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History of the Consumer/Survivor Movement

 Sally Zinman

 Gayle Bluebird

History of the Consumer/Survivor Movement



Presented by and told from the point of view of mental health consumer/survivor

**Sally Zinman,
CAMHPRO**

Purpose:

Learn about the history of our movement in order to rededicate ourselves to its core values and inform our ongoing work.

Learning Outcomes

- Describe the core principles of our consumer/survivor movement.
- Recognize the transition and challenges in moving from grassroots militant action to providing funded mental health services.
- Explain the major progressive effect and changes that the consumer/survivor movement has made in the mental health system.
- Recognize the influence of history on art, and of art on history.

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History of the Consumer/Survivor Movement



Sally Zinman,
CAMHPRO

Introduction

- 1960s and 1970s social change movements
 - Civil rights movement; African-American, women, gays, and people with physical disabilities organized
 - For decades, mental patients were denied basic civil liberties and suffered systemic inhumane treatment
 - Spent lifetimes locked up in State hospitals.
 - New laws limited involuntary commitment
 - Now big State hospitals were shut down and people released

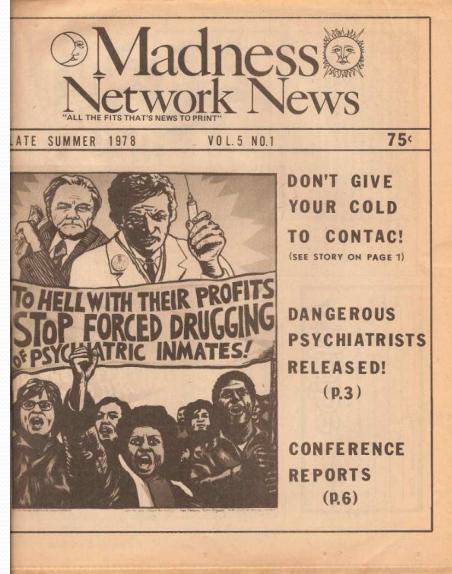
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New Liberation Movement

- Once released from the hospital people held groups
 - Former “patients” shared anger about their abusive treatment
 - Their peers validated their feelings.
 - Expressed the need for independent living in the community
- A new civil rights movement was born from these isolated groups across the country
 - Based on the desire for personal freedom and radical systemic change
 - A liberation movement

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1970's



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The Beginnings The 1970's was a time

- Of finding each other
- Of realizing that we were not alone
- Of militant groups and actions
- Of self and group education
- Of defining our core values
- Of finding and growing our voice out of the anger and hurt bred by the oppression of the mental health system.
- Of separatism as a means of empowering ourselves.

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Processes

- Groups autonomous, belief in local control
- No money from mental health system
- Separatist
- No major outreach

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Principles

- All within context of a civil rights movement for people diagnosed with mental illness, we were:
 - Against Forced Treatment
 - Against Inhumane Treatment – medications, ECT, lobotomy, seclusion and restraints
 - Sanism
 - Anti-Medical Model verging on anti-psychiatry
 - Emergence of concept of mental patient run alternatives to mental health system and peer support
 - Involvement in every aspect of mental health system

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Activities

- Political militant activism – demonstrations
- Developing and defining values and positions
- Annual Conference on Human Rights and Against Psychiatric Oppression
 - held at campgrounds, college campuses, unfunded
- Madness Network News –news vehicle for communication
- Small groups, mostly on two coasts
 - Militant names, e.g., Network Against Psychiatric Assault, Insane Liberation Front, Mental Patient Liberation Front
- Most common self-description is as “psychiatric inmate.”
- Self and group information and education
- Support, consciousness raising groups

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Landmark book
published 1978:

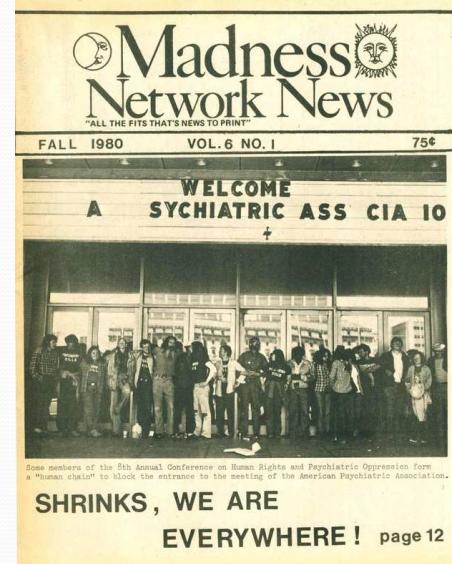
***On Our Own:
Patient Controlled
Alternatives to the Mental
Health System***

by Judi Chamberlin



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Demonstration against the APA



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Transitions in 1980s

- Howie the Harp



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Moving Forward

- The 1980s was a transitional time
- We made major movement decisions that left many of the more purist activists behind.
- We began the process of reentering the world that had so hurt us.
- It was a time that some significant founding endeavors ended, and new ventures began.
- There were indications that many of our goals were beginning to be realized, a transitioning from words to deeds, conceptualizing to implementing.

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1980s Processes

- Mainstreaming
- Centralizing
- Money from mental health system
- Collaborations/ beginning Reentry

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Activities

- Growth of mental health system funded consumer run and staffed/peer support programs, early drop-in centers
 - 1983 On Our Own in Baltimore, Maryland
 - 1985 Berkeley Drop-In Center, Berkeley CA
 - 1985 Ruby Rogers Drop In Center Cambridge Mass.
 - 1986 Oakland Independence Support Center, Oakland CA
- Federal government, Community Support Program, NIMH, begins to fund consumer/survivor-run programs
 - 1988 13 consumer run demonstration projects funded
- Beginning of statewide consumer run organizations
 - 1983, California Network of Mental Health Clients

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More Shifts

- Discontinuation
 - of Madness Network News and decline of radical militant groups
 - of Conference on Human Rights and Against Psychiatric Oppression
- Many MH system funded trainings and conferences
 - First national Alternatives Conference 1985
- Rights Protection gains/legislation
 - Growth of rights protection organizations
Protection and Advocacy, Inc.
- Beginning to walk inside, social change from the inside as well as the outside
 - More “clients”, “consumers” sitting on decision making bodies

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Getting What We Wanted

- Fruition of changes that we had sought in the mental health system
- Basic values remain the same, we rephrase them
- Consumer/survivor- run programs, employment, and educational opportunities flourish
- Attitudes about recovery change

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Principles

The same principles as the earlier days expressed in positive rather than negative ways

- Self Determination and Choice
- Rights protections
- Stigma and Discrimination reduction
- Services responding to multiple life needs of person: friends, housing, jobs, community.
- Self- Help/Peer Support programs
- Involvement in every aspect of mental health system
 - “Nothing About Us Without Us”
- Concept of Recovery – encompassing all of the above

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Where We Have Come

- Employment, in addition to in consumer run programs
 - In mental health system
 - Consumer/survivors in MH management level jobs
 - Offices of Consumer Affairs
- Big growth in consumer run/peer support programs with system funding
- Incorporation of consumer run/peer support into system, such as Recovery/Wellness Centers, peer support specialists, peer certification, and medi-cal funded peer support
- Peer Certification is implemented in 34 States

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More Progress

- Multiple training opportunities, including consumer developed trainings
- Noticeable consumer involvement at most levels of mental health system
- Consumer participation and partnership with other constituency mental health groups
- Research on consumer run programs/peer support, and emergence of consumer researchers
- Working with policy makers to legislate and otherwise change policy

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More Progress

- Development of new consumer driven models such as peer run respite centers and self directed care.
- More diverse and inclusive consumer movement
- Creation of National Coalition for Mental Health Recovery, a national advocacy voice for consumer/survivors, and International Association of Peer Supporters that promotes the use of peer support services worldwide
- Effective advocacy from the inside

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System Culture Change

- Evidence of system culture change as a result of consumer involvement at all levels of MH system.
- Consumer values embedded in California's Mental Health Services Act (MHSA)
 - Voluntary
 - Promotion of self-help/peer support programs
 - Involvement of consumers at all levels of MH system
 - Involvement of consumers as part of and in training of MH workforce
 - Promotion of recovery as a goal

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System Culture Change

- Concept of Recovery inspired by and attributed to consumers
- Recovery replaces maintenance as the goal for people diagnosed with mental illness
 - “We envision a future when everyone with a mental illness will recover.”
 - *Achieving the Promise: Transforming Mental Health Care in America, The President’s New freedom Commission on Mental Health*, July 2003.
- Consumers have initiated new genres of services
 - Consumer run programs and peer support are essential components of most mental health systems and designated as best practices

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Liberation

- Initial goal is to advocate for others
 - Liberate others so they will not experience same abuse we did, so people who follow us will not have the same horrendous experiences that we did.
- Realize in the very process of advocating for others
 - We are freeing ourselves
 - Raising ourselves above internalized self-disparaging images
 - Recreating ourselves in new empowered ways.
 - Creating new people
 - Redefining ourselves, individually and collectively
 - Created new program genres
 - Client-run drop-in centers and other client run programs
 - Influential in development of supportive housing and recovery.
- Final understanding: we are also liberating the system
 - Making it better for everyone that works in the mental health system, a liberating and healing environment for all.

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The scope of our achievements of the past is an indicator of the possibilities for our future.



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Acknowledgments and Contact Information

- Thanks to the thousands and thousands of advocates who have and will continue to shape the consumer/survivor movement history.

Contact: Sally Zinman, Executive Director
California Association of Mental Health Peer Run Organizations
(CAMHPRO) szinman@camhpro.org

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California Association of Mental Health Peer Run Organizations (CAMHPRO)

- The California Association of Mental Health Peer Run Organizations (CAMHPRO) is a nonprofit statewide organization consisting of local consumer-run organizations and programs reaching the thousands of mental health consumers who participate in these programs.
- Mission: transform communities and the mental health system to empower, support, and ensure the rights of consumers, eliminate stigma, and advance self-determination for all those affected by mental health issues by championing the work of consumer-run programs and organizations.

California Association of Mental Health Peer Run Organizations
870 Market Street, Suite 922, San Francisco CA



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Questions?

Please use the Chat feature

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The Influence of the Arts

To recognize the influence of history
on art
and of art on history

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Presenter Gayle Bluebird, RN

- Active in the consumer/survivor movement since 1974
- Developed Office of Consumer Affairs in Florida in 1993
- Coordinator of Office of Technical Assistance for Peer Networking, for the National Association of State Mental Health Program Directors, 2004-2006
- Delaware State Director of Peer Services 2010-2015
- SAMHSA VOICE Award recipient 2010
- Retired in 2015 still doing independent consulting
- Writer, author, arts consultant, dreamer and schemer

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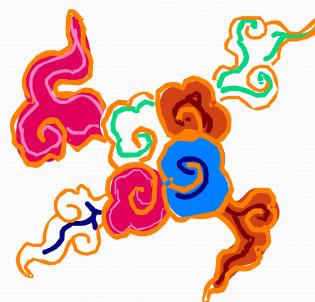
"Arts Illustrating and
Making History"

By Gayle Bluebird

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The Beginnings 1970's

- Art was used to reflect anger, outrage, protest, and political ideology
 - Posters
 - Newsletters
 - Chants
 - Songs
 - Music
 - Poetry

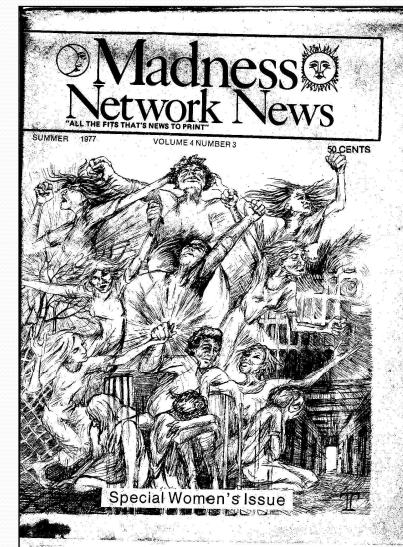


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“Madness Network News”

A national newsletter published
from the 1976 to 1986

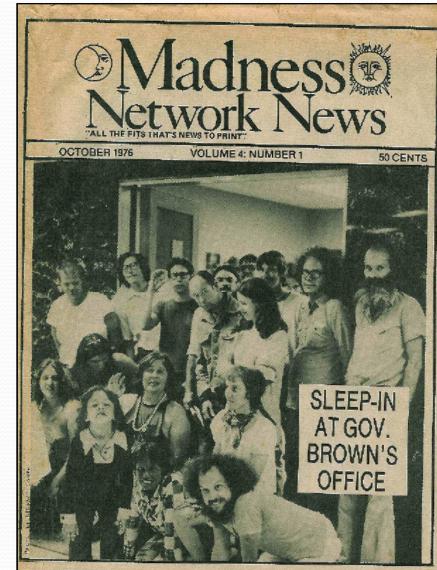
Cover by
Tanya Tempkin
Berkeley, CA



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1976 Cover

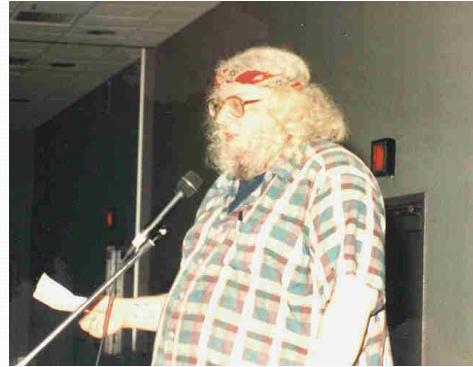
Photograph of a 30-day
“sleep-in” protest in then-Gov.
Jerry Brown’s Office to protest
deaths and abuses in State
hospitals in California



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Howie the Harp

1953-1995



“Crazy folk” (as he called us) are the most talented people in the galaxy. Instead of diagnosing, locking up, and treating us, the world should recognize our true worth and support our talents, creativity, and sensitivity,” Howie carried a harmonica with him everywhere, to make music, mediate conflict and create peace.

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The 1980's *Transitioning with the Arts*

- Talent Shows
- Drop-in Centers beginning
- Self-help Research Projects
- Individual Artists
- Theater Groups Popular

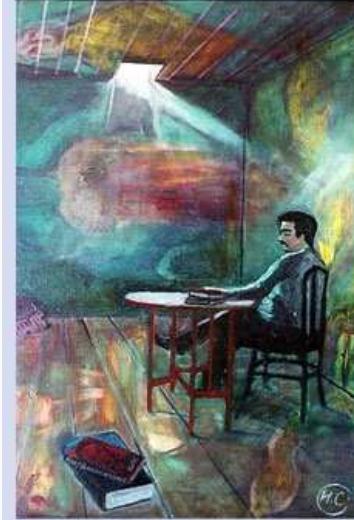


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Well-Being Project CA 1987 Jean Campbell

Research by and for mental health clients

- 500 persons interviewed
- 61 percent of clients stated creativity essential to their well-being
- 24 percent stated they lacked creativity in their lives
- Art by Jean Campbell



Alone and Waiting
1984 oil on canvas
24" x 18"

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“Talent Showcase”

“Social Change”
performers who
performed
at various Alternatives
Conferences



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Second Step Players

Second Step Players (formed in 1985) is a theater troupe that writes and performs original comedy and drama about the experience of being labeled with a mental illness. Seeks to promote recovery and community change through creativity and art; does 20 shows per year.



Uncasville, CT

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**Sybil
Noble**
Kansas City,
Missouri



“Falling Faces”



“Three Faces”

Sybil is the only (known) mental health survivor to receive an Eli Lilly scholarship to attend art school. She earned her B.A. in Art with a concentration in Art Therapy at Avila University in 2006. She is also selling her art at increasing high values. Her art work is being exhibited in many local and national venues.

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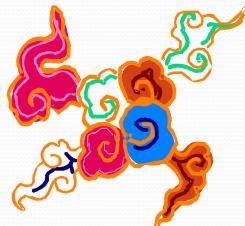
Cookie Gant
1949--2003
“Artiste Extraordinaire”

Early activist: outspoken poet, and performance artist; she spoke as a person with a disability, shock survivor, African American lesbian, and seller of buttons and other wares.

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The 1990's

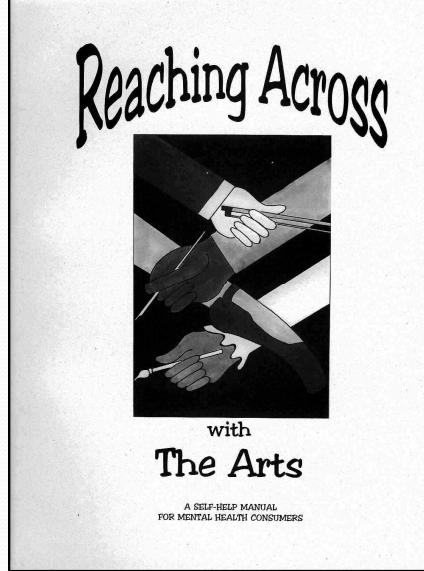
- Individual artists
- Holistic Healing
- Arts guidebook published
- Self-Determination and Self-Sufficiency
- Addressing Childhood Trauma
- Confronting Stigma and Discrimination



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A self-help arts guide published in 2000 with funds from CMHS with information that is still relevant and helpful to mental health consumers today

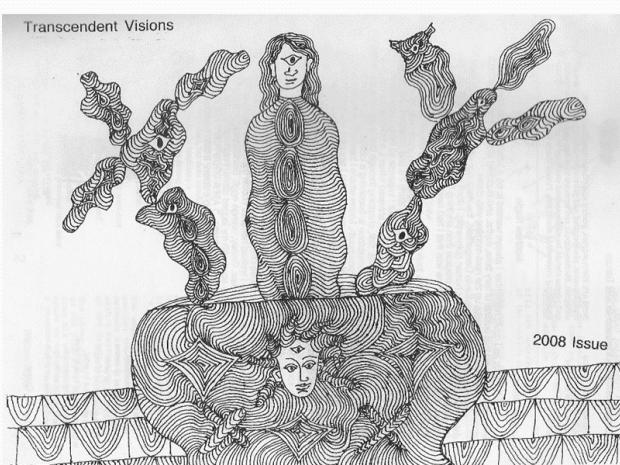
www.alteredstatesofhearts.com



The cover of the self-help arts guide features the title 'Reaching Across' in a large, stylized, cursive font at the top. Below it is a black and white photograph of several hands reaching out and interacting with each other. Underneath the photo, the subtitle 'with The Arts' is written in a smaller, bold, sans-serif font. At the bottom, the text 'A SELF-HELP MANUAL FOR MENTAL HEALTH CONSUMERS' is printed in a small, all-caps font.

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Cover of David Kime's ZINE ***“Transcendent Visions”***



The cover of the ZINE 'Transcendent Visions' features a central figure, a woman with a serene expression, standing on a large, ornate, circular object. This object appears to be a stylized representation of a face with a crown of hair. From behind the figure, three stylized, branching forms resembling trees or roots extend upwards, each ending in a face. The entire illustration is rendered in a dense, swirling line art style. At the top left, the title 'Transcendent Visions' is written in a small, sans-serif font. At the bottom right, the text '2008 Issue' is visible. The ZINE is presented against a white background with a decorative red and blue wavy border at the top.

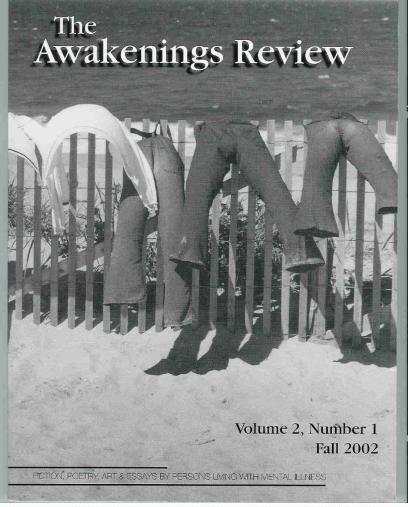
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Awakenings Project
Irene O'Neil



9/11/2015

The Awakenings Review

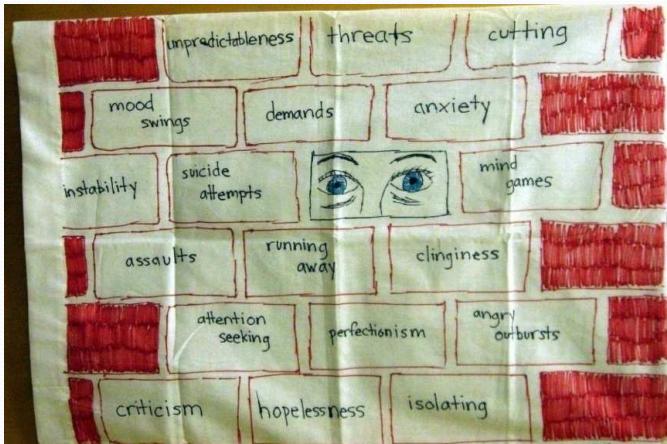


Volume 2, Number 1
Fall 2002
POETRY, POETRY, ART & ESSAYS BY PERSONS LIVING WITH MENTAL ILLNESS

Robert Lundin
Editor

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“Pillows of Unrest”
Fulton State Hospital Exhibit, Fulton, Missouri



- “If pillows could talk, they would tell a story of our struggles...”
- Reflects issues of recovery & effects of stigma
- A traveling exhibit of poetry & art on pillowcases
- A clothesline exhibit you can do!
 - www.alteredstatesofhearts.com

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The 2000's

- Mad Artists
- Performance Artists
- Visual Artists
- Musicians
- Specialized Art Centers
- Memorials

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Mark Davis Philadelphia, PA “Drag with a Tag”

Mark created his act to educate and raise consciousness about being gay, living with HIV, and mental health issues. He received a “VOICE” award in Los Angeles, 2009.



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Wambui Bahati New York City

Once a Broadway performer, Wambui later created a one-woman show "Balancing Act" based on her mental health experiences. She has also written an enlightening memoir, "You Don't Know Crazy", that describes how she found inspiration and exhilaration out of despair.

www.wambui-bahati.com



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Sharon Wise

Washington D.C.

"I Love Music"
From
The Peace Series

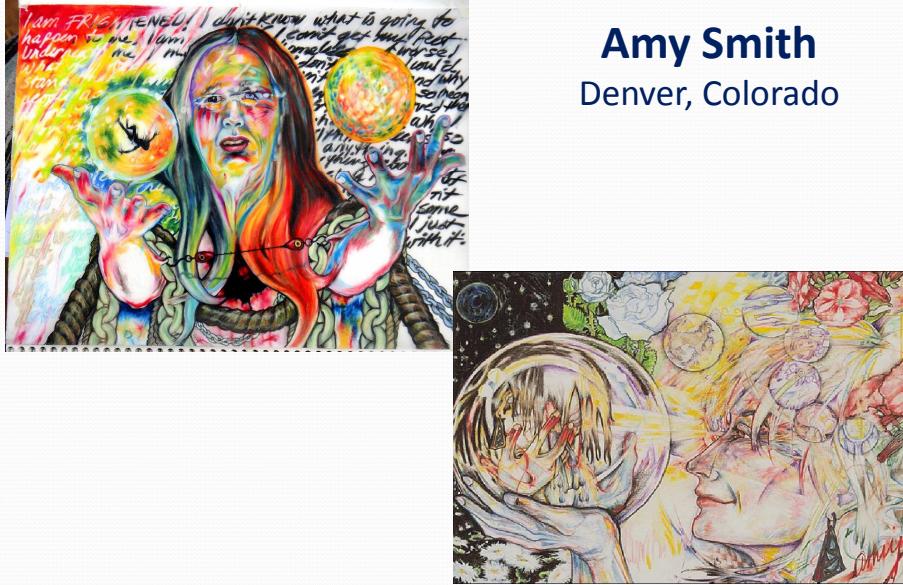


"Sisterhood-
Women Do
Survive"



"Things I can't say in words I can say through my art; I paint in vibrant colors that reflect my culture and history of trauma and childhood abuse." Sharon is known not only as a talented visual artist but also for her amazing "Butterfly" dance performance, as well as being a writer and producer of plays. She received a national VOICE award in 2008.

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Amy Smith
Denver, Colorado

9/11/2015

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Jerome Lawrence
Atlanta, Georgia

Jerome is a talented and nationally recognized artist known for his works of beauty and color; one of his paintings in the "Tulips are People" series, hangs in the rotunda of the Carter Center in Atlanta, GA. He has sold paintings at auction for over \$10,000.

www.jeromelawrence.net

Tulips are People IX

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Michael Skinner Manchester, NH



Mike Skinner started an organization called “The Surviving Spirit” whose purpose is to promote Hope, Healing and Help for those impacted by trauma, abuse or mental health concerns. He writes music, plays music, and now art is his primary source of his income. www.michaelskinner.net
www.mskinnermusic.com



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Meghan Caughey Portland, Oregon



“Hugging Form”
 From Meghan’s early work

Meghan’s transformative art evokes strong emotions when viewing it, from the very deep and painful to the light and joyful. “My life has been rather raw and hard to look at but I have tried to make it into something that has beauty...and art has done that for me.”

www.meghancaughey.com



“Lotus with Sparks”
 From Meghan’s Lotus Series later in Recovery

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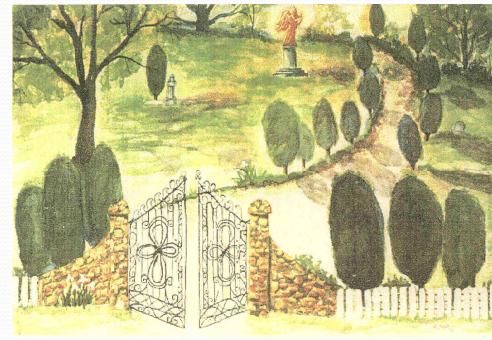
Creative Vision Factory

Wilmington, Delaware

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The Cemetery Project

Milledgeville, GA



Current memorial on left in state of Maine, On right the first cemetery restored with beauty to honor 25,000 people who had been buried in unmarked graves at Central State Hospital since 1842.

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Arts History in the Making

- Art as significant player in mental health transformation
 - arts and trauma,
 - arts and wellness,
 - peer specialists trained to use the arts
 - artists going on the road showcasing their work and stories.
 - Arts festival: 2016 (needs your help)

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Presentation by
“Bluebird” - “Henrietta”
Arts Consultant
1106 NE 9th Ave.
Gainesville, FL 32601
gaylebluebird@aol.com
302-981-2786



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Resources

- ARTREACH – Second Step Players Theater Group, www.artreachheals.org
- Bahati, Wambui www.wambui-bahati.com
- Campbell, J., The Well-Being Project, <http://mimh200.mimh.edu/mimhweb/pie/database/GetArticle.asp?value=1601>
- Caughey, Meghan www.meghancaughey.com
- Cemetery Projects, Pat Deegan & Larry Fricks <http://www.patdeegan.com/links.html>
- Lawrence, Jerome www.jeromelawrence.net
- Noble, Sybil arkfriends@kc.rr.com
- Skinner, Michael www.mskinnermusic.com; www.michaelskinner.net
- Wise, Sharon thehouseofsharon@msn.com

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Questions?

Please use the Chat feature

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Special thanks...

*Special thanks to Optum
for their ongoing support of
this series **and their dedication to**
quality in the practice of peer
support*



To receive a **certificate of attendance** go the
iNAPS website: www.inaops.org
Click the quiz link in the *upper right corner*.

Please be certain to complete your contact
information completely and correctly. A
certificate will be sent to you in 4-6 weeks.

**On behalf of the
International Association of
Peer Supporters (iNAPS)
and Optum**

Thank you!

