



Capital Connection

A PUBLICATION OF THE CONSUMER LEADERSHIP FORUM

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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.

DC Consumers Attend Alternatives Conference

By Leah Harris

For too long, the mental health system has assumed a stance that recovery is rarely possible and that mental health consumers lack insight into their own condition. Transformation to a consumer-driven, recovery-oriented system requires a real paradigm shift on the part of professionals, who have often assumed a paternalistic, custodial role over their clients, and consumers, who have become overly dependent on professionals to “fix” them or solve all their problems for them.

Alternatives is an annual conference funded by the Center for Mental Health Services and organized by a rotating group of consumer-run organizations. Over 800 consumers and their allies were in attendance from all across the United States. The workshops represented an exciting and creative outpouring of promising practices developed by consumers and allies that support recovery, hope, and healing. At the heart of almost all of these practices is a perspective that embraces and promotes wellness rather than focusing on illness. This wellness perspective promotes taking responsibility for one’s own health and well-being, and looking at the importance of physical as well as mental health. One of the emerging needs is for more wellness-based programs.

One of the most exciting practices I encountered was the one presented by Dr. Pat Deegan -- the Common Ground Center, a peer run decision support center within a psychiatric medication clinic. The software program associated with the system helps consumers to take charge of their recovery and to work with their doctors as partners by developing a “Common Ground Report,” which they take to their doctor before each appointment. In this way, the doctors have critical background information they need at the start of the appointment, which leaves more time for the doctor and consumer to make shared decisions about what it is and isn’t working in treatment. The guiding philosophy of the program is that when a patient gets together with his or her doctor, there are not one but *two* experts in the room. Compliance isn’t enough — we as consumers are the ones who know best how a particular treatment is affecting us. What was most revolutionary is the concept she introduced of “it’s not what you take, it’s what you do,” which figures recovery as an active process of wellness. The program uses the idea of “personal medicine” to help people to develop a list of wellness tools. Some of the affirmations adopted by the consumers in the program include: “I will live my life, not my diagnosis” and “My dreams are the stars that guide my journey of recovery.” The program encourages consumers to develop what are called “Power Statements,” or a statement of the motivation that drives the consumer to recover. The program also involves hiring peer specialists to help consumers with using the software and thinking through their wellness plans, which also fulfills the goal of involving more consumers in providing services. It is my hope that this excellent program will (con’t on p. 2)



This year’s Alternatives was held from October 10-14 in St. Louis, MO

DC Consumers Attend Alternatives 2007

be adopted at a variety of treatment settings nationwide.

Several other promising practices presented at Alternatives, such as the Trauma Knowledge Utilization Project, look at the importance of trauma-informed services – an approach that assumes that people with mental health diagnoses have had some experience of trauma in their lives, and works to avoid any type of treatment which might serve to re-traumatize people. In addition, at many sessions people brought up the importance of supported employment that allows people to pursue their passions in life – such as entrepreneurship. Another clearly emerging need is to involve more youth in the consumer movement – the Alternatives attendees were largely over 40 years of age. There was only one teenager in attendance at the conference, who complained about the lack of young people in attendance.

Other practices presented at the conference focused on holistic healing, such as the importance of regularly connecting with nature to promote mental health and well being. Finally, a range of practices serve to help consumers connect with their creativity and spirituality, such as the Sacred Circle Dance, collage and recovery, and creative writing. I led a workshop on mindfulness as a tool for mental health recovery, which was very well attended. It was a pleasure to share with people across the country how mindfulness meditation has helped me in my recovery. I also presented a workshop on spoken word performance tips, and it was a great deal of fun to “kick it on the mic” with my fellow consumer poets.

Terry Cline, Ph.D., SAMSHA Administrator, gave a very exciting keynote speech in which he announced that SAMSHA and CMHS will be moving from a behavioral health to a public health approach that focuses on preventative health care rather than “crisis management.” I wholly support such a shift. It is time that the mental health care system focuses on prevention and wellness, including the importance of physical health to overall mental health. A true wellness approach would look at each person holistically and work with that individual to help them take responsibility for their health – mind, body, and spirit. We also need to look at the political and economic context of how people live — how the stress of living in poverty and without adequate housing affects peoples’ physical and mental health.

One of the DC attendees, Charlesette “Cha Cha” Ransom, had this to say about her experience of attending Alternatives for the first time:

“In my opinion it was very informative and very enlightening. I learned a lot and I shared a lot with other people. Attending the conference helped me to confirm to myself that I want to become a peer specialist because I care about people who cannot stand up for themselves, who are afraid to stand up for themselves. I do it voluntarily. I met a lot of friends at the conference and they gave me a lot of vital information. I made important connections who helped me find out about local resources for continuing education. The experience of attending Alternatives is like none other, and I encourage other consumers to attend next year. I was surprised to know that there were so many people who had mental illness that hold high positions. That encourages me, so it might encourage others that they can be whatever they want to be. I am going to be a certified peer specialist. You, too, can be whatever you want to be.”

Dorothy Adams had this to say about her experience of attending the conference:

“It was a very positive experience. It was my first time, and I really learned a lot, about things like business and grant-writing, etc. What really stood out for me, though, was when one speaker was talking about how people have a tendency to stay in the house and think things are going to get better just by taking medication and seeing their therapist. When you are feeling bad, the best thing to do is to get out of the house, rather than to just depend only on medication and therapy. People need to get out of their environment and move around and rejoin society in order to feel better. That one insight made a huge difference for me.”

Please do include CLF member Loreen Jackson in your prayers. She fell ill at Alternatives, and we wish her a speedy recovery.



CLF News



Paolo del Vecchio, MSW,
Associate Director of Consumer Affairs at the Center for Mental Health Services (CMHS)

By Dorothy Adams and Denise McNeal

October Meeting Highlights:

Paolo del Vecchio, MSW, Associate Director of Consumer affairs at the Center for Mental Health Services, was the featured speaker at the October CLF meeting. He said, "It's a beautiful thing that you all get together to do what you do. Over the past 12 years of hearing our stories, it's a great way to frame what works and how to change." He talked about his own story of recovery. His emotional issues began in elementary school, where he felt that he was different, out of the norm, and had to see a counselor. He described facing stigma attached to mental illness growing up as a young person in Philadelphia. Like many of us, he turned to alcohol and drugs to cope, and eventually became suicidal. His road to recovery began when he attended a work-study program. After 7 years, he decided to work for change from the inside. He cites his family as a big part of his support and recovery, as well as medication, exercise, and a holistic approach to wellness. Reading from a handout he provided, he said, "Only we can direct our own lives with the special decisions, looking at pros and cons of treatment options. Your voice, your choice."

Mr. del Vecchio also talked about recent CMHS initiatives such as the national summit meeting, and the wellness institute. He reminded us that recovery is not a step by step approach. Recovery is possible. Illness is learned. He directed people to the SAMSHA website for further information, handouts and books on consumer/survivor issues: 1-800-789-2697; www.samhsa.gov

Mr. Samuel Awosika invited consumers to participate in the Run for Mental Health sponsored by the DC Community Services Agency on Oct. 13 at Carter Barron. Several CLF members volunteered to help and had a great time.

CLF News

The CLF is recipient of a mini-grant to help organize a teach-in and conference about transformation of the DC Metro Area Mental Health in 2008, along with several other consumer-run organizations. Stay tuned for more details next year!

We also have made a connection with the Capitol Food Bank so that we can provide consumers with food as part of our outreach efforts.

Denise McNeal, Tracy Leak, Michael Sterling, and Dorothy Adams, will be attending the conference of the National Association on Rights Protection and Advocacy (NARPA) in Los Angeles from Nov. 11-14.

Outreach Update

We went to Miriam's Kitchen and connected with some people there. Dorothy participated on a meeting at the DC CSA and did a presentation about the work of the CLF there. We presented ideas about workshops and trainings for consumers for the new year. We want to offer specific trainings on leadership, etc. and certificates to go along with it.

CAN Corner

The weather is still warm but autumn has come!

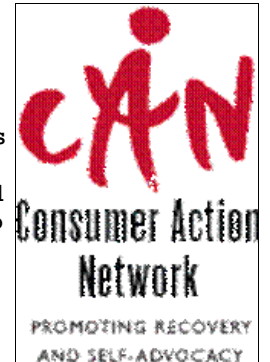
The annual Community Services Review (CSR) is coming up again soon. It seems we just finished working on the last one earlier this year! This program is important for DMH and is decreed by the Dixon Court Monitor (Denny Jones). We will be coordinating again for 2008 and will be setting up more reviews this coming year than for 2007. Reviewers have comprised people of various professional backgrounds in mental health. We are happy that CAN continues to play an integral part of the CSR's coordination and review process. Finally, we encourage anyone selected who wants to participate in the review process to contact us or DMH.

On October 30, we will be meeting with a representative, Esther Dickerson, from the Social Security Administration to learn more about the policies and programs around Supplemental Security Income (SSI) and Social Security Disability Income (SSDI). This will be very informative for consumers we serve. The more we can arm ourselves with the facts around benefits for consumers, the more consumers can advocate for themselves.

We wanted to announce an event which may have occurred by the time this issue *Capital Connection* comes out but something which may be of help to all for future purposes. This is the Joint Utility Discount Day (JUDD), which is being held at the Washington Convention Center on October 31. This is sponsored by the District of Columbia Department of Energy and its Low Income Home Energy Assistance Program (LIHEAP). The program covers gas, water, electricity and phone and will have representatives from PEPCO, Washington Gas, WASA and Verizon. We have referred several of our clients to this event and encourage anyone to call the Department of Energy for more details.

CAN has continued with its outreach events at various agencies in the area including Washington Hospital Center at Trinity Square, McClendon Center, Anchor Mental Health, and the Community Council for the Homeless at Friendship Place.

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.



Beatniks' Corner

By Peter R. "Beatnik Pete" Warner

See the Beatniks' Web site this month for after-dinner speakers at www.bethesdabeatniks.org--we're having some last-minute changes.

Hats off to Dr. Bob Litman, Medical Director of CBH Health and a tremendous fan of the dinner club and "Newz and Viewz U Can Ze" magazine, for springing for a whopping \$3,000.00 audio recording rig for the Beatniks and for his company's use. Now, we'll be able to make professional-caliber recordings of poetry and music events, and quickly post them to our Web site along with digital photos. We need more friends in high places like generous Dr. Bob!!

Speaking of recording, the Beatniks are planning a large scale music/poetry/visual arts show/post-holiday party to take place at Alfio's on Saturday night, January 3rd, 2008. Our first large-scale poetry event, which took place at Alfio's last April, featured musical accompaniment by over ten pro musicians, and drew rave reviews from all concerned. We're planning an even bigger and better event for January 3rd...ALL BUDDING CONSUMER/POETS: PHONE PETE PROMPTLY AT (240)449-5988 FOR AN UPDATE ON POETRY/MUSIC REHEARSAL DATES AND TIMES. WE'LL HAVE FOUR TO FIVE HOURS OF PARTY TIME TO FILL, SO THE MORE POETS, THE MERRIER!!



Promoting Wellness at the Individual Level

Excerpt from a talk by Lauren Spiro, Director of Public Policy, the National Coalition of Mental Health Consumer/Survivor Organizations (www.ncmhcsso.org)

Presented at the Substance Abuse Mental Health Services Administration/Center for Mental Health Services, National Wellness Summit to Reduce Co-morbidity and Early Mortality of People with Mental Illness

Rockville, Maryland, September 17-18, 2007

Each individual's life depends on the society they live in and the services and supports that are available to them. To frame the co-morbidity and early mortality rate as simply a medical issue is not only inaccurate but an injustice to everyone. The problem of co-morbidity and early mortality is an indicator of a broken system within a broken society. The coalition was formed because the survival of our brothers and sisters is being threatened by the oppressive policies, services and attitudes of the system and of society. We die young because we have no hope. We die young because our dreams have been crushed. We die young because our voice is neither heard nor understood. We die young because many of us live in poverty, and some of us live on the streets. We die young because our physical health needs are routinely ignored, often because any problems we have are attributed to our mental illnesses.

To promote my wellness, broad-based systems changes are needed. I need to be a full member of the community and given complete respect for my rights

I need to be in the center of decisions that affect my life. I need people who care for me, respect and believe in me. I need hope, a job, a home and an education. I need to be in charge of my life. I need the same opportunities for life, liberty and the pursuit of happiness that every individual should have. I need an enlightened society that understands that people recover and that every person who comes in contact with a person on their recovery journey can assist in that journey by being hopeful.

In order for my basic needs to be met, the definition of disability needs to focus not on fixing me or adjusting to my deficits but rather on providing services, supports, and treatment designed to assist me to attain or maintain independence and to promote wellness and community integration.

I need health insurance that is independent of my disability status and my employment status.

I need a transformed mental health system that is consumer-driven.

I need consumer/survivors to be proactively engaged in the following five areas: healthcare and mental health planning, policy formulation, training, service delivery, and evaluation.

I need control of my healthcare dollars through self-directed care, which allows public funding to follow the person rather than the provider. This way I can design a personal road to recovery by making decisions to the greatest extent possible with respect to service provision and spending my allotted dollars (e.g., www.flfdc.org, Florida Self-Directed Care). I need personal care assistants, which are also covered under a Medicaid waiver, to help with my basic needs such as getting groceries and living on a budget.

I need changes within the mental health system such as alternatives to hospitalization, peer-run crisis respite (e.g., www.charityadvantage.com/people/RoseHouse.asp), and wraparound community-based services that maintain a client-directed approach.

I need accessible, culturally appropriate, flexible and affordable services that treat me with dignity, respect my rights, and support my self-defined needs. This range of services must include consumer-run and -operated programs, such as peer support, advocacy, self-help, and recovery education services (including Wellness Recovery Action Planning and crisis planning), along with consumer-driven, recovery-oriented professional services. These services and supports help me build internal and external resources and link me to a recovery community. These services need to be available in school mental health programs, programs for older adults with mental health problems, and institutions (such as correctional facilities, nursing homes, and psychiatric hospitals).

I need a safe, affordable, accessible place to live. I need to not be warehoused in institutions, including jails and nursing homes...

(For text of the entire talk, please see www.ncmhcsso.org)

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

Next Consumer Leadership Forum Meeting

Friday, December 7, 12 – 3 pm

**The McClendon Center
1313 New York Avenue, NW
Lunch will be provided.**

Dialogue on the DC Community Service Agency (DC CSA)

Ms. Juanita Price, CEO of the DC CSA will be attending our meeting to have a dialogue with consumers about the DC CSA. Please bring your suggestions and ideas for how to enter into a creative consumer-provider partnership for positive change!

ESSAY/POETRY CONTEST: WHAT DOES DIGNITY MEAN TO YOU?

DEADLINE: November 12, 2007

First prizes: \$50.00 voucher from Giant

Two runner-up prizes of \$25 each.

Webster's Dictionary defines Dignity as: - 1. the quality or state of being worthy, honored, or esteemed. 2.a. high rank, office, or position, b. a legal title of nobility or honor. 3. formal reserve of language or manner.

What does dignity mean to you?

Please submit an essay or a poem answering this question in less than 300 words.

Only entries that are legible will be considered — can be typed or handwritten. Must have name, address, telephone number on the entries, pages must be numbered and must be the original work of the person submitting the essay or poem.

Please mail entries to:

The Consumer Leadership Forum
C/O Dorothy Adams
1023 FAIRMONT STREET, NW #101
WASHINGTON, DC 20001

**Or email as an attachment to:
Dorothyadams@clfofdc.org**

Consumer Leadership Forum

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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!**

Housing	<u>Regular meeting time:</u> 12:00 pm—2:00 pm 3 rd Thursday of each month
Crisis-Care	<u>Regular meeting time:</u> To Be Determined
Peer-Specialist	<u>Regular meeting time:</u> To be determined
St. Elizabeths	<u>Regular meeting time:</u> To be determined
Consumer Leadership Forum	<u>Monthly meeting</u> – 1 st 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