

**SABE
Board Meeting
Pawtucket, Rhode Island
Friday August 5, 2011**



Max called the meeting to order and let people know that he will be running the meeting because Betty was not able to be at the meeting. Betty joined by conference call to listen in on the meeting.



Moment of Silence for Victor Robinson who is in the hospital after being hit by a train a few days ago.

Board members shared stories about Victor. He is a true fighter for self-advocacy. His spirit is with us. He will get through this and wake up and be with us again.

Review of the minutes from the Kansas City Meeting



Clint thanked everyone for all the caring that people showed toward him at the last board meeting. Eric Treat made a motion to accept the minutes from the Kansas City Board meeting held in April 2011. Carol Robinson seconded the motion and the motion passed unanimously.

Max reviewed Board member responsibilities



The reason Max is bringing this up because there have been some issues with board members not showing up at meetings and also not giving their alternates enough time to get funding and make arrangements to attend the meeting. We are bringing this up to remind everyone of their responsibilities.

Jason – reported that Jim is having problems getting funding to attend the meetings. He also is not staying in touch with SABE. He says he cannot come anymore.

Bill said that his DD Council is not supporting him to attend meetings.

Carol said that the executive committee should talk to Jim.

Eric suggests having conference calls with the state presidents in your region.

Jason suggested people should be able to join the meeting by phone.

Bryon suggested that people can Skype into the meeting.

Bernard said that people agreed to come to the meeting when they ran for region rep and people need to do the things they are responsible for. If the Alternates have any problems then they can talk to their region reps because it is the region reps job to work with the alternate.

Bill said that people could go to the DD Councils or other groups that support self-advocacy and ask to do the call from their office.

There have been some issues with communication between region reps and alternates. The executive committee is talking about ways to address this.

Adviser Election



Max read the rules about who can run for a national adviser position. The adviser elections will be held by secret ballot. The term for a national adviser is 2 year. Chester suggested that the board look at when national advisers are elected and possibly make it closer to when the national conference takes place. SABE will elect three national advisers at this meeting. Of the current advisers, only Vicki and Hannah can run for another term. Essie has served two terms and cannot run again. Any adviser who is interested in running for a national adviser position must turn in a letter of recommendation to Max during the break.

Presidents Report

Sub Minimum Wage: Provision 14C of the Rehabilitation Act of 1973 says that people with intellectual disabilities can be paid less than minimum wage. Senator Harkins is working on a bill to eliminate sub-



min wage. This will be called Provision 511 in the Workforce Investment Act. It would only affect people transitioning out of school.

There is another bill being introduced about sub min wage that goes against what SABE believes.

The board discussed these two bills.

Max asked the Close the Doors committee to investigate the two bills and write a position statement about them. If the bill is submitted to a committee by Sen Harkin then SABE will consider putting this statement on the website.

Grant Opportunities

Arc of the US: Ann Caldwell and Joe Caldwell want to help SABE find



money to have an office in DC and hire an executive director. Most of the other national organizations that SABE works with have offices in DC and have a good presence there. SABE is starting to get a bad reputation because we cannot be at all the meetings in D.C. like other national groups.

We would like to set-up our own bill about self-advocacy for the DD Act and ask Bernie Sanders to introduce this bill for us. Max asked the Legislative, Executive, and PR committee to work with Ann Caldwell to move forward with getting office space and raising money to hire an Executive Director. Betty said that we should ask Ann to come to our Phoenix meeting to talk about how we would move forward with this.

Chester asked what would happen if we had an office at the Arc in DC and had to make a statement that disagreed with the Arc. Chester said that if we do a bill then we should network Sen Harkin who is the Chair. Bernard is worried that SABE may have to give up some power if we let someone give us a free office. Topper let SABE know that ASAN and the Sibling Network has the same agreement with the Arc to get free office space and they the Arc does not control those groups.

University of Delaware: They have a grant to send out a survey to find out how self-advocates are living in the community. They would like SABE to partner to get the grant out. They would give SABE \$2,000 each year for 3 years.



Tennessee Now: They have a grant about tokenism. They would like us to gather information from self-advocates on boards who feel like they are being pushed aside or not listened to at a board meeting. They would give SABE \$4,000. SABE will be asked to have 5-10 SABE members participate in a focus group run by Bill Krebs and Max Barrows. The focus group will talk about tokenism and serving on board. These focus groups will take place at two different board meetings in 2012. The executive committee will meet in the next few weeks to formally vote on whether or not to do this grant. The deadline is August 22nd.



Conference Call about Self Advocacy Groups Loosing Funding



California People First has lost its funding from their DD Council. They have asked SABE to host a conference call for self-advocacy groups like theirs that have lost all of their funding and brainstorm the kinds of actions that groups can take. Jason said that this has happened to Montana as well.

Alliance for Full Participation (AFP)



The executive committee sent out a letter asking what states are going to the AFP conference. Betty was asked to be a keynote speaker at the AFP conference. Betty doesn't know if she should go because SABE has already decided that they will not be a part of the AFP because they are not enforcing their own mission.

Chester said that he would vote "no" because the board already said that they will not be a part of this groups. Betty is the president of SABE. Even if she is going as herself and not affiliated with SABE, people will still think of her as representing SABE since she is the

president. 10 Board members said “No Betty should not go” and 6 board members said “Yes Betty should go”.

Project Vote Grant



Nancy gave a report about the Project Vote grant. This grant is sometimes called the National Technical Assistance Center for Voting and Cognitive Access. This grant is ending on September 30th of 2011. SABE is going to apply for another year of funding to work on this grant. Nancy handed out information about what the Project Vote team wants to do with the grant next year.

SABE is hosting a conference call about voting on August 25th.

On the Project Vote Website, which you can get to from the SABE website, you can find a list of state contacts. This is a good way for region reps to find out how to contact the self-advocacy groups in their region. If region reps try to call a number on the website and it doesn't work, then they should let Nancy Ward know right away and she will update the website with the new contact information.

Essie shared more about the goals for the next year of Project Vote. We will work on making all of the Project Vote Voter Education training and information available on the website. All of the trainings materials will be saved in a way that lets you add your own state specific information. All of the information will be easy to understand and user friendly. A review team will look at the website to make sure that it is easy to use for people who use screenreaders.

Ohio will be doing another Presidential Debate in 2012 and SABE has been asked to co-host this and help with writing the questions.

Self-Determination Grant

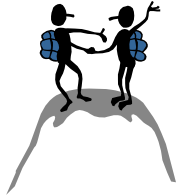


Tia gave a report about the self-determination grant. A newsletter was done and passed out at the SA Summits. Some people said that some of the language in the newsletter was not accessible. Tia said that this was done because those parts were for university professionals. To make the newsletter more accessible they made a video to go with it.

They are gathering resources and materials about self-determination. Our goal is to create a manual that can be given out to individuals and self-advocacy groups. They made a letter and a flier asking for help to get these resources so that they can make a manual for everyone to use. The resources that people send in will not be changed. Organizations will have their names on their information so that people know who created it.

The self-determination grant has a facebook page. All of this information will be on this page so go to facebook and friend us. The self-determination committee needs SABE board members to pass this information along to other groups in their region.

Self Advocacy Summits



At the end of July there was a meeting to talk about how the summits went. They decided to have three more summits held in 2012. 20 states who have not attended one of the self-advocacy summits will be asked to participate in these summits. The location of these three future summits will be

- 1) Baltimore Maryland,
- 2) Chicago Illinois, and either
- 3) Denver or Seattle Washington

Hillary from AUCD talked about a report that they did that talks about what happened at the different summits. Liz Weintroup and Julie Petty are working on an easier to read version of this report. You can find all of the information about the summits online at <http://alliesinselfadvocacy.org/>

SABE is working with ADD and AUCD to improve the next round of summits. Tia suggested that people go to their state teams and find out what is happening with their state plans and how they can help. Don't forget about the work that was done just because the self-advocacy summits are over. Keep the movement going forward.

Leadership Institute

We have been asked to be a part of a leadership institute that looks at the self-advocacy movement



and how we can make the self-advocacy movement stronger. There have been several conversations about how different self-advocacy groups work together and the different kinds of supports and accommodations that they use. The partners on this project are NYLN, ASAN, University of Delaware, and the Human Services Resource Institute (HSRI). The major concern with this project is disagreement between groups. The SABE Executive Committee feels that it is our choice to decide who should support us and if we are the most comfortable with a support person who advises a self-advocacy group then we should be able to ask them to help us. Some of the other groups do not agree with this. Hope said that sometimes it is good to trust other groups. Bryon said that Nancy did a leadership project with Utah a while back and he was not allowed to bring staff. Nancy said that support is a very personal thing and good support comes from trust. She feels it is hard to get good support from someone you don't trust. No one should be told who they should get their support from. Max said that there is fear that if a self-advocacy group adviser supports someone at this institute then they would "hijack" the leadership institute. Betty said that on one of the phone calls one of the SABE advisers was on the phone call but didn't say anything because we didn't ask her to say anything. She was there to support us if we needed information or support. Chester said that in some ways we have been too nice. Sometimes other groups of people with disabilities don't need support to help them with information. Some groups don't need help interpreting information. We should have a training to let people know how we work with advisers. Some other groups think that they know how we should be supported and say because one group get support in a certain way then we should get the same report. We need to tell them what we need. We all need some kind of support. Vicki said that they think about leadership is that sometimes you need advise and sometimes you done. In her state they run their own group. Their advisers help them get some of the work done but she has run meeting without any adviser at the meeting. Bill said that he has a mentor that helps him go over the agenda. He chooses his own mentor. They don't tell him what to say or do. Hope said that it sounds like people are concerned that we will not have a choice about who supports us. She asked if we have a choice to be a part of the grant? Betty said that we have a call on August 22nd to talk about if SABE is going to be a part of this grant. Hope said that she doesn't think that new support people will

try to push their way onto us since they don't know anything about SABE or self-advocacy.

Transportation to the airport



Vicki went over the arrangement for transportation to their airport on Sunday.

LUNCH and Committee Meetings

Legislative: Add names of people here

Grassroots: Add names of people here

Policy: Bryon Murray (Chair), Vicki Wray, and Hope Finley

PR: Max Barrows (Chair), Consuelo, and Chaqueta Stucky

Close the doors & R-word: Add names of people here

Finance & Membership: Add names of people here

Bylaws: Vicki Wray (Chair), Bryon Murray, and Hope Finley

SABE Board Meeting Pawtucket, Rhode Island Saturday August 6, 2011

Max called the meeting to order

Carol Robinson led an energizing song, "Step by step the longest march, can be won, can be won. Many stones can form an arch. Singly none. Singly none. And by union what we will .. drops of water turns the mill. Singly none. Singly none."

Elections for SABE National Allies



Max announced the candidates for National Allies; Vicki Turnage, Juliana Huerena, Frank Latham, and Laura Jackson. Max told the four candidates that they should leave the room and that he will call them back one at a time to answer some questions.

Max read the qualifications for Adviser.

Each candidate was asked to come back into the room, one at a time, to answer the following questions. Frank Latham went first, Juliana went second, Laura went third, and Vicki went last.

- 1) Why do you want to be a national adviser
- 2) Do you have the time
- 3) Explain to the SABE board if there was a conflict between individuals/organization and the SABE board
- 4) Would you be able to support board members at other meetings if needed
- 5) Do you have experience arranging meetings in different areas for a large and or small group

Board members asked follow-up questions as needed.

Secret ballots were cast. Max and Essie counted the ballots on the flip chart in the front of the room. The votes were very close. The new SABE Allies are Vicki, Juliana, and Laura.

Autism Now Grant



Topper gave a report for the Autism Now grant. This grant is not just about Autism. It is about all kinds of developmental disabilities. Here is what is done on this project

- 1) The grant team meets once a month
- 2) Decide what goes on the Autism Now website
- 3) The big challenge: The Administration on Developmental Disabilities just wants information on the website that has research to back it up. SABE thinks that it should be information about true inclusion. Some of the parents on this group agree with SABE.
- 4) We've gone three webinars/conference calls. One on July 19th about the joys and pains of working. The other on July 26th about what people with disabilities need to run their own self-advocacy groups. Our next conference call/ webinar is going to be about supporting people with disabilities to be parents.
- 5) We did four regional summits and have one more to do. The Autism Now Summits were held in Florida, California, Maryland, and Indianapolis. We host focus groups at the summits or present information.

6) We are looking for 10 states to run a focus forum for SABE to learn about living situations, community based employment, level of supports, and self-advocacy from the self-advocacy perspective. We want each group to have 10-20 self-advocates and we will give each state the questions to use. The state will need to give us notes with exact quotes from people by September 7th. We will give the state \$400 for leading these groups.

National Self Advocacy Conference

Oklahoma is interested in hosting the conference in 2014. Minnesota is thinking about hosting the conference in 2012. Carol said that they talked about this at their last meeting and they need to check on a few resources before they can say yes or no.

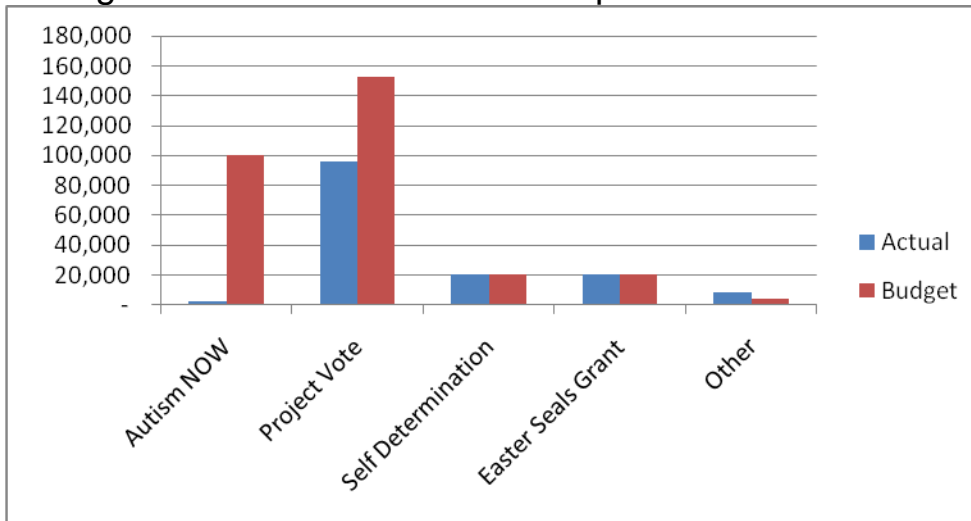
Bernard and Clint said that they will help with planning the conference once a location is chosen.

Max said that he is going to call Tennessee to see if they are interested in hosting the 2012 conference.

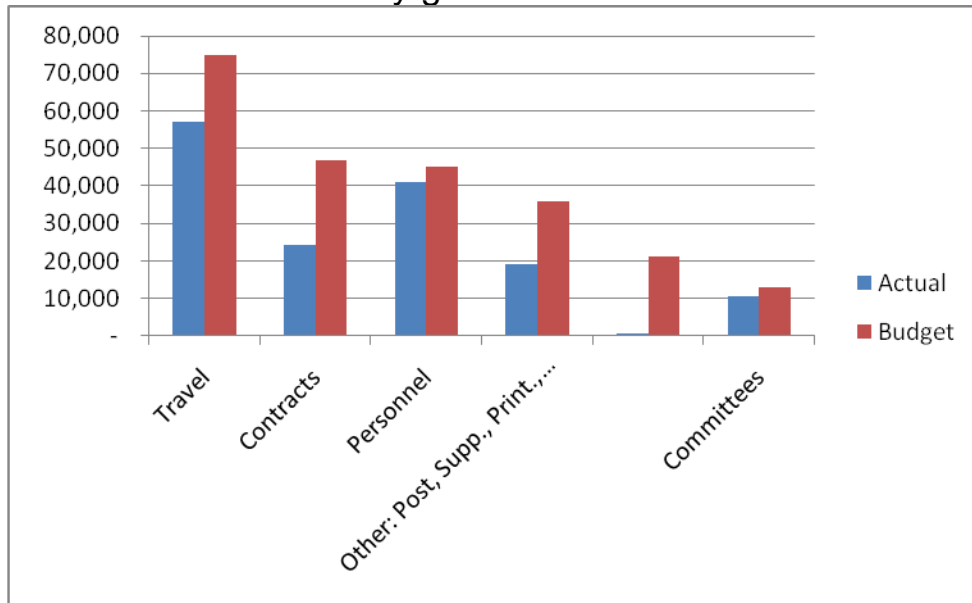
Committee Reports

Finance and Membership Committee:

John gave the finance committee report. This is SABE's Income



This is where the money goes



Bill gave a report about Membership...

The Finance committee decides if money is available to help pay for board member hotel rooms. To make this decision, the finance committee needs to board members to do these things...

- 1) Alternate information should be made available on the website.
The Finance committee recommends that the PR committee does this before the next meeting. Every board member and alternate should have their name and at least one way to contact them on the website.
- 2) Region reps need to talk with their Alternates at least once a month.
- 3) Essie and John will send an announcement letter naming all the current board members to the DD Network partners in each state. The letter will not ask for financial support but will thank them in general for supporting participation on the board.
- 4) SABE will only pay for hotel fees for a board member who requests funding from John Britton at least 6 weeks which is September 18, 2011 before November board meeting in Phoenix, Arizona. Airfare will only be paid under special circumstances which include participation on special grants and other requested committee work.
- 5) SABE will replace non-active board members with alternates.

- 6) Finance committee recommends that each region rep and alternates stay in contact once a month with each other and that they all be listed on the website.
- 7) What has each committee done with the money given to them and have they spent it all? The Finance Committee would like every committee chair to email John and let him know how much money was spent from July 2010 to June 2011 and what was done with the money.

John asked for a motion to pass the finance committee report. Clint made a motion and Carol seconded the motion. Motion passes with two abstentions.

LUNCH

PR Committee:

Max gave the PR Committee report.

We worked on the Summer edition of the Self Advocacy Nation. A copy of the Summer Self Advocacy Nation Newsletter was passed out. If anyone has changes then they should let Max know by the end of the day. A final copy of the newsletter will be sent out to all board members so that they can share it with others.

This will be put on the website and be emailed to the member list. Is there any other way that this needs to go out? Any other lists? Hillary at AUCD could send it out to the UCEDs. We could email it out to everyone who went to the self advocacy summits.

We came up with a list of guidelines for the Self Advocacy Nation. Formatting: The Self Advocacy Nation should have a similar look every time. That way people start to recognize it as SABE's newsletter and know what to expect.

- we will use arial as a font
- font size 14 or above
- no hyphenated words that break in the middle onto the next line
- pictures will be used to help people who do not read well to understand what the newsletter is saying
- there will be page numbers on each page
- the SABE logo will be included somewhere on the self advocacy nation

- a table of contents will be included
- a list of board members will be included

What will be included in the Self Advocacy Nation:

- articles about self advocacy
- updates from each region
- updates about about SABE grants
- updates from SABE committees

The next issue is due in the fall (November)

Question for the board:

- max would like consuelo and chaqueta to help with the newsletter
- consuelo and chaqueta would like to be on the conference calls to help with the newsletter
- we do not know of any rules that say that alternates cannot help committees during concern calls. We would like to have Consuelo and Chaqueta participate on calls. Is this okay?

Committee Conference Calls

- August
- September
- October

Max asked who else this should go out to other than the SABE membership list.

- Bernard confirmed that the grassroots committee could email it out to all of the self-advocacy groups.
- Hillary offered to send it out to all 63 UCEDD advisory councils. The board said yes.
- It could be sent to the P&As (NDRN) and DD Councils (NACDD). The board said yes. Project Vote will do this. People can email or fax them to others.
- Send it to everyone who attended the self-advocacy summits.
- Send it to Sharon Lewis from ADD
- Max will send it out to everyone who attended the Autism Summits
- Add the newsletter to the website
- Bryon will send it to the sibling network
- The PR Committee will send it to the Adviser list

- Project Vote will send it to Betsy at NYLN and ask her to send it to other
- Send it to Arie at ASAN and ask him to get it out.
- Project Vote could send it out to the Arc of the US and ask them to send it out to

Add on the email with the newsletter “join SABE to get regular information” and add a link to where to register on the newsletter. SABE members pay \$15 and they get to vote, get a membership card, and get a SABE pin. Everyone who attends the national conference becomes a SABE member.

- Only paid voting members can run for the board
- Only paid members with disabilities can vote (buying a membership may need to be a required part of registration)
- If the state group is a member then how many people from that group are members?
- Should scholarships be offered?
- Richard suggested that the board look at the 501c3 and see if SABE is incorporated as a member group or a board run group.
- Bryon made a motion to have the Finance/Membership Committee talk about this during a conference call and present some recommendation to the board in the fall. Carol seconded the motion and the motion passed with one abstention. Essie will talk to the Finance Committee about this.

Carol recommended the newsletter is printed and mailed to her.

Consuelo asked how to add your name to the mailing list? We are not sure who is in charge of keeping track of the mailing list? People can send their email address to Hannah to join the SABE Member List.

To make it available for people who use screen readers we should have the newsletter available in word with few pictures or graphs. Hillary said that there is new pdf software available that makes pdf's accessible to screen readers. Chester said that this is not always true. Chester agreed to help the PR Committee look at different ways to do the newsletter so that it is accessible to people who use screen readers. It is possible that html (website files) might also work.

Clint said that if it is okay with the committee then it is alright. Chester said that it has always been okay to involve who over they want on the committees. The only reason that other people weren't involved was because all the work was done at the board meetings. Now that work is being done on conference calls between meetings we may want to involve other people. Vicki Wray checked the bylaws and it said that the board of directors manages the affairs of the organization. It does not say that the board has to do all the work by themselves.

Jason made a motion to accept the PR report. Hope seconded the motion passed unanimously.

Legislative Committee: Bill gave the legislative committee report.



The Legislative Committee was fortunate to have had Hillary Spears join our meeting. She shared her knowledge and insight with us which were a great help.

The Committee determined that there are three legislative issues that we need to follow closely. The first of these is the recently passed Budget Control Act. The main concern with this Bill is how it will be implemented. While it did not contain any immediate cuts to entitlements the Bill did contain a provision for spending caps on discretionary non-entitlement spending in 2012 through 2021 which will create serious problems for most self-advocates. There are also other very serious budget cuts that will trigger automatically if certain budget reforms are not accomplished by a select committee. This Bill has the potential to cause a great deal of harm to self-advocates. Your Legislators need to hear from you on this.

A second bill that is important is the Reauthorization of the Combating Autism Act which will expire on Sept. 30, 2011. Much of the funding in this Bill will go to LENDS for research and training that has the potential to help all people with disabilities. We should contact our Legislators to support this Reauthorization.

The third bill is the Reauthorization of the Workforce Reinvestment Act (WIA). This is a compromise bill with many good provisions that will put statutes into place that will promote and reinforce competitive

integrated employment for all people with disabilities including those with the most significant developmental and intellectual disabilities and mental illness. This bill can be a huge step forward in our efforts to achieve integrated competitive employment opportunities. It is very important that all of us contact our Legislators to support this Bill and it is even more important that we immediately contact the Legislators that sit on the HELP COMMITTEE where this bill is waiting for a vote. The names of these Legislators and much more important information about this Bill is included in the attached email document that was sent out to you on August 5, 2011.

Please take the time to contact your Legislators about these issues, we can make a difference!

Carol made a motion to approve the legislative committee. Eric seconded the motion and the motion passed unanimously.

Bylaws Committee:



The Committee reviewed the board member qualifications and responsibilities. After this review, all committee members agreed the By Laws are clear on these issues and the By Laws need to be enforced.

The committee recommends that the Executive Committee advise current Board members that they are in violation of the By Laws and if necessary request the resignation of the member.

Other recommendations include:

Provide information to the Alternates on their responsibilities. The By Law Committee will send out the requirements and contact all members and alternates to discuss their responsibilities.

It is also suggested that a quarterly teleconference, video conference or a regional meeting be held with the State Representatives from each region to get updates from the states.

The By Laws committee will develop a form that has all the responsibilities of the alternate and/or representative listed. The form

will also require that any individual who runs address their qualifications for the position. The form will also include a signed statement from their self advocacy group of their endorsement. In addition the self advocacy group will have to agree that they will support the person running for the position and their support person (if necessary) for 8 Board Meetings.

By Laws Committee will call all Representative and Alternates and discuss their responsibilities.

Policy Committee Report:



1. Reviewed Position statements on the Website to see if some of the statements need to be updated to make the language easier to understand.
2. Reviewed Closing Institution Statement
Recommend that we reword to:
 - i. Self Advocates Becoming Empowered believes all people regardless of the severity of their disabilities should live in the community with the support they need and that all institutions should be closed.
By Self-Advocates Becoming Empowered
Adopted April 1995, Revised August 5, 2011
3. The following statements will be reviewed by conference call prior to the next board meeting: aversives, hate crimes, guardianship and voting.
4. We also recommend that we add the position statement on community living (old and the new one) to our website. It may be there but we could not find it.

Clint made a motion to approve the committee report. Consuelo seconded the motion and the motion passed unanimously.

Grass Roots Committee:

Jason gave the grassroots committee report. The grassroots should be contacting the states that are struggling and provide them with

assistance on how to keep going when times are rough. Bernard said that he would work on this.

Karen said that about 10 years ago SABE applied for a grant with the southern collaborative to support a group in Florida to get organized another time SABE applied for a grant in Kentucky to support a group to develop in that state. Both times the funders decided to give the money to provider groups to do this. There are templates for how to apply for grants to do this. Essie has a bunch of historic documents that we can use and look at.

The grassroots committee made business cards for all of the region reps. Jason passed them around this morning and got corrections to all of the contact information. They have all of the correction done and Raylynn has added them.

A Board Contact list was update. Bernard made it clear that this contact information is for board members only.

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

Next Board Meeting

The next meeting will be in Phoenix Arizona on ?

Carol made a motion to give the executive committee the power to decide when the next four meetings will be. Clint seconded the motion and the motion carried.