

**Speaking Up and  
Speaking Out for  
Mental Health  
in the  
Washington, DC  
Metropolitan  
Region:**

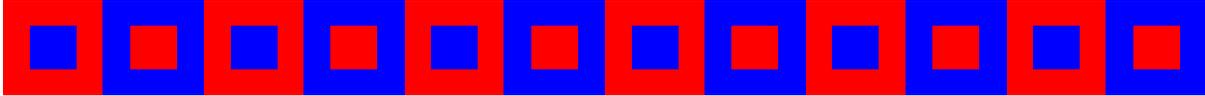
**A Call to Action**



**National Coalition  
of Mental Health  
Consumer/  
Survivor  
Organizations**

**December 2008**

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Consumer Health Foundation*



## **Executive Summary**

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The National Coalition of Mental Health Consumer/Survivor Organizations (NCMHCSO) was created to ensure that consumer/survivors have a major voice in the development and implementation of health care, mental health, and social policies at the state and national levels, empowering people to recover and lead a full life in the community. To this end, the NCMHCSO, funded by the Consumer Health Foundation, held a day-long “Teach-in and Speak-out for Mental Health in the Washington, DC Metropolitan Region” on September 16, 2008.

The Teach-in and Speak-out brought together 150 consumer/survivors, advocates, providers, and administrators from Washington, DC, Maryland, and Virginia who shared knowledge, resources, information, ideas and their vision of how to transform the mental health system to consumer-driven, recovery-oriented system of care. Groups represented included The Recovery Group, the Ida Mae Campbell Wellness and Recovery Center, University Legal Services, the Silver Spring Drop-in Center, Capital Area ADAPT, Disabled Individuals for Real Empowerment and Community (DIRECT) Action, and many others.

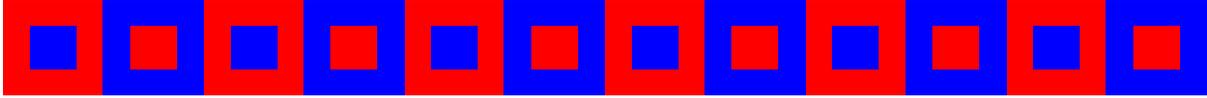
Although the mental health recovery movement has made great strides in overcoming oppressive policies and practices and in changing perceptions about mental health recovery, the voices of people with mental health problems continue in large part to be unheard. At the Teach-in and Speak-out, the collective experience and passion of people who rarely find themselves in the same room resulted in a powerful cross-fertilization of ideas. The day resulted in an outcome of 6 goals with recommendations to transform mental health care in the DC Metropolitan region:

- 1. Build on existing efforts in order to strengthen a District-wide consumer coalition.**
- 2. Increase consumer/survivor participation in systems change via the formation of community-wide coalitions and collaboration with other agencies/groups.**
- 3. Advocate for a shift from institutional to community based care.**
- 4. Increase education and training opportunities for consumer/survivors, families and other stakeholders.**
- 5. Promote awareness that homeless and housing are health care issues and that a safe and comfortable place to live is necessary for recovery.**
- 6. Reform the criminal justice system to promote mental and physical health.**

**“If you don’t have consumers involved, it’s just someone telling us what they think we need— as opposed to us being part of planning the change and then actually receiving the services we need.” —Speak out participant**

**“It was inspiring to see so many people giving their voices towards transforming not only mental health services but society itself.”  
— Speak out participant**

**“The gathering of so many diverse stakeholders and allowing us to speak out was a powerful process ... together we create a force to be reckoned with.”  
— Speak out participant**



## What we did

The conference planning team for the Teach-in and Speak-out was comprised of consumers from state-wide consumer-run organizations. NCMHCSO brought together Consumer Action Network (CAN) and the Consumer Leadership Forum (CLF) from the District of Columbia; On Our Own of Maryland; and the Virginia Organization of Consumers Asserting Leadership (VOCAL). The planning committee was also supported by the McClendon Center, the Judge David L. Bazelon Center for Mental Health Law, and the DC Department of Mental Health's Office of Consumer and Family Affairs.

The day started with a teach in; we heard from visionary people representing Washington DC, Maryland and Virginia, culminating with a national perspective - sharing their view of the landscape of today and their vision of creating a system that met the real needs of real people. The goal was to go beyond a critique of the current system and create a vision of tomorrow.

After the morning teach-in, conference participants organized themselves into speak-out groups based on their chosen topics of interest. For the remainder of the conference these groups were tasked with coming up with solutions and recommendations in their respective areas to transform mental healthcare in the Washington DC Metropolitan Region: multi-cultural/cultural competency, recovery education, trauma, criminal justice, homelessness and housing, gay, lesbian, bisexual and transgendered (GLBT) issues; Cross-disability organizing, Spirituality and motivation, and Economic empowerment.

## What we Heard: The Teach-In

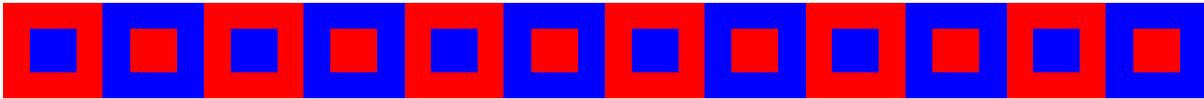
We heard from a diverse panel of speakers representing consumers and advocates from Washington, DC, Maryland, and Virginia. **Vivi Smith** of the Department of Mental Health's (DMH) Office of Consumer and Family Affairs talked about the new initiatives at DMH, including an internship/supported employment program and the Ida Mae Campbell Wellness and Recovery Center. **Iris Gonzales**, Associate at Covington and Burling, LLC, gave an overview of the District's compliance with the



*Dixon* mandate, a court-ordered plan designed to move the mental health system from a hospital-based system to a community-based mental health system. **Michael Sterling**, Advocate with the Consumer Action Network (CAN), spoke on "Advocacy in Relation to Mental Health," and outlined CAN's efforts in promoting advocacy and education on consumer rights and recovery. **Nathaniel Stanley** of the McClendon Center spoke about the principles of the Wellness and Recovery Action Plan (WRAP) and how these are so essential to both individual recovery and consumer-driven mental health systems. **Clarissa Netter**, Director of the Office of Consumer Affairs at

the Mental Hygiene Administration in Maryland spoke on "Recovery with Responsibility," and praised the efforts of the District of Columbia to promote recovery with responsibility in Washington, DC. She also described Maryland's efforts at recovery with responsibility, including the creation of a diverse coalition of consumer leaders who work as advocates to "galvanize the consumer's voice at the forefront of policy, decision-making and implementation that leads to effective change in the mental health system, providing hope for every consumer." **Ann Benner**, Program Director of the VOCAL Network, expressed Virginia's support for transformation in the DC Metropolitan Region and described the work of VOCAL, including a "Network" to help build multimedia communications bridges to connect consumers across Virginia for advocacy, and the Recovery, Education and Creative Healing (REACH) program that trains WRAP facilitators. **Dan Fisher** of the NCMHCSO spoke on the importance of consumers and their allies learning to navigate Medicaid to secure funding for consumer-driven, recovery-oriented programs and learning how to influence decision-makers to make change. He used the acronym "STEP" to encourage consumers to get involved in the following areas: "Services and Supports," "Training and Education," "Evaluation," and "Planning and Policy." **Claudia Brown** of the Center for Medicaid Services spoke about how to work with

**"Numbers are important. When you have a collective group of voices saying the same thing at the same time to the right individual, that is a powerful message." --Claudia Brown**



Medicaid to move to a more recovery-based approach and to make sure that funding is responsive to the recovery and wellness agenda. She encouraged consumers to bring their advocacy groups together to lobby for change and to find people who can bridge the Medicaid and mental health “languages.” **Steve Baron**, Director of the DC Department of Mental Health (DMH), gave a background of the District and noted that there is a long history of consumer activism and advocacy. He recognized the challenges facing public mental health systems in providing individualized services, and encouraged consumers to push for a system that focuses on individualized consumer needs.



### The Speak-Out

The speak-out groups met for over two hours, which gave participants an ample opportunity to share their opinions about the identified problems and their recommendations for change. What emerged was a broad picture of the challenges facing those who wish to reform the mental health system in the District of Columbia.

### Multicultural/Cultural Competence

From the multicultural group, we heard about the ever-present language barrier problem and how there are not enough staff in certain mental health settings to communicate with culturally diverse people. This necessitates work-

force development and a strategy to secure qualified multicultural and linguistically competent professionals

### Trauma

The trauma group spoke about the lack of trauma informed care in mental health settings. One basic element of trauma-informed care is the need to eliminate seclusion and restraint and other coercive practices. One speak-out participant recommended more of a focus on trauma support services for men. The group as a whole agreed that when services are consumer-driven, they are inherently trauma-informed, as mental health consumers tend to have an inherent understanding of the connections between trauma and mental health issues.

### Criminal Justice

The criminal justice group identified several key issues. One problem is when mental health crises become criminalized by law enforcement because police are not adequately trained to recognize and address mental health issues. Intense police training along the Crisis Intervention Team model is a possible solution. The speak-out group also noted the lack of mental health services available in the jails: people tend to cycle in and out and never receive services. Mental health treatment requests are sometimes denied by prison staff, and crises are responded to punitively. One recommendation on this issue is for all consumers to be connected with a community-based mental health core service agency before release or transfer to federal prison so that mental health treatment can be coordinated prior to their return home.

There is also a need for correctional staff to be trained on

recovery concepts. A third identified problem was the lack of supports as people re-enter the community ; they are often completely overwhelmed and receive little to no assistance from probation or parole officers on how to connect with community programs.

There are some transitional programs that assist people but problems are rampant due, in part to, a lack of accountability and monitoring by the agencies that contract them. Some recommendations for addressing transition problems were for advocates to provide education/motivation to ex-offender peers to help with goal-setting and life skills; and to advocate for quality individualized treatment for people in transition.

### Homelessness and Housing

The homelessness and housing speak-out group identified the primary issue as lack of affordable housing, and not enough oversight on housing conditions. A related issue is that those who do receive housing, some after years of homelessness, do not receive enough individualized, consumer-driven supports to assist them in the transition. The group recommended more education and training for housed people on how to sustain their homes and live in the community.

*“It’s not about money. It’s about whether or not society is willing to see people living in the street -- especially people with mental health issues.”*  
— Speak out participant

### Gay, Lesbian, Bisexual, Transgender (GLBT) issues

The GLBT group identified many commonalities with mental health

consumers overall, including stigma and a lack of understanding in community about GLBT issues. There is a lack of services geared to GLBT people, and an inability to access services in some cases. There are pockets of providers who work effectively with GLBT consumers, but overall there is a lack of coordination among service providers and an added layer of misunderstanding and discrimination as evidenced by individuals constantly being referred from agency to agency, thus falling

***“We need quality services for GLBT consumers, not just a handshake and pills.”***

***--Speak out participant***

through the system cracks. Some of the recommendations included more education about GLBT issues within the broader mental health community, and more accountability and responsiveness from service providers.

### **Spirituality & Motivation**

The spirituality and motivation group agreed that spirituality was not adequately taken into consideration by providers as a factor in mental health recovery. Spirituality was not discussed in terms of religion but rather as a holistic approach to health and recovery. Some of the group’s recommendations were to expand the use of wellness centers as places

***“We defined [spirituality] in terms of your own inner essence, sense of self, something that creates your own awareness; connectedness with community and your people and with your greatest innate potential.”***  
***--Speak out participant***

where people could go to safely explore spirituality. Another suggestion was to utilize life coaches (e.g., trained family members, fellow peers) to provide mentoring in spirituality. Additionally, there is a need for consumer speakers’ bureaus (Toastmasters’ model) for public speaking training and sharing stories of recovery and spirituality.

### **Cross-Disability**

Barriers identified by the cross-disability speak-out group included the fragmentation of agencies, and pervasive communication problems between agencies and organizations. Responsibilities are passed from organization to organization with little follow up or accountability. A recommendation from the group was for the DC Office of Disability Rights to establish a multicultural cross disability committee composed of people with disabilities, advocates, families, and any other interested parties.

This coalition could fulfill many functions, including Cross-training and education (such as rights trainings for individuals, including access to interpreter services for deaf people); holding a service fair where all of the departments who work with disabilities would provide “one-stop shopping” on services for people with disabilities; and the creation of an online resource directory for people with disabilities. The group also saw the need to improve interagency coordination and collaboration amongst mental health administration and providers with other disability administrators and providers. Advocates need to encourage different agencies to collaborate more. Providers also need to be aware of new and existing policies pertaining to disability issues, and grantees should be held account-



able for providing the services they have promised to provide.

### **Economic Empowerment**

The economic empowerment group identified persistent poverty as a major barrier to recovery. Consumers are afraid to lose their Social Security health benefits if they go to work and earn too much to qualify for benefits. Some suggestions for economic empowerment included: education and training for providers and consumers on programs available to them, such as Individual Development Accounts and the Plan for Achieving Self Sufficiency (PASS) through

***“It’s not just about money and self-interest, it’s about empowering people to pull themselves out of poverty.”***  
***—Speak out participant***

Social Security. There is a great need for financial literacy training among consumers, which could include debt counseling and budgeting programs. Additionally, consumers could benefit from better vocational rehabilitation programs which included programming on self-employment and business skill development. Finally, the group recommended better access to benefits planning, which would include information about how SSDI/SSI works, how people can access Veterans Administration (VA) benefits, as well as food stamps, medi-

cal assistance, and other types of assistance.

### **Recovery Education/ Peer Support**

The recovery education/peer support group identified the major problem as lack of coordination between the many positive efforts being made by many individuals and organizations in the District. The group saw a need for a consumer leadership coalition to bring disparate efforts/projects together. The coalition could also harness consumer voices/political will to bring the Wellness Recovery Action Plan (WRAP), peer education, and a whole host of programs that would support consumers towards recovery. There is a need to speak out with a unified voice for the peer-run services that are essential to transformation to a recovery-based mental health system.

### **Medicaid**

One of the biggest issues identified at the speak-out was the lack of understanding about how Medicaid dollars could be leveraged to support recovery-oriented programs. There was an in-depth discussion on the need for a “Medicaid 101” training for all stakeholders (consumers, advocates, providers, administration, family members) to learn about available services and how the funding works. A related recommendation was for a comprehensive Medicaid advocacy-focused coalition of providers and other



advocates to identify common issues, form recommendations, and to bring about transformation to the District’s mental health care system.

## **Goals and Recommendations for Regional Action and Next Steps**

Many of the recommendations put forth by the various speak out groups were consolidated into six goals and recommendations for action.

### **Goal 1. Build on existing efforts in order to strengthen a District-wide consumer coalition.**

The purpose of this coalition would be to ensure that consumer voices are leading the way to transformation of the Washington, DC mental health system to a consumer and family-driven system of care.

Bring together a steering committee of core consumer leaders in Washington, DC. From this steering committee expand to a larger core of consumer leaders for ongoing dialogue and community-building to carry out the following five goals.

### **Goal 2. Increase consumer-survivor participation in systems change via the formation of community-wide coalitions and collaboration with other agencies/groups.**

Consumers/survivors should have a seat at the table in existing cross disability and criminal justice system interagency coalitions.

Consumer/survivors should have a central voice in planning, evaluation, and along the continuum of systems transformation.

### **Goal 3. Advocate for a shift from institutional to community based care.**

Advocate for increased peer sup-

port resources, including Medicaid changes to support consumer run services;

Promote community-based alternatives to hospitals and institutions;

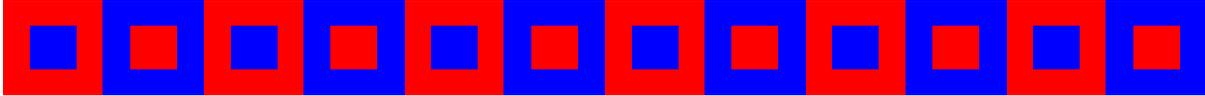
Promote life skills and sustainable living through life skills coaches, training in social security benefits as they apply to work, and other strategies for economic empowerment and poverty reduction.

### **Goal 4. Increase education and training opportunities for consumer/survivors, families and other stakeholders.**

Whenever possible, under the principles of consumer-driven systems, consumers should provide the trainings to others – whether to fellow consumers, family members, providers, or policymakers. All trainings should be delivered in culturally competent manner, including sensitivity to gender/sexual orientation, cross disability issues and other related issues to ensure access to information, resources and opportunities.

Speak-out participants identified the following areas in which training is most needed:

- Workforce development, Trauma informed care, Recovery education, spirituality, speakers’ bureaus;
- Cross-education/training: Crisis intervention training/ other police training;
- Trainings for family members to be greater allies to their consumer/survivor relatives and to help them in transitions from jail/hospital back into the community;
- “Medicaid 101” training in how to make the most of Social



Security and aspects that are advantageous to consumer/survivors ; and

- Trainings in economic empowerment, such as self-employment/entrepreneurship, financial literacy/money management.

**Goal 5. Homeless and housing ARE health care issues. Part of recovery is the stability of having a safe and comfortable place to live.**

End homelessness in the District of Columbia;

Increase affordable housing stock in safe areas of the city; and

Provide training and support for people in order to assist them with the life skills needed to maintain their housing.

**Goal 6: Reform the criminal justice system to promote mental and physical health.**

Mental health care should be readily available to all people in prison, regardless of previous diagnosis;

Provide trainings for prison staff about mental health and recovery; and

Consumers should have a clear mental health care plan upon discharge from prison and increased support with the transition process.

As mentioned in Goal 4, family members should receive information and support to help their loved ones with the transition back into the community.

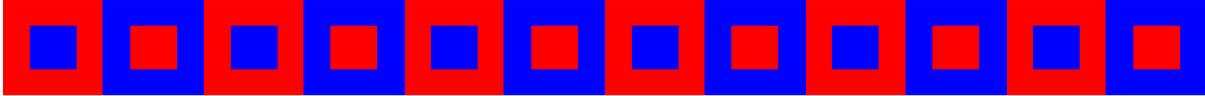


**Conclusion**

The disability rights movement rallies around the motto of "nothing about us, without us." Yet when it comes to people with mental health issues and psychiatric disabilities, this vision has not been realized, in large part due to the domination of the field by provider organizations, and the continuing underestimation by professionals of the capabilities of mental health consumers. Paradoxically, Washington, DC is where national mental health policy is set, yet it is home to some of the most horrendous abuses in the mental health system, as was noted in a recent Department of Justice report on conditions at St. Elizabeths Hospital. The District of Columbia, in particular, lags far behind their neighbors of Maryland and Virginia, and the rest of the nation when it comes to mental health consumer-driven services.

Consumer-led services are informed by the philosophy that those who have "been there" make the best helpers. The values of choice, empowerment, self-determination, freedom, hope, and recovery guide these services. This distinguishes them from the medical model of mental health, which values compliance over self-advocacy, and custodial care over active consumer engagement and involvement. In recent years, trends in the mental health system are increasingly supporting consumer-led and consumer-driven services, as they are known to be more effective and more efficient than many provider-favored interventions in promoting recovery, empowering people, and reducing recidivism. Transformation towards a recovery-based system would amount to no less than a revolution in mental health policy and mental health care. The combined passion and enthusiasm of all who participated in the Teach-in and Speak-out provides promise and hope that such a revolution is well within reach.





## Acknowledgments

### **PLANNING COMMITTEE**

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### **Consumer Health Foundation**

The mission of the Consumer Health Foundation is to improve the health status of Washington, DC area communities - particularly the most vulnerable members of these communities - and to support the activities that enable people to be more actively involved in their own health.

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