



Consumer & Family Advocacy Work Group

Minutes

December 1, 2010
11:00 – 12:00

Attendees: Janet DesGeorges, Laura Douglas, Mary Sterritt, Angie Lawson, Ami Garry, Mary Pat Graham-Kelly, Ann Tinkham, Jennifer Pfau, Rebecca Kahn, Rachael Moore, Rebecca Herr

Action Items

- **Action Item:** Training with WeCan
 - Description: Touch base with WeCan to find out some dates they are available for trainings, and bring them back to the group.
 - Responsible party: Mary
- **Action Item:** Get in touch with Pat Doyle and discuss how Daylight and the PAMI Program might collaborate.
 - Responsible party: Rebecca Herr
- **Action item:** Discuss scheduling mental health first aid sessions with WE Can
 - Responsible party: Mary Sterritt
 - Status: Ongoing; scheduling needs further discussion among work group.
- **Action item:** Review revised flyer/information sheet to recruit new advocates
 - Responsible party: Ami Garry, entire work group
 - Status: Ongoing; discussion about the flyers will be place on next month's agenda.
- **Ation Item:** continue to work on someone to develop the videolog.
 - Responsible Party: Angie

Introductions

- Jennifer Pfau is new to the group. She has used mental health services in the past. She moved to California last year, and has now moved back and is ready to contribute to this project.

Review of Action Items

- **Action item:** Meeting with NAMI contact. Rebecca Herr asked about the possibility of getting funding for national group, and is meeting to talk about it on Tuesday. The NAMI contact was not encouraging about funds. Her suggestion was to work through local groups and get funding that way. NAMI is not usually in a position to provide funding. As a reminder, we were asking for money for consumer advocates to take the Mental Health

First Aid Training, or the Family to Family training, or other trainings – for communication access for those. They qualify for the excessive financial burden exception to ADA, so they can't cover CART for any trainings.

- Responsible party: Rebecca Herr.
- **Action item:** Communication Access. Mary Pat contacted one person by the name of Sumners – a state senator who used to be involved with alliance. Mary Pat also spoke with Laurie with the city of Denver – Laurie is the coordinator or interpreting services. The City of Denver would be willing to give some money for communication access, so Mary Pat will be working with her.
 - Responsible party: Mary Pat Graham Kelly.
 - Other possibilities for communication access: Pat Doyle at the Legal Center – she's been on this committee and hasn't been able to attend – she is aware of the project.
- **Action item:** Discuss training with WeCan. Mary talked to WeCan about doing that after the new year. Do people want to try to find a date now? The training is three 4hour sessions. They wanted to split it up into shorter training sessions, rather than having two 6 hour days. We could send out a Meeting Wizard to see what people have available. Should we start with them to find out their availability? Yes. Mary will touch base with them to see what they have open. The training is about recognizing how to get help for people who need it.
 - Responsible party: Mary.
- **Action item:** Review revised flyer and info sheet to recruitment advocates. This is also an item on our agenda, so we will get to that later.
- **Action item:** Review status of modules
 - Responsible parties: Rebecca Herr, Mary Pat Graham Kelly, Mary Sterritt
 - Status: Completed; work group will review modules during this meeting. Quinn Lung has taken over the mental health/substance abuse module from Jan Dabroski.

Review of Modules

Deafness and Hearing Loss

- This module is for people who are already deaf or hard of hearing – how to present the deaf and hard of hearing experience to hearing people. We have to do some cross training so the deaf people know what the hard of hearing experience is, and vice versa. There could also be some hearing people – relatives of deaf and hard of hearing people. Not staff- those people will go to other trainings – this is for the advocates, not the staff.
- Effective models to show what deaf and hard of hearing experiences are – the human experience for these communities. Although those kinds of simulation activities don't provide the day to day experience, the training programs for mobility specialists still include a huge part of going day to day under a blindfold or earplugs.
- The Colorado School for the Deaf and Blind requires trainings for every staff member on campus that have some simulated activities to show the experience of the deaf or blind – it is very valuable – even if it is not a perfectly accurate representation of

the full experience. It is not the end-all be-all, I don't think we should rule out some type of activity to help people understand a little more what it is like to be deaf or hard of hearing, at least to heighten their sensitivity.

- The people taking the training are already deaf or hard of hearing, so they don't need to be shown what it is like to be deaf or hard of hearing. But with this group we might need to have a two-fold approach, because there several types of folk who might be at the training. Hearing family members need to be involved.
- The mission is to develop a network of trained advocates across the state. Train the trainer. An outcome will be for our trained advocates to be a part of that training program as advocates. Draw on these advocates when there's a bill in the legislature, etc. All purpose deaf and hard of hearing advocates, sensitive to mental health and substance abuse issues. How to express to other people what it is like to be deaf or hard of hearing. When you train the advocates – what skills should they acquire?
 - Coordinate with the Evaluation WG – set up measurements of what we want to achieve. We need Anita to guide us on what the evaluation criteria to be.
 - Would it be helpful for the advocates to be able to role play giving mini presentations? Yes, role playing, definitely.
 - What is the point of presenting deaf 101 and hard of hearing 101 to consumers and family members? The art of story – how do I compress my life experience into 3 minutes at a committee meeting, to get a point across about my life experience?
 - Also being somewhere on behalf of the people across the continuum of hearing loss – a deaf person representing deafness as well as hard of hearing experience.
 - Another purpose of deaf 101 – deaf people don't know a lot about hard of hearing people, and vice versa – training should help them understand each other. We do need that overlap. We need people ready to talk about all the experiences, not just their own particular niche. Generalists, who do it respectfully.
 - Who do these advocates present information to? Policy makers, advisory councils, legislators, committees, local and state government. Increase the visibility about deaf and hard of hearing issues. Also out in the community – church groups, community organizations.
- Ann and Mary Pat met last month. Mary Pat also brought information from Janet, and got the Mental Health part from Mary. For Deaf 1001, we had limited information. Ann and Mary Pat will be meeting again tomorrow.
- Suggestion: a document with the 8 to 10 essential teaching points to convey.
- What new knowledge skills or behaviors would you like people to learn?
- If people have ideas, please, send Mary Pat an email at mpgkelly@sprint.blackberry.net. She hopes to have answers to all the questions for Ann tomorrow.

- The Deaf 101 and Hard of Hearing 101 would be a four hour training. We are discussing splitting the deaf and hard of hearing portions into 2 hours each.
- We need to consider the audience. Cultural awareness activities. The audience for the training is the advocates. Personal advocates, talking with providers, talking with legislators. So the focus is on how the advocates develop their skills and abilities to present this information to those who don't have an awareness of these issues.

Mental Health and Substance Abuse Module

- Quinn and Ann are in the process of adding activities, discussion, and review. It is on its way to being close to completion.

Instructional Design – What is it?

- Instructional Design is designing learning and training so that you meet your goals and objectives. You start with a set of objectives, so all trainings are designed and aligned with those objectives, and then you test to those objectives. You design the training so that you know exactly what the learners will walk out with.
- Some basic tenets of good instructional design include developing presentations to add as much activity as possible, repetition, and review. You want to walk out with the learning having been reinforced. Repeat, review, activities around teaching points. You need to keep focused on a small number of key points, not a whole encyclopedia.

Plan for Recruiting Advocates and Flyers & Info Materials

- We need to have the flyers ready by the beginning of this year.
- We need the where of the trainings. Guessing the first trainings will be in the Denver area, but need to find locations. We will look to the Core Team for guidance on the where.
 - We have the early adopters and the mental health centers in the various areas of the state. Could we look at partnering in a regional area where the early adopters are?
 - CSDB has an obligation to provide trainings – and would be willing to provide some logistics help. Grand Junction, Centennial, Larimer – there is a critical mass of families in those areas. We could solicit people who are connected, perhaps through Janet's communication network. Focus on the areas where we have the EA agencies. CSDB would be willing to help with logistics. We can coordinate with Laura Douglas on this.
 - Janet's reach will be limited to families with kids who are birth to 18. But CSDB's cohort will expand on that population.
 - Budget for training – stipends for participants – calling it a consultation fee of \$25/hr, to cover any expenses associated with it. What is the max number of people we can train at that rate? We need to sit down and do the math to figure that out!

- Areas where CSDB has networks of family members: Colorado Springs, Grand Junction, the Ft Collins-Greeley Area, and Denver. Not so much in Sterling/Centennial area. Because it is a mult-day training we may not have the resources to launch simultaneous trainings in different areas. Focus on one or two sites – one Denver area one to start, and then learn from that event and then take it to another site. Refine what we are doing with the training modules.
- Perhaps try for one training early in 2011 in Denver, and a second one in May in another part of the state.
- It might be a mistake to say the first one is in Denver, ask people where they would be willing to go.
- Flyer.
 - There are Hearing Loss Association events where flyers can be distributed.
 - We envision a short press release – 2 paragraphs that can be inserted in a newsletter, and a longer, one-page announcement, so when anyone sees an opportunity they can get the announcement inserted right away.
 - Include the hourly rate: \$25, and that it is a 3 four hour training commitment.
 - Are we using both flyers, or only the colored one?
 - Another place to recruit would be NAMI and WeCan – they both have newsletters.
 - We need to think about how we would we handle the money – is it for people who complete all 3 trainings only?
- Videologs (vlog):
 - Right now it looks like we don't have a person who can edit and develop a vlog. We can develop the scripts, but the vlogs may not be ready for the recruitment. We don't have anyone with the time edit them.
 - Suggestion: The new lab director at Front Range.
 - When Angie had a discussion with the Colorado Association for the Deaf, she asked them the best way to get information out to everyone, and many people responded that vlogs were effective. We do want to address a variety of people, so it may be worth pursuing vlogs.
- Application: not done. Who is going to develop that? Not decided yet!
- Action Item: Developing the announcement and recruitment materials.
 - Responsible Party: Ami and Janet and Rebecca Herr. If people have suggestions for what should go into the recruitment piece, please email those to Rebecca Herr.
- Interview Process
 - We need to have an interview process –a form for them to fill out so we can screen the applicants. Who will do the interviews?
 - Ami could adapt Dove's materials in collaboration with Janet

Evaluation Work Group

- The Evaluation WG is looking for C&F members to join – please send ideas to Angie or Anita. angielawson22@gmail.com, focuseval@comcast.net.