 3-5, 2020

SAVE THE DATE!

The TASH Conference brings together self-advocates, family members, advocates, professionals, researchers, providers and other allies to gain information, learn about resources, and connect with others across the country to strengthen the disability field.

Subscribe to our newsletter (tash.org/TASH-in-Action) for upcoming news and dates about the 2020 TASH Conference.

www.tash.org/conference2020



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Letter from the President of the Board of Directors

Dear Fellow Tash Members,

Five years ago, TASH celebrated 40 years of progressive leadership, including longstanding TASH members who experience disabilities. Today, we celebrate the 30th anniversary of one of our strong partners- Self Advocates Becoming Empowered (SABE) and over a half century of a social justice and reform movement- self advocacy.

At the core of self-advocacy is the universal human desire to be the author of one's own life and to control the decisions-large and small- in your journey to be seen and understood for who you are, and to be free to become all that you can be.

When I came into the field in 1976, I was shocked to learn that people were being locked up in segregated institutions for having a disability. I went searching for answers to why this was happening and met- among other people- Dr. Gunnar Dybwad. He explained about the social, political and economic reasons this was happening. He made it clear it wasn't about anything intrinsic to being a person with a disability. And then he talked about self-advocacy as one of the most important parts of any reform to bring people home to the community. He cited the meeting of self-advocates in Malmo, Sweden in 1968 as the historical beginning of self-advocacy. At the time, a parent organization for children with developmental disabilities had the motto, "We speak for them." Gunnar cheerfully quipped, "**Them**' days are over!" He assured me that people's voices needed to be heard, would be heard, and that would make all the difference. I understood then that breaking down the practice of seeing fellow citizens through the lens of "us and them" was core to any effective advocacy work and true reform.

One of the first self-advocates I met at that time was Ruth Sienkiewicz-Mercer, who wrote an essential book, "I Raise My Eyes to Say Yes." She passionately taught all of us in her life- and everyone else who would listen- that we all had a story to tell and our voices needed to "be heard," even if some of us did not use traditional speech communication. I was holding her hand when

she died, but what I learned during our long friendship, stayed with me forever. Self-advocacy, culturally typical life experiences, the valuing of human life, and appropriate supports, make a huge difference in bringing people with disabilities out of exile and liberating people's personalities.

Ten years after meeting Ruth, Tia Nelis and Nancy Ward came to Massachusetts to help us form Mass Advocates Standing Strong (a powerful statewide self-advocacy organization). Lifelong friendships were born in the process of launching this and many other local, state and national self-advocacy organizations and networks.

The story of the still-unfolding self-advocacy movement is one that is deeply personal to me. Over the years, I have had the opportunity to work together with self-advocates to testify in landmark class action lawsuits, and before state and federal congressional and senate committees, to protest funding schemes and policies that segregate people with disabilities and often create more harm than good. Self-advocates have been an important influence in my life and a core group of our TASH membership since our inception in the '70's.

This edition of Connections lifts up the voices of leaders in the Self Advocacy Movement and celebrates the work and triumphs of people with disabilities taking the lead, expressing what is most important, and helping people at risk of being misunderstood, shut away, silenced, to find their voice and to make a difference in all of our lives.



*Ruby Moore,
President of
the Board of Directors*

A handwritten signature in black ink that reads "Ruby Moore".

Ruby Moore
Board President

Letter from the Executive Director

Dear Fellow Tash Members,

This special edition of Connections features the voices of a self-advocacy movement that contributed to over three decades of social change. The lead article shares the history about how a small group of individuals with intellectual and developmental disabilities based in Oregon laid a foundation for self-advocacy groups across the country to build upon. Other articles feature the voices of early leaders as well as present day self-advocates. Their messages are clear and straightforward; Nothing About Us Without Us.

It was my distinct honor to have been on the ground level of the self-advocacy movement, almost from its inception. In 1982, I helped a small group of people with disabilities start a local chapter of People First in Nashville, TN. I consider the years that followed to be the richest and most impactful of my professional career. I had found my passion and it was helping people who had been among the most disenfranchised in our society find their voice.

By 1984, that group had helped five other groups start and People First of Tennessee, Inc. was born. Their initial vision was true and steadfast; everyone was entitled to learning about self-advocacy and how to assert their rights. To them, that included the over 2,000 individuals in Tennessee's state-run developmental centers. In 1991, the leadership of People First of Tennessee voted to file a class action lawsuit against the Arlington Developmental Center to liberate their peers. This Federal case was the first case to be filed by people with intellectual and developmental

disabilities themselves. It would lead to the closure of all of Tennessee's state-run institutions and fundamental restructuring of the state's system of community services.

The emergence of strong, state-wide self-advocacy organizations run by and for self-advocates led to the formation of Self-Advocates Becoming Empowered (SABE). As a national advisor, I was again honored to serve and support the growth and development of an organization that has unfailingly stood for freedom, human rights, and self-determination. This fall, SABE will celebrate its 30th anniversary. The landscape of disability rights has changed dramatically over the past thirty years and will continue to change as human and civil rights issues remain unaddressed. What I learned from my own experience as a former advisor and now volunteer with the self-advocacy movement is the solutions to all of these challenges are best found by making sure that the people themselves are fully engaged in the conversations that impact their lives.



*Ruthie-Marie Beckwith,
Ph.D., Executive Director*

A handwritten signature in cursive script that reads "Ruthie-Marie Beckwith".

Ruthie-Marie Beckwith
Executive Director

Introduction

By Tia Nelis and Paige Bradford, Guest Editors

Self-advocacy is at the root of many victories in disability rights. Countless self-advocates have used their voices to further the rights of people with disabilities, creating a better and more inclusive future for everyone. This issue of Connections focuses on the self-advocacy movement of the past, present, and future. In their own words, self-advocates discuss their impact and contributions to the self-advocacy movement.

The articles and stories in this issue represent a broad array of self-advocates who have worked or are working to further the rights of people with disabilities across the country and the world.

Articles from Our Contributors

Our Common History: Fighting for the Rights of People

By Paige Bradford, Tia Nelis, and Ruthie-Marie Beckwith

Introduction

Over time, members of minority groups have joined together to fight for their human and civil rights. This paper describes the history of the African-American Civil Rights Movement, the LGBTQ Movement, and the Self-Advocacy Movement.

African-American Civil Rights Movement

The African-American Civil Rights Movement started in the mid- 1800s. After the Civil War states passed laws that limited the rights of black people. These Jim Crow laws made it hard for black people to vote. The laws said black people could not go to the same places or do the same things as white people.

In 1909, a group of people started the National Association for the Advancement of Colored People (NAACP). It wanted to fight for the rights of all people. The Civil Rights Movement was strongest in the 1950s and 1960s. In 1953, Reverend T. J. Jemison started the first bus boycott in Baton Rouge. He started the boycott so black people could ride the city buses. The boycott ended when the bus company agreed to let black people to ride in the back of the bus. White people could sit in the front.

After the Baton Rouge boycott, people in other communities started more groups. They organized to fight for their rights. African Americans met in their churches to talk about their rights and what to do about the Jim Crow laws. Members of these groups came together at the Highlander Folk School in Tennessee. They talked about better ways to organize and how to change the way black people were treated. Dr. King and Rosa Parks were two people who went to the Highlander Folk School. The Southern Christian Leadership Conference was important to civil rights. Dr. King was the leader of that group. Groups started meeting in high schools and colleges. The Student Nonviolent Coordinating Committee (SNCC) started having sit-ins at restaurants to protest discrimination.

Over the years, the African American movement fought for many rights. Two important fights were about segregation and voting. Until 1954, some school systems had separate schools for black children. The U.S. Supreme Court ruled that schools had to let black and white children go to school together.

In 1964, Congress passed the Civil Rights Act. It ended segregation in public places. It banned employment discrimination on the basis of race, religion, sex, and national origin. In 1965, Congress passed the Voting Rights Act. This law told states that they could not discriminate against black people voting in elections.

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Issues and Problems for the African American Movement

Freedom and Independence

One of the biggest problems African Americans faced was segregation. Some school systems had separate schools for black children. Some communities even had separate hospitals and libraries. Black people could not stay in the same hotel as white people. Segregation limited their freedom and kept people from being full citizens. When black people started to speak up, they were arrested. Some black people who spoke up were murdered by mobs or the Ku Klux Klan.

Another important concern for the freedom of the Civil Rights Movement was the freedom to congregate and meet. In 1963, the 16th Street Baptist Church in Birmingham was bombed. Many other black churches were burned to keep people from meeting about their rights.

Human and Legal Rights

One of the most important problems the African-American movement worked on was voting rights. Some counties and states came up with rules to make it hard for black people to register to vote. They would ask questions like how many bubbles are in a bar of soap. They would make them recite the constitution. White people did not have to do these things. These counties and states did not want black people to vote because they did not want them to run for office. These white people did not want to share governing power with black people.

African American Civil Rights activists had to fight against discrimination in the area of relationships and marriage. Black people could not date or get married to white people. People in mixed-race relationships were at risk for being arrested and facing other legal penalties.

Meaningful Participation

Being part of any community means having access to the same things and services that everyone enjoys. Separate programs and buildings that were set up for black people did not have the standards or quality. Black children did not get an equal education. After schools started to become desegregated, some governors closed schools because they believed that it would avoid negative interaction.

LGBTQ Civil Rights Movement

Before the LGBTQ Civil Rights Movement, many people thought that homosexuality was a crime that needed to be punished. People thought being LGBTQ was a disease. LGBTQ people were arrested and put in mental institutions. The Gay Rights Movement started early in the 1920s. The Society for Human Rights started in 1924. Between 1950 to 1961, members focused on providing services. They worked on educating and making allies. Mattachine was a large group for gay men. The Daughters of Bilitis was a large group for lesbian women. The National Planning Conference of Homophile Organizations started in 1966. It had a newsletter and a legal defense fund for allies.

In the 1970s, gay rights activists targeted science, religion, and businesses. Pride marches became common during the 1970s. They started using symbols like the rainbow flag as a banner for their struggle.

Three big events happened in the 1990s that changed the Gay Rights Movement. The first event was the AIDS epidemic. Many LGBTQ people caught AIDS and had problems getting health care and access to drugs that were used to treat AIDS.

The second big event was about how the military treated LGBTQ soldiers. President Clinton started a policy called Don't Ask, Don't Tell (DADT) in 1994. It said that "closeted" LGBTQ military personnel could not be harassed or discriminated against.

The third event was the 1998 murder of Matthew Shepard. He was a student at the University of Wyoming. He was tortured and left to die because of his sexual orientation. His murder led to a push for hate crime legislation in the United States.

The LGBTQ movement continued to fight for the right for LGBTQ couples to get married. Some states legalized civil unions and partnerships. Other states legalized marriage. In June of 2015, the Supreme Court ruled that same-sex marriages were legal. They said that states could not prohibit such marriages or refuse to recognize certificates from other states.

Issues and Problems for the LGBTQ Movement

Freedom and Independence

An important issue related to freedom was the right to engage in preferred jobs, such as in the military. The military banned Gays and lesbians from serving in 1945. After that, gays and lesbians

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who joined the military were kicked out if they were exposed. School fired teachers and other personnel who identified as homosexual.

People identifying as gay or lesbian also had difficulties meeting and having events. The police also harassed them by doing raids on places where gay people got together, and other tactics.

Human and Legal Rights

LGBTQ people also had problems with marriage. Many states passed laws against LGBTQ people getting married. Gay and lesbian couples who wanted to get married did not have the same rights as other people. This was a problem for people when they got sick and wanted their partner to help them. For example, Karen Thompson was severely injured in an accident. She wanted her partner, Sharon Kowalski, to help her. The hospital would not let Sharon visit Karen. Sharon had to become Karen's guardian so she could help her.

States would not let Gay and lesbian couples adopt children. If their partner had children and the partner died, the children were taken away. People were also denied the right to adopt children or lost the children if their partner passed away.

The LGBTQ movement also led the fight for health care because of the AIDS epidemic.

Meaningful Participation

LGBTQ people were denied meaningful participation across settings. Military service was illegal. The government forced LGBTQ employees to resign. College professors were the victims of lengthy and harmful interrogations. LGBTQ people were put into institutions.

Self-Advocacy Civil Rights Movement

For hundreds of years, people with intellectual or developmental disabilities (I/DD) had labels like retarded or moron. Some people thought they were dangerous. Parents were told to put these children in institutions.

The self-advocacy civil rights movement started because people with I/DD did not want to be called these labels. In the 1960's a group of people with I/DD in Europe started clubs to plan outings in the community. They made their own choices and mistakes. Then the Swedish Parents' Association had a national

conference for the people in these clubs. They came together to talk about their lives and concerns.

In 1973, the "First Convention for Mentally Handicapped in North America" happened in British Columbia. It focused on self-advocacy. A lot of people with I/DD from Oregon went to the conference. The people from Oregon decided to start their own group. They named their group People First because they wanted to be called by their names and not their disability label. They decided to have their own conference. Over 600 self-advocates attended that conference in Salem, Oregon in 1974.

More self-advocacy chapters started after the Oregon conference. By 1975, there were 16 People First chapters. In the 1980's the number of self-advocacy chapters continued to grow. The first national self-advocacy conference happened in 1990. It took place in Estes Park, Colorado. Self-advocates who went to that conference elected a committee to plan a national group.

The second National Self-Advocacy Conference happened in 1991. The conference was in Nashville. Over 700 people with I/DD came from 32 states. They voted for the national group's leaders. These leaders named the group Self-Advocates Becoming Empowered.

The Self-Advocacy Movement believes that people with I/DD should make their own decisions. They want to be treated like everyone else in their communities. Self-advocacy groups teach people about their rights. Groups work together to change laws in their states. They work on closing institutions. They work on voting rights. They work on transportation. They work on how to get jobs. They work on being treated with respect.

Issues and Problems for the Self-Advocacy Movement

The Self-Advocacy Movement has had a big impact. It works on problems that are the same as other civil rights groups. It also has problems that other groups don't. Most self-advocates don't drive or use public transportation. They need help getting to meetings. Most self-advocates depend on government benefits. It is hard for them to get money to go to big events. Self-advocacy groups use advisors to help them get and stay organized. It is hard to find advisors who know how to help people fight for their rights. Sometimes advisors speak over or instead of the members of the group.

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Freedom and Independence

The self-advocacy movement has worked hard on stopping members from being put into institutions. Ray Loomis was a self-advocate in Nebraska. He got out of Beatrice State Home in 1974 and organized a self-advocacy group. He started “Project Two,” a group that worked on home and community-based services and self-advocacy.

Self-advocates want the freedom to live independently. They want to have a say in how they receive services in the communities. They advocate for the closure of state-run institutions. They also fight for the same employment and housing settings as people without disabilities.

Human and Legal Rights

People with I/DD had medical procedures without their consent. They were sterilized so they couldn't have children. The Virginia Eugenical Sterilization Act was repealed in 1979 but people with I/DD are sterilized today. People with I/DD also have problems with voting. States passed laws that said they were not smart enough to vote. The self-advocacy movement works on voting projects to let people know about their voting rights. People with I/DD have problems with the police. Some people forced people with I/DD to confess to crimes they didn't do. People with I/DD died because the police hurt them when they had a problem in the community.

Community services are part of health care services in the United States. The Self-Advocacy Movement works on getting more funding for services. It also works to fight laws that would change health care services.

Meaningful Participation

People with I/DD have problems trying to be part of their communities. For example, they couldn't get library cards. They were kicked out of movie theaters. They want to work in regular jobs instead of sheltered workshops. They want to make their own decisions.

Tactics: Tactics are activities that groups use to get things changed. Some tactics use the legal system. That is called legal activism. Some tactics focus on laws and politics. That is called political activism. Some tactics use things like protests and demonstrations. That is called direct action.

Legal Activism

Legal activism uses the legal system to get things changed. All three movements have used the legal system to get things changed. issues described above.

The African-American Civil Rights Movement used the legal system to fight discrimination. The NAACP launched a campaign in 1930 to change policies and practices. During the 1930s and 1940s they filed lawsuits to get more rights.

In one case, *Loving v. Virginia* (1967) was about Richard and Mildred Loving. They were an interracial couple who lived in Virginia. Virginia had a law that said black people could not marry white people. They sued and won the right to get married.

One of the most famous cases is *Brown v. Board of Education* (1954). In this case, the Supreme Court ruled that black children could go to the same schools as white children.

The LGBTQ Movement has used the court system to fight discrimination, too. In 1962, the California Supreme Court overturned two convictions for same-sex encounters that happened in a bathroom. In 1990, the Americans with Disabilities Act included people with AIDS. In 2017, the U.S. Supreme Court ruled that LGBTQ people had the right to get married.

Self-Advocacy Movement groups have filed lawsuits, too. People First of Tennessee filed three lawsuits to close institutions in 1991 and 1994. By 2017, all of Tennessee's institutions had been closed. People First of California and Washington joined lawsuits against institutions, too.

Two self-advocates named Lois Curtis and Elaine Wilson filed a lawsuit to get out of a Georgia institution. The Supreme Court ruled in 1999 that they had the right to live in the community. This ruling was called the *Olmstead* decision. This decision has been used by other advocates to stop segregation.

Legislative and Political Activism

The first law against discrimination was the Civil Rights Act of 1886. It said that all people born in the United States were citizens regardless of race. The 15th Amendment of the Constitution gave black people right to vote. Another important law is Executive Order 8802. It said that the defense industry could not discriminate.

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The LGBTQ Movement worked to get LGBTQ people elected. It advocated with government officials to change policies. Members of the LGBTQ Movement used “zaps” to put government officials on the spot. Zaps were used to embarrass people and put them on the spot. A famous Zap happened when LGBTQ activists through a pie in the face of Anita Bryant because she led an anti-gay campaign.

The Self-Advocacy Movement used political activism to fight segregation. In Nebraska, a boy named Johnathan Allen lived in an institution. He had bruises that no one could explain. Members of Project 2 met with Senator Vard Johnson. He asked them to go with him on an unannounced tour of the institution. After that, the Senator changed his mind about institutions.

As self-advocates have focused on voting and other civil rights. They spoke out about how the justice system treats people with disabilities. In 2015, self-advocates formed the Ethan Saylor Alliance for Self-Advocates as Educators. Ethan Saylor died when he was dealing with the police.

Marches, Protests, and Demonstrations

The African-American Civil Rights Movement had many marches and protests. They had bus boycotts in Baton Rouge and Montgomery. Students in SNCC held sit-ins in restaurants. One famous sit-in was at Woolworths in North Carolina. SNCC also had Freedom Rides across the south. They did this to stop segregation on Trailways and Greyhound buses. Several students were beaten during the Freedom Rides. One of the students was John Lewis. After the Freedom rides he became a Congressman for Georgia.

The LGBTQ Movement used protests in the 1960s. In 1964, they demonstrated at a military draft center. In 1965, they had another protest at the White House. protesters gathered in front of the White House. The LGBTQ Movement also used boycotting to change practice and policy. They started The Day of Silence as a way to show the silence experienced by gays and lesbians each day. The Day of Silence has happened every year for 22 years.

One of the most well-known protests of the LGBTQ Movement happened at the Stonewall Inn. Police raided this bar on June 28, 1969. The people in the bar fought back. They threw things at police officers. This turned into a riot. After the Stonewall Riots, more LGBTQ protest groups started to speak out across the country.

The LGBTQ Movement has had several marches throughout its history. The First National March on D.C. for Gay and Lesbian Rights happened in 1979. 100,000 people attending the march in D.C. In 1987, the Second National March on D.C. for Gay and Lesbian Rights occurred. At that march 64 people were arrested for demonstrating.

Members of the self-advocacy movement worked hard to help pass the Americans with Disabilities Act (ADA). A group of 475 people with disabilities went to Congress to protest delays in passing the ADA. They got out of their wheelchairs and crawled up the stairs. In 1990, 2,000 people with disabilities came to Washington to watch President Bush sign the ADA. The first Disability Pride Parade was in 1990.

In June of 2017, Congress tried to pass a new bill that would cut Medicaid services. Members of ADAPT and other self-advocates went to Senator Mitch McConnell’s office to protest the bill. Sixty protesters attended the event and 43 people were arrested.

Discussions and Intersections

African Americans, LGBTQ people, and people with disabilities were denied basic rights. All three movements worked to fight unfair and unequal treatment. They worked on segregation in schools, the military and institutions.

These movements happened at different times and places. They were all active in the 20th Century. They are all active today. Leaders of all three movements went to workshops at the Highlander Education Center. This helped them understand how to speak truth to power. Speaking truth to power means they would tell officials how wrong laws that discriminate were. Name calling was an issue across the groups. Each of the groups work against negative name-calling. This helps them fight the oppression of marginalized groups. Members of each group fight discrimination. LGBTQ people with disabilities who are not white deal with more discrimination.

All three movements will continue to work on changing attitudes about their group’s members. These movements have started to work together to solve problems. Joining together gives these groups strength in numbers. It helps all advocates have a louder voice and make everyone’s lives better.

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Who's In Control

by Roland Johnson

Speech presented at International People First Conference In Toronto, Canada (June 1993)

I'm glad to be here today. I'm very glad to be here at all this three days. Today we're gonna talk about: How to be in control; who's in control. I want to know--raising hands--who are in control.

Are staff in control?

Well, I understand that you need to be in control, and some of them are not in control because staff tells you what to do; advisors tell you what to do and staff tells you what to do. I don't believe that you are in control over your life. And there's some people out of state needs to understand that you are--the people are-- 'posed to be in control of your life: how to set up, how to do things, how to make people understand you, how to make people love you and care for you.

I come back in Pennsylvania, I speak in front of a hundred people in Philadelphia.

My name is Roland Johnson and I'm glad to being here for welcome you here.

Control means being in self-control...who's in charge over you.

Are you in charge?

Is staff in charge?

But who's in charge?

Well, some people tell me that sometimes staff is in control, that you don't be in control over your life. And doing things in your workshops or in day program and in where you live -- staff in control.

I want to know who is telling you what to do. If you're telling yourself what to do or are you letting staff tell you what to do.

I can't hear you!

You're supposed to be in charge, right?

I can't hear you!

Who's in charge?

All right.

Are the workshop people in charge?

How about people getting the jobs?

How do you go to your supervisor or your staff, that you want to get a real job and work in the community and on real jobs? How do you do that?

Can anyone tell me how you do that?

-Voice-

You go to your people whenever you want?

-Voice-

You tell them what you want. But do they listen?

-Voice-

And are they supposed to be serving you? I think that they sometimes want to take control. And people are supposed to be taking in 'trol; staff is not taking in control. If this is supposed to be a movement -- I think that you supposed to be in how to tell them what you want done. And how to do things. And how to tell them, "Get off my back; let me be in charge; let me have control over my life!"

I don't know how to put it in this way, but I understand that there are a lot of people sometimes are not in control over their life; are not saying to themselves and saying to themselves and saying to staff, "I want to be in charge of my own life. I want to be in charge."

Articles from Our Contributors

Who's In Control

Can you say that? With me?

I want to be in charge over my own life.

Not telling me what to do.

I want to be in charge of my own life.

And I have a lot of people telling us that sometimes people just don't listen. There're people out there doesn't really listen to you. I know in Pennsylvania they don't listen very hard, very nicely. So we have to waken people up and make people understand that we are in control of our own life and tell us what to do. 'Cause when I was in Pennhurst, Pennhurst State School, I had people who controlled my life. I had people control me and tell me what to do, tell me when to get up, tell me when to go to bed, tell me what not to do: "If you don't go to work, if you don't do the things that you're supposed to do, then your privileges will be taken away from you."

How many people be in a situation like that? Show of hands.

Quite a few. Quite a few of you have been in situations like that, just like me.

How many people have been in programs that tells you: "You can't do such-and-such a thing; you can't do it here, not here, not in here." Show of hands.

Good.

And the only way to break that barrier is to tell people that you are in control. You are in control over your own life and in your own ways. And tell people -- be honest and be sincere -- and say that: "I am in control over my life; not you tell us what to do and how to control your money and how to control who's in control." And that's what I go around the country saying: "Who's in control?"

I been at London, England 'bout three years ago and I said the same thing and I got the very round of applause, clapping: Who's in control? Because sometimes people think that you can't do it; you can't do the things you're 'posed to do. They don't trust you enough. If you be honest enough that they might trust you, if you do the things you're supposed to do.

I mean every day that you live in your program, that they're not supposed to tell you how to make changes come. How to make people listen to you?

Listen -- listen: is two different things. Listen and telling somebody what to do is two different things. And it's hard to listen to, to understand people.

I'm not going to take too much of your time, I'm gonna' just say: Thank you for this, for me to come here and speak. I'm want to give honor to Patric Worth for allowing me to come here and speak to you and for all this week. Thank you very much.

Roland Johnson (1945 - 1994)

An Introduction to Self-Determination

By Bonita Scott

Speech given at Advocacy Forum, Philadelphia, PA: Spring 1999

Hello, my name is Bonita Scott. I live in Lexington, Tennessee. I am your state president. We have over 1000 members statewide. Today, I want to give you an introduction to Self-Determination. Self-determination is making decisions, having power over what you buy to eat, wear, having power over your own life, having control over the things you want in your own life, choosing who you want to live with, and with whom you want to get married in your lifetime.

The words I will be using today are the following words:

1. Decisions
2. Rights
3. Feelings
4. Authority
5. Responsibility
6. Freedom
7. Support
8. System
9. Opportunity
10. Dignity & Respect
11. Goals

Decisions: Decisions are very important in people's lives. It is very important for people with disabilities to have the opportunities to make our own decisions. If people with disabilities are not given the opportunity to make decisions, we won't learn how to make decisions in our lives. In the last few months I have made two major decisions in my own life. The decisions are to get married and to move to Jackson. Both of those decisions will change my life forever.

Rights: People with disabilities have the same basic rights as everyone else. Rights are given to everybody no matter if you have a disability or not. Rights are very important to people with disabilities.

Feelings: People with disabilities should be able to express our feelings in every way possible. People with disabilities need to be taken seriously about things that are important to them. Most of the time, people don't think people with disabilities know what we want in our lives. People need to stop and listen to us.

Authority: Authority is having power over your money and where the money goes. This should include the money for your services and supports also.

Responsibility: People with disabilities want to learn how to take responsibility over our own lives. As people with disabilities we have the responsibility to let people know this. We want the responsibility to make our own decisions in our own lives.

Freedom: When we talk about freedom, people don't seem to listen to people with disabilities. Freedom means that we have the freedom to vote, live, work, have relationships, and to have a normal life. Freedom is taken for granted when it comes to people with disabilities.

Articles from Our Contributors

Introduction to Self-Determination

Support: Supports are services that people need to live in their communities. We need to help find support services for people when they move out of the state run institutions. We need to support all people no matter if they have a disability or not. People with severe disabilities may need more support than other people. People need all kinds of support, people need to have natural support as well as other supports.

System: People with disabilities want to change the current system. We want the old system to support self-determination. We also want the old system to change to a new and effective system. We want a system that works for all people, not just people without disabilities.

Opportunity: People with disabilities need to have more opportunities to do the following things; work, drive, get married, buy a home, vote, to have a happy life, to be happy with someone you love and care about very much.

Goals: Self-determination is being able to set your own personal goals for yourself. Goals are a very important part of people's daily lives.

My personal goals are:

- To get married
- To own a house with a white picket fence around it and a swimming pool in the backyard
- To own a red mini-van
- To own my own business—Bonita's Daycare Center
- To be known as a person who stood up for her rights and for the other people's rights
- To be known as a self-advocate to my friends who may need one.

I would like to leave you with three important words to remember:

I will, I can, I did it!

*Speech given at Advocacy Forum, Philadelphia, PA
Spring 1999*

Bonita G Scott (1963 - 1999)

When I Was Little

By Gloria Steinbring

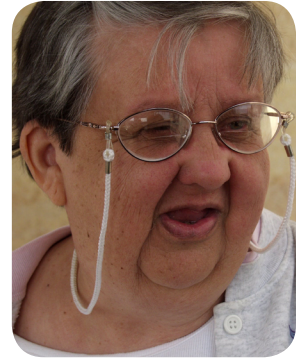
When I was little, doctors told my mom and dad to put me in an institution because I would never make anything of myself. They didn't and I am glad. I went to 7th grade when there was no more school for me so I stayed at home and took care of my little brother. When I was 23, I moved to Minneapolis because there was nothing for me in Hibbing. I moved to a place I call 'H-E Double Toothpicks', if you know what that means. One time staff accused me of stealing money. No trial. No jury. They convicted me and locked me in a closet for 24 hours. No blanket, no food, no water, nothing.

I helped found Advocating Change Together (ACT) in 1979 because people with disabilities need to speak up and change things. We were not being listened to or respected with organizations founded by parents and professionals. We needed our own organization to have power. One of the first

things we did was help write a bill to make it illegal for staff in group homes to try to change people by using lock-ups or hurting the person the way I was hurt. The bill was called Adverse Treatment and I testified on it. After I gave my testimony, my state representative came up to me and put his arm around me and said 'Gloria, you did a good job, you should be proud' I am very proud that I helped this bill get passed because I don't want others to be hurt like I was hurt."

Gloria later said, "We're tired, we're gonna fight back and we're gonna keep fighting back until we win our rights."

Gloria Steinbring (1945-2016)



My Self Advocacy My Journey

By Elouise Woods

I was born in Tuscaloosa, Alabama. I lived with my mother and father and 13 brothers and sisters. My first lesson in self advocacy came from my mother. She treated me the same as my brothers and sisters, encouraging me to do everything that they did. She encouraged me to speak up about things that were important to me. I went to school attending special education classes. These classes made me feel I was different. I became very shy and did not often speak up.

When I graduated from high school, I went to day programs for several years. In 1986, I began my self-advocacy journey. I attended an ARC program where I was involved in a group where we discussed our dreams for our lives and how we felt about having a disability. I was pretty shy about talking about these things. One day the group talked about self-advocacy and watched a film about a group of people with disabilities who formed a group called People First. They used this name because they wanted People to see them as People First, not as their disabilities. I was so excited about this that I and the rest of my friends wanted to start a group in Tuscaloosa. I started feeling better about speaking up. We decided to start a People First group in Tuscaloosa. We talked about our rights and our dreams of working and living on our own.

We decided that we would talk about self-advocacy with other people in our state. We asked for help from People First of Tennessee and the Arc of Alabama to start a state People First chapter. I helped with the conference, and self-advocates from all over Alabama decided that we wanted to start a state chapter. I was elected the Chapter's 1st sergeant at arms. Then I became



President. I have recently served as Treasurer of the organization. I led People First in their efforts to close institutions and also worked with them to organize local chapters in the state. We are now working on Employment for people and recruiting youth

I became involved with Self Advocates Becoming Empowered (SABE) in 1990. I decided that I wanted to run for regional representative for my Region and won. Later I became Sergeant of Arms and then Vice President. I was now a National Leader. I trained other people on how to become strong leaders and how to speak up for themselves. I represented People First and SABE on many boards, committees and as a trainer. I have been a keynote speaker for many state, national, and international events.

Articles from Our Contributors

My Self Advocacy My Journey

In my personal life, my mother passed away in the early 1990's. I moved in with my sister for a few years. In 2009 I decided that I wanted my own apartment, so I moved in with a roommate. We had a great time. I really enjoyed my apartment. I had some health problems in 2017. So, I had to move in with another sister (I do have a really large family).

I have worked in many places. I worked in a sheltered workshop, restaurants, hotels, as a receptionist, public speaker, and trainer. I have traveled to many states and internationally. I retired from my receptionist position after 20 years for health reasons. I continue to speak up for myself and others. I recently went to a regional meeting in Texas to share with people how People First helped close all of their institutions in Alabama. I am also

speaking out on how to change our waiver services in Alabama. My next dream is to travel on vacation to Hawaii. Hopefully this will happen soon, I am saving my money.

I realized that the self-advocacy movement is a civil rights movement led by many strong voices. Voices speaking up for our rights. The right to good paying jobs and careers, having close relationships, living in our own places with who we want, being a part of our community. The self-advocacy movement, SABE, and People First have been so important to me in my life journey. The movement has helped me be a strong and powerful person who speaks out for myself and others about the things that are important in our lives. My mother would be proud.

My Vote

By Jeff Ridgeway



They say I can't vote

They say the decision is not mine

They say I don't understand

I guess they think they are being kind

I wonder what they would say or think

if they only knew

That when they call the President

"Our President",

I want to call him mine too.

Why I Got Involved in Self-Advocacy

by Bernard Baker, Chester Finn, Debbie Robinson, Cheri Mitchell, James Meadours, Julie Petty

Bernard Baker

I got involved in the self-advocacy movement through a friend. I became a leader through ADAPT. ADAPT has made a difference because we marched, went to our state representative, and got the ADA passed. To support the movement, I have become the President of Self-Advocates Becoming Empowered (SABE).



Chester Finn

When I was at a provider agency, one of my friends was in a self-advocacy group. He went to the statewide conference and told me some of the issues: Civil Rights, voting, and making changes. I wanted to go so I joined the group and I've been involved ever since.



I have always been a leader ever since I was a child. I never followed anybody and always made my own path and came up with the ideas. I would speak up at meetings and people would recognize me and ask me to speak for and represent them.

We've made a difference on many levels. Locally, we speak up in the community, talk with policy-makers and serve as an example for people in the community. We help and teach each other how to become better advocates by holding each other accountable. If you can't do that, you can't be effective. We also meet on the statewide level and also serve as role-models.

Right now, I am speaking around the country and talking to people about how to work with and treat people with disabilities and serving as an example to others to keep the self-advocacy movement going strong.

Cheri Mitchell

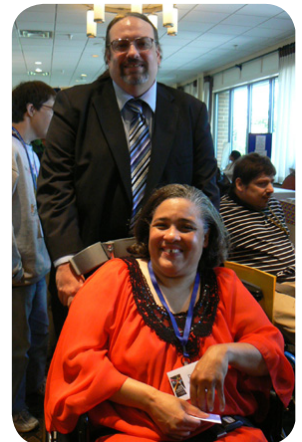
I became a self-advocate so I could help myself and others. I got involved in self-advocacy when I was working at a center for independent living. I met Bernard Baker, Kate Gainer and Mark Johnson and they mentored me. Mark Johnson taught me about why it is important to get involved. I was in my 30's. We were looking at nursing transition and working on attendant care. I became a self advocate so I could help myself and others. I learned about self advocacy when I became a member of People First of Georgia and ADAPT, as well as the local Center for Independent Living. People first is a self advocacy organization and ADAPT is a disability civil rights organization; we support one another. These self-advocacy groups have made a difference because we organized and supported each other to speak up. We have collaborated, done marches, spoke to legislators, and worked with Money Follows the Person to get real change to happen. We also did Long Road Home.



I am supporting the movement by being on advisory boards, doing trainings and workshops, mentoring and supporting other self advocates. I am a member of ADAPT and People First. I write to raise awareness. I am the chair of Long Road Home.

Debbie Robinson

I got involved in the Self-Advocacy Movement when I joined an organization called Speaking For Ourselves. Roland Johnson was my mentor, and helped me to become a leader. My Self-Advocacy group made



Articles from Our Contributors

Why I Got Involved in Self Advocacy

a difference by supporting self-advocacy, working with disabled individuals, working the disability system, and participating in our communities for disability rights. To keep the movement going strong, I am still involved in advocating and very active in participating in meetings, and I serve on state and government boards.

James Meadours

I got involved in the self-advocacy movement because I wanted to go to a meeting to change my voting card address. I traded my phone number with an advisor and I lost her number. She lost my phone number. A year later we saw each other again. My life changed forever.

I felt like my peers saw me as a leader. They elected me to office and trust me to do my job and talk about key issues like funding the waitlist, closing state run institutions, better paid support staff, and closing sheltered workshop programs.



My self-advocacy group worked in Texas to change from mental retardation (MR) to intellectual disability (ID). Now, I train other self advocates to know their leadership role. I also have someone tag along with me during board meetings and at the state capital.

Julie Petty

I got involved in self-advocacy in 1998 when I began working part time for Arkansas People First. I became a leader by helping start groups all over the state and going through many different leadership trainings, most importantly Reaching My Own Greatness.

Self-advocacy groups have made a difference by giving people the courage to speak up and say what they want and need, and make their own decisions. I continue to work with people with intellectual and developmental disabilities to model that way and show them that they can make their own decisions and have the life they want.



The Jerry Lewis Telethon Beginning

By Nancy Ward

I got involved in the self-advocacy movement when I saw a commercial on TV about Jerry Lewis's Telethon where they were parading kids across the stage. I got mad so I yelled at the TV. As you can see, I knew how to direct my feelings in a negative way but I didn't know how to direct my feelings in a positive way. That's when one of my friends invited me to attend an Advocacy First meeting. This is one of the Nebraska People First chapters, and I loved it. I've been involved in the Self Advocacy movement ever since.

My Self Advocacy skills are very important to me because it took me five years to gain the confidence in myself. Nebraska was one of the first states to have People First. I had friends who were professionals telling me I was advocating for myself which was cool, but it's not the same as having your peers tell you because more than likely they've been in the same situation and not had the confidence in themselves to speak out. I don't want it to take anyone else five years to gain the confidence in themselves, which is why my self-advocacy skills are so important to me.

I now live in Oklahoma, and one of the ways my self-advocacy has made a difference is in my work with one of our legislators to put into state law our Respectful language law. Also, Oklahoma People First (OPF) helped close our state institutions. We asked the people that believe in us to teach us to do it for ourselves so we have developed 6 different trainings that are taught by us to our peers. We planned a National Self Advocacy Conference. OPF also hosts DD Awareness Day at the capitol.

Today, I am Working on helping Oklahoma Self Advocacy Network (OKSAN) develop a legislative caucus in different areas of the state so the different partners from each of the areas don't have as far to go to meet with their legislators. I am also working on helping Oklahoma Self Advocacy Network develop new trainings on Sexuality and Decision Making, and working with schools teaching self-advocacy skills. I am working on helping Oklahoma Self Advocacy Network educate doctors about people with disabilities.



Growing Up, I Advocated for Myself

By Brad Linnencamp

Growing up, I advocated for myself in school. Upon graduation and moving to another community, I advocated for individuals with disabilities through my work with a service provider. Following several years volunteering and joining the local advocacy group, I was offered a position with the Self-Advocate Coalition of Kansas (SACK). I have been advocating on the local, state and national level for the past twenty years. Because of my early opportunities, experience, and education I felt comfortable in a leadership position. I felt comfortable advocating for myself and for others. I have made a difference by successfully assisting in the passage of Employment First in Kansas, assisting in the adoption of legislation that decreased the use of seclusion and restraint and developed new standards for evaluation, promoting a new model of Leadership based on and in collaboration with the Kansas Leadership Center, and having an effect on systems concerning people with IDD and who also experience sexual violence. I also worked to develop new toolkits, training, and a fresh way of looking at collaboration.

In order to support the movement, I am currently a mentor for individuals with IDD who wish to further their advocacy and leadership skills. I also provide training to both consumers, service providers and the community at large. I am currently in the process of taking a new job with the UCEDD at the University of Kansas that will allow me to remain connected to the state organization (SACK) and advance projects and programs at a national level.



There Should Be a Place for GLBTQIA

By David Frye



Well, having a disability myself and seeing what things I struggle with in life, I know what it is with a disability and I am always thinking about fighting for our rights. When I was young, I went to a facility where the nuns took care of us. They were very strict. They would get mad at me because I would get the “D’s” and “B’s” mixed up. I remember speaking up one time when they asked me to do an event and I told them I did not want to do it. They honored my wishes of not participating. When I went to high school I was able to go to classes with everyone else, like English class, which I liked a lot.

I had a niece who was born premature. When she was born she wasn’t fully developed. She died when she was 9 years old. She was the one to tell me that I needed to do this kind of work whether I got paid or not. She said that I should let my voice to be heard. I got involved in the Green Mountain Self-Advocates. This allowed me to speak up for myself and work with others to speak up. I tell my story and speak up to help further the movement.

As I am doing this kind of work now, I see even in Vermont where there are huge gaps in rural areas in Vermont where people are not getting services.

I believe that there should be a place for GLBTQIA people with disabilities to go and have a group of their own and also be a part of their community.

“How I Proudly Became a Self Advocate”

by Teresa Moore

After a visit out west, our family was ready to move. Arizona here we come! Turns out thousands have the same idea each month. It was hard to get started. We moved away from our large family. I had seen our Phoenix relatives two times before the move. The crowds seemed to make me very shy. I had trouble meeting people. I was given a newsletter with activities for Ability 360. The Phoenix Independent Living Center or ILC. I joined the Writers Club. Later I would be asked to host the club. Some members had their short stories published. I volunteered several years for different events. I did some small paid jobs for the ILC.

The Advocacy Director asked if I would be like to work more. A grant would help youth with disabilities. They would use self advocacy to get the jobs they want. I had gone to the state capital with the ILC to advocate for services. It sounded like that, but not. I had to tell her. She arranged for a self advocacy training. The rest is like many of my friends say in their story.

I was a self advocate before I knew what it was called.

The Parent to Parent group in Phoenix wanted an adult with disabilities to use a mapping process with families. I helped families focus on their teenager's dreams for work. One meeting we had was about self advocacy groups in Arizona. They did many great things with support of families or agencies. They were not led by the people with disabilities. I was asked if I would like to go to a People First conference. The people lead the group with support from Advisors. I remember the YES came

out louder than it should be to your boss. She was glad I was excited. She added make sure you try to meet Nancy Ward from Oklahoma.

I made it. My first national self advocacy conference in Oklahoma City 1996. The opening ceremony, people everywhere. A voice from the stage; “Introducing our President of the Steering Committee Nancy Ward.” The crowd screamed so loud, I jumped. There she was. I didn't think someone so famous would talk to me. Self advocates from all over the country were my teachers. I watched, listened and learned. They presented, told stories and led the whole conference. It was the Region Meeting that was the most confusing to me. Arizona didn't have a representative to help groups. Our Region picked me and a young man from California. We had to go on stage and say our name and region. Screams for us. Yikes, I thought, but ok. Done.

Electing Officers from the representatives was next. One of old board members was helping with the elections. She asked if I was running for a position. I told her oh no, not me. I am new. She said that only one person was running for Vice President. We need two to make the election exciting for everyone. I figured that my region was small that she would win. I had an early flight and went to bed. The next morning people came up to me saying. Congratulations. Thank you, over and over. Thank you I am really excited to be the Region 2 Rep. I said. One of the self advocates that I had made friends with said sure, but you are the new Vice President. What. It was true.

On the board, I would be mentored by two women who would forever change my life. Nancy Ward and Tia Nelis. Each made sure members knew of chances for training, grants and committee work. I would be invited by states that were doing projects. We worked with Human Services Research Institute. This was when I met John Agosta. John would give me the opportunity to start my own business.

Articles from Our Contributors

"How I Proudly Became a Self Advocate"

Self Determination Movement made funding to states. Arizona was one state. I was part of writing our project proposal. It's My Life, made it possible for our ILC to host our People First group. I was included in hiring our State Advisor, Lynn Black. Our state being selected for the grant made us a Eligible for visits from the father of self determination Tom Nerney. If you control the money you have control your life. Blessed are the self advocates that heard him talk then spent time with him.

Our group was part of the Self Advocacy Coalition of Arizona. They existed for a short time that made a huge impact. Stopped the use of R word in state paperwork. People First of Arizona group spent the next couple of years developing a reputation for self advocacy training. Later, they became an expert in GoVoter and Arizona continue to have a strong relationship with Arizona Center for Disability Law doing training.

SABE received a Kennedy grant to write vote training. Nancy Ward, Tia Nelis, Laurie Powers Hannah Bowen contributed to the beginning of the GoVoter project. We work with the National Disability Rights Network to provide our Distance Training is on-line training. We support State Teams the Protection & Advocacy Organization and a Self Advocacy Organization to and partner. We also collect Voters with

Disabilities Experience Surveys. We want to know how things went at the polls on Election Day. We have been hosting the officer elections for years. Making sure it is exciting for everyone who votes for SABE Officers. Our GoVoter Team includes Essie Pederson, Tia Nelis, Juliana Huerena and Bill Lucero.

My next adventure started with the 2011 and 2012 Self Advocacy Summits. Information from all over the country wanted to shared with the Administration on Developmental Disabilities AIDD now called Administration on Disabilities (AoD). Resource Center that everyone could be part of. SABE was selected to lead the Self Advocacy Resource & Technical Assistance center SARTAC. I am so grateful for the creative partners of Green Mountain Self Advocates, University Missouri Kansas City, TASH, ASAN. Self Advocates Becoming Empowered Vicki Turnage and I work together with the Board of Directors. This amazing team of talented organizations have opportunities in the project. Website filled with resources to support self advocacy organizations. Making sure that amazing individuals have Scholarships, personalized technical support, study comparing history and videos from history of movements, and toolkits about policy and legislation. Toolkits and other reports from the Advisory Committee.



ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

1990

- 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

- 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

- 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.)



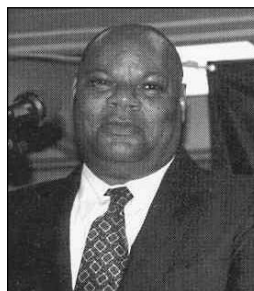
ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED



- 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

- 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

- 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



ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

1996

- 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

- 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

- 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

- 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 5th 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

- 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

ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED



2002

- 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 6th 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



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

- 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

- 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.
- 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.



2006

- 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



ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

2008

- 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



2009

- SABE partnered University of Missouri in Kansas City UCEDD, Beach Center, University of Illinois – Chicago UCEDD, and the Valhalla UCEDD to establish A National Gateway to Self Determination Project. SABE serves as a member of the Center’s Advisory Committee; and, as a direct liaison to People First/Self Advocacy groups around the country to collect the tools and 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

- 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.

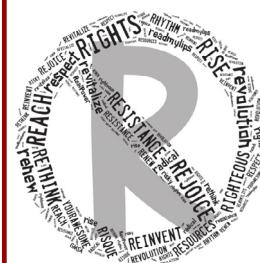


ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

2011

- SABE joined with the Arc USA and ASAN to form the National Autism Resource and Information Center (Autism Now) funded as a project of National Significance by the Administration on Developmental Disabilities (AIDD). Our work included: 5 Regional 2-day Summits on core values for guiding supports for people with autism and other developmental disabilities. Held in Maryland, Indianapolis, Orlando, Austin and Los Angeles. SABE held webinars, conference calls, and blogs on best practices in self-advocacy.

SABE R Word Policy Statement



*Be it
resolved,
it is time
for
citizens
and local,
state and*

*federal officials to come out
and put a stop to using the
R word.*

- AIDD and national DD network programs held 5 regional Summits Envisioning the Future: Allies in Self-Advocacy. Each state and territory developed a team with the same amount of self-advocates and professionals. State teams made plans to make the self-advocacy movement in their state stronger.

- SAGE continued our work with AIDD and the DD Network programs to hold 4 more Allies in Self-Advocacy Summits across the country. The final report included recommendations to support self-advocacy at the national and state level.

- SABE received a mini-grant, Our Community United to provide training to states in how to run a self advocacy n. The grant was made possible through funding from Admin- Intellectual and Developmental Disabilities.

- SABE National Conference “It’s about Fairness” was hosted by Advocating Change Together in St. Paul, Minnesota.

2012

2013

- SABE awarded a three year grant by the Administration on Intellectual and Developmental Disabilities to establish a Regional Technical Assistance Center. The Center was named Our Community Standing Strong. The project developed peer to peer technical assistance support to nine Southern States to strengthen the self advocacy movement.
- Nancy Ward, Co-Director of SABE's National Technical Center for Voting and Cognitive Access, testifies at the National Council on Disability. She talked about the importance of accessible voting machines and poll worker education on creating a good voting experience.



ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

2014

- SABE promotes the Declaration of the Rights of People with Cognitive Disabilities to Technology and Information Access.
- Oklahoma People First hosts the 2014 National Conference in Oklahoma City. The conference theme was “The Sooner we are Equal the Better”.

2015

- SABE began a 5-year partnership with the University of Massachusetts in Boston working on the Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities. SABE wrote white papers on best practices in employment for people with disabilities.



2016

- SABE completes its work with Our Community Standing Strong. The outcomes of this project included a grassroots survey on self advocacy, 92 video blogs on self advocacy issues and technology and strong partnerships between self advocacy organizations and other DD partners in these states.
- SABE awarded a 5 year grant of National Significance by the Administration on Community Living to lead the National Resource Center on Self Advocacy. SABE partnered on this grant with Green Mountain Self-Advocates, Autistic Self Advocacy Network (ASAN), Southwest Institute of Family and Children, University of Missouri in Kansas City Institute for Human Development (UCEDD) and TASH. SABE named the Center SARTAC (Self Advocacy Resource and Technical Assistance Center). The center objectives included setting up a website for self advocacy resources, establishing an advisory committee of self advocates to provide input into the project and develop best practice tools for self advocacy organizations, developing a fellowship program for 24 self advocates to work on policy and leadership projects, and to research the history of the movement and its commonalities with other civil rights movements.





ACCOMPLISHMENTS OF SELF-ADVOCATES BECOMING EMPOWERED

2017

- SARTAC employed 8 self advocates on the management team for SABE and partners. Six self-advocates were supported to complete Fellowships on leadership and community organizing. The SARTAC Clearinghouse Website was launched featuring the work of the 6 Regional Self Advocacy Technical Assistance Centers. A one-of-a-kind Easy Read and Plain Language toolkit was created *A Self Advocates Guide to Medicaid*.

2018

- People First of Alabama, Arkansas People First, People First of Georgia and SARTAC with support from Our Community Standing Strong states hosted the 2018 National Self Advocacy Conference. The theme was: Let's make it happen! Disability Rights are Civil Rights. The conference was held in Birmingham, Alabama.
- SARTAC released the revised SABE Self Advocacy Toolkit. A plain language article was written about the history of the self-advocacy, African American, and LGBTQ social justice movements. Plus technical assistance and training to hundreds of self-advocates and allies across the country.



2019

- Go Voter published the results of 1200 surveys on voting access
- SARTAC continued to strengthen the self-advocacy movement. A Toolkit on Coalition Building was created. We completed 15 video interviews with leaders of the self advocacy movement and parallel movements. The website, selfadvocacyinfo.org, has more than 300 resources created by and for people with intellectual and developmental disabilities. Technical assistance was provided in-person and over the phone to more than 40 states and territories.



2020

The SABE National Conferences returns to Colorado to celebrate the 30th anniversary of the beginning of our organization. People First of Colorado will host the conference in Denver., Colorado October 1-3, 2020. The theme of the Conference is "Moving Mountains."

[Home](#)[A quick tour of our website](#)[Find Self-Advocacy groups](#)[View stories from Self-Advocates](#)[Learn about Self-Advocacy](#)[Research for All](#)

[Click here to find a self-advocacy group near you.](#)

Self Advocacy Resource and Technical Assistance Center

“Self-Advocacy and Beyond!”



[Self Advocates Becoming Empowered](#) (SABE), the oldest national self-advocacy organization in the country, has been awarded a grant from the [Administration for Community Living](#) to establish the first-ever National Resource Center for Self-Advocacy. The resource center is funded as a [Project of National Significance](#) by the [Administration on Intellectual and Developmental Disabilities](#) under the [Administration on Disabilities](#).

What is the name of SABE’s new Center?

Self Advocacy Resource and Technical Assistance Center (SARTAC)

What is the mission of SARTAC?

The mission of SARTAC is to strengthen the self-advocacy movement by supporting self advocacy organizations to grow in diversity and leadership.

What are the activities of the Center?

- Create and manage a website where self advocates can learn about the best ways to organize and support the self-advocacy community
www.selfadvocacyinfo.org
- Communicate with the community through social media like Facebook and Twitter <https://www.facebook.com/SARTAC1/>
- Share best practice tools created by the Regional Self-Advocacy Technical Assistance Centers and by self-advocacy organizations and allies from across the nation
- Work with a 12 person Advisory Committee to review information created by the Center
- Write a paper, make a video and lead a webinar about the history of the self-advocacy movement



TASH Membership Form

Referred By: _____

Organization Name (If applicable): _____

Organizational members must fill out the following fields for the Primary Contact only. To submit five staff members that would like to receive TASH benefits, please attach the Organization Member Sub-Account Form (available at www.tash.org/join).

First Name: _____ Last Name: _____

Address: _____

City/State/ZIP: _____ Country: _____

Phone: _____ E-mail: _____

Membership Level

TASH offers membership at a variety of levels. Please review the details below and choose the membership level that is appropriate for you. Individual and organizational memberships are available. Membership dues can be paid annually or monthly. A complete summary of member benefits can be found at www.tash.org/join.

	Regular	Reduced			Organization \$385 year \$33 month
	Professional \$165 year \$14 month	Associate \$85 year \$7.50 month	Self-Advocate, Family & Sup- porter \$35 year \$3.25 month	Student \$45 year \$4 month	
Research and Practice for Persons with Severe Disabilities, the official TASH research journal (print copy)	X				1 COPY
Research and Practice for Persons with Severe Disabilities, (online access to current and archived issues)	X	X		X	X
Connections, the quarterly magazine written by and for TASH members	X	X	X	X	X
Connections Library (includes access to 10 years of Connections archives)	X	X	X	X	X
TASH webinar archive	X				X
Reduced registration rates for TASH conferences and events	X	X	X	X	5 STAFF
Discounts for TASH Training webinars, publications & other offerings	X	X	X	X	5 STAFF
Access to TASH's professional network, forums & blogs	X	X	X	X	X
Affiliation with a TASH Chapter (includes policy and expertise, Capitol Hill Days, Chapter communications & activities)	X	X	X	X	X
Advocacy Alerts & Updates	X	X	X	X	X

Demographic Information

This information is collected for TASH's use only so that we can better serve our members' needs.

What is your race or ethnicity? (Optional; select all that apply)

- ☐ American Indian or Alaska Native ☐ Native Hawaiian or Pacific Islander
- ☐ Asian ☐ Black or African American
- ☐ White/Caucasian ☐ Hispanic/Latino
- ☐ Other _____

Which of the following best describes you? Select all that apply. (not applicable for organizational members)

- | | | |
|---|--|---|
| <input type="checkbox"/> General Educator | <input type="checkbox"/> Parent of a person with a disability | <input type="checkbox"/> Government – State |
| <input type="checkbox"/> Special Educator | <input type="checkbox"/> Sibling of a person with a disability | <input type="checkbox"/> Government – Local |
| <input type="checkbox"/> Education Administrator | <input type="checkbox"/> Other family member of a person with a disability | <input type="checkbox"/> Attorney |
| <input type="checkbox"/> Transition Educator | <input type="checkbox"/> Early Intervention Service Provider | <input type="checkbox"/> Public Policy Advocate |
| <input type="checkbox"/> University Faculty | <input type="checkbox"/> School-Aged Related Service Provider | <input type="checkbox"/> Student |
| <input type="checkbox"/> University Researcher | <input type="checkbox"/> Adult Service Provider | <input type="checkbox"/> Other Advocate |
| <input type="checkbox"/> Person with a disability | <input type="checkbox"/> Government – Federal | <input type="checkbox"/> Other _____ |

How did you hear about TASH? _____ How would you like to receive info from TASH? ☐ Email ☐ Postal

Please indicate your areas of interest. Select all that apply.

- | | | |
|---|---|--|
| <input type="checkbox"/> Early Childhood | <input type="checkbox"/> Community Living | <input type="checkbox"/> Assistive Technology |
| <input type="checkbox"/> K-12 Education | <input type="checkbox"/> Aging Issues | <input type="checkbox"/> Communication |
| <input type="checkbox"/> Transition | <input type="checkbox"/> Advocacy | <input type="checkbox"/> Diversity & Cultural Competency |
| <input type="checkbox"/> Post-Secondary Education | <input type="checkbox"/> Public Policy | <input type="checkbox"/> Human Rights |
| <input type="checkbox"/> Employment | <input type="checkbox"/> International Issues | <input type="checkbox"/> Other _____ |

Additional Information

Your Date of Birth (Optional): ____/____/____

If you are a family member of a person with a disability, fill out the date of birth of your family member: ____/____/____

If you are a student, please fill out the following fields:

University Name: _____ Expected Completion Date: _____

Major/Department Name: _____

If you are a university educator, what is your field of study? _____

Payment Information

Monthly membership must be paid with a credit card for automatic renewal purposes.

Credit Card (select card type)

☐ **Check** (make payable to TASH)

☐ **Purchase Order**

☐ American Express ☐ Visa

☐ MasterCard ☐ Discover

P.O. #: _____

(send copy with membership form)

Card #: _____ Expiration: _____

Name on Card: _____ CVV: _____

Authorized Signature: _____

Would you like to make a tax-deductible donation to TASH?

☐ \$10 ☐ \$25 ☐ \$50 ☐ \$100 ☐ \$ _____

Total Payment (add membership total and donation, if applicable) \$: _____

Please submit this membership form via mail, fax or e-mail. If you have questions, please call (202) 817-3264.

1101 15th Street NW, Suite 206
Washington, DC 20005

Fax (202) 999-4722
E-mail info@tash.org

www.tash.org to learn more about TASH

www.tash.org/join for an overview of member benefits





NEW!

Welcome to **TASH Amplified**, TASH's new podcast series. This series seeks to transform research and experience concerning inclusion and equity for people with disabilities into solutions people can use in their everyday lives.

Season One Episodes

A Brief History of PBIS

Special Education Teachers and the General Education Curriculum

Teaching Math to Students with Disabilities: What We've Learned in 10 Years

What Matters to Family Members when a Relative Transitions to Community Living

Reflections on 40 Years of Agency Community Supports

Building Communities to Support People with Disabilities

Faith and Flourishing: Equipping Your Church to Reach Out to People with Disabilities

Presentations on Recreation and Leisure for People with Disabilities at the TASH Annual Conference

Faith and Flourishing: Welcoming Children with Disabilities and their Families

Faith and Flourishing: Hidden in Plain Sight

Barb Trader Reflects on a Lifetime of Accomplishment in Disability Rights

www.tash.org/amplified



TASHConnections

Equity, Opportunity and Inclusion for People with Disabilities since 1975

TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people.

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities. Items in this newsletter do not necessarily reflect attitudes held by individual members of the Association as a whole. TASH reserves the right to exercise editorial judgment in selection of materials. All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please visit www.tash.org.

TASH Mission & Vision

As a leader in disability advocacy for more than 35 years, the mission of TASH is to promote the full inclusion and participation of children and adults with significant disabilities in every aspect of their community, and to eliminate the social injustices that diminish human rights. These things are accomplished through collaboration among self-advocates, families, professionals, policy-makers, advocates and many others who seek to promote equity, opportunity and inclusion. Together, this mission is realized through:

- ♦ Advocacy for equity, opportunities, social justice and human rights
- ♦ Education of the public, government officials, community leaders and service providers
- ♦ Research that translates excellence to practice
- ♦ Individualized, quality supports in place of congregate and

segregated settings and services

- ♦ Legislation, litigation and public policy consistent with the mission and vision of TASH

The focus of TASH is supporting those people with significant disabilities and support needs who are most at risk for being excluded from society; perceived by traditional service systems as most challenging; most likely to have their rights abridged; most likely to be at risk for living, working, playing and learning in segregated environments; least likely to have the tools and opportunities necessary to advocate on their behalf; and are most likely to need ongoing, individualized supports to participate in inclusive communities and enjoy a quality of life similar to that available to all people.

TASH has a vision of a world in which people with disabilities are included and fully participating members of their communities, with no obstacles preventing equity, diversity and quality of life. TASH envisions communities in which no one is segregated and everyone belongs. This vision will be realized when:

- ♦ All individuals have a home, recreation, learning and employment opportunities
- ♦ All children and youth are fully included in their neighborhood schools
- ♦ There are no institutions
- ♦ Higher education is accessible for all
- ♦ Policy makers and administrators understand the struggles of people with disabilities and plan – through laws, policies and regulations – for their active participation in all aspects of life
- ♦ All individuals have a way to communicate and their communities are flexible in communicating in alternate ways that support full participation
- ♦ Injustices and inequities in private and public sectors are eradicated
- ♦ Practices for teaching, supporting and providing services to people with disabilities are based on current, evidence-based strategies that promote high quality and full participation in all aspects of life
- ♦ All individuals with disabilities enjoy individualized supports and a quality of life similar to that available to all people
- ♦ All individuals with disabilities have the tools and opportunities to advocate on their behalf