



Capital Connection

A PUBLICATION OF THE CONSUMER LEADERSHIP FORUM
 WWW.CLFOFDC.ORG

Made possible by a grant from the DC Department of Mental Health Office of Consumer and Family Affairs

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Consumer Leadership Forum

STATEMENT OF PURPOSE

The purpose of this meeting is to unite our best efforts as mental health consumers to reshape/reform/reinvent the D.C. mental health system.

We will not expect the meeting to be a place where we resolve our personal issues but will support each other and network as desirable / possible outside the meeting.

While gathered as a group, we will focus on the vision of the type of mental health system we want to create and the process for getting there.

Welcome Ms. Vivi Smith to the OCFE

LH: Can you please share a little bit about your background and how you became interested in mental health advocacy?

VS: I grew up in DC, went to DC public schools, UDC for college and the DC School of Law. Growing up in DC, I've had family members in the past who were consumers in the public mental health system in DC. So my entire family had always been mental health advocates. That's what I've known all my life – to help others who need assistance, especially family members. When I went to DC School of Law, in my first year we were given cases in the clinics. That began my formal advocacy on behalf of people with all kinds of disabilities.

That's what I did then and I've loved it ever since. I was fortunate enough while in law school to work for the Maryland Protection and Advocacy agency. And then from there I worked with University Legal Services. I've been fortunate enough that I've been able to combine a personal passion along with a professional passion, and that's mental health advocacy. And I'm still a family member of a consumer in Washington. In the course of helping make the system better for my family members, hopefully I can help others, too.

LH: What is the most rewarding part of being a mental health advocate?

VS: The most rewarding part is when someone, a group, or an individual says to me, "Someone listened to what I had to say and found what I had to say relevant. Because no one else was hearing me." That's where I really get gratification, because historically, in this city one has to somehow learn how to navigate systems to get the assistance one needs. I can intervene and say, "I hear what you're saying. This is a solution." And it works for them! Instead of someone saying, "No one's hearing me. I'm getting frustrated." That really makes me feel good that I am able to make a difference. It doesn't take much.

LH: What do you see as the direction of mental health advocacy in the future? What are the trends that you find really exciting in advocacy?

VS: What I find most refreshing is the recovery mode of mental health treatment. We're getting away from the stigma that individuals with mental health issues will all one day wind up in a "bedlam" type of environment. We're beginning to accept that people do go into recovery and stay in recovery. People will go for years and then sometimes their life is interrupted by mental health issues. And with recovery we can get them back to where they were. And that is so great. The first person that I was an advocate for when I came to ULS was a woman who was a health professional. When I met her, she was at John Howard. (con't on p.2)



Ms. Vivi Smith, new Director of the Office of Consumer and Family Affairs at the Department of Mental Health

Vivi Smith (con't from p. 1)

Before that, she had her own practice. And because her support system, a family member, died, her life spiraled out of control. I was able to assist her in picking up the pieces. She got the right therapy, and the right care, so she could go back to her life. She's in recovery. That is a good trend and that's what I'm excited about. That we're looking to recovery and to get people back to where they once were. Getting back to work, to parenting, relationships with families and friends.

LH: Helping people realize their dreams.

VS: Definitely, definitely. I went to a meeting recently, and that guard at the desk said, "I can tell you're not one of the people who come to this organization because you don't look like that." I had to take a minute to talk to him and say, "What do you mean I don't look like that?" You don't know what issues I have. Everyone has something." But the thing about it, he was open to listening, and apologized for that statement and said he learned something that day.

LH: I think what we need to do is to educate people one-on-one to break down the stigma, and I find they are usually open to it.

VS: Mental health does not have one face – even though the media and comedians sometimes put a negative spin on people with mental health issues and that's what the public realized. That's another thing I am looking forward to in the future – developing ways that we can work to de-stigmatize mental health issues. Stigma is a lot of what keeps people from seeking assistance. Even people who used to have cancer or HIV had the same stigma, and I think a lot of that especially with HIV is dissipating.

LH: Now I know this is only your first week, but I was wondering if you had a sense of what your vision was as the new Director of the Office of Consumer and Family Affairs?

First thing is getting this community-based, consumer-focused activity center open! Nothing is required except to come and receive or come and be there. The vision is to have one center like this in every quadrant of the city. You get to just go there and be comfortable. You don't have to do anything except to enjoy the place. Maybe you're just tired and you live in a shelter and you don't want to be there. One young man told me that he didn't have his high school diploma. But he couldn't start the program because he said that he didn't have any peace and quiet in the shelter where he lived. And that's someplace where he can go in the afternoons. And whatever consumers want it to be, it will be. This is great. That is one of the visions of consumers and families—to have places like this up and running in the community and being everything that consumers want and need. My other vision is just to have the public mental health and all services easily accessible and very responsive to consumers. A system that works that way consumers and families want it to work. In a perfect world, it would be a system where no one has any complaints about anything. That would be the perfect world. The reality is as few grievances or complaints as possible. A system that responds very quickly to consumers' needs and families' needs. Especially in regards to affordable, appropriate housing. It's a big systemic issue. Not only with the Department of Mental Health, but with every other system in DC. To find affordable, adequate housing for individuals and families. And then beyond that is to look at home ownership for consumers and families. That is something I'd like to see this office involved in, helping to expand the capacity for affordable housing.

“My vision is just to have the public mental health and all services easily accessible and very responsive to consumers. A system that works that way consumers and families want it to work.”

LH: Having worked in both Maryland and in DC, what do you see as some of the unique challenges to working in DC, and some of the positives in doing advocacy work in DC?

I don't know if this is a "positive" but in DC, given that it's such a small geographical place, that the homeless population is very visible. You cannot ignore them. In Maryland, especially the rural parts, you'll drive through there and you won't see people who are homeless. It's a hidden population. In DC, unless you put blinders on, you cannot deny that there is a homeless population. At least the population is very visible. Hopefully people cannot ignore them, and can see that we have to all of us do whatever we can to address this problem and find some resolutions for it. In DC, I do know that we do have a lot of community advocacy organizations that are willing to work together to address different issues – children, developmental disabilities, mental health issues – whatever the issues, DC has a strong community involved regarding it, and that is really great. We're all concentrated in a small geographic area, so we are sometimes forced to work together. Advocacy organizations work across interests to promote the interests of whatever base they are seeing. Also, you don't have to travel ten miles to get to a meeting with the DC. Advocates can be very present everywhere. In MD sometimes I think the long distances that people have to travel to meetings gets prohibitive. You can't always tell how many organizations are out there. (con't on p. 4)

CLF News

By Dorothy Adams

Outreach Meetings:

Washington Hospital Behavior Center: We talked to the group about the tax package and how they can file for it this year. The group asked many questions and were very interested in what we were saying. We also invited the whole group to our meeting for May.

Mary Claire House:

CLF continued to talk to the group about triggers and how to cope with them. They participated in an activity and ask us many questions about CLF. The group wants to come out to activities that CLF is doing. They will be coming to May meeting also. The group looks forward to the outreach meetings and one particular member was really interested in getting to know the group.

April CLF Meeting:

Nathaniel Stanley talked about how to go on a job interview and how to do a resume. He gave us a sample of a resume and talked about what questions the interviewer can and can not ask. Mathew from the EOC came to the meeting and talked about what questions they can ask people with disability and what types of accommodations they should provide. We also learned that some organizations hire people because they are willing to learn and not for skills or education. Nathaniel said that he would come back and talk about how to keep a job once you get it. Angela Agnew, peer advocate from University Legal Services came and talked to the group about her and what she will be doing. She is a consumer also.

ACT Meeting:

CLF participated in changing some of the guidelines and wording for the DMH on how to help consumers that are participating in the ACT program. We discuss ways that the DMH can help consumers in the system. I suggested that they provide some form of daycare for parents when they need to go into crisis treatment and other programs that require them to leave their children, so that they will get the treatment they need. I also asked them to make some changes in how the treatment programs are structured. We can only go so far and then there is nothing for us to do. They don't have a middle ground or a place under for consumers who are not there yet (in their recovery). We always talk about consumers having choices and rights to do what they feel is best for them and that they give us the opportunity to do that if even if we need to come back and try again.

CLF Outreach Meeting:

We focused on how many meeting we are willing to do on a monthly basis. We have an outreach meeting coming up with Rachael's Shelter to talk about the purpose and mission of CLF in hopes of getting the women to start coming to group meetings.

Campaign for Mental Health Award Ceremony Dinner:

The ceremony was very exciting. We took pictures of all the people that received an award. We met Vivian Smith, who will be working as the Consumer Affairs Office. I will invite her to our next meeting so she can get to see what the group does.

Testimonies for the Budget Hearing:

Tracy Leak and I did one. There were not a lot of people giving testimonies. Councilmember Cantania said that the budget was not cut for the DMH. He stated that the money was still there and that they put it under other programs. but that they cut staff positions because no one was working these positions anyway.

It has been a busy spring. We have several other meetings to schedule for May -- a conference with the food bank; Rachael's Shelter; Ms. Suzanna Henley to talk about food and how to get it; Jamie at Isaiah House to talk about WRAP; DMH Partnership meeting; and three other conferences and meetings as well.

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Vivi Smith (Con't from p. 2)

LH: This can be a depressing field to work in because sometimes it's hard to see progress. What gives you hope and keeps you going as an advocate on a day-to-day basis?

VS: I was talking to my father one time and I told him, "I love what I do." And he told me, "You're very fortunate. Not everyone is passionate about the type of work they do." I had been a communications undergrad major, and I worked at McGraw Hill, but I didn't have a passion for it. Mental health advocacy is my life, and it's also my passion. I'm lucky that my day-to-day life fuels my passion. What keeps me going is that even if I weren't in this job, I'd be doing this advocacy to make systems work better for my family members. I'm living what I do. It's not just my job, it's my life. That's what keeps me going. I'm just lucky to be getting paid for what I'm doing all the time, anyway.

LH: I find that people don't generally fall into mental health advocacy by accident. Either they themselves have had mental issues, or a family member has. That's what makes it so interesting, I think -- because so many people are so personally passionate.

VS: I think the fact that I can personalize really has driven me to advocate zealously for people who for whatever reason cannot advocate for themselves.

LH: Thank you, Vivi, for taking the time to speak with me during your busy first week on the job! We're glad you're here!

Exciting New Opportunity for DC Consumer-Survivors with ODL

I am writing to invite you and your colleagues to participate in the District of Columbia Olmstead Planning Council. This Council will help to shape the course of the District's efforts to serve people with disabilities in their communities, rather than in institutions. In 1999, the United States Supreme Court issued its decision in *Olmstead v. L.C.* indicating states could not legally require people with disabilities to remain institutionalized in order to receive health care services. The Court ruled that this unjustified isolation is discrimination based on disability. Following that ruling, each state must address the issue of assuring home and community-based care for individuals.

The District of Columbia Office of Disability Rights (ODR) is responsible for the development of the Districts Olmstead Plan and is in the process of developing a framework that will ensure a successful and comprehensive planning process. Our initial task is to convene an Olmstead Planning Council comprised of consumers, parents, guardians and other caregivers, government officials, advocates and representatives from the provider community. We are looking for people who understand the need for, and the value of, a system of self-directed, individualized supports for people with disabilities. The Olmstead Planning Council will develop a plan that embraces the following guiding principles for people with disabilities:

- The right to live in the most integrated community setting appropriate to the needs of people with disabilities;
- The right of people to leave institutions and receive home and community-based services;
- An individual, client directed support plan written and updated regularly;
- Access to, and purchase of, self-directed care providers and selection of community supports;
- Identification, assessment and prioritization of the need for services from the spectrum of people with disabilities presently residing in institutions;
- Training for consumers, families, advocates, community support networks and other identified stakeholders.

To that end, the Office of Disability Rights is extending this invitation for participation on the Olmstead Planning Council, and your assistance in the recruitment of Council members (i.e., posting this invitation on an agency/group website, bulletin board or newsletter; announcement and discussion at local organization meetings; etc.). Our initial meeting is scheduled for:

Wednesday, May 7th 2008, 1:00 pm – 3:00 pm
441 4th Street NE
Judiciary Square, Conference Room 1117 (11th Floor North)

Participation on the Olmstead Planning Council will be voluntary and require attendance at regularly scheduled meetings and events. Interested candidates should contact Derek K. Orr, Deputy Director - Office of Disability Rights @ 202-727-8005 or email derek.orr@dc.gov. To learn more about the Office of Disability rights please visit our website at <http://odr.dc.gov>.

CAN Corner

CAN's most recent focus group was on treatment and discharge planning. We invited consumers to come and voice their concerns and understandings about this topic. The outcome was varied with consumers saying that they must be vigilant in their planning to others saying that providers must be more aggressive in getting things done. Topics for the focus groups (and more to come) are from previous feedback in our expectations survey work and we will be conducting new surveys in expectations and satisfaction later this year. It will be interesting to see the outcomes to compare them to those of other survey work we have been working on and with DMH and the hospital. Other focus group topics include educational opportunities and daily activities.

CAN will be involved in an important initiative concerning trauma training with Dr. Joan Gillece. The training program that Dr. Gillece has coordinated has brought trauma training to staff at various wards at SEH and CAN will be continuing the training at both the civil and forensic sides.

CAN was honored for the third time in Santa Fe, New Mexico with the Timothy Coakley Leadership Award from the American College of Mental Health Administration.

CAN had a booth at the exhibit hall at the National GAINS Center conference in mid-March at the Hyatt Regency near Union Station. This was a good networking opportunity to share information. It was a very informative three days as we learned more about expanding jail diversion initiatives nationwide. Having worked on the BJA Grant project last summer, CAN particularly enjoyed the performance at the National GAINS Conference that was put on by consumers, called "A Life Interrupted", and produced by the Thresholds Theater Arts Project in Chicago. A presentation by Jonathan Brooks from JHP Consumer Council was supported by Kevin Chambley, Ward Administrator for Ward 2, John Howard Pavilion.

CAN hosted an entrepreneurship event in late February that introduced our entrepreneurship initiative to the mental health community. Steve Baron, Director of DMH, and Mary Blake of SAMSHA spoke at the event and we had several personal accounts of entrepreneurship by consumers including Dick Dougherty, Michael Sterling, and Peggy Templeman. Attendees from Maryland and Virginia participated.

CAN is once again coordinating the Community Services Review (CSR) for Denny Jones. Two staff completed the training for reviewers and shadowers as well as participating in debriefing sessions at the end of each set. The 2008 CSR is in full swing with the first half completed and a success. Nearly 80 child consumers were reviewed and CAN was pleased to have coordinated all of these reviews, beginning with obtaining consents from parents and guardians to scheduling the review dates for the consumers, families, schools, and core service agencies (CSAs). CAN is now working on the nearly 90 adult consumer reviews that will take place in June and then finish the CSR process for this year.

CAN has expanded its outreach and rights training. We have been to multiple agencies to inform staff and consumers about out work and about various rights around advocacy. Housing and money are always the two largest issues that people bring up. Some of our large consumer audiences have attended outreach events that are a chance to target different groups of consumer audiences: women, children and families, homeless, and so forth. We have approached women's shelters, child agencies, and religious-oriented groups. CAN is training regularly at community agencies.

If you or anyone you know needs help or needs to talk about recovery, rights, dealing with grievances or concerns about treatment, call CAN at 202-842-0001 or e-mail dlewis@can-dc.org. CAN's mission is to empower mental health consumers and their families by promoting recovery and self-advocacy. We are a vehicle for people to have their voices heard at the individual and systems levels. We look forward to our continued collaboration with all of you in the community to improve services and open doors for consumers in recovery.

WE WANT YOU... TO CONTRIBUTE TO CAPITAL CONNECTIONS

The *Capital Connections* newsletter belongs to all people in the DC Metro area who care about human rights, recovery and mental health. We welcome contributions, especially from DC consumer/survivors, and story ideas about the issues that matter to you. We would love to receive:

Poetry Editorials/Op-ed Interviews Stories of recovery
Events and conferences of interest to DC consumers and their allies

Please submit all story ideas or articles to Leah Harris, Editor, by the 18th of each month for publication the following month.

You can email them to consumerleadershipforum@gmail.com or send them via regular mail to:

CLF Newsletter c/o Dorothy Adams, 1023 FAIRMONT STREET, NW #101, WASHINGTON, DC 20001

Consumer Leadership Forum



Our Vision



1. We seek an end to our isolation and we refuse to have our existence limited;
2. We seek a community that looks after the health and well-being of each individual, that respects the choices we make about our lives and our care;
3. We seek an improved system of crisis care and continuous care, where holistic healing, progress, and recovery are the key components. We need services that are individualized and self-directed as well as community supports such as consumer-driven respite and wellness centers;
4. We seek to engage with one another and to create a grassroots movement where we can support one another and keep our morale high. To forge our own identity as individuals and as a movement, separate and distinct from the provider community, but working in partnership with those who support use;
5. We seek a system that is driven by the needs, choices, and voices of consumers, not large pharmaceutical companies, providers and others in positions of power;
6. We seek a system of natural supports, where we can recognize that it is ok to fail, to make mistakes, to test new ground for ourselves in all that we do and in safety move beyond the system;
7. We seek an end to homelessness among persons with mental illness, and the creation of a network of affordable housing;
8. We seek to support and encourage consumer-run businesses and enterprises and to foster job opportunities;
9. We seek a community that respects the diversity within our movement and protects our traditions through a culture of competency and understanding. We seek to support families, youth and individuals to prevent isolation from one another and to provide training and information so that our community is empowered to cope with the unique challenges we face;
10. We will seek support from communities that are willing to partner with us and respect our choices and goals.

If you come to help me, you are wasting your time. But if you have come because your liberation is bound with mine, then let us work together. - Lilla Watson, Aboriginal elder

May CLF Meeting

**Friday, May 2
12—3 pm
The McClendon Center
1313 New York Avenue, NW
Lunch will be provided.**



Ms. Eve Hill, Director of the Office of Disability Rights (ODR), will speak to the group about how the office can be of assistance to DC consumers and how consumers can support the ODR. The mission of the DC Office of Disability Rights (ODR) is to ensure that the programs, services, benefits, activities and facilities operated or funded by the District of Columbia are fully accessible to, and useable by people with disabilities. ODR is committed to inclusion, community-based services, and self-determination for people with disabilities.

OF INTEREST...

The National Alliance for the Mentally Ill (NAMI) DC is looking for consumers to speak about their recovery experience through their In Our Own Voice™ program. Training will be provided. Please call 202-546-0646 if you wish to be considered for this program. You will be contacted later on for an interview. NAMI DC is looking for consumers from a wide variety of experiences to be a part of this program including youth. In Our OWN VOICE is a national program that has been recognized for reducing stigma in communities. This will be the first time the program will be introduced in Washington DC.

Requirements?

You must be willing to go out and speak openly about your experience as a person with a mental illness.

Attend a 2 day training over a weekend.

Also agree to be available to speak 2 times during the next year once trained.

Call 202-546-0646 with your contact information.

UPCOMING EVENTS/ MEETINGS

Get involved with the CLF!

**Unless otherwise specified, all meetings
take place at the McClendon Center
1313 New York Avenue, NW
For more information, call 202-609-4751**

**May 6, 12—1:30 pm
Outreach meeting**

**May 8, 12—1:30 pm
Peer Support meeting**

**May 13, 12-3 pm
Crisis Care Meeting**

**May 15, 12-1:30 pm
Housing Meeting**

Consumer Leadership Forum

c/o Dorothy Adams
Co-Executive Director
1023 FAIRMONT STREET, NW #101
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Visit us on the web at www.clfofdc.org



Consumers Uniting for Freedom and Choice

Taskforces Under the Consumer Leadership Forum

**If you're not on one – you should be –
Great things are happening!**

May 6, 12—1:30 pm
Outreach

May 8, 12—1:30 pm
Peer Support

May 13, 12-3 pm
Crisis Care

May 15, 12-1:30 pm
Housing

Consumer Leadership Forum

Monthly meeting – 1st Friday of each month.
12-3 pm at the McClendon Center
1313 New York Avenue, NW



You're only
given a little
spark of
madness. You
mustn't lose it.

– Robin Williams