

CFAC Minutes
July 13, 2006

In attendance: Billie, Michael, Judi, Heather, Allen, Cheryl, Bradley, Ken, Edward, Steve, Leslie, Marcus, Gwyn, Megan, Shira, Ellen, Virginia, Andy

Virginia brought the meeting to order and introductions were made. Billie announced that Michael Norton, Client Rights Coordinator at OPC would be assuming the role of CFAC Liaison in August with Lynne Hamlet acting as the Management Team Liaison.

Andy explained the role of a facilitator and reviewed the desired outcomes, agenda and ground rules. The group agreed on the ground rules and the agenda, which was slightly changed as the minutes and farewell to Billie will be moved to 7:55 before adjourning at 8pm.

The group began by addressing the question, "what do we mean by 'stigma'?" Several CFAC members told stories about first hand experiences with stigma. Ken recalled that the first time he experienced stigma was when he was 19-20 and was applying for a job, for which he didn't get hired because the employer learned that he had been in the hospital. Bradley commented that he is unable to drive and cannot reveal his true self even to his friends. Judi explained that the assumption of a person's character is stigma. For instance, she was asked to stop feeding her son through a tube in a restaurant because it was 'gross'. Now she plans her trips to restaurants according to his feeding times and when she doesn't order food for him, it is assumed that she is a bad mother. She also spoke about the fear of using the word 'retarded' and how a teacher referred him to as 'special'. This was offensive because she feels all of her children are special. Megan talked about the fact that she has a lot of adaptation skills and thus is considered fairly high functioning, which has created problems with accessing services. While no one wants to be labeled, it was acknowledged that the label (i.e. diagnosis) is the key to accessing services. Megan also talked about the assumptions that she can not make the same accomplishments as other people. Ellen explained that in grade school, she was not allowed on the playground or to go downstairs to eat lunch and that her brother called her hurtful nicknames. Edward told a story related to the assumptions and stereotypes that developmentally disabled people do not have the capacity to be mean or manipulative. His youngest daughter was always very jealous of his oldest daughter who has downs syndrome and his family could have better respected the struggles of their youngest daughter. Cheryl discussed the challenges of getting disability income because she has learned to present well and adapt to her disability. This brought up the notion of "hidden disabilities" and the silly metrics for diagnosing or determining the severity of disabilities. It was again discussed how access to services is often based on functionality, as well as being scrutinized and penalized 'for trying.' Gwyn had to learn to adapt while working at a bookstore and it was very difficult and draining. When she lost this job, a friend recommended that she seek services from vocational rehabilitation to get assistance in going back to school but she was not eligible for services because she was 'not disabled enough' and had a work history.

Andy asked the group to break into pairs to discuss what actions CFAC could take to reduce stigma. The results were as follows:

Shira, Ellen and Virginia-

- Educating the community
- Making personal friends with people in power and ask them to take a journey with a disabled person to experience how difficult it is
- Inspire people with other disabilities to organize and replicate the successes of the DD advocacy effort
- Make noise; 'squeaky wheel gets oil'; don't assume someone else is doing it for you

- Start efforts to reduce stigma with young people (start early); do advocacy and education in and with the schools
- Empowering people with disabilities by teaching them where to go and how to take care of themselves
- Invite someone from NAMI to speak about advocacy and how to be powerful

Megan and Gwyn-

- Teaching through being very inclusive; theatre group of people with disabilities and without disabilities to show complete harmony (for example NC TASH's theatre group); no 'special' treatment, all are special;
- Groups for siblings of people with disabilities
- School group for children of parents with addiction disorders or disabilities
- Creative conflict resolution group

Leslie and Marcus-

- Educate people about different disabilities through bring people together to show who we're all different yet the same

Steven, Edward and Ken-

- Make sure that people are informed and educated that each disability has great variety and experiences; can't categorize or stereotype
- Greater awareness and getting to know people with disabilities; spending time with people with disabilities; exposure to the variety and to show that people with disabilities have particular talents
- Honor famous people (who are alive) with disabilities
- Develop meaningful work that responds to particular talents
- Keep moving forward with the peer support conference which is aimed at gathering people together to reduce stigma and is inclusive of peer support for people with disabilities and 'normal' peer support
- Name the disability, 'mental' disability, so no euphemizing

Bradley, Allen, Cheryl, Judi, and Heather-

- Display talents and knowledge; speaking up about your own knowledge
- Create awareness through education, especially with kids, like 'show and tell'
- Find ways to decrease internal stigma
- Live on another planet and isolate yourself
- Create more opportunities for people in general-the group gave some examples of what opportunities already exist: Parks and Rec.; Club Nova; Carrboro, Churches, Weaver St., OE, Karoke, mental hospitals, frame shop peer tree; schools; websites; mental health softball team; brushes with life art gallery; big brothers/big sisters; girl/boy scouts; compeer.

Andy reviewed the ideas that were generated for reducing stigma and asked for suggestions about how CFAC can organize and develop this into a plan. The following suggestions were made:

Edward-Identify what we are already doing to reduce stigma and what is working well;

Judi-Compare efforts across counties;

Bradley-Community Awareness Plan;

Billie-Media Plan;

Virginia-Connect with other advocacy groups; prepare for national mental health awareness week with NAMI in Oct; reach out to MH person at Chapel Hill Schools; Ask TASH to do something for MH Awareness week;

Ellen-RANE already doing community awareness so CFAC can partner with them;

Allen-Profile 'highly visible people' in newspapers;

Judi-Identify who we want to educate and in what order (i.e. kids, parents, older adults, etc.) and write letters to the editor;

Megan-Publish disability focused poems in newspapers like the Indy

Billie noted that some recurring themes were developing. These include: Partnering with other agencies; media/public awareness campaign; work with children.

Andy again asked organizationally, where CFAC would like to go from here? It was suggested that we might want to develop a subcommittee or several subcommittees that function as arms (that deal with media, partnering, and kids). It was noted that we should identify basic parameters/guidelines that direct this work. In other words, to be deliberate about ensuring that the process itself is destigmatizing and that we are educating others in everything that we do. It was also advised that changing social institutions like stigma takes time and that taking it in steps may work and feel better.

Judi, Ellen and Ken agreed to work together on a subcommittee to digest the information created during this meeting and report back to CFAC about what steps should be taken next.

The group then did a brief evaluation of this meeting. The following comments were made:

- Enjoyed having the facilitation that kept us on track;
- A lot of good contribution because we kept things moving with high energy;
- We knew where we were going and the agenda was not too full;
- Going around and soliciting information and small groups gave people opportunity to participate;
- Taking turns gives everyone an initiative/opportunity to contribute;
- Reviewing the agenda up front promoted buy-in;
- Discussion about and posting the guidelines was helpful;
- Email in advance helped;
- We learned about each other.

The June minutes were reviewed and a motion to approve them was made. The motion was seconded and carried. Billie was presented cards, plants and a gift certificate as a farewell present from CFAC members. The meeting was then adjourned.