# ALTERNATIVELY SPEAKING

## Where's the AAC in Democracy?

nce again, Alternatively Speaking looks at an adult activity that historically hasn't been expected of people who use AAC. In the past, we have discussed employment, higher education and marriage. This issue of Alternatively Speaking shines a light on political activities.

IN THE SPOTLIGHT

Political activities are activities that pertain to public policy, or to politics, or that relate to affairs of state or administration.<sup>1</sup> Political activities are not just for politicians. In a democratic society, all citizens participate in governance. A democracy is "a government in which the supreme power is vested in the people and exercised by them."2 People who use AAC can, and should, exercise their democratic power. It is a responsibility of citizenship. In addition to becoming involved in city, state and country governments, people can exercise their democratic power in organizations of all types.

The language to describe participating in democratic processes is sometimes highly charged with emotion. "Voting" is generally clear, although there are national variations. For instance, people with disabilities are discouraged from voting in some countries,

while voting is required of all citizens in other countries. But involved in "politics." This is apt to cause some consternation. "Politics," "political action" and "political activities" may bring to mind controversial responses to uncomfortable social issues.

just try asking someone if they are

#### **INSIDE THIS ISSUE**

Where's the AAC in Democracy?



Trusting the Black Box



**Picturing** Ourselves **Politically** 



AAC and the Vote





**Active Citizens** 



There are many ways to participate actively in democracy. Many people who use AAC have told me that they do not participate in democracy. They probably do, but they don't think of their activities as political actions.

Participating in democracy can be as simple (or difficult) as voting. It can be as simple (or difficult ) as placing a political bumper sticker on your automobile or wheelchair. It can be as fast (or slow) as telling a group, "I like that idea."

#### **Learn about issues**

Participating in democracy makes your community a better place now, and for future generations. Participating in democracy includes learning about issues that affect your community. You can read, listen and discuss topics you feel are important. There is much food for political thought on the Internet, in newspapers, books and magazines and on the radio and TV. Informal chats with friends and colleagues as well as more structured lectures, forums, rallies and meetings are also good ways to learn about issues.

#### **Speak out**

Participating in democracy includes sharing ideas and opinions. Speak out at meetings, write articles and be interviewed. Write

Continued on page 2

### Message from the editor

was ten years old when I got interested in politics. It was a hot July night and I was lying in a tent in California's Sequoia National Park. Somebody nearby had a radio on full blast. Men were yelling, "Goodbye, Harry! Goodbye, Harry!" It was the Democratic National Convention of 1948 being broadcast from Philadelphia. The people yelling were convention delegates from some of the southern states who were walking out of the convention because the party's nominee for president, Harry Truman, had insisted that the issue of civil rights be included in the democratic platform.

After the convention, most people thought Truman had no chance of beating the Republican candidate, Thomas Dewey, especially not without those states who had walked out of the democratic convention.

Truman won the election despite everyone's predictions to the contrary. Mass communications were so slow in the 1940s that people in the eastern and Midwestern sections of the country had gone to bed thinking Dewey was the president elect. The Chicago Tribune newspaper was so certain of this they published a special edition of the paper with the banner headline, "DEWEY DEFEATS TRUMAN."

There's a famous photograph of Harry Truman holding up a copy of that paper with an ear to ear grin on his face. The thrill of victory has never looked so sweet.

I have a copy of that photograph hanging in my office. It reminds me that even though things may look very certain, they may not turn out the way you think. It also reminds me of the importance of counting every vote and having every vote count.

I have voted in every election I was eligible to since turning voting age, no matter how minor the election. Some people look at me like I'm absurd when I tell them this. These are some of the same people who say their vote doesn't count.

Oh yeah? Tell that to Harry Truman.  $\Lambda$ 



ALTERNATIVELY SPEAKING (ISSN 1075-3982) is published three times a year by Augmentative Communication, Inc., 1 Surf Way, Suite 237, Monterey, CA 93940. Telephone: 831-649-3050. FAX: 831-646-5428

One Year Subscriptions: By personal check U.S. & Canada=\$35 U.S.; Overseas=\$45 U.S.; Institutions: U.S.A. & Canada=\$50 U.S.; Overseas=\$60 U.S.; Single Issues=\$13 U.S. Special rates for consumers and full-time students.

Second-Class Postage Paid at Monterey, CA. POSTMASTER: Send address changes to ALTERNATIVELY SPEAKING, c/o Augmentative Communication, Inc. 1 Surf Way, Suite 237, Monterey, CA 93940-3451.

Copyright 2004 by Augmentative Communication, Inc. Reproduce only with written consent.

Editor: Michael B. Williams Technical Editor: Carole Krezman Guest Authors: Meredith Allan, Martin Pistorius, Johana Schwartz, Faye Warren, Bob Williams

#### Continued from page 1

letters to the editor, to elected officials, to policymakers and to gatekeepers.

#### **Be present**

Sometimes participating in democracy requires someone to be a witness, to sign on in favor of an idea, to stand with a group at a rally, march or parade, to watch elected officials or cops (including institution enforcers) to ensure they do their jobs correctly, to demonstrate, picket or sit in protest.

#### Work

Contribute your time and energy to a project, an idea or a person who you believe will improve your community.

#### **Be true**

Be true to your beliefs by letting your actions speak. Give your business to establishments that have front door access and treat people who use AAC with respect. Insist that people who use AAC are fully included in all levels of any organization you support.

#### **Organize**

Organize a group to change a policy, elect a candidate, educate a community, support an initiative or publicize a problem.

#### **Break tabus**

Go where people who use AAC are not welcome. Do the unexpected. Be the first in your community to challenge artificial barriers to equal participation in your community.

#### Govern

Join the board of directors of an organization, club or government agency. Take on leadership roles in your school, workplace or community. Run for elected office. Put yourself in a position

to make or enforce policies, laws or regulations.

#### Join

Participate in one of the many non-governmental democratic organizations in your community. You can usually find democratic organizations anywhere people come together in groups to live, work or play. Neighborhood associations, workers organizations and chess clubs are all examples of democracies in the community. The International Society for Augmentative and Alternative Communication3 (ISAAC) is a democratic organization of people who are interested in AAC. Participating in the governance of one of these organizations by voting, going to members' meetings or standing for office can be an interesting way to exercise your democratic power.

#### **Advise**

Share your experience with the advisory board of a private business, government agency or educational or medical institution. These institutions are not typically governed democratically, but the members of their advisory boards represent the diverse interests of the communities they serve.

#### Blaze the way

Anytime you are the first, the only or one of the few to do anything—get on the bus, get an education, shop, raise a family have a successful career—you are participating in democracy in a very powerful way. As a person who uses AAC, just stepping or rolling out your front door and living your life changes the people you encounter and

Continued on page 8



## Trusting the Black Box

One of the hot topics swirling around disability circles in recent months is the viability of casting a ballot by touch screen voting systems. There's no question these systems make the voting process smoother for many people with disabilities. It certainly has for me. Before touch screen voting, I had to convince a poll worker to insert my ballot into the punch card contraption; then I had to deal with the small but deadly-sharp stylus used to poke holes next to my choices. In addition to all this, I had to turn the pages on the punch card contraption that represented the ballot. The whole process was agonizingly cumbersome. With the touch screen system, I just pull up to the device and start whapping away at the screen.

Recent laws enacted on the federal level in the USA and in my home state of California have created an incentive for counties to purchase computerized voting equipment (which includes touch screen voting systems) and move away from paper ballots and earlier mechanical voting systems. This has led some members of the public to raise concerns regarding the security of the

electronic systems. Essentially, the argument is that electronic voting equipment relies on a "black box" computer with proprietary source code and object code hidden from the public. The reliability and security of touch screen voting systems is uncertain.

My use of touch screen voting machines in previous elections has certainly provided me with an overwhelmingly positive experience. However, when I listen to the naysayers out there critique electronic voting, doubt creeps into my mind. It was easy to vote, but was my vote counted?

In a wild up and down struggle, California's Secretary of State decertified most of the electronic voting systems in the state, only to re-certify them again a few months later after a series of vague criteria were met.

This doesn't bolster a person's confidence in these newfangled things.

Will I use a touch screen in the coming election? Well, let's just say if a pollster calls, I'll tell them I'm an undecided voter. \( \)

#### **Organize:** Meredith Allan, Australia

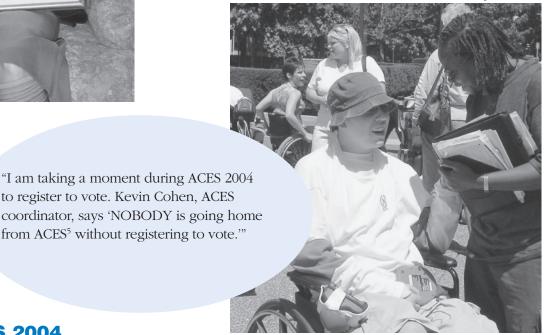
## Picturing Ourselves....



"The award on the right is honorary life membership of Wheelers Hill Young Liberals. I held several offices including Branch President. The award on the left is a national union activism award given to me in March this year. I am a union delegate at work and secretary of the union for my office."



#### Vote: John Haus, USA



Bryen4

#### **Be Counted: Participants, ACES 2004**



"ACES participants engage in political debates and check candidates' websites. Here, we raise our hands in reply to the question, 'Who is registered to vote?""

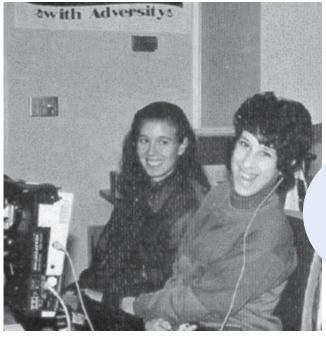
## ....Politically

## **MartinPistorius, South Africa**



"I was a guest speaker at the Launch of the National Accessibility Portal.<sup>6</sup> This photo shows Minister Essop Pahad, Minister in the Presidency; myself; Sebenzile Matsebula, the director of the Office on the Status of Disabled Persons in the Presidency; and Kagiso Chikane, from the CSIR."

#### Lobby: Johana Schwartz, USA



Washington, D.C.. Once in Washington, we had and Dianne Feinstein on the Capitol steps."

"I am sharing my views at a strategy planning meeting with my delegation. We are preparing to lobby our senators during our class trip to a productive talk with Senators Barbara Boxer

#### "I want people with speech impairments to have the same rights and freedom as everybody without disabilities. Because of my communication device, I am able to have a good job and live the way that

I want to live."





## AAC And the Vote

## by Bob Williams

hen I think of what makes it both possible as well as imperative for me to vote, I think of Ruth Sienkiewicz-Mercer, the author of *I Raise my Eyes to Say Yes*, 8 who spent most of her life on the back ward of a state institution battling with all her heart and mind to convince others she had much to say and do in life as well as for the fundamental right and ability to do so.

Sienkiewicz-Mercer may never have crossed the Pettus Bridge in Selma, Alabama where the sight of civil rights marchers being beaten bloodied on national TV became the turning point in the passage of the Voting Rights Act of 1965,9 but she, and many others like her, pushed across another bridge helping to shatter or at least ease stereotypes, prejudice and discrimination that others of us who rely on AAC have faced and often continue to endure. They demanded to be heard, and the lives and futures of those of us that have followed have been made the better for it.

Their example teaches us an important civics lesson: Voting is a form of augmentative communication—another way of demanding to be heard. Like all other forms of expression, it is a fundamental right, ability and obligation that we cannot afford to take for granted.

Our vote is our voice. If we do not use the one, chances increase that we will lose both. Here are ten reasons to make your voice and vote count on November 2.

- 1. The next president and Congress will decide issues of war and peace, whether to protect or destroy our environment and how best to defend against terrorist attacks while preserving our civil liberties.
- 2. They also will choose between continuing to give huge tax cuts to the rich or investing in education, Social Security, Medicare, MiCASSA, accessible and affordable housing, employment opportunities, public transportation and our collective future writ large.
- 3. By naming one more Supreme Court Justice, the President and Senate also will be deciding the fate of the ADA, the right to choose and other civil rights laws.
- 4. The governors and state legislators we elect this November will continue to deal with severe budget shortfalls by raising taxes and/or cutting essential services.
- 5. Your governor and legislators—not the federal government—also decide how much Medicaid funds are spent on institutions vs. community living services.
- 6. They set rules for who gets personal assistance and who will not—determining the daily freedom and independence of thousands of children, adults and seniors with disabilities in your state.



- 7. Your mayor, city council and board of education decide how accessible your community truly is and whether all kids, including those with disabilities, get the quality education they need to succeed in life.
- 8. Americans with disabilities of all ages often rely on the government for the services, supports and opportunity we need to secure our personal liberty, independence and human dignity.
- 9. Yet, we register and vote at levels below any other group of eligible voters. This must change if we are ever going to live as first class citizens of our country.
- 10. And, we're the only ones with the power to change it.

Choose or lose. Become enfranchised: Register to vote. Make sure your voice is heard by voting on November 2. And, make certain all your family and friends register and vote as well.

To register online, go to http://www.dontblockmyvote.org, a national campaign sponsored by UCP to secure equal access to the polls.

It's Our Lives...Our Civil Rights...
Our Votes!!!

## Active Citizens

AAC-RERC

SPREAD THE WORD

ost people want the rights and responsibilities of citizenship. An individual who uses AAC is not going to enjoy freedom or be able to protect his rights without being an active citizen. Since voting is a very direct, visible and universal responsibility of citizenship, I asked the research partners in the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC) some questions about voting. Five of the nine queried partners responded.

I asked, "Are you aware of any barriers to political participation by people who use AAC?" David McNaughton compared political participation to employment, observing that "Political participation should be more flexible than employment, but some of the same barriers are there—transportation, societal attitudes, architectural barriers." Frank DeRuyter, principal investigator of the AAC-RERC, commented, "An individual's type of AAC device and output mode are likely to be potential barriers as is the rate of communication."

#### The projects

The question, "Do any of your AAC-RERC projects encourage people who use AAC to be active citizens or to participate in the democratic process?" looked directly at the partners' activities. David McNaughton felt that the projects with goals to improve literacy would enhance individuals' ability to participate in the electoral process. Frank DeRuyter responded, "I would hope that all

of the projects have the ultimate goal of encouraging people who use AAC to be active, participating citizens. If that is not the case, we have missed the boat!"

Targeting voting, I asked, "Do any of your AAC-RERC projects make voting easier for people who use AAC?" Summarizing the AAC-RERC grant, Frank DeRuyter replied, "No projects are specifically designed to make voting easier. However, several projects have the potential for making the process of voting and political participation easier. These include the visual scene display and interface projects and the two projects looking at enhancing performance and usability."

#### **Getting specific**

Next, I got specific. "What, if anything, do you think you COULD do to support the active participation of people who use AAC in the political process?" Diane Bryen, David McNaughton and Kevin Caves thought the AAC-RERC website and the partners' websites could disseminate voting guides for people who use AAC. These partners emphasized collaboration with people who use AAC and with experts on voting access.

Recognizing the AAC-RERC's efforts to make small technical changes that will make a big difference in the long run, Frank DeRuyter said, "A number of Technology and Policy Watch activities are specifically geared toward improving access and impacting policy changes."

I pushed further. "What, if anything, could NIDRR or the RERCs do to support the active participation of people who use AAC in the political process?" Frank DeRuyter suggested that participation in the AAC-RERC by people who use AAC is effective political action. "In recent years, people who use AAC have actively participated in and contributed to the work of the AAC-RERC by guiding and directing the research and development agenda as well as conducting the work and critically evaluating the work. This participation has created that 1+1=3 synergy that has led us as a collaborative partnership to have a greater influence." He added, "Improvements to technology and access enable people who use AAC to participate on a more level playing field."

#### **Summary**

The AAC-RERC could have more impact on the potential for people who use AAC to participate in the democratic process. For this to occur, people who rely on AAC must inform and challenge the AAC-RERC partners, other RERCs and NIDRR to address our expectations of adult life and our right to be involved as citizens in our communities.

The AAC-RERC section is partially funded by the National Institute on Disability and Rehabilitation Research under grant number H133E03 0018. The opinions are those of the grantee and do not necessarily reflect those of the U.S. Department of Education. Published September 2004.

### Sources & Resources

- 1. Definition of political is from the Webster's Revised Unabridged Dictionary, © 1996, 1998 MICRA, Inc.
- 2. Definition of democracy is from the Merriam-Webster Online dictionary at http://www.m-w.com
- 3. To learn more about ISAAC, go to http://www.isaac-online.org or write ISAAC at 49 The Donway West, Suite 308, Toronto, ON, M3C 3M9 Canada
- 4. Photos by Diane Nelson Bryen of ACES 2004 at Temple University. http://disabilities.temple.edu dianeb@temple.edu
- 5. To learn more about the ACES program, contact Kevin Cohen at kcohen@temple.edu

- 6. To learn more about South Africa's National Accessibility Portal, go to http://www.csir.co.za/plsql/ptl0002/PTI0002\_PGF038\_ARTICIF/ARTICIE\_NO=7191273
- 7. To learn more about CSIR,go to http://www.csir.co.za
- 8. *I Raise My Eyes to Say Yes* by Ruth Sienkiewicz-Mercer and Steven B. Kaplan is available in paperback from Houghton Mifflin.
- 9. The role of the Pettus Bridge in U.S. voting rights is described in the Library of Congress "Today in History Archive" at http://memory.loc.gov/ammem/today/mar07.html

- Meredith Allan may be contacted at mmallan@netspace.net.au
- Martin Pistorius may be contacted at martin.pistorius@up.ac.za

Johana Schwartz may be contacted at johana.schwartz@stanfordalumni.org

Faye Warren may be contacted at FsuMario@aol.com

Bob Williams may be contacted at bobrw@bellatlantic.net

Thank you to all who provided photographs. Thanks also to Bob Williams for his article, as well as his tireless advocacy to secure the vote for people who rely on AAC.

### Websites that Get Active!

#### **Voting websites**

Institute on Disabilities at Temple University http:// disabilities.temple.edu

League of Women Voters http://www.lwv.org/join/elections/

Don't Block My Vote http://www.dontblockmyvote.org

Smithsonian website on the History of Voting http://americanhistory.si.edu/vote/intro.html

#### The language of politics

For an interview transcript of Frank Luntz go to http://www.pbs.org/now/printable/transcript327\_full\_print.html

For a interview transcript of George Lakoff go to http://www.pbs.org/now/printable/transcript330\_full\_print.html

#### **Political action websites**

American Association of People with Disabilities http://www.aapd-dc.org

Disability Awareness in Action http://www.daa.org.uk

Disabled Peoples' International http://www.dpi.org

Justice for All E-mail Network http://www.aapd-dc.org/JFA/ JFAabout.html

National Organization on Disability http://www.nod.org

National Council on Disability http://www.ncd.gov

Unlocking Autism http://www.unlockingautism.org

U.S. voting laws and regulations http://www.disabilityinfo.gov

#### Continued from page 3



changes your community.

Getting involved with your community and nation can have a powerful impact on your life. Going to a community meeting and saying one or two sentences will get you noticed. Going to the polls and voting sends a very powerful message to your neighbors and friends. Actively participating in democracy shows that you take your responsibilities as a citizen seriously and that you care about your future, your community and your nation.