

Firewalkers

An Anti-Stigma Proposal from the VOCAL Network



Written by
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In collaboration with
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Project Approach & Activities

The Fire Walkers Project

It is a difficult time to be a person with Mental Illness in our state. In the wake of the shooting tragedy at Virginia Tech, many of us have noticed a change in the climate and culture of Virginia. There is a great deal of fear and misinformation, and a widespread belief that people with mental illness are dangerous, violent or untrustworthy. This affects many of us in our day-to-day lives, jobs, and families, and has also begun leading to changes in laws and policies that threaten the human rights of people with mental illness.

We hope to reach out across our state with a message of a different way of viewing mental illness, and create a deeper understanding of what it means, and what is possible. We plan to create a new project called *Firewalkers: Stories of People Transformed by Mental Illness* – telling the stories of ordinary people whose experiences with mental illness have transformed their lives.

Mental illness has allowed me to step outside the box. Because of the struggle I've been through, I'm a more compassionate, empathetic, and understanding person. Everything in my life wouldn't be if it wasn't for the journey I went through.

 Peer from Region Ten Consumer Advisory Council

Seven Storytellers

We will begin by seeking and selecting seven peers who can serve as ambassadors and representatives, sharing their stories across the state. We will interview each of these seven people charting their life stories, personal path with mental illness, descriptions of what it is like to live with mental illness, and reflections on the ways their lives have been transformed. We will seek stories and speakers that are clear, compelling, moving, rich, and diverse.

Firewalkers Book

Our book will be called *Firewalkers: 7 Stories of 7 People Transformed Mental Illness* will include these seven stories, along with an introduction written by a peer editorial team, including things we want people to know and understand about mental illness. The book will juxtapose personal stories with a larger picture – including sidebars or end boxes with information about mental illness and anti-stigma information, as well as an appendix with recovery resources and next steps.

Firewalkers Photo Project

We will photograph each of the seven peers who share their stories, showing them in their natural lives and putting a face on their stories. We hope to get across the message that people with mental illness are not strangers to be feared – we are the teachers, doctors, neighbors, family members, and people in your lives. Photos will be included in our book and poster.

Creating Teaching Tools

Our Peer Editorial Team and community partners will put together a booklet and guide for “how to use this book” – with suggestions for activities in classrooms, medical schools, college orientation programs, mental health programs, and other settings. Once the book is completed, we will begin reaching out to schools with offers to share our book and send one of the peers from the book to come speak in their classroom. We will begin with the University of Virginia School of Nursing, one of our partner programs that plans to incorporate this book into their curriculum.

Reaching Out Across Virginia

To publicize this project, we will produce materials that will be distributed throughout the state by consumer-operated programs, mental health association offices and other community settings. We will also host a book launch to generate energy and publicity; and we will contact the press to invite them to this book launch and other events, and encourage them to review our book. We will also create a webpage with information on the book and information on how to schedule guest speakers in classrooms and other settings. In addition to raising awareness about our project, we hope these outreach efforts will also introduce more people to the consumer movement and our statewide consumer network.

Diversity & the Many Voices of Mental Illness

The stories in this project will come from a wide range of people, including peers from diverse racial and cultural backgrounds, ages, genders, sexual orientations, socio-economic backgrounds, and walks of life. We want to create a project that many people can relate to and find glimpses of themselves inside. For the book, we will specifically screen and select seven stories from a diverse range of people. This year, we also plan to form a Latino Consumer Group and a Veterans Consumer Group, which will contribute to this project. For these projects we will partner with VOPA, which is working to bring information on disability rights to Mexican-American communities; and with Mental Health America Virginia, which has developed *Entre Nosotros, Una Familia Con Salud*, addressing stigma within the Latino-Hispanic community.

In Years to Come

In collaboration with our partner programs, a peer editorial team, and the seven peers in this book, we hope to continue to speak out through the vehicle of this project for many years to come. Our partner organizations will help us spread the book to other settings, including medical school classrooms, family groups, consumer groups, mental health associations and universities. Our Program Director, Ann Benner, will promote the use of these materials in social work training, through her role as Adjunct Faculty of Virginia Commonwealth University School of Social Work. The seven peers whose stories are included will become ambassadors for our program, reaching out at conferences, classrooms, and events to share their story, distribute the book, and spread the message of transformation and the consumer movement in our state. Together we will work to help heal our state in the aftermath of the Virginia Tech tragedy, and change people’s hearts, minds, and opinions about people with mental illness.

Objectives

The goal of this program is to change the way people feel about mental illness, to offer a new paradigm for understanding the journey of mental illness and to help change the climate and culture of our state after Virginia Tech. Project objectives include:

A peer-led consumer-driven anti-stigma project

- ◆ Selecting 7 peers who will serve as ambassadors and storytellers for this project
- ◆ Assembling an editorial team of 5-10 peers, and all peer leaders for Staff

Innovative anti-stigma materials

- ◆ Creating a photo project of 7 storytellers
- ◆ Creating a book with 7 in-depth stories of transformation
- ◆ Creating a webpage with information on peers available for presentations

Reaching out throughout Virginia

- ◆ Distributing 500-1,000 books
- ◆ Distributing 500 anti-stigma posters
- ◆ Distributing 100-200 “teaching tools” booklets
- ◆ Creating a webpage that is accessible worldwide
- ◆ Reaching 50-100 people at a book launch and a UVA classroom presentation
- ◆ Placing book reviews or articles in 2-10 newspapers
- ◆ Establishing a long-term publicity plan and booking presentations in classrooms to reach across the state in years to come.

Target Audience

Our goal is to create materials that will be useful in many different settings. We will place a particular focus on reaching college campuses, where there is heightened fear and misinformation post-Virginia Tech. National Anti-Stigma Campaign materials show that people ages 18-25 are often in the greatest need of mental health services and the least likely to seek help. We will create a “teaching tools” booklet with suggestions for using our book in a classroom setting, and we will contact universities to book classroom presentations. We also plan to work with UVA Nursing School to incorporate this book into their curriculum, and to help construct presentations and materials that will be useful in a medical and nursing school classroom environment.

Another primary target audience is mental health consumers, and those who have been recently diagnosed, and their families. Being diagnosed with a mental illness can be a time of great fear, confusion and despair. We hope to offer people a deeper understanding of the journey and all of the potentials that lie within it.

Our long-term publicity plan includes reaching out to many different settings. We will contact programs to tell them about our book and project, offer to send a peer from the book to come and speak, and ask if they are willing to host a reading or include this book in their group or classroom. We will suggest that host organizations offer a small stipend, if possible, for the peer who comes to speak to their group – we hope this will help the project to be sustainable for years to come. Some of the sites we plan to approach include: college orientation programs, public mental health programs, mental health associations, consumer-operated programs, family groups, medical schools, and associations of providers and mental health professionals.

Key Activities & Timeline

First Quarter

Peer Editorial Team – Assemble a diverse group of peers to serve as a peer editorial team. Facilitate editorial team meeting. (Firewalkers Editor)

Project Vision – Contribute vision and ideas for project. Develop process for finding and selecting seven peer stories. Create interview questions. (Peer Editorial Team)

Peer Outreach – Announce project, seek out peers who will share their stories, invite and welcome diverse voices. (Firewalkers Editor)

Gathering Stories – Collect stories from peers, distribute to editorial team & facilitate meeting, notify peers who are selected for book, offer everyone positive feedback, arrange for permission for publication. (Firewalkers Editor)

Selecting Stories – Select stories to be in book. Select a range of stories from diverse class, race, and cultural backgrounds. Seek clear compelling stories that fit well together and explore Firewalker theme. (Firewalkers Editor)

Program Leadership & Collaborations – Provide leadership and vision for project. Coordinate collaborations and oversee partnerships activities. Oversee grant contract management, financial management, evaluation, and purchases. (Program Director)

Second Quarter

Story Interviews – Conduct interviews on the themes of recovery, mental health journey, and how mental illness has helped us grow. Conduct and record interviews and/or arrange for peers to interview each other. (Firewalkers Editor)

Faces of Mental Illness Photos Project – Photograph seven peers for book. Select photos and edit for publication. (Firewalkers Editor)

Prepare for Interviews – Schedule interviews and travel, coordinate signed releases, purchase recording equipment, arrange for transcription service. (Editor & Director)

Book Content – Edit interviews. Circulate book draft. Facilitate editorial team meeting. Revise draft based on peer feedback. (Firewalkers Editor)

Book Message – Contribute ideas and/or writing to the book introduction. Explore what we want people to know or understand about Mental Illness. Review book draft and offer feedback and comments for revision. (Peer Editorial Team)

Program Leadership & Collaborations – Provide leadership and vision for project. Coordinate collaborations and oversee partnerships activities. Oversee grant contract management, financial management, evaluation, and purchases. (Program Director)

Third Quarter

Anti-Stigma Research – Research anti-stigma information, written anti-stigma information that can be re-printed, views of mental illness in other cultures, and recovery resources. (Firewalkers Editor)

Anti-Stigma Writing - Write book appendix including information on recovery resources and how to become involved in consumer movement. Write book introduction. Write sidebars or end boxes with anti-stigma information. (Firewalkers Editor)

Book Materials - Write book acknowledgements, materials about VOCAL, materials about this project, and back cover. (Firewalkers Editor)

Book Assembly - Assemble draft of all materials, circulate draft, and facilitate editorial team meeting to review draft and give input. (Firewalkers Editor)

Poster Creation – Working with editorial team, create ideas for a poster that will publicize the Firewalkers project. Select, hire and work with graphic designer and poster. Coordinate poster content & production. (Program Director)

Publicity Plan - Working with partner organizations, develop a publicity plan & long-term outreach plan. (Program Director & MSW Intern)

Booklet & Poster Vision – Contribute ideas or writing to outreach booklet/curriculum guide, and to outreach poster (Editorial Team)

Book Production – Select, hire and work with graphic designer to produce book cover, poster, and book layout. (Program Director)

Program Leadership & Collaborations – Provide leadership and vision for project. Coordinate collaborations and oversee partnerships activities. Oversee grant contract management, financial management, evaluation, and purchases. (Program Director)

Fourth Quarter

Final Draft – Revise final draft based on editorial team feedback. Assemble final draft for graphic designer. (Firewalkers Editor)

Outreach Presentations – Contact universities and other settings to introduce book and offer classroom presentations. Make arrangements for presentations at UVA Nursing School and other settings (MSW Intern)

Teaching Tools Booklet – Collect ideas and input for booklet with activities and suggestions on how to use material. Write, revise, edit, design booklet (Firewalkers Editor)

Firewalkers Webpage – Construct webpage with Firewalkers photos and bios and information on how to arrange for guest speakers in your classroom or program (Director)

Book Production – Select, hire and work with book publisher to produce published book. Coordinate book distribution. (Program Director)

Book launch Coordination – Coordinate book launch and outreach, contact local newspapers, coordinate meeting to prepare presentations (Program Director & MSW Intern)

Book launch Event – Read stories at book launch, speak about project (Everyone)

Long Term Publicity Plan – In fourth quarter and over the next year, distribute book, arrange for readings and events throughout the state, share book in community settings, talk to press, read and share stories at universities, medical schools, mental health associations, peer-run programs, mental health programs, and in other community settings (peer editorial team, community partners, VOCAL board and staff, peers in book)

How this project is innovative & unique to our community

We know that there are already many books with stories of people with mental illness. We want to create something different, something that can really move people, open their hearts and minds, and help them see things in a new light.

There is a lot of writing about the struggle of mental illness, and (more recently) about the process of recovery – but we rarely hear the story of the deep growth and transformation that can come through this journey. The ways our lives change in ways we never imagined. The people we become that we never thought we could be. The way after we walk through the fire, and everything burns away from us, our lives become different and – for some of us – deeper, richer, and strangely more powerful.

We want to give people the message that being diagnosed with a mental health disability is not a death sentence. It's not the end of the line or the last thing that will ever happen in your life. It's a strange and unexpected journey that most of never asked for, or ever wanted. But after walking through the fire, it has brought us somewhere. And for some of us, we would not go back. Even if we could.


It is a common understanding – you can't give one thing up without replacing it with another. Nature abhors a vacuum. If we say stigma is bad, we want to get rid of it, what are we replacing it with? We are all already fairly aware of what the negatives are. What is the flip side? We hope that the stories in our book, and the people in our book, will show a different way of understanding the journey.

Along with personal stories, we will also include the “bigger picture,” so people can see things in a larger context. We will include information on different ways of viewing mental illness. For example, in some native cultures people who have schizophrenia or bipolar disorder are not feared, but are instead seen as having special powers and are taught to become shamans and healers. We will also discuss how people can define mental illness by their personal experience, and it can be understood differently by every person.

We will also include anti-stigma research – demystifying fears and false beliefs about mental illness. We will also look at the disability pride movement, as a different way of viewing and understanding living with a disability. And we will include practical resources for learning about recovery, and getting involved with the consumer movement.

We hope that by weaving together these deeply personal stories, alongside information about the bigger picture, we will help create a link in people's hearts and minds, transforming us all.

Going through the crucible of mental illness, we have grown as people. It is a rough road, but we ended up somewhere more powerful and deeper. It is being broken open, buried, lost in the void, lost in outer space. The question is, at the end of it, when you step out of the fire – Are you still whole? And how have you changed?

 Brian Parrish, Executive Director, VOCAL

Project Director & Partnerships

About VOCAL

The Virginia Organization of Consumers Asserting Leadership (VOCAL) is a statewide consumer organization dedicated to mental health empowerment, recovery, and peer leadership. The vision of VOCAL is to achieve a consumer-driven mental health system. VOCAL is 100% consumer-run – all of our staff and board members identify as people in mental health recovery. VOCAL runs three statewide programs:

The VOCAL Network, founded and run by people with mental illness, connects people to people and works to improve Virginia’s Mental Health Services. The purpose of the VOCAL Network is to increase individual well-being and allow support and information to be exchanged, and to work with other pro-consumer organizations to improve services and counter discrimination.

REACH (Recovery Education and Creative Healing) provides education and training on recovery and wellness for adults with mental illness. REACH provides training on Recovery and Wellness to peers and providers and equips peers with skills for monitoring and decreasing the severity and frequency of symptoms.

The VOCAL CO-OP stands for Consumer Owned & Operated Programs. The CO-OP is a collective of peer-run, self-help mental health programs in Virginia. CO-OP projects include: free trainings in nonprofit management, leadership retreats for consumer leaders, free toolkits on building peer-run programs, mini-grants for grassroots projects, development of new consumer-led programs, and statewide gatherings and events


Project Leadership

Program Director

Ann Bohr Benner, LCSW, is the Founding Program Director of the VOCAL Network, a statewide program that connects people to people and works to improve Virginia’s mental health services. Ann received her Masters in Social Work from the bi-cultural Our Lady of the Lake University. Her thirty year career in social work included work at the The Charlottesville Department of Social Services, and Family and Children’s Services of Tulsa. Ms. Benner also served as Director of the nonprofit peer-run program ABIDE (Awareness of Body Image and Disordered Eating). With a special interest in expressive visual art, she also has provided art therapy in private practice. She is currently an adjunct faculty member at VCU School of Social Work. Ms. Benner is a mental health consumer and family-of-origin member of mental health consumers.

The VOCAL Network has been so amazingly powerful for me. The opportunity to be with other peers, to test my own thinking, to be with people I had never been with before, to have a safe space to explore my leadership style, & to learn about listening and diversity.

I never would have dreamed I would be where I am today. The VOCAL Network really changed my life.

 *Lauren Spiro, Director of Public Policy, National Coalition of Mental Health Consumer/Survivor Organizations*

Role in project: Ann Benner will serve as Program Director for this project. Program Director will be responsible for overseeing partnerships activities; overseeing grant and financial management; coordinating book and poster production and distribution; coordinating consultants; coordinating book launch and publicity.

Firewalkers Editor

Cassandra Nudel is an award-winning writer and photographer, with publications in over 30 magazines and literary journals. Her documentary photography has been exhibited at The Smithsonian Institute and The National Library of Congress. As a person in mental health recovery and an advocate for disability rights, she has worked for seven years to help build and strengthen the consumer movement in Virginia. She has designed and co-created many new programs, including: a mental health disability rights network, a recovery education training program, a mini-grant program for self-help projects, a peer-to-peer recovery survey, a system transformation newsletter and website, and a collective of grassroots mental health programs. Cassandra is the author of four other guidebooks on peer-run mental health programs and the consumer movement:

- ◆ *Bricks and Dreams: A Transformation Guide to Peer-Run Programs*
- ◆ *The Grant Seeker's Treasure Map & Orienteering Guide*
- ◆ *Blueprints for Change: How to Create a Peer-Run Program*
- ◆ *ROSI: Highlights from Virginia's First Statewide Peer-to-Peer Recovery Survey*

Role in project: Cassandra Nudel will serve as Editorial Consultant for this project. Editorial Consultant will be responsible for: Assembling Peer Editorial Team and facilitating meetings; seeking peer stories; overseeing selection process; conducting interviews; taking photographs; editing photos; editing written materials; circulating book drafts; researching anti-stigma information; writing appendix, anti-stigma material, introduction, and other book pieces; assembling final book draft; creating guide booklet on ways to use this book; producing report of activities; and participating in publicity and book launch.

Project Partners

Consumer Advisory Council of Region Ten is a group of mental health consumers who provide advising, leadership and input on Region Ten public mental health services. This group organizes and hosts an annual Recovery Conference and has recently completed a collection of recovery stories. Please see attached list for full contact information.

The University of Virginia School of Nursing is committed to educating future leaders, extending the boundaries of nursing and health care knowledge through research, and providing high-quality and compassionate health care in service to the citizens of the Commonwealth of Virginia, the nation, and the world. Please see attached list for full contact information.

Consumer-Operated Programs throughout Virginia - VOCAL serves as a collective of over 20 consumer-operated programs in Virginia. There are over 20 peer-run mental health programs in Virginia – Drop In Centers, Employment Centers, Training Programs, Warm Lines, Advocacy Projects, Transitional Housing, Recovery Groups, and more.

Complete descriptions and contact information for these programs can be found on our website at: www.vocalsupportcenter.org/directory.htm.

Mental Health America Virginia (MHAV) is a citizens’ organization dedicated to promoting mental health, preventing mental illness, assuring the proper treatment of the mentally ill and eliminating the stigma associated with mental illness. MHAV runs Consumer Empowerment Leadership Training Academy, and has trained hundreds of consumers in leadership and advocacy skills they need to make a positive impact on Virginia's mental health system. Please see attached list for full contact information.

Virginia Commonwealth University School of Social Work – Guided by the principle of promoting social and economic justice in a diverse and multicultural society, our Virginia Commonwealth University School of Social Work programs focus on service to and empowerment of people who experience oppression or vulnerability due to inadequate or inequitable distribution of personal, social or institutional resources. Please see attached list for full contact information.

Partner Roles

Partners	Roles
Consumer Advisory Council of Region Ten	CAC representatives will serve on a Peer Editorial Team along with other consumers. This team will select peers who will be interviewed for this project, develops interview questions, contribute ideas and/or writing to introduction, contribute ideas and/or writing to “teaching tool” booklet, contribute ideas to poster, and reviews and edit book draft.
University of Virginia School of Nursing	Integrate book into Nursing School curriculum. Host classroom presentations from peer representatives. Provide guidance and input on “teaching tools” booklet and other project materials. Provide guidance and input on reaching other universities, and creating materials and presentations that will be powerful in a university classroom setting.
Consumer-Operated Programs	Collaborate in local outreach to consumers across the state. Display posters and books at drop-in centers, recovery centers, employment centers, and other peer-run programs.
VCU School of Social Work	Provide a Social Work masters student who will collaborate with VOCAL staff and peer volunteers to conduct publicity and outreach, and coordinate speaking events at Universities.
Mental Health America - Virginia	Collaborate in community outreach. Publicize project to chapter programs throughout the state. Help seek local chapters to host book readings

Project Effectiveness

Surveys and evaluation questions will be developed by our peer editorial team, in collaboration with a professional mental health evaluator from Virginia DMHMRSAS, through an in-kind donation. We will collect written and verbal feedback from our peer editorial team, community outreach partners, participants in our book launch, and students who attend presentations at the UVA School of Nursing. We will also include a written survey in our book to collect input from readers.

Outcomes evaluation will explore topics including:

- ◆ Changes in awareness – improved self-awareness of people’s own health needs
- ◆ Changes in knowledge – improved understanding of what mental illness actually is, rather than how it is stereotypically portrayed
- ◆ Changes in beliefs – people with mental illness no longer being viewed as predominantly violent or dangerous
- ◆ Changes in understanding - increased sense of hope, increased understanding that there can be both positives and negatives to living with mental illness
- ◆ Cultural accessibility of materials

Process evaluation will include meeting the following objectives:

A peer-led consumer-driven anti-stigma project

- ◆ Selecting 7 peers who will serve as ambassadors and storytellers for this project
- ◆ Assembling an editorial team of 5-10 peers, and all peer leaders for Staff

Innovative anti-stigma materials

- ◆ Creating a photo project of 7 storytellers
- ◆ Creating a book with 7 in-depth stories of transformation, plus anti-stigma information and resources
- ◆ Creating a webpage with bios of 7 peers available for presentations

Reaching out throughout Virginia

- ◆ Distributing 500-1,000 books
- ◆ Distributing 500 anti-stigma posters
- ◆ Distributing 100-200 “teaching tools” booklets
- ◆ Creating a webpage that is accessible worldwide
- ◆ Reaching 50-100 people at a book launch and a UVA classroom presentation
- ◆ Placing book reviews or articles in 2-10 newspapers
- ◆ Establishing a long-term publicity plan and booking presentations in classrooms to reach across the state in years to come.

We will use the outcomes from discussions, focus groups, and written surveys to revise and strengthen materials, create new approaches to presenting materials, and include new or different ideas in our “teaching tools” booklet. As materials and outreach continue to develop, we also will explore applying for other sources of funding to create a more formal research evaluation process. Evaluation outcomes will also be used to monitor the success of this program, and to set goals for future anti-stigma initiatives.