



Depression and Bipolar
Support Alliance

We've Been There. We Can Help.

Transformational Technical Assistance: Effectively Engaging Consumers and Family Members in State Mental Health Systems

Depression and Bipolar Support Alliance (DBSA)

Gayle Bluebird, Consumer Advocate

**Children and Adults with Attention-Deficit/Hyperactivity Disorder
(CHADD)**

The National Schizophrenia Foundation (NSF)

Presenters:

Sue Bergeson, President, DBSA

Matt Mattson, Director of Training, DBSA

Gayle Bluebird, RN, Faculty, NASMHPD Nat'l Executive Training Institute

“Perhaps no change has as much impact on the workforce as the emerging redefinition of the role of the consumer in making healthcare decisions.

This is as true in behavioral health as it is in general medicine. Trends such as illness self-management, peer support approaches, and increased access to information via the internet are remodeling the relationships among practitioners, patients, and their families and posing new challenges for the workforce.”

-ANNAPOLIS COALITION

(THOUSAND VOICES The National Action Plan on Behavioral Health Workforce Development. 2006)

Why Engage Consumers / Family Members?

- Person driven, recovery oriented services are the watchword for quality mental health treatment

(President's New Freedom Commission, IOM Quality Chasm Reports, Surgeon General Reports)

- Consumers are the “True North” for the system
- Using peers allows a more culturally sensitive approach
- In synch with CMHS evidence based practices

So who is providing this TA ?

- The Depression and Bipolar Support Alliance
 - Sue Bergeson, MBA -- Matt Mattson, MS
 - Lisa Goodale, LSW, ACSW
- Gayle Bluebird, RN
- Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
 - E Clarke Ross, PhD -- Beth A Kaplanek, RN, BSN
 - Linda P. Smith, BA -- Mary Durham, BS
 - Ruth Hughes, PhD, CPRP
- The National Schizophrenia Foundation (NSF)
 - Eric C. Hufnagel, MPA



Depression and Bipolar Support Alliance (DBSA)

- Consumer-run national organization
- 4+ million/year people request & receive help
- 1,000+ peer-run support groups across America
- 90+ million/year website visitors



Depression and Bipolar Support Alliance (DBSA) (cont)

- 3,000+/month personally answered calls
- 80,000+/month downloaded brochures
- 1+ million patient centered, recovery oriented, educational brochures distributed free of charge each year
- DBSA's message of hope, help, and support was placed in the media a mind boggling 1,603,598,454 times last year

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

- National family based organization with 14,000 members
- 200 community chapters and support groups
- Provides: A support network for parents and caregivers; A forum for continuing education; Serves as a community resource; Disseminates accurate, evidence-based information about AD/HD to parents, educators, adults, professionals, and the media; Promotes ongoing research; Advocates for the AD/HD community

Children and Adults with Attention Deficit/ Hyperactivity Disorder (CHADD) (cont)

- Recognized and financed by the Centers for Disease Control and Prevention (CDC) as the National Resource Center on AD/HD
- Operates a structured, seven-week orientation program utilizing the lived experiences of AD/HD, titled “Parent-to-Parent: Family Training on AD/HD”

The National Schizophrenia Foundation (NSF)

- Only national organization in existence focusing solely on schizophrenia and related disorders, and associated consumer issues, with a major emphasis on the consumer perspective
- NSF: Fosters the development and maintenance of support groups for those affected by schizophrenia as well as their families and friends; Educates the public about schizophrenia and related disorders; and Provides related information about schizophrenia to persons seeking assistance

Gayle Bluebird, RN

- Faculty member of the National Executive Training Institute of National Association of State Mental Health Program Directors (NASMHPD)
- Independent consultant and national trainer
- National authority on development of Comfort Rooms
- Editor of two manuals *Participatory Dialogues* and *Reaching Across With the Arts*, with funds from the federal government (SAMHSA)

- **Gayle Bluebird, RN**
- In 2006 she produced and edited a film/video titled, *Leaving the Door Open: Alternatives to Seclusion and Restraint*, SAMHSA (TBR 2007)
- Currently she is working on a guidebook: *Pioneering Peers in Inpatient Settings* (a story guide), NASMHPD (TBR summer, 2007)

Participatory Dialogues:

A dialogue is a forum in which two or more groups of people are brought together as equals to explore their differing views. Can be done in varied groups and for different purposes:

- Between clients and staff on issues, e.g. seclusion and restraint
- For Consumer Satisfaction with clients – (Dialogue/Focus Groups)
- For discussion on special issues or controversial topics
- Dialogues and Role Plays on hospital units to reduce conflicts

- **Participatory Dialogues--
Outcomes:**

- better communication and improved staff and patient relations
- greater participation and involvement of persons in care
- shared problem solving and reduction in use of coercive practices

Peer Roles in Inpatient Settings:

- Peer roles in Hospitals and state institution settings are becoming common
- Peers have the ability to act as transformative agents in hospital settings to create alternative environments
- Peers can provide individual help to other peers in their recovery processes
- Peers can work in partnership with clinical teams to give the peer perspective in all decision making and policy development
- Many different types of roles have been created, including advocacy positions, as peer counselors, in crisis settings, as evaluators, researchers or discharge planners, and for transitioning persons in care into the community

Quotes from the Peer Roles Guidebook:

“In some cases peers may be the most able to reach someone, particularly if they approach them with their own history of seclusion and restraint, their history of trauma, or their own vulnerabilities as a person who experiences symptoms from their own psychiatric disability (or mental illness).”

(Deni Cohodas, Patient Liaison/De-briefer, Worcester State Hospital, MA)

Quotes from the Peer Roles Guidebook:

- **“Every day is an adventure, like live TV. You don’t know what’s going to happen. But it does take focus to be here, really truly be here for the patients. That’s what works even for those who doubt you. When you’re here for the patients everything else follows.”**

(Laura Van Tosh, Director of Consumer Affairs, Western State Hospital, WA)

Quotes from the Peer Roles Guidebook:

- **“I think like a mediator. I see the importance of each party at the table dialoguing so that each other’s perspective can be understood and valued. Understanding brings ‘richer’ relationships and partnerships.”**

(Cindy Mayhew, Recovery Specialist, Alton State Hospital, IL)

Other Training Topics from Bluebird include:

- Recovery definition
- Importance of people's stories and narratives
- Language issues
- Dialogues: both informally and formally
- Comfort Rooms and Personal Safety Plans
- Trauma Informed Care
- "Appropriate Touching"
- Debriefing by Peers
- Creativity and the Arts

TA Outcomes

- A set of core values embraced by the consumer and family community, and embraced by state mental health leadership about the most effective roles of consumers and family members working within that specific system to support transformation
- A check list of what works and does not work in using consumers and family members within the state. This will be developed by an identified core group of senior management and consumer/family leaders.

TA Outcomes, continued

- An assessment based on the tenets outlined in *Crossing the Quality Chasm*, the *President's New Freedom Commission*, and the *Annapolis Coalition* reports, completed by senior management and consumer/family leaders of where consumers and family can be of most support in transforming systems, and how they can be engaged
- A core group of at least 25 motivated and empowered consumer and family leaders identified and trained to support the work of the state system in embracing transformation as outlined in the *Crossing the Quality Chasm*, the *President's New Freedom Commission*, and the *Annapolis Coalition* reports



Assessment

The mental health collaborative will conduct a thorough distance-administered assessment with partnering states. This assessment will be conducted using a targeted telephone and E-mail / Internet approach that will identify current strengths and future opportunities for inclusion of consumers within the state mental health system.



Facilitated Dialogue Sessions:

--Two staff from the mental health collaborative will conduct a day of on-site, in-depth dialogue with key stakeholders

--Three meetings will take place during this day.

1. A meeting of active and emerging consumer leaders from within the state will be convened to discuss current realities, desired outcomes, and opportunities for commitment to action.

2. A meeting of selected state administrators, providers, and healthcare professionals will be convened to discuss current realities, desired outcomes and opportunities for commitment to action.

3. Finally, a town hall meeting with both of these stakeholder groups will be convened to identify a plan of action to move the state forward in its inclusion of consumer leaders in appropriate and empowering ways.



Training Emerging Leaders

Two staff members from the mental health collaborative will conduct one day of on-site training for consumers within the state that focuses on developing the knowledge, skills, and abilities of emerging consumer leaders to be actively engaged as partners within their state mental health system. This training will utilize the best practices of other state initiatives, paired with the expertise of the mental health collaborative partners' experience.



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Q & A



Thank You

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