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The Office of Consumer Affairs

focus

PROMOTING CONSUMER INCLUSION AND NETWORKING
SUMMER 2012

Success, Hopes, and Dreams 2012

The Statewide Behavioral Health Conference: Success Hopes and Dreams had a record breaking 450 people in attendance this year. This was a wonderful year full of workshops and unprecedented speakers. Keynotes included: Patricia Deegan, Laura Prescott, Paolo Del Vecchio, and Tom Lane. The Office of Consumer Affairs sponsored scholarships, a booth, a presentation on the Office of Consumer Affairs, and awards from the Conference Committee (see page 4). Pat Talbot and the Mental Health Association of Nebraska (Pat photographed to the left with Carol Cousins de Reyes) continues to coordinate and create a memorable learning and sharing opportunity for all.



(Below Left to Right: Annette Murrell and Scott Loder, Lincoln Regional Center Recovery Specialists, Scot Adams at a break-out session with Division of Children and Family Services, and Candy Kennedy, Director of the Federation of Families for Children's Mental Health.)





Patricia Deegan, Ph.D., is an activist in the disability rights movement. She is an adjunct professor at Dartmouth College School of Medicine and at Boston University, Sargent College of Health and Rehabilitation Sciences. She is the creator of CommonGround, a web application to support shared decision-making in psychopharmacology consultation.

“Why do we keep going?” asked **Pat Deegan**, keynote speaker at the second annual Success, Hopes and Dreams behavioral health conference held May 21-23 in Lincoln. The reason: a sense of hope. “Hope gathers us together today.”

When she was a 17-year-old senior in high school, Pat experienced a psychotic break. She began hearing voices and thought people were trying to hurt her. She was admitted to a mental hospital and diagnosed with schizophrenia. She was told it was like diabetes—she would have to take medications for it for the rest of her life.

Pat was advised to avoid stress and told not to return to high school. Her dream of being a coach was gone. The heavy medications she was on muffled her symptoms. There were still voices but she didn’t shout at them any longer. All she did was sit in front of a TV that wasn’t even on, smoking, drinking Coke, and staring into space. She was numb, couldn’t think at all, couldn’t feel. She slept a lot and didn’t see friends. She was basically disabled, not by her illness, but by the meds, not living at all, she said. The only thing she felt was despair.

She called this period her “handcaptivity,” meaning years of life lost in a netherworld.

She experienced profound hopelessness, believing she couldn’t get well. Life seemed devoid of purpose and meaning. The treatment system did not provide any hope—no pathways to a better life.

“We are not the problem, but part of the solution,” Pat said. “Recovery means changing our lives, not our biology.”

Those with psychiatric disorders can be responsible for their own recovery, she said. Refuse to succumb to despair. Start asking how to create hope.

“They need to stop asking what’s wrong with people and start asking how to develop a hope-filled environment.”

Pat got better at managing symptoms and took less medication. She could get up and around, exercise, meditate and pray. These activities had a cascading effect, leading to a stronger sense of self and personal

confidence.

Pat said she used her “personal medicine” to help her cope. Headphones and music helped drown out the voices. Other personal medicine:

Family/friends

Music, TV, movies

Exercise

Religion/faith

Personal philosophy

Hobbies and games

Reading

Meditation

“Personal medicine helps find the pathway to hope,” Pat said.

Pat still hears voices, but can manage them now. She doesn’t feel it’s a problem. It’s just part of her life.

She said that people should make this affirmation: I will pursue my goals today. Goals and dreams must guide the journey to recovery. You shouldn’t wait to get well, then pursue your goals. Resolve that “I will live my life, not my diagnosis. I am a person, not an illness.”

People with psychiatric disorders can make good choices, Pat said. Family, friends and providers should remain engaged, no matter what decisions are being made. People should be accorded the dignity of risk and the right to failure. They can grow from their mistakes to fulfill their human potential.

“Help hurts when a person can’t make their own decisions,” Pat said. “Choice is an affirmation of human dignity.”

Recovery is real, but it’s hard work. Medicine can help open the door, but it takes hope and courage to go over the threshold to a new life.

Those in the audience, she told attendees, are part of a conspiracy of hope.

By Marla Augustine



Laura Prescott is the founder of Sister Witness International, an organization that celebrates the lives and memorializes the deaths of women and girls that were formerly institutionalized. She told several heartbreaking stories that highlighted her theme of breaking the silence by sharing details of familial abuse, institutionalization, and living with a wheelchair at one point in her life. Today Laura leads **Sister Witness International** and is an avid skier.

She had several recommendations: 1) Create socially valued roles, ensuring visible leadership of people willing to disclose their experiences. 2) Decrease pathology and blame, stop asking what is wrong with you and ask what happened to you. 3) Ask people what safety means to them and listen closely. 4) Meet people where they're at— be creative and flexible so people can avoid being re-traumatized. 5) Support people in having a dream. 6) Support the dignity of risk, don't protect someone from things that will help them grow. 7) Believe recovery is possible for everyone, provide messages of hope. 8) Support each other in reclaiming power, telling our stories.



Paolo Del Vecchio is the acting director for the Center for Mental Health Services at the Substance Abuse and Mental Health Services Administration. He is the former deputy director of the Office of Consumer Affairs at the Center for Mental Health Services. Paolo share details of his own story growing up with an alcoholic father and with his mother being institutionalized for periods of time, as well as his own lived experience engaging mental health services. He also shared the family that he celebrates recovery with.

Paolo shared the SAMHSA definition of Recovery:

Recovery is a process of change whereby individuals work to improve their own health and wellness and to live a meaningful life in a community of their choice while striving to achieve their full potential.

Principles of Recovery

- **Person-driven;**
- **Occurs via many pathways;**
- **Is holistic;**
- **Is supported by peers;**
- **Is supported through relationships;**
- **Is culturally-based and influenced;**
- **Is supported by addressing trauma;**
- **Involves individual, family, and community strengths and responsibility;**
- **Is based on respect; and**
- **Emerges from hope.**



Lori Hack, Consumer and Family Representative with Nebraska Magellan

Tom Lane (seen above) the national Director, Consumer and Recovery Services for Magellan Health Services discussed the measurement of peer support in his keynote address to the conference. He noted that clients served by case management teams with peer specialists demonstrated greater gains in several areas of quality of life and overall reduction in the number of major life problems experienced. People served by peer support had enhanced self-esteem and social functioning.

Self-help participation results in improved daily functioning and improved illness management. He noted there is strong support that everyone benefits from the provision of peer support/peer provided services. Peer providers serve a valued role in quickly forging therapeutic connections with persons typically considered to be among the most alienated from the health care service systems.

Tom explained that in comparison of peer support consumers with traditional day treatment, consumers showed improvement over time which was significantly greater than those receiving traditional services.

Consumer managed Crisis Residential Programs had an average length of stay of 7 days at \$211 per day for a total of \$1497 compared with Locked inpatient facilities with an average length of stay of 6 days at \$665 per day for a total cost of \$3876.

showed that those who participated regularly had a significant increase in confidence and superior outcomes related to general empowerment and functioning.

Tom noted that people with serious mental illness served by the public mental health system die on average 25 years earlier than the general population. The number one cause was Cardiovascular Disease.

Peers help peers live longer using peer support whole health. Values are consistent with peer support for mental health recovery. It looks comprehensively at a person's health lifestyle. It stresses creating new health lifestyle habits and disciplines through self-determined strategies and choices.

Peer support whole health training is built on a person centered planning process that focuses on six health lifestyle domains: healthy eating, physical activity, restful sleep, stress management, service to others and support network. Peer support whole health is an emerging best practice for peers to help improve their health.

Tom noted that researchers are beginning to design studies that measure aspects of peer support that haven't been looked at completely. Tom concluded that the hope instilled in people recovering from mental illness through the dynamic exchange of peer support has the potential to foster hope and change for the mental health system.

2012 Conference Awards



Darlene Richards
The Recovery Muse



Ken Timmerman
The Intentional Peer



Cindy Scott
Wind Beneath My Wings



Diana Waggoner
Recovery is Real



Diane Meadors
Regional Community
Leader



Dean Settle
Visionary Powers



Candy Kennedy
The People's Choice

*Special Thanks to the Awards Committee Members several of whom had to sit out during different nomination categories, because they were nominated for awards also:
Vicki Grossenbacher, Dan Powers, Cindy Sullivan, Ken Timmerman, and Carol Coussons de Reyes.*



Beth Baxter
2012 Director's Award Recipient
Individual Award



St. Monica's Alumni Association
2012 Director's Award Recipient
Team Award

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**Pony Express Riders 2012
Raising Awareness of Children's Mental Health**



Yolanda Chavez Nuncio at her presentation on *Immigration and Children* at the 2012 BH Conference: Success, Hopes, and Dreams

SAMHSA's Recovery Support Initiative identifies four major domains that support recovery:

- **Health:** overcoming or managing one's disease(s) as well as living in a physically and emotionally healthy way;
- **Home:** a stable and safe place to live that supports recovery;
- **Purpose:** meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income and resources to participate in society; and
- **Community:** relationships and social networks that provide support, friendship, love, and hope.



Below: Success, Hopes, and Dream 2012 Statewide Behavioral Health Conference

