



**SABE Board Meeting
Friday June 25th
Cincinnati, Ohio**



Board Members: Chester Finn (region 8), Tia Nelis (region 5), Victor Robinson (region 7), Jim McNamara (region 1), Marie Braun (region 6 alternate), John Britton (region 2), Liz Lyons (region 2 alternate), Gayle Gardner (region 1), Max Barrows (region 8), Vicki Wray (region 3), Bryon Murray (region 3), Nancy Ward (region 9), Bill Story (region 4), Bernard Baker (region 6), Jeff Ridgeway (region 6), Carol Robinson (region 5), Cathy Enfield (region 4), Eric Treat (region 9)

GUESTS/SUPPORT: Essie Pederson (National Adviser), Hannah Bowen (National Adviser), Vicki Turnage (National Adviser), Wilbur Neushwander-Frink (Carol support), Richard Enfield (Cathy support), Robin Wilson-Beatty (Bernard support), Gaylinn Mumford (Bryon support), Juliana Huerena (John support), Carol Moore (Marie support), and Karen Topper (Max support).

Chester called the meeting to order.

MINUTES

Cathy asked if there were any changes. Essie corrected the name of the guest from the Easterseals committee. Her name is Diana Mairose.

Cathy asked for a motion to accept the minutes with changes. Carol made a motion to accept the minutes with the change. Nancy seconded the motion and the motion carried unanimously.



PRESIDENTS REPORT

- **Justice For All Action Network:** Chester has been participating in this group on behalf of SABE. It is a group of cross disability organizations. They



have been working on healthcare reform for people with disabilities. The two parts were the Community Choice First Options which will help with things like hiring people to come to your home to help. This passed but not everything will go into effect until October 2011. The second part is insurance for people with and without disabilities. Part of what we get is Medicaid. What people get under Medicaid will be mostly the same but some things will be added to it so that you can work and pay into the Class Act so that you can get a cash benefit of \$25,000 to use for equipment and personal assistance if you pay into it for 5 years. This group continues to work on health care issues.

- **VOR:** They are a parent organization that believes that people with disabilities should not be living and participating in the community. VOR advocates against the Protection and Advocacy (P&A) groups that protect the rights of people with disabilities. They advocate against respectful language bills and will corner and yell at people with disabilities who testify. When going to testify it is important to go in pairs so that you are not alone. VOR has a lot of money and a lot of power. Chester is going to partner with the Autistic Self-Advocacy Network (ASAN) to write a letter supporting people to live in the community and ask other organizations to sign on to this letter. They are going to include information about laws and policies taken by the Obama Administration. SABE and ASAN are going to actively educate VOR about the desires of people with disabilities. We also need people to advocate in their local area.
- **ADD:** Chester met with the new commissioner of ADD, Sharon Lewis. She has three proposals for SABE. One, take pictures at the SABE conference that ADD can use on their materials. Two, prepare a SABE training about self-advocacy for the staff at ADD. This is exciting because SABE will be training a federal agency about self-advocacy outlining how we want them to work with us. CMS heard about this training and decided that they would also like to get the training from SABE. SABE is being recognized as the group who has the answers about self-advocacy. Three, she would like SABE to help with regional calls about strengthening self-advocacy. Tia read an email from Commissioner Lewis about these regional calls.
- **Funding for Self-Advocacy:** The executive committee is working on a business plan to have SABE be able to receive money and work as a funded and well known organization. Money would go to SABE, as the national group, and then to the state organizations through SABE.

The Exec Committee will come up with a business plan and then share it with the rest of the board.

- **National Council on Disability:** Chester has been appointed to the National Council on Disability. Essie has sent the press release out to contacts that she has in the media.

FAMILY SUPPORT PROJECT

Max gave a report about the Easterseals grant.

The monthly conference calls are going well. The number of people calling in has doubled and tripled. Here is a review of what we've done recently.



“Let’s Get Rid of the R word” gave advice on what to say to a stranger when you hear them use the “r” word. Over 150 phone lines called in with people and groups from all over the country. Check out the SABLE website for practical tips and tools to use when presenting to groups about treating people with disabilities with respect.



The New Healthcare Law: Great News For People With Disabilities! This call sold out with over 200 individuals and groups signing up! We discussed details about this new program and its many benefits. In case you were not able to join the call you can get notes by going to www.sabeusa.org.



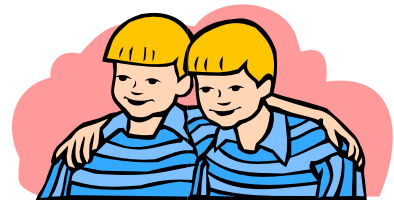
Social Security and You provided helpful information on how you can work and still maintain some of your benefits. You can listen to the recording of the call until July 16th by dialing 800-642-1687 and using ID number 80358938.

The next call is July 21th. The title is, “Guardianship Is It Needed Or Is There Another Way?” The United Nations passed a convention or treaty on the rights of people with disabilities. Article 12 says that persons with disabilities have legal capacity on an equal basis with others. In other words, an individual cannot lose his/her legal capacity to act simply because of a disability. We will have one or two speakers on the call to talk about what the new UN Treaty will do to help work on getting rid of guardianship.

The call on August 18th is called, "Partnerships...Let's Shake It Up! Are You With Us Or Not?" We have invited Kurt Decker who oversees all the P and A's, George Jesien who oversees all the University Centers and Mike Brogioli who oversees the DD Councils to be on the call. It will be about how self-advocacy organizations form partnerships with family support organizations. Through this project we have been getting the message out about self-advocates and families working together. We would like to continue to work with family support groups and want to hear your ideas. From our perspective, what we got out of it this grant is SABA has established a foundation for needs to happen next.

SIBLINGS NETWORK

Bryon announced that the sibling network is hosting the *International Conference on Siblings of People with Disabilities* on August 7th and 8th.



This is a conference for siblings of individuals with developmental disabilities, featuring keynote speakers **Don Meyer**, Director of the Sibling Support Project; **Chris Burke**, best known for his role as Charles "Corky" Thatcher on the hit ABC-TV show "Life Goes On;" **Dr. Tamar Heller**, Professor and Director, Institute on Disability and Human Development, and of the Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago (UIC); and **Tia Nelis**, Vice President of Self Advocates Becoming Empowered and Self-Advocacy Specialist, UIC. Breakout sessions will provide siblings, parents, other family members and professionals in the disabilities field with insight on sibling experiences. Attendees will have opportunities to share stories and information, and to learn more about current research and best practices in the disability field. For more information, visit www.siblingconference.org.

NATIONAL SELF-ADVOCACY CONFERENCE

Cathy handed out registration forms for the SABA Board members



VOTE PROJECT

Hope, Nancy, and Tia gave a report on the Vote Project (sometimes called the National TA Center on Voting and Cognitive Access). The vote team meets biweekly. We have hosted one conference call this year. Our next conference call is on ideas for training poll workers. We have a quarterly

newsletter about voting and self-advocacy. We are updating our website, please check it out at www.govoter.org. We are taping SABLE board members during the next few days talking about how people with disabilities feel about voting. If you need a time to film tonight then talk to Hannah. We are doing Project Vote trainings. This year we added a new piece to the training about collaboration between P&As and Self-Advocacy groups. We have done training in Ohio and Maine. The Secretary of State was at the Ohio training and offered the P&A and self-advocacy group money to do more trainings together and get voting education to people in Ohio. We are doing one more Project Vote training in Philadelphia in August.



SELF DETERMINATION PROJECT

Bryon and Tia gave the Self Determination Project Report. We are going to have a website where people can ask questions about self-determination. We are going to ask questions of partnering advocacy organizations.



Bryon is going to contact each of the board members to ask some questions about self-determination. If anyone knows of someone from their self-advocacy group who has a good self-determination story then please contact Bryon.

We are doing a short SurveyMonkey survey about self-determination. Tia asked that everyone fill this out and ask their groups to fill it out.

COMMITTEES

The board broke into committees at 2:30pm.

SATURDAY
June 26, 2010

BYLAWS COMMITTEE

Bryon, Vicki, and Hope gave the bylaws report. The bylaws committee is proposing three changes to the SABE bylaws.

Vicki read the first proposed change to the bylaws. Remove the word “consecutive” from Article 4:3.7 which says “Representatives and alternates shall have a limit of two consecutive terms.” Eric made the motion and Liz seconded the motion. A yes vote means that you DON’T want to change the bylaws. A No vote means that you DO want to change the bylaws.

Region 1: Gayle Gardner, Yes. Jim McNamara, Yes.

Region 2: John Britton, Yes. Liz Lyons, Yes.

Region 3: Bryon Murray, No. Vicki Wray, No.

Region 4: Cathy Enfield, Yes. Bill Story, Yes.

Region 5: Tia Nelis, Yes. Carol Robinson, Yes.

Region 6: Bernard Baker, Yes. Jeff Ridgeway, Yes.

Region 7: Victor Robinson, Yes. Hope Finley, No.

Region 8: Chester Finn, Yes. Max Barrows, Yes.

Region 9: Nancy Ward, Yes. Eric Treat, Yes.



Motion did NOT pass with 15 Yes votes and 3 No votes. The bylaws stay the same.

Vicki read the second proposed change to the bylaws. Remove the word “consecutive” from Article 5: Section 1 which says “no officer shall serve more than two consecutive terms in the same position.”

Nancy made the motion and Bernard seconded the motion. A “yes” vote means to change the bylaws. A “no” vote means to keep the bylaws the same.

Region 1: Gayle Gardner, No. Jim McNamara, No.

Region 2: John Britton, No. Liz Lyons, No.

Region 3: Bryon Murray, Yes. Vicki Wray, Yes.

Region 4: Cathy Enfield, Yes. Bill Story, Yes.

Region 5: Carol Robinson, Yes. Tia Nelis, No.

Region 6: Jeff Ridgeway, Yes. Bernard Baker, No.

Region 7: Victor Robinson, Yes. Hope Finley, Yes.

Region 8: Chester Finn, No. Max Barrows, Yes.

Region 9: Nancy Ward, Yes. Eric Treat, Yes.



Motion did NOT pass with 11 Yes votes and 7 No votes. The bylaws stay the same.

Vicki read third proposed bylaws committee change. SABE will support one former board member to attend board meeting for 2 years to mentor a new president. The mentor does not have any voting power. The mentor will be chosen by the new president. Eric made the motion and Carol seconded the motion.

A Yes vote means change the bylaws to include a mentor for the SABE president. A no vote means do not change the bylaws.

Region 1: Gayle Gardner, Yes. Jim McNamara, Yes.

Region 2: John Britton, Yes. Liz Lyons, Yes.

Region 3: Bryon Murray, Yes. Vicki Wray, Yes.

Region 4: Cathy Enfield, Yes. Bill Story, Yes.

Region 5: Tia Nelis, Yes. Carol Robinson, Yes.

Region 6: Bernard Baker, Yes. Jeff Ridgeway, Yes.

Region 7: Victor Robinson, Yes. Hope Finley, Yes.

Region 8: Max Barrows, Yes. Chester Finn, No.

Region 9: Eric Treat, No. Nancy Ward, Yes.



Motion passes with 16 yes votes and 2 no votes. The bylaws will be changed.

CLOSE THE DOORS COMMITTEE

Tia gave the close the doors committee report. Goal is to get Michelle Obama to support the “eliminating the R word” campaign. They are going to write a letter. They need all Board Reps to go into their regions and ask their groups what they are doing to eliminate the R word in their area. Email answers to Frank at frank.latham@njcdd.org



Chester made a motion to approve the report. Eric seconded the motion. The motion carried unanimously.

FINANCE COMMITTEE

Liz, John, and Victor gave the finance committee report.

Chester is attending a series of CMS meeting over the next three years. Chester will be paid \$2,000 for going to these meetings. This money goes to SABE since Chester will be representing SABE.



Tia made a motion to accept the finance committee report. Eric seconded the motion. Motion carried unanimously.

PR COMMITTEE REPORT

Max gave the PR Committee Report. The next newsletter will be completed and distributed by July 9. The committee is going to; add a paragraph on New York Name Change (Max will talk with Chester and get a paragraph by the end of Board Meeting), add Nomination for Roland Johnson Award, add the Website link to the survey monkey, add cut-off date of August 23, add pictures, add Close the Door report (Tia and Max will do), Family Support Committee report (Topper will do), Project Vote report (Nancy, Tia and Jeff will do)



SABE 20th Anniversary Newsletter will be ready by the Conference. Topics will include the history of SABE, current issues, our future, and additional topics.

We are working on the Website. We will post contact information on Board Members by July 9nd. Rachel will complete Hannah's office Phone and Chester's Office Phone.



Eric made a motion and Liz seconded the motion. Motion carried unanimously.

POLICY COMMITTEE

Bryon gave the policy committee report. Bryan discussed the "R word and talked about "Rosa's Law" which is pending federal legislation that will ban the use of the "R" word and related language in federal documents.

Bryan read a draft of the policy statement concerning the “R” work which was not complete. It was agreed in discussions with the Chair and the Board that the Committee would revise and finish the resolution today.

It was determined that a copy of the statement on employment and on sheltered workshops (14c) should be placed in packets for the National Conference.

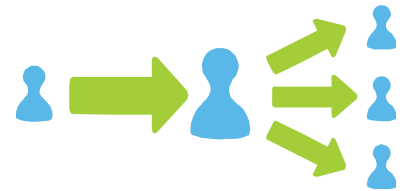


Eric made a motion to accept the position statement. Carol seconds the motion and the motion passed unanimously.

Eric made a motion to accept the committee report. Liz seconded the motion and the motion passed unanimously.

GRASSROOTS COMMITTEE

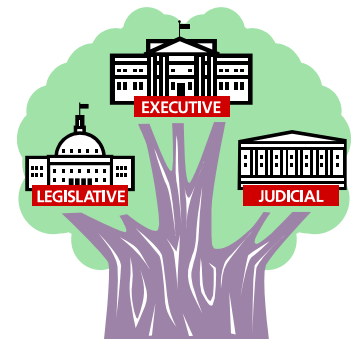
Gayle, Eric and Bernard gave the grassroots committee report. They presented a draft of a brochure explaining the responsibilities of regional representatives. Tia asked that something is added says that state groups are responsible for contacting their regional reps to help with the regional reports.



Carol made a motion to approve the report. Tia seconded the motion. The motion passed unanimously.

LEGISLATIVE COMMITTEE

Nancy and Bill gave the legislative committee report. The Legislative Committee talked about some of the provisions in the Health Care Reform Bill and when they will be implemented.



The Committee members spoke primarily about two major programs that are included in the bill. The first one is the CLASS Act which provides a national long term care insurance program. This program will allow almost anyone who is employed to participate by paying a minimal monthly premium into the program. After five years a person is eligible to receive benefits if they become unable to work even if they had pre-existing conditions. This program is scheduled to go into effect on January 2011.

The other major program is the Community First Choices Act which will enable a person on Medicaid to decide if they want their Medicaid funding to pay for services in an institution, a nursing home or for in home supports in the community. This program also provides additional federal matching funds to states for these services. The problem with the Community First Choice Act is that it was passed as a state option and not as a Federal mandate. Efforts are underway to get a similar bill passed as a federally mandated program. In the meantime we should encourage our legislators to include the Community First Choice Act option in our own states. This program will be available to States that choose to participate in October 2011.



Bernard made a motion. Carol seconded the motion and the motion passed unanimously.

Chester reminded everyone that SABE Board members should do work by conference call between meetings to get work done.

NEXT MEETING

The Board will meet on Thursday before the National Self-Advocacy Conference.



Tia made a motion to adjourn the meeting. Bryon seconded and the motion passed unanimously.