

Statewide Network for Cultural Competence (SNCC)
March 22, 2005

MINUTES

Bill Gaventa called the meeting to order at 2:20 PM welcoming all.

Introductions from all present, including the two ASL interpreters

The minutes from the last meeting were reviewed and accepted

Kudos to Nancy for last meeting's minutes

Moderator: Bill Gaventa

There was discussion about posting the minutes from all meetings on the listserv and even on the website so others joining or interested in SNCC can follow the history of the group.

There was discussion of ethnic identity and how to focus services in the community to meet their needs.

Sheziah Adham was supposed to do a partial presentation on the South Asian conference, but was unable to attend. The project she is involved in is to cover NY and NJ and they are trying to develop a resource directory for the South Asian community. This ties in with what SNCC is trying to do and we hope to have her present at a later meeting.

Zeneida was appointed "jargon buster" for this meeting. Basically, anyone knowing the meaning of an acronym used during the meeting will give a definition. We may want to develop an acronym list for the future.

Bill Gaventa advised that he will be leading an all day training on cultural competency at NJP&A, on April 14, 2005 and he had enlisted several individual from various ethnic background to speak on the panel.

Guest Speaker: Ed Madera, of Self-Help

Ed shared with the group his intense background in community development and how this allowed him to bring the Self-Help Clearinghouse to life.

- He started by keeping a list of groups and those wanting to start groups, then bringing them together with people who had been through something and were looking for support groups.
- In 1980 they made a grant proposal to the NJ State Division of Mental Health to have one person keep this database of groups
- They were funded in 1981 and Rosemary Bloomer was the coordinator
- The first Self-Help Handbook was published by Hoffman-LaRoche even prior to the first Self-Help Clearinghouse Directory, and it was a list of local groups and best practice models from around the nation.
- Today there are over 4,500 local NJ groups listed and about 1,100 national and on-line groups
- The on-line groups are the most helpful in addressing issues regarding language barriers

- Groups are started by people who need supports having gone through something. They pool general knowledge and experiential to provide mutual support. These groups also attract professionals, who will come and speak to the groups free of charge.
- The groups listed cover a broad spectrum of problems---bereavement, unemployment, parents-survivors of child suicide, etc. The groups often also call for needed legislation around various issues.
- Division of Mental Health funded a group for those who lost a child to terrorist attacks.
- There are Parents Anonymous groups, which provide support for parents who never learned to be parents and take their anger out on their children.
- There a group for African Americans with MS, which is particularly more aggressive in African-Americans.
- There is a Korean language cancer support group in Bergen.
- There are also groups listed for cultures and languages. There is a list of Spanish language groups---A.A, Alanon, Battered Women, Mocha Moms, Sister's Network, etc.
- Self-Help Clearinghouse brought people together and they started the first AIDS (then known as the gay men's disease) group in 1982
- Started the first Lyme's Disease group in NJ
- A Philadelphia doctor called them regarding latex allergies and started the first support group for those with latex allergies
- Believe NAMI's Latino Outreach to be a good model for reaching other ethnic groups
- The two women who (?) the breast silicon implant suit, started their group through self-help
- The Men with Breast Cancer group started through self-help in Long Island
- Always ask groups to reach out to colleges or other community groups to bring interpreters. If there is enough interest they may break off to form their own group.
- Cultural issues must be taken into consideration. There was a group where women stopped attending meetings because their husbands did not want them going out speaking of family matters in the general community—but the church was okay. The meetings were moved to a church, which allowed the woman to say they were going to church.

One of the group members mentioned that some people reported discomfort with some groups which were not too accommodating or welcoming. What are they to do when there is no formal complaint process or establishment to file a complaint?

Ed shared what happened when the National Cancer Society would not allow women with breast cancer to come together to share their good or bad stories about doctors. The women organized, showed their scars with a note advising that some doctors were butchers and others were sculptors---they found a way to let people know.

Ed advised that self-help means **member-run**, but here in NJ they include professional groups in the listings is they are free of charge. It is important that people feel it is their group, no leading founder. The value of having someone who has gone through or is going through something, to help others is immeasurable. These individuals are uniquely qualified to do so having had the personal experience.

Bill offered that Self-Help is really called “Being in the community” and Ed added that forming these groups gives meaning in the lives of those who come seeking support and find that they can give support as well.

In closing Ed made a call to all present to refer any existing groups or call if we are aware of groups trying to get started. He also advised we can search for groups on the web at www.selfhelpgroups.org NJ now has three data bases and you can call for the most updated information as well.

Barbara Andrews posed the following question to Ed: What efforts have been made to outreach to ethnic communities or to you wait for them to come to you?

Ed advised that they aim to educate professionals in those communities, helped put on a Spanish conference with self-help groups and it was done completely in Spanish. They also write to the Spanish speaking papers to have articles published informing the community of groups and services.

Ed advised that they also offer weekly workshops throughout the NJ on how to start groups and also have faith-based groups to partner and form self-help groups.

Zeneida advised that she had referred a Caucasian woman who has a child with sickle cell to a sickle cell group in Monmouth County, but the woman advised that the group was not welcoming at all and she wanted to find a Caucasian group.

One of the members present offered that though sickle cell is predominant in Blacks, it is also found in people in the Mediterranean and of Mediterranean decent. There maybe other groups already around.

Thanks given to Ed Madera for an insightful and very informative presentation.

Liz gave an update on the website. She handed out sheets showing what the site looked like for review.

- DHSS has been in contact a great deal in getting the site up and running. The contacts surveyed have been entered, but it is still running in the test phase.
- Liz advised that we must decide on what to say to those who have sent in their surveys---Do you want to be listed on the website and participate??
- The website also has SNCC’s Mission Statement and who we are
- There is a fact sheet with a chronological history of the group
- The last page is a participating agencies website link
- Liz advised she had some difficulty grouping participating members from the same agencies. Barbara advised that she make a list of the core member agencies. The problem is that there are numerous office and divisions under each agency, i.e. DHSS has members from various divisions not connected.

There was discussion regarding the “criteria” for being a member of the group. Some things mentioned were: being an active member, coming to meetings, providing support, help with promoting cultural competency. Should we have this on the website? Should we have an official contact to call to see if we should drop those who don’t show up?

Jason offered that he believes it is more important to help agencies than to look at who is coming or participating.

Other members offered that we need to come up with a definition of what "participating member" means.

Bill offered to "take a stab" at composing something around this area. See below.

Draft: March 23, 2005
New Jersey Statewide Network for Cultural Competence

To be listed as a Participating Agency, an organization must:

- * Agree with the mission of the NJSNCC.
- * Play an active role in the Network by regular participation at NJSNCC meetings, activities, and/or projects.
- * Promote the NJSNCC to others, e.g., encouraging them to enter their organization in the data base, join the listserv, etc.
- * Provide a link to the NJSNCC Web site from an organization's Web site.

The Network will review the list of participating agencies annually, and reserve the right to remove the names of agencies and organizations who have not been active.

Listserv

Once the listserv is moved to the Office of Information Technology, the listserv guidelines are as follows:

1. People requesting to join the listserv will fill out the "subscribe" information listed on the messages and Web site information about the listserv, and will be approved by the NJSNCC listserv moderator. The current moderator will be Bill Gaventa, email: bill.gaventa@umdnj.edu. If the moderator has questions about an organization or applicant, he/she will consult with the NJSNCC Executive Committee.
2. An applicant who is turned down can appeal to the NJSNCC Executive Committee.
3. The listserv will be an open listserv for the members, with all members able to send a message to the full listserv without prior approval of the Moderator. That openness will depend on appropriate use of the listserv. These are the guidelines:
 - * The listserv is for the purpose of sharing information about training, resources, and information about cultural competence, either in New Jersey or nationally, or information about the activities of the NJSNCC.
 - * The listserv is not to be used for sharing jokes, political statements that do not relate to cultural competence, etc.
 - * Opinions and concerns can be discussed on the listserv, but all members are requested to do so in a professional manner.
 - * The membership moderator and the Executive Committee of NJSNCC reserve the right to remove anyone from the listserv who is using it for purposes other than those listed above.

Liz advised that she is not sure just when the Web site will be up. She will email Janet at DHSS to see where she is at with this. Anyone working for the state is on the state system, and would be able to access the website and review it.

Maggie asked: Do you link to different agencies? Liz advised have not done this yet, but it has been discussed with Janet. Connie Clark also wants to know if NJ Helps could be linked. Will people be able to enter their own information on the website to be on resource list?

The Office of Information Technology offered to support the listserv. Anyone can send information on the listserv. To unsubscribe---Bill's secretary does that.

Q1. If someone subscribe, do we want the subscription approved?

Q2. Do we want the listserv moderated or not?

Barbara advised that once out on the Web, it is public domain. They could subscribe, but it would be approved prior to making them a part of the list serve.

Bill advised he would rather be the gate keeper for who wants to come on, but not having to be the gate keeper for messages

Jason advised that he ran a Yahoo group in MN for DHH people. He would check comments to see if related to topic---he would let them know if not appropriate. He feels there should be open messages and a gate keeper only for who becomes a member.

We may want to include a waiver advising that the listserv is to share upcoming events re: cultural competency—questions, events conferences.

The Office of Information Technology had concerns about spam. Liz will speak to Janet about this.

Training Resource Network Bank—this would be a list of people who could be resources for training events. Shahira, Stacy, Beth and Janet Gwiazda enlisted to work on building a group of people, through the network that we know and trust---of various cultural groups.

Training Strategies –good exercises, what is our understanding in providing culturally competent trainings

Jackie in partnership with Community Health Coalition of Cultural Competency Task Force. The task force was established in June and is going to organizations conducting training. Will be completing training for all of Bergen County. They are also developing a curriculum. They are launching, along with The Record, an 8-week series with cultural competency which will be in the paper and then following up with 350 nurses and teachers to use with children and also parents could use with children. They will be running this program for Bergen, Hudson and Passaic teachers of public and private schools on May 5th at Giant Stadium, and then at the Multicultural Garden State Mall on October 15th. Jackie will check to see if they will allow exhibits.

Bill suggested that Jackie be the next speaker at our May meeting and she agreed.

Barbara reached out to Jason to have him on the agenda to interface with DDHH's. He advised that Brian Shomo assigned him to be the representative for DDHH.

Respectfully submitted,

Maritza Williams
Secretary Pro Tem