

Promoting Wellness on the Individual Level

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Administration/Center for Mental Health Services**

National Wellness Summit to Reduce Co-morbidity and Early Mortality of People with Mental Illness

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Good morning. I want to thank Paolo del Vecchio and the Center for Mental Health Services for inviting me to speak about promoting wellness on the individual level. My name is Lauren Spiro and I am the Director of Public Policy for the National Coalition of Mental Health Consumer/Survivor Organizations. Our coalition was formed last year. Currently our members include 27 statewide consumer-run organizations and the three national consumer-run technical assistance centers.

I grew up about 20 minutes from here in a middle-class neighborhood. I didn't have to worry about my next meal or a safe, decent place to live; I took those resources for granted. I don't take them for granted today; many people who need mental health services and supports don't have these basic resources.

Like so many of our stories, my story includes abuse, neglect and trauma. By the age of 16, I was in a mental institution. What I most needed was someone to talk with me, to listen to me, love me, respect me, and provide support so I could figure out who I was and find a meaningful place in the community. Instead, the services I received taught me about coercion, force, and control by others, which added layers of trauma and humiliation.

I was diagnosed with chronic schizophrenia. My family was told that I would neither recover nor have a meaningful life in the community; I would spend the rest of my life in mental institutions and I would always need psychiatric drugs.

Fortunately, the experts were wrong. I am the evidence that recovery happens. I have worked very hard to find wellness, and building a strong support network was key. I have had resources, supports, and people who loved me and believed in my ability to heal. I have come a long way from the time I was locked in a seclusion room at the age of 16.

I am not surprised that data show the significant impact trauma plays in the development of mental health problems. I used to blame myself for things that happened to me. I no longer do that. Learning to liberate myself from the damage that was done to me has been the greatest challenge of my life. This process of liberation – learning to be whole and healthy – has given me the greatest rewards I have ever known: love; a sense of meaning, purpose and belonging; and a lot more.

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.flcdc.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.

I need for everyone involved in my treatment and support to maintain a philosophy of hope that we can heal mind, body and spirit. I need you to believe that I am capable of living the life of my dreams.

I need service providers to understand my experience, including the complex effects of trauma and oppression, before settling too quickly on a diagnosis. A mutual understanding of these dynamics, and the impact they have had on my sense of self, will strengthen our healing relationship.

I need service providers to understand the difference between coercion and alliance and how to share power. Coercion destroys my sense of personhood and identity. Building a collaborative alliance is empowering.

I need education and access to self-initiated, non-pharmaceutical strategies to improve my physical, emotional, and spiritual wellness. These alternative approaches enhance my self-esteem and my sense of meaning, purpose and accomplishment. These approaches (such as yoga, homeopathic medication, vitamins, massage, acupuncture, etc.) need to be affordable.

I need to be in the center of medical decisions that directly impact my life. That means that I respect you, my psychiatrist, as an expert by training: you have knowledge of the scientific literature and clinical experience. And I expect you to respect me as an expert

by experience. I know how my body and my mind react in situations or with particular psychiatric medications. I need a relationship built on alliance, not on compliance. I need a collaborative relationship in which we share information and forge a partnership of equals, where we establish consensus on the problem, the goals, and the criteria for success. If I decide that the treatment is worse than the side effects, I need you to work with me to find medications and alternative healing methods that support my unique needs on my journey to wellness.

I need more opportunities for people who have been through the mental health system to train healthcare providers.

I need suicide prevention services, such as consumer-run warm-lines, to enhance peer support, build social networks and reduce crisis center use and hospitalization.

I need to contribute significantly to the community. To reclaim a valued social role, I need meaningful choices that give me the freedom to be in charge of my life.

I need a seat at the table where decisions are made about my life and the lives of my peers. When I speak, I need my voice not only to be heard but to be understood.

I need full disclosure so that I can make informed decisions based on complete and accurate information, so that I understand the consequences of my choices.

I need for my psychiatric advance directive to be honored and respected so that I may determine my treatment based on my values and preferences.

I need integrated, flexible care that is coordinated between mental health and primary healthcare providers, and to have everyone involved, including hospital emergency room staff, adopt a values-based, recovery-oriented approach.

I need diversion programs and prevention programs so that my mental health problems do not become criminal justice problems. When law enforcement does get involved, I need procedures that reduce and/or eliminate re-traumatization (for example, alternative transportation methods, minimizing use of handcuffs and shackles, etc.).

I need school-based, preventive services and supports that focus on building resiliency and wellness before I develop mental health problems.

Someone said that a journey of a thousand miles begins with a single step. Forming the coalition was one step. We need more coalitions at the state and national levels.

Consumer/survivors need to be central in transforming the system. Our voice must be heard. We are the ones dying. We are the ones that have the most at stake in fixing the system.

Lastly, I think the goal of this summit should not be to reduce co-morbidity and early mortality. The goal should be to eliminate it.

Thank you for listening.

References

Deegan, P.E., Drake, R.E., (2006). Shared Decision-Making and Medication Management in the Recovery Process, *Psychiatric Services*, 57(11), 1636-1639.

Schauer, C., Everett, A., and del Vecchio, P. (2007). Promoting the Values and Practice of Shared Decision-Making in Mental Health Care, *Psychiatric Rehabilitation Journal*, 31(1), 54-61.

Mental Health Consumer/Survivor Operated Resources

Crisis Respite Programs:

Our Place, 1663 East Main Street, Lancaster, OH 43130, Phone 740-654-0477, email
Executive Director: Patricia Waits pawaits@ohiopps.org

Rose House, Orange and Ulster Counties, NY, Phone 845-795-2346, Address 1612 Route
9W, Hilton, NY 12547; Mailing address PO Box 525, Marlboro, NY 12542,
<http://www.charityadvantage.com/people/RoseHouse.asp>

Stepping Stone Peer Support & Crisis Respite Center, 108 Pleasant Street, Claremont,
NH. 03743; 603-543-1388, Email stepping_stone@verizon.net,
www.Steppingstonenextstep.org

Sweetser Learning & Recovery Center, 174 Mere Point Road, Brunswick, Maine 04011;
(207)373-4273; Web site: www.sweetser.worldpath.net/peers.aspx

Youth Movement

Icarus Project, www.theicarusproject.net

Youth MOVE National, 9605 Medical Center Drive, Suite 280, Rockville, Md. 20850
Tyrus Curtis, Chair of the Board

Other

www.ncmhcsso.org

www.contac.org - For information on national and international organizations go to
www.contac.org/national.htm

www.mentalhealthpeer.com

www.mentalhealthrecovery.com

www.mhselfhelp.org – go to Consumer Directed Services Directory (CDS Directory)

www.patdeegan.com

www.power2u.org