

Oklahoma City, OK October 18-19, 2013



October 18, 2013 Meeting started at 9:00 am.

People participating introduced themselves.

Board Members

President: Bryon Murray, Utah
Vice President: Cathy Enfield, Missouri
Secretary: Betty Williams, Indiana
Treasurer: Ryan Duncanwood, California
Sargent of Arms: Chaquetta Stuckey,
South Carolina
Bill Story, Kansas
Amira Rasheed, New Mexico
Carrie Varner, Minnesota
Consuelo Castillo, Texas
Samuel Jenkins, Oklahoma
Jason Billehus, Montana
Clint Perrin, New York
Max Barrows, Vermont
Bernard Baker, Georgia
John Britton, Arizona

Alternates

Mike Grengs, South Dakota
Eric Treat, Arkansas
Eric McVay, Maine
Darren Morris, Alabama
David Taylor, North Carolina

National Advisors

Juliana Huereña, Arizona

Allies

Richard Enfield, Missouri
Ernestine, New Mexico
Arlene Poncelet, South Dakota
Darlene Martin, California
Glenda Hyman-Singletary, South Carolina

Project Staff

Tia Nelis, Illinois
Nancy Ward, Oklahoma
Essie Pederson, Ohio
Teresa Moore, Arizona
Karen Topper, Vermont

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We started with a song led by Carol Robinson. It goes....

Step By Step the longest march. Can be won.

Many stones can form an arch. Singly none, Singly none. And by union what we will can be accomplished still. Drops of water turn the mill. Singly none, Singly none.

Meeting Minutes



- Clint made a motion to table reviewing the minutes from the Utah meeting in July.
- John second the motion.
- Motion passed unanimously.



PRESIDENT'S REPORT

United Nations Treaty on the Convention of Rights for People with Disabilities



We need to encourage our Senators to vote to ratify the United Nations Treaty on the Convention of Rights for People with Disabilities. This Disability Treaty is an international treaty inspired by the ADA. We need self-advocates across the country to email or call their Senators to educate them why it is important to pass the Disability Treaty. For more information go to:

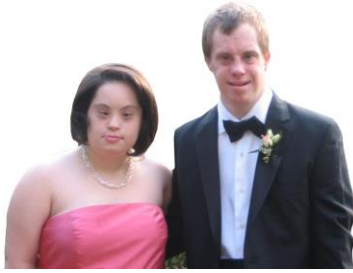
<http://www.disabilitytreaty.org/>

Marriage Penalty



Brian reviewed a letter sent to states. We are continuing to work on the Marriage penalty that affects people on Social Security benefits. If you receive SSI or SSDI and want to get married, this could affect the amount of money you and your spouse receive monthly. We would like to address this issue but we need your help. We need stories from people who are currently on social security benefits and married and how your benefits have been cut. We also want stories from people who have chosen to live together but

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want to get married but can't, because you will lose benefits. If you know of anyone, or this has affected you personally, please write us a one to two page paragraph about your situation and feelings. Please try to be as specific as possible about the amount of money lost and the impact that has on you and your spouse or the amount of money that you would lose if you did get married. Please include your contact information in case we have questions about your personal situation. Please send your stories to Bryon Murray, SABE President at reg3sabe@hotmail.com or to Troy Justesen at troyjustesen@yahoo.com. If you need any assistance writing your story, please let us know and we can help. We are asking for the letters to be returned to us by December 29, 2013. I believe that this marriage penalty is an important issue that we, as members of SABE, can have an impact on changing. Let's stand together, because together, we can change anything. We are grateful for your time and I look forward to hearing from you.

Comments: Consuelo said the Grassroots committee will work to push it out. Eric McVay said Speaking Up For Us of Maine is collecting stories.

Business Plan



Executive Committee worked on creating a business plan it for 3 days. The next step is to hire two people to work part time for SABE out of Washington DC. We have a committee that will be working on developing job descriptions for the two part time positions. The committee members are: John Britton; Bryon Murray; Amira Rasheed; Bernard Baker; Chaquetta Stuckey; Bill Story.

The committee must come up with the job descriptions for the 2 positions by the next board meeting on January 9, 2014. Both people will be working and living in Washington DC. SABE has money to go ahead and hire these 2 people.



Oklahoma 2014 SABE conference

Board members met with members of People First of Oklahoma and toured the Renaissance Oklahoma City Conference Center. There were positive reports of the hotel. The rooms are attractive and comfortable. The hotel staff appear to be willing to make changes so the hotel is accessible. If

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requested, they would be willing to take doors off of the restrooms if necessary for large wheel chairs. There will be rooms set aside for first aide and a couple of quiet rooms. The dates for the conference are October 9-12, 2014 in Oklahoma City, Oklahoma. The theme is The Sooner we are Equal the Better

NTAC for Voting and Cognitive Access SABE Board Quarterly Report July – September, 2013 Activities



Webinars: The second webinar presented by Project Vote was on September 26, 2013 on Accessible Ballots and the future design of a universal voting equipment. Our speakers were Michelle Bishop, NDRN Vote Coordinator, Juan Gilbert and Jim Dickson of Clemson University. It was one of our best webinars so if you missed it go to the govoter.org website to hear it.

Testimony Before the Presidents Commission on Election Administration: On September 20, Diana Mairose, SABE Region 5 Board Alternate, testified before President's Commission on Election Administration members about what voters with cognitive disabilities consider best practice in the election process. She stated that having a disability is not the problem with voting, it is having the accessible equipment, accessible locations and respect to do so! She urged PCEA to recognize the value of "universal equipment". Poll workers would only need to understand how to use one piece of equipment, people with disabilities would not have to go a segregated part of the room to vote and encouraged panel members to take a closer look at the Prime III equipment developed by Clemson University as a model. She talked about the physical accessibility of polling locations and recommended if a location is not completely accessible that a person (paid just like a poll worker) be stationed outside to direct/assist voters to the most accessible route to take. Lastly she focused on the importance of disability awareness training for poll workers and recommended that all poll workers be trained by a person with a disability in that area.

2013-14 Grant Application to AIDD:

Because of a series of problems SABE had working as a subcontractor with NDRN this past project year, the Project Vote Team met with the SABE Board of Directors and advised that SABE go after the next grant directly without NDRN. When SABE informed NDRN of their decision, NDRN was upset and convened a meeting with the Project Vote Team to discuss

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the issues and see if they could be resolved. After several very intense conference calls to resolve issues, SABE finally decided to once again subcontract with NDRN for the next AIDD grant application. To prevent these issues in the future, NDRN and SABE will sign a Memorandum of Agreement before the start of the next grant cycle. The 2013-14 grant with NDRN was funded and Project Vote received \$95,000 to do our work.

Project Vote Goes “Google”:

Our team meeting here in Oklahoma City was primarily spent on getting the team connected thru Google Calendar, Google Hang Out, and Google Drive. Our team meetings and working papers will no longer be done by conference call but on Google Hang Out.

Communities United Grant

October 2013 Quarterly Report to the Board

In attendance: Eric M., Cathy, Eric T., Bernard, Glenna, Richard, Bryon, Betty, Darren, and Chaquetta.

Today's meeting goals:

1. Look over next Webinar. Anyone want to present?
2. States that have a Facebook:



- Arkansas
- Maine
- Indiana
- Vermont
- Utah
- Georgia, personal one now and will develop one

3. Can SA groups join SABE Facebook
4. Review report; Review topic scoring for the last 2 Webinars
5. How to improve attendance on Webinars



- a. Explain how to get on the webinars
- b. Some members are sending out to their groups
- c. Brainstorm benefits of Webinars
- d. Help people
- e. Figure out technology
- f. Added to what I already knew and reminded me of things I had forgotten, Refresher course
- g. Interesting and feedback

6. What are the goals to wrap up the project? Would like to see the group continue and meet. Find another grant, to keep the topics going.
7. Welcome OCSS grant Committee
8. What are your plans? What can OCU help with?

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Autism NOW Grant October 2013 Quarterly Report to the Board



Autism NOW is a project SABE is doing with The Arc of the United States and Autistic Self-Advocacy Network. Max Barrows, Nicole LeBlanc, and Karen Topper work on it for SABE. This is Year 4 of the grant.

Accomplishments since our meeting in Utah:



SABE produced a video (25 minutes in length) on Building Relationships with Policy Makers. <http://www.youtube.com/watch?v=ifByvtW7LfQ>



Max said, “It was the first time I presented a video as a live interview. I enjoyed it because it was an opportunity to interview someone who uses Augmentative and Alternative Communication. It increased my skills in making sure I give an AAC user the time needed to respond to my questions. I also learned how to follow-up and ask clarifying questions on my own.”

SABE was pleased to include Tracy Thresher who is an international advocate for people with autism and an AAC user. Tracy is known for his clear message on presuming competence.



Nicole emphasized that the reason we opted to create this video, “If you are not at the table people are going to make decisions about your life for you. We are the experts. People with I/DD know best. It is one thing to talk around us and another thing to talk with us. Our message to policy makers is *Why not ask us.*”

We produced a webinar called: Taking Charge: Tips for Self-Advocates. If you find it hard to give feedback to your support staff... This webinar is for you! It was held on September 10, 2013, from 2:00 to 3:30 PM EST.



Nicole commented, “We choose this topic because self-advocates are reluctant to give feedback to their support workers. We need to learn how to give feedback in a way that our concerns will be heard.”



Max added, “Because people with disabilities are so used to being told what to do, it is easier sometimes to have someone else make decisions for you. But we need to speak up. What if decisions, staff make for us, are not ones we agree with? A person could be put in an uncomfortable situation or miss out on a new opportunity.”

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SABE recruited Katie Griffith a peer leader from People First of Arizona to be a presenter on the webinar. She belongs to a coop where people with disabilities share support workers and do the hiring and supervision.

To prepare for the webinars SABE had focus forums with local self-advocacy groups to identify preferred qualities of support staff. We used information gleaned from these focus forums to create two role plays used in the webinar. These role-plays addressed the issue of support staff using their cell phones to text and call while working and the issue of being on time for work.

Our goals for October 2013 to October 2014 year are:



1. **Produce 6 videos** on Autism or ASD related topics. The board made the following suggestions for video themes: Success stories from Maine; Tips for peers to welcome and support a person with autism to participate in a meeting (including tips about sensitivity to sensory issues); On employment and how to interview (including disclosing your disability); Health and wellness; What is autism?; Accepting autism and not fighting against it.



2. Present two webinars on Autism or ASD related topics. The board suggested the following ideas; Figure out how a person living in a rural area get options; Dealing with health care in terms of making the right choices; How to make a service plan so that people understand what the supports are that people need.



3. Author six stories for the Autism Now Center's Toolkit (working title: Supporting Organizations to Shift from a Staff-Driven Environment to a Self-Advocate Driven Partnership). The board members who want to support the Autism NOW committee in developing these stories are: Amira, Clint, Carrie, David, Nancy, Betty, Eric, Carol and Mike.



4. Publicize Autism Now Center (e.g. website, resources, blogs, webinars, YouTube videos, and call for blogs) via SABE's communication strategies.
5. Chair the National Advisory Committee. Nicole and Max to participate as members of the National Advisory Committee.

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Coleman Institute



The Coleman Institute each year publishes a report called the state of the state. It has all the details about how much money is spent on services in each state. The report is hard to read. So they have a small contract with SABLE to produce an easy to understand summary of the report.

Also the Coleman Institute just had their annual conference. Cathy Enfield represented SABLE at the conference. They passed a resolution: People with intellectual/developmental disabilities have an equal right to technology and information access. A coalition of disability organizations and individuals are asserting this right in a formal declaration, announced at the Thirteenth Annual Coleman Institute National Conference on Cognitive Disability and Technology, held October 2, 2013, in Broomfield, Colorado. You can view the declaration on the SABLE website.

Our Community Standing Strong Grant Quarterly Report October 2013



Administration on Developmental Disabilities awarded SABLE a Regional Self Advocacy Technical Assistance grant to work with the Southern Collaborative in Regions 6 and 9. The grant is for \$100,000 for three years.

Name of Grant: "Our Communities Standing Strong" (OCSS)

Who are our Allies and Partners?



OCSS is a partnership of Self Advocates Becoming Empowered (SABLE), I.M.P.A.C.T (Individuals Motivating People to Achieve Change Together) South Carolina, A and M

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Consultants, and 8 states (Alabama, Arkansas, Florida, Georgia, North Carolina, Oklahoma, South Carolina, Tennessee) from the Southern Collaborative (Region 6 and 9)

Allies include many of the DD Councils, P an A's, UCEDD', ARC's in the Southern Collaborative operated by self-advocacy leaders.

What is the purpose of the grant?



To create a regional technical assistance center to strengthen the participating states capacity to increase and support self-advocacy through relationships and partnerships at the community level. The objectives of the project include: 1) peer advocacy and mentoring, 2) training and leadership development, and 3) educations and outreach.

What will we work on during the first year?



Collecting 1200 surveys on what are the technical assistance needs of the state and region. Developing state and regional plans for peer to peer technical assistance. SABLE is also excited that ASAN and NEAT in Region 8 were also awarded one of the grants and look forward to working with the other Regional Technical Assistance Projects to strengthen self-advocacy.

Who will work on grant?

Chaquetta Stuckey and Vicki Hicks Turnage will Co Direct the Project for SABLE. Glenda Hyman Singletary will also assist Chaquetta in her role.

Juliana Huerena will be assisting with web support, webinar and other technical assistance support.



Two representatives and one alternate from each state will serve on the Southern Collaborative Steering Committee. Allie will be ask to participate as partners.



When will the Advisory Committee meet?

First meeting will be by Webinar on October 29, 2013. The Committee will meet in February with the SABLE Board.

Board adjourned for lunch at 12:30 pm Meeting resumed at 2:18 pm

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People First of Oklahoma, their Ally/executive Director, their president and Rosalyn from University Center had an informative and casual meeting with board to answer and questions or concerns about the SABE conference. They gave T-shirts, cups and wrist bands to all present.

Board Members met in committees 2:30 to 5:00 pm



Saturday October 19, 2013

Board meeting came to order at 8:45 am.

Election of National Advisors

The board members spent over an hour interviewing 3 candidates for the 3 national advisor open positions. The questions and answers were thoughtful and a real tribute to the respectful working relationship the SABE board members have with their allies. Board members voted by secret ballot. SABE is pleased to announce the national advisors for October 2013 through October 2015 are:



Glenda Hyman-Singletary,
South Carolina



Leanne Roth
Illinois

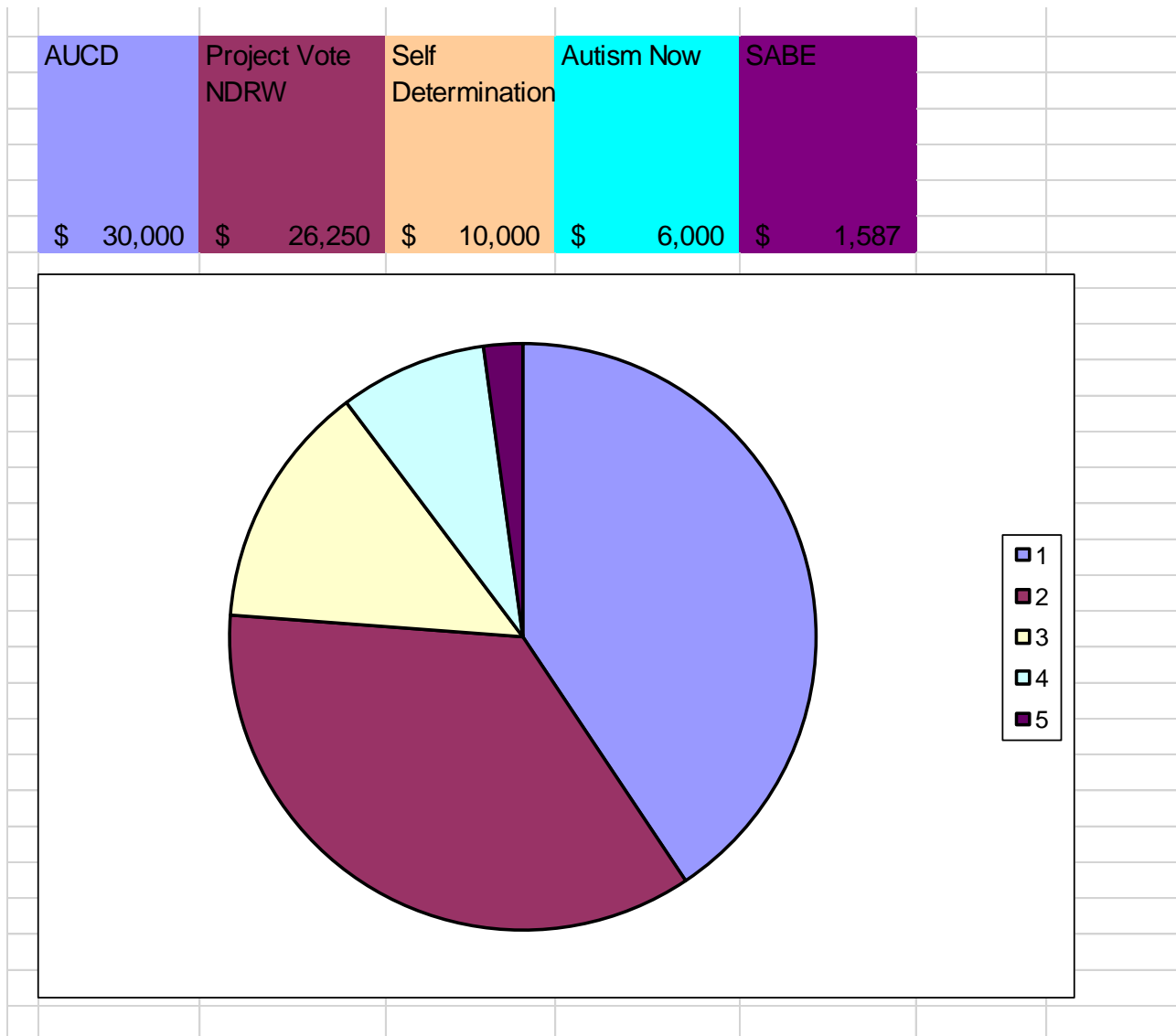


Juliana Huereña
Arizona

Finance Committee Report to be submitted by Essie Pederson

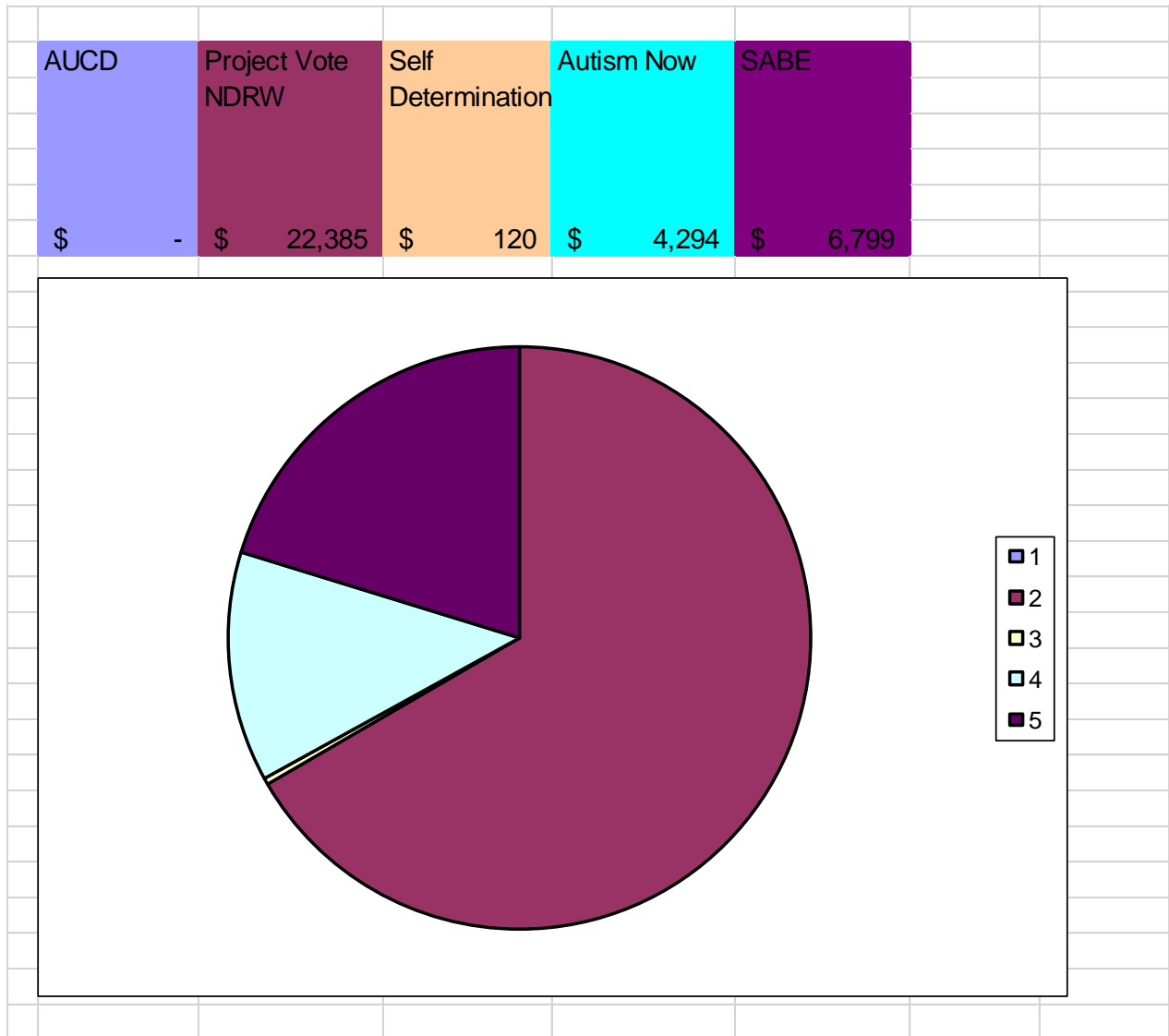
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SABE Revenue July 1. 2013 – September 30 2013



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SABE Expenses July 1, 2013 – September 30 2013



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SABE Budget with possible Infrastructure

Self Advocates Becoming Empowered Revenue July 1, 2013 thru 9/30/2013						
	Revenues	Expenses	Available to support infrastructure	Amount		
OC UNITED ACD	30,000	30,000				
OCSS ACDD REG TA	100,000	100,000	Audit and information/comm. system TA	10,000		
Project Vote	97,500	97,500	Audit and Information system TA	10,000		
Self Determination	10,000		in reserves			
Autism Now	14,000	14,000				
SABE	3,000	1,000			2,000	
Coleman	3,000				3,000	
U of Minn	5,000	1,000			4,000	
NADD	1,000				1,000	
Total	263,500	243,500				
Reservees	126,000					
Total Equity	389,500				30,000	

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- Clint made a motion to have the conference membership fee be \$15 and after that increase to \$20.
- Bill seconded the motion.
- Motion passed unanimously.

Grassroots Committee Report October 2013

Recommendation to the board

The Grassroots Committee is recommending that the toolkit as it exists is no longer needed. The way we do things has changed. Today there are new ways using technology to teach groups how to get started. For example look at all the webinars Communities United created. Now there are 3 new grants, like Communities Standing Strong, who have the mission to strengthen and increase peer to peer connections.



- Sam made a motion that the toolkit be removed (as a SABE resource).
- Jason seconded the motion
- Motion passed unanimously

Our Mission

Reach out to the states groups with information for state and local groups. We want to make sure we are sending out a consistent message. Pay attention to the states that are struggling who don't have state self-advocacy group.

October List of topics we want to send information about to the grassroots.

1. Converting sheltered workshops to employment programs. There is a lot of pressure from CMS for states to show a plan to close them.
2. Affordable Health Care Act
3. Marriage penalty stories from each state by December 29th. (South Carolina has both positive and negative stories.)
4. Closing the door, shutting institutions. Expect resistance and fight it by giving communities knowledge.
5. UN Treaty – talk to your senators – just because we have a disability we still do have human rights. We are encouraging every state to send us a copy of the email you send to your Senator.

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The topics for the October 2013 Grassroots' Flyer is sending letters to Senators about passing the UN Treaty and to send in stories about the marriage penalty. We want a contest. For the state that sends in the most letter or emails to their Senators they will win special recognition at the national conference in Oklahoma. They can earn an award for your grassroots efforts.

Send out a flyer with information about these topics to each state. Send it by email. Information is a two way street. Please send information back to us about these topics or anything else.

Each meeting we will present to the board a good or bad situation being faced by a state. We don't want to just be giving examples of bad things but also what is working.



- Carrie made a motion to accept the Grassroots Committee Report
- Jason seconded the motion
- Motion passed unanimously

Adjourned for Lunch at 12:00

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Self-Advocacy Nation

More than 1,200 local and state self-advocacy groups



Consuelo
Castillo



Chaquetta
Stuckey



Clint
Perrin



Darren
Morris

Action Alert!



The Disability Treaty (known as the Convention on the Rights of Persons with Disabilities, "CRPD") is an international treaty inspired by ADA. So far more than 100 countries have signed it. Last year the US Senate voted on joining the treaty BUT we lost by 5 votes. Senator Harkins said It was a sad day in the United States for people with disabilities, their families and allies.

Good News! We have another chance to get the treaty passed. Please call, email or write to your Senator. Tell them to support the Disability Treaty It is easy. Just click on this link <http://www.disabilitytreaty.org/> Then click on **Tell your Senators you want the Disability Treaty ratified!**

Dear Self-Advocates,

Stories Needed!



If you get SSI or SSDI and want to get married, this could affect the amount of money you and your spouse receive monthly. We would like to change this rule. We need stories from people whose social security benefits were cut when they got married. We also want stories from people who have chosen to live together but want to get married but can't, because you will lose benefits. Please write one to two page paragraph about your situation and feelings.

Please send your stories to Bryon Murray, SABA President at reg3sabe@hotmail.com or to Troy Justesen at troyjustesen@yahoo.com

We are asking for the letters to be sent by December 31, 2013.
Let's stand together, because together, we can change anything.
We are grateful for your time and I look forward to hearing from you.

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PR Committee Report

The committee will move forward by using Drop Box. This is a way for all to see what articles are coming in and going out for the newsletter. We will put files of the older newsletters in drop box. Committee members will get an email so they can get access to the Drop Box folder. You will need to download the program Drop Box to your computer. The program is free.

Tasks the committee members are comfortable doing are:

- Collecting stories
- Writing articles
- Promote more collecting stories from state groups

Max will get the latest contact information for the regions from the SABE website. Max will send out an email asking for stories that are written, edited and ready to go for the newsletter. The committee members will also send out the notice to the states in their region.

Conference calls changed 5:30 Mountain Time.

Committee members and supports present	
Max Barrows	Cathy Enfield
Amira Rasheed	Ernestine
Carrie Varner	Richard Enfield

Date	Committee <u>PR Committee</u>	
Topic	Discussion	Action needed
1. Newsletter	Content (Articles and Reports)	2 newsletters a year.
2. Collecting Articles from State Contact(s)	Want to improve on getting articles. Each PR Committee member will send out announcement in Region.	Will pull correct email addresses for state contacts off the SABE website.
3. Using Drop Box	Content for newsletter and website sharing.	Set up drop box and start using.

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4.Communications	Conference calls	Continue to do conference calls
5.Website	Update website with state and regional reports materials as necessary.	Need technical assistance.



- Mike Grengs made a motion to accept the report from the PR committee.
- Chaquetta seconded the motion
- Motion passed unanimously.

Legislative Committee Report

Working on getting a price for T-shirts to advertise the CRPD Treaty. The cost of the T-shirts is around \$9.00. The committee is spending their budgeted funds to buy 30 of them.



- Carrie made a motion to accept the report from the Legislative Committee report.
- John seconded the motion
- Motion passed unanimously.

Policy Committee Report

Committee members and supports present	
Bryon	David
John	Bernard
Jason	Juliana
Carol, guest	

Date 10/18/13	Policy Committee	
Topic	Discussion	Action needed
1. Jason's video	Looked at video	Show others
2. Read letter from Troy	He mentioned 4 point. 1st Congress needs to change the law 2nd tax deduction and income tax filling	Call Troy and get clarification Encourage people with disabilities to write personal letters about marriage to set up an appointment with

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	3 rd Cost billions of dollars, OBAMACARE rules, Department of Labor with overtime attendant care 4 th point says to connect with Senator Orin Hatch who is part of Senate Finance committee responsible for making changes to Social Security Law.	Call Senator Orin Hatch to get an appointment with his staff.
3. Committee members talked about their personal stories	SSI, SSDI, spending down, common law marriage, couples living together, partners, government rules, working and saving money, trust, living in facilities	Write to congress and ask <i>them</i> to survive with a small amount of money

Name of committee member	Activity responsible for	Due date of activity
Bryon and Amy	Call Troy to set an appointment	By November 1, 2013
Policy committee members	Have a telephone conference	Before December 29, 2013 TBA Depends on Troy's schedule
Bryon	Collect letters from SABE members and friends	December 29, 2013
Nancy and Pastor Mark	Collect stories from people and give to Bryon	By November 1, 2013

The committee showed a video produced by the Summit ILC (Independent Living Center) in Missoula, Montana.

Go to <http://www.youtube.com/summitilc>

Click on the video on the bottom left. It is called Social Security Rules – Bad for Everyone.

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WATCHED

5:11

Social Security Rules - Bad for Everyone

Below is a letter from Troy from Utah who is an advocate SABE is working with on Marriage Penalty issue.

Hi everyone,

I learned some information to help you decide your next steps about the problem of losing SSI money when two people get married.

First, it is law and not policy that the Social Security Administration reduces SSI payments when two people marry. This means the US Congress would need to change the law and that is very difficult to get Congress to change such a law.

Second, some people in the government feel that since married people get a tax deduction that single (people) do not get it overall balances out fairly. Although many people who get SSI do not file taxes, it does at least create a perception that married people get tax deductions and makes it hard to change what people think. And many people feel that it is not a penalty to people receiving SSI because it is cheaper for two people to live together than to live separately.

Third, changing the law will cost a very huge amount of money to the federal government...like hundreds of millions of dollars if not billions of dollars over time. Because the Affordable Care Act (Obamacare) starts to become effective (October 1 starts some parts of the law) and because the US Department of Labor announced final rules on attendant care pay for overtime and other new requirements, the disability community is focused on not losing the current supports that some members of Congress want to change that may affect people with disabilities badly.

Fourth, although the above three things are not good, it is always possible that you could change the law for the better. Utah's Senator Hatch is a member of the Senate Finance

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Committee and that committee is important to change this law. It would be possible to get a meeting with Hatch's staff to talk about this.

I hope this helps. Have a good day!



- Sam made a motion to accept the Policy Committee Report.
- Clint seconded the motion
- Motion passed unanimously

The Bylaws Committee is an adhoc SABE Committee. Bryon appointed Cathy Enfield, Bernard Baker and Bryon Murray to be on the committee.



Next meeting is in Nashville, Tennessee. January 10 and 11. The executive committee arrives January 8. Board arrives January 9

Spring SABE Board meeting will be in April in Washington DC Area. Board meeting is April 11 and April 12. Executive Committee arrives 4/9 and Board arrives April 10.

Sibling Leadership Network

Network held Quarterly Conference call in September. Discussed success of annual conference held in June in Pittsburgh. Check out website to see what sib-shops (workshops) are happening across the country. <http://siblingleadership.org/> Next call is in December.

Meeting Adjourned 4:30 pm