

Discovery & Innovation in Mental Health Care



Expect Recovery. Hope Matters







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Dear Friends of *Excellence*,

As we approach our ninth year, we want to thank every one of our donors and volunteers who have made us so successful in funding independent research, education, and programs that support recovery-based practices in mental health care.

In this report, you will see a few of those projects and funds that foster recovery for people who experience mental health challenges and their families.

Here is our challenge to you! There is so much more we can and should do together to make an impact. As a community foundation intent on leaving the legacy of mental health recovery and efficient financial stewardship of your charitable giving, we rely on your continued dedication of time and resources.

As you browse through these pages, please consider how much you can give this year and let us know where you would like your support focused. If you have special skills, talk to us about volunteer opportunities and help spread the word by inviting your friends to follow us on Facebook, Twitter, and YouTube and by sharing our eNewsletters.

Thank you for taking part in building the *Excellence* community.

With gratitude,

The Excellence Board of Directors

You're looking for answers. We're finding them, together.

Today's mental health care has let you down. You know recovery is within reach and you want to change the world.

You've come to the right place.

We help donors achieve their dream of bringing the hope, knowledge and tools for recovery to every community by funding promising research and innovation in mental health care worldwide.

We are paving the way to a new era of mental health care that centers on recovery-based treatment and programs. We are moving toward a world of care which is safe and effective, fulfills our need for authentic connection and respect, and restores hope for a meaningful life.

Together we are changing the face of mental health care around the world.

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Lived-Experience Transformational Leadership Academy (page 16) Fellow Claire Bien, M.Ed., is a writer, grantwriter, mental health advocate and educator, and survivor from Connecticut. She began hearing voices at 31, was hospitalized, and placed on medication. Thanks to compassionate therapy and the support of family and friends, Claire learned to regain control of her mind and her life without the need for ongoing medication. Claire kept silent about her hospitalizations and diagnoses for 26 years. She has since become a passionate advocate for reform, calling for a change in the medicalpsychiatric profession's approach to diagnosis and treatment of people with mental health conditions. She is a founding member of the Board of Directors of NAMI Elm City (New Haven) and facilitates two Hearing Voices Network support groups. Her memoir, Hearing Voices, Living Fully: Living with the Voices in my Head, was published in 2016.



FOUNDATION FOR EXCELLENCE IN MENTAL HEALTH CARE

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2017-2018

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Competitive Grant Project Reports

Grants were reviewed by the Foundation's Scientific Advisory Council and selected by the Board of Directors.

Micronutrient Study Actively Recruiting Eligible Children in Oregon, Ohio and Alberta, Canada

The first North American trial of a 36-ingredient micronutrient formula is underway at Oregon Health & Science University, The Ohio State University and University of Lethbridge in Alberta, Canada.

In only three months of recruiting, the Micronutrients in ADHD Youth (MADDY) Study has enrolled 40 participants among the three sites, nearly one-third of its target number. The children must be off of psychotropic medication for at least two weeks prior to starting the study.

Children, ages 6-12 years of age, who have ADHD and some irritable mood symptoms are participating in an 8-week randomized controlled trial. During this phase, they will receive either the active product or a matching placebo. Neither the participants' families nor the clinicians will know which one.

Afterward, all the children are eligible to receive the active product for a further eight weeks. Researchers are collecting data on the children's mood and behavior at baseline and comparing them to reports at the end of the treatment. Blood, urine, stool, hair and saliva samples will also be analyzed to begin looking at the biological basis for why some children benefit and others do not.

The MADDY Study is based on research from Dr. Julia Rucklidge's lab in New Zealand in which she found that the children with ADHD and irritable, angry moods reported the most benefit from the treatment.

Several of the families who have completed the initial 8 weeks report significant improvements in their child's functioning.

While we don't know which pills they were taking (active or placebo), it is encouraging



to hear the positive stories of improvement in mood and attention, reduced anger and an ability to get along better with friends.



Fort Collins Research Collaborative Tests **Novel Youth Program**

The Learning and Self-Development Collaborative is midway through supporting its first group of young adults experiencing moodrelated distress. A second group has just begun.

Nearly three-quarters of the first group have prior mood disorder diagnoses and have tried psychiatric medications like antidepressants. They found the medications to be ineffective. and intolerable side effects had left them searching for an alternative way forward when they decided to enroll in the program.

These young adults are currently medicationfree and their outcomes on mood distress, social connectedness, empowerment, and quality of life at six months will be compared

to other young adults receiving usual care and daily psychiatric medications in the community.

Participants have received naturopathic care, including multi-vitamin supplements, fish oil, and coaching on diet and lifestyle, along with weekly peer support sessions alternating with educational sessions. They have so far explored the larger social context we live in, oppression, social expectations and pressures, spirituality and spiritual crisis, listening to our inner self and our body, and how we use medicines and drugs of all kinds to alter ourselves.

Participants use a stipend allotment to engage with activities of their own choosing which, for this group, incorporates kick-boxing, group nature hikes, voice lessons, yoga, and memberships to a climbing gym.

Preliminary feedback indicates the value of the naturopathic doctor "giving me advice based on the full spectrum of life," "being able to talk openly to everyone" in peer support groups, and "interesting" educational topics "helping to change my life."

Online Curriculum Will Preserve Historical Lessons for the Next Generation of Health Professionals

The education of America's health care professionals is missing the important history of public mental health care and the effect that history continues to have on real people. Young and even many seasoned professionals know little of the tragic past of our public mental hospitals and the kind of neglect and abuse that once flourished in many of them.

Believing in the power of personal narratives to shift attitudes and inspire positive change, filmmaker Lucy Winer has teamed up with critically acclaimed author and historian, Nancy Tomes, PhD to create the new online curriculum Unlocked: Stories of Public Mental Health Care.

It brings together first-person accounts of patients, peers, family members, direct care staff, clinicians, administrators, inmates. law enforcement and corrections personnel. These very different realities together provide a balanced overview that inspires open dialogue and better understanding, promoting practices that rely on mutual respect between caregivers and those seeking support.

The 12-part curriculum of stand-alone, multi-media modules each focus on a different thematic aspect of public mental healthcare; an extensive video library



Development and testing of the curriculum prototype is a partnership between Collaborative Support Programs of New Jersey, A Peer Led, Statewide, Non-profit Organization; The University of Pennsylvania School of Nursing; The Columbia University Psychiatric Residency Program; and The SUNY Stony Brook Department of History.

Social Network Study with OnTrackNY at **MHA Westchester**

The New York State Psychiatric Institute at Columbia University, in collaboration with the Mental Health Association (MHA) of Westchester is conducting a study to evaluate the feasibility of offering Social Network Meetings to individuals enrolled in New York State's first episode psychosis program, OnTrackNY.

These Social Network Meetings are derived from the Need-Adapted Treatment and Open Dialogue models and view psychotic disorders as unique experiences requiring individualistic treatment. These models integrate an individual's social network throughout the entire treatment process and provide a consistent treatment team throughout the person's recovery.

This study is open to all English speaking OnTrackNY clients (ages 16-30) and family members of their choosing.

The study team is exploring ways to increase enrollment and will be focusing enrollment efforts on individuals who are newly entering the OnTrackNY program. The study team hopes that, by offering social network meetings within the OnTrackNY program, individuals will receive enhanced social support allowing them to make greater strides toward reaching their recovery goals.

Voices for Choices







Emily Cutler

"Voices for Choices" project is training psychiatric survivors, family members, and allies to advocate effectively for choices and alternatives in the mental health system

This project honors everyone's potential to be a leader, even those in the back wards of the most restricted psychiatric facilities. It connects people with lived experience of mental health challenges with peer mentors, equipping them to change the system of care in their communities. Sarah Smith at MindFreedom International is the project coordinator.

The first two in a series of recorded webinars are now available online featuring panelists David Oaks, Jim Gottstein, and Emily Cutler in the first and Adrian Bernard, Caroline Mazel-Carlton, and Hilary Melton in the second, presenting their findings from years of working with people in distress.

In a fast-paced world, the value of taking time

The Open Dialogue approach to early psychosis stands in striking contrast to the standard practice of immediate diagnosis and prescribing of antipsychotic medication for people experiencing early psychosis. Instead, the 'person at the center of concern' and their family and friends team up with at least two health professionals and meet as a group as often as needed.

Treatment decisions are made collaboratively in the presence of the whole group. Diagnosis, and often drug treatment, are delayed while the team explores all aspects of the person's health, environment and trauma-history that might be contributing to the crisis. The treatment plan is then built on the individual's expressed desires and strengths.

Five-year outcomes for first-episode crises in those diagnosed with schizophrenia and psychotic disorders include 79% of participants symptom-free and only 20% on disability and using antipsychotic medication.

Dr. Doug Ziedonis, Professor of Psychiatry at UC San Diego Medical School, is leading a

Adapting **Open Dialogue** to the United States

multi-year *Excellence*-funded project to adapt this successful Finnish program for use in the United States.

Fidelity criteria were published in 2015. The clinical manual and implementation guide are currently in the works and will pave the way for U.S. health systems to incorporate the approach and for insurers to understand the financial benefit of covering the program costs.

Initial results of our first pilot program at Advocates, Inc. in Framingham, Massachusetts, were published in the journal Psychiatric Services in July 2016.

The project team began training the latest pilot site in June 2016 in partnership with Emory Medical School and Grady Memorial Hospital. The Atlanta pilot is testing a new, much shorter initial training curriculum which, if it achieves the same recovery outcomes, should further aid the adoption of Open Dialogue across the nation.

In its seventh year of research and development in the United States, the approach is gaining momentum as organizations across the U.S. and Europe come together to organize and share the costs of training clinical staff in Open Dialogue practices.



Drs. Robert Cotes and Keith Wood at Emory Medical School are implementing the Open Dialogue approach with colleagues at Grady Memorial Hospital, providing clinical care to 20-24 participating individuals and their families for an *Excellence*-funded pilot study. These leaders recognize the need for better, recovery-oriented approaches that engage individuals to be full participants in their care and recovery. Currently, only about 20% of people who are hospitalized actually connect with their first regularly scheduled outpatient appointment.



The Collaborative Pathway Fund enables the program to serve families of ordinary means by supplementing their health insurance with philanthropic support. Fund donations also support the necessary training and research to show the safety, effectiveness and cost-effectiveness of this clinical model so that it can be adopted by communities across the nation and the world. Glen Cote, (pictured) is a Collaborative Pathway alum.

Collaborative Pathway Fund

For young people experiencing early psychosis, treatment options are often limited and focus on rapid and early pharmacological interventions. Many young people experience the current mental health system as harsh and devaluing. Both families and the person at the center of concern feel inadequately involved in critical decision making about care, including whether, when and for how long to use psychiatric medications.

In response, Advocates Inc. in Massachusetts has developed an Open Dialogue team they call the Collaborative Pathway with a 24/7/365 mobile crisis team on which the program is based.

Open Dialogue, developed in Finland, serves young people experiencing psychiatric crisis, including psychosis, by providing a mobile, multi-disciplinary team which meets with the person at the center of concern and the family network, at home or in the least pathologizing setting possible.

The team provides services that allow for open discussion of what might be contributing to the present crisis, and what options might be available to help.

Social workers, psychologists, nurses and psychiatrists are all part of the team, as needed. In a spirit of openness and transparency, the clinical team commits to the person at the center of concern and the family that all decisions will be made in front of the network, with the network invited to comment or disagree.

This is true for all decisions, even those which have to be made unilaterally by the team.

In this system, there is time and space for the natural resolution of problems. Medications are used, but are used more sparingly and for shorter periods of time than is general practice in the U.S. "Well I'm alive, that's one thing that wasn't a certainty for the whole time.

I've definitely improved significantly with the support I've gotten. It didn't feel like I was being spoken to, it felt like I was being spoken with.

I had a say in how my care was being implemented. I think just the radical act of treating you with humanity is enormous. That specifically is what has helped me.

I just live my life. And that wasn't always an option."

Our early results show that this approach is safe and very much preferred by the people we've served.

Our pilot data indicate a greater than 70% decline in hospital days after initiating care in the Collaborative Pathway, and a significant increase in days working or in school; a very high degree of satisfaction with care and reported sense of collaboration and partnership.

Some young people manage their crisis with less or no antipsychotic medications; others find antipsychotic medications and other treatments that feel effective and helpful to them – both ways represent their own active choice, rather than treatment imposed upon them.

Transforming lived experience into expertise to transform mental health around the world

The Lived Experience Transformational Leadership Academy prepares persons with lived experiences of mental ill health and recovery to take on leadership roles within their own local, regional, and national systems of care across the globe.

Such leadership is currently missing at all levels of mental health care policy and planning, to the detriment of our systems of care and the people they are designed to help.

The development of leaders with lived expertise must nurture a shared identity and collective narrative, critical thinking, recovery values, community development skills, and a vision for a humane, holistic, and coercion-free system of care. It must also attract and be responsive to the needs of people as diverse as the countries from which they come, with a particular emphasis on cultivating future generations.

The Academy trained its first cohort of fellows from across the United States from September 2017 through April 2018, graduating a class of eight exceptional fellows. A second cohort began in the summer of 2018 in collaboration with the Center for Addiction and Mental Health at the University of Toronto in Canada.

A four-month mentorship period will follow the 10-week course.

Additional funding is being sought for future cohorts that will be drawn from other member countries of the International Initiative for Mental Health Leadership. The curriculum will be accessible online and on-site at Yale University and partner institutions.

The academy also hopes to host seminars, support research, produce theoretical papers, and collect and make available a wide variety of resources for leadership education and system transformation from around the world.

"I grew up 18+ years in foster care. My purpose most days is reversing the mental devastation that being raised by Child Welfare causes.

Transformation and transmutation are the perfect frameworks for leveraging my life experiences to live bigger than my diagnosis, my labels, the statistics, the prejudice, the racial disparities, the poverty, etc. that my peers stubbornly face off with every moment of everyday."



In Philadelphia, Let's LEAD first cohort fellows Shaiheed Days (pictured) and Steven Jackson are launching a youth and young adult peer advocacy fellowship experience within the national Youth MOVE movement. The Philadelphia Chapter of Youth MOVE will enroll a number of fellows in a training framework that serves their wholeness as persons with lived experience. These Youth MOVE fellows will be nurtured and supported as the next generation of disruptive mental health visionaries.

International Leadership Academy Fund



Lead trainers Caroline Mazel-Carlton (r) and Marty Hadge (l) present their work at the "Trauma and Hearing Voices" session held at Mount Holyoke College, offered by the Hearing Voices Training and Research Project

New Hearing Voices Peer-Support Groups from Seattle to Atlanta Strengthen Nationwide Network

For nearly 30 years, the Hearing Voices Network - an international collaboration of professionals, people with lived experience, and their family and friends - has been developing an alternative approach to coping with voices, visions, and other extreme states that is empowering and useful and does not start from the assumption that people who have these experiences suffer from a chronic illness.

A large body of peer-reviewed research now provides support for key aspects of this approach, and the hundreds of support groups that have developed in countries around the world are enabling voice hearers to learn to cope more effectively or rid themselves of the negative effects of their voices.

With a large multi-year grant, *Excellence* donors are helping the team at the Hearing Voices Research and Training Project to build a well-trained regional network of groups in the United States.

Trainers crisscross the country, conducting multi-day workshops for new facilitators of Hearing Voices peer-support groups.

Ongoing technical assistance and a monthly networking call for U.S. group facilitators helps new groups get up and running. A weekly online support group, attended

US.

by voice hearers across North and South America, serves those without a local group.

Mini-grants are spurring creative diverse outreach in local areas where the Hearing Voices approach is still unknown.

The research team is seeking out the experiences of participants to identify the precise characteristics that make Hearing Voices groups so effective for so many people.

With a clearer evidence base, the researchers hope to foster wider acceptance of the Hearing Voices approach among clinicians and other mental health professionals in the

The Project's collaborative team of voice hearers, peer workers, and researchers have created a short film, offering a powerful introduction to the approach through the stories of people whose lives have been changed.

Hearing Voices Research & Development Fund

Revealing the power of nutrition in mental health

Dr. Bonnie Kaplan, professor emerita and researcher at the University of Calgary has powerful stories to tell of individuals who suffered life-changing mental health challenges restored by multi-nutrient treatments.

Nearing the end of her academic career, Dr. Kaplan opened the Nutrition and Mental Health Research Fund in 2015 to support the next generation of nutrition scientists to research and educate on the ability of broadspectrum nutrient treatments to reverse and prevent the onset of psychiatric symptoms.

It is an area of study that has not yet been considered a priority by traditional funding sources which tend to look for 'magic-bullet' single-nutrient solutions.

The Fund has already raised over half a million dollars from private donors.

Grants have been awarded to clinical scientists conducting trials of micronutrient treatment in New Zealand, Canada, and the U.S. The trials involve children with ADHD and mood dysregulation and adults with bipolar disorder. Much progress has been made by all of the researchers funded so far: e.g., the studies in Canada and the U.S. are all halfway through recruitment of their target sample sizes.

All of the existing funds have now been distributed, but we are nowhere near finished with the work!

In some of the currently funded projects, biological samples will be drawn for microbiome analyses, epigenetic markers, and nutrient levels. These assays are very expensive and will require an additional \$150,000 in donations to complete.

Funding is also still needed for a study coordinator in a very busy laboratory in New Zealand and for an American scientist wanting to devote her career to this topic.

There are also additional clinical trials in need of funding: one would allocate children in mental health crisis in the emergency room to receive either micronutrients or medication, another in adolescents who are displaying self-harm, etc. There is so much good yet to be done!

Nutrition & Mental Health Research Fund



Clinical psychologist Professor Jeanette Johnstone, MFT, PhD, Director of the Mental Health and Nutrition Research Group at the Oregon Health & Science University in Portland, Oregon. Her primary research interests are complementary and integrative interventions for attention, mood, and anxiety issues in children and adults. Currently, she is the principal investigator of the The "MADDY" Study (Micronutrients in ADHD Youth), a study on supplementation with multivitamin/minerals in children with ADHD.

RxISK.org is making medicines safer for all of us

RxISK.org is a free, independent drug safety website to help you weigh the benefits of any medication against its potential dangers.

All drugs have side effects, but people often don't link the effect they are experiencing to starting, stopping, or changing the dose of a drug. RxISK provides free access to information and tools to help you assess the connection between a drug and a side effect.

Visitors can search by drug or by side effect to see manufacturer product information, warnings, and reported side effects in an easy-to-read format.

In addition, personalized tools like the RxISK Report and TaperMD, help you and your doctor make informed decisions about the risks and benefits of a given medication, assess whether a new symptom is actually a drug side effect, and review potential harmful interactions when taking or thinking of taking multiple drugs at the same time.

The TaperMD[™] app was originally developed to help reduce the medication burden in seniors. It is now in clinical trials in Canada and Australia and will be rolled out to the public this year.

The RxISK Fund

The RxISK Prize

Most people are aware that antidepressants can cause sexual side effects but almost no-



one knows these can endure permanently after treatment stops – sometimes only emerging after treatment stops. This a problem facing tens of thousands of people, leading to suicide, relationship and family break-up, job loss and a lot of wasted money on dangerous options held out as cures. At present, there is almost no support for those affected.

The RxISK Prize is a movement powered by people whose sexual functioning has been destroyed by SSRIs, isotretinoin or finasteride, aimed at drawing attention to and finding an answer for this common devastating problem. The fund has already collected \$60K of its \$100K goal, but more importantly it has collected a lot of ideas for possible solutions.

Visit RxISK.org to join in the race.

FINANCIAL STATEMENT HIGHLIGHTS

SUMMARY OF CONSOLIDATED STATEMENT OF FINANCIAL POSITION December 31, 2017

ASSETS	\$
Cash & Cash Equivalent	1,301,624
Investments	161,467
Contributions receivable	5,604
Other assets	8,163
TOTAL ASSETS	1,476,858
LIABILITIES	
Payables & accrued expenses	59,108
Grants payable	438,727
Other current liabilities	4,625
TOTAL LIABILITIES	502,460
NET ASSETS	
Unrestricted	703,203
Temporarily restricted	271,195
TOTAL NET ASSETS	974,398

SUMMARY OF CONSOLIDATED STATEMENT OF ACTIVITIES 2017

REVENUE & GAINS	\$
Gifts, grants & contributions	1,049,373
Investment income (loss)	1,018
Program & other revenue	4,946
TOTAL REVENUE & GAINS	1,055,337
GRANTS & OTHER EXPENSES	
Grants	1,039,176
Fund expense & program services	225,062
Administrative expenses	318,883
TOTAL GRANTS & OTHER EXPENSES	1,583,121
CHANGE IN NET ASSETS	-511,547
NET ASSETS, BEGINNING 2017	1,485,945
NET ASSETS, END OF 2017	974,398

If you would like a copy of financial statements audited by Carter, P.C., call EXCELLENCE's main office at 503-816-5676. Our 990's are available online at MentalHealthExcellence.org.

Wall of Honor

Our collective dedication to the integrity of mental health care springs from our profound love for the following individuals in whose name many gifts have been given.

Honoring

David Alt Oliver Armen Oryx Cohen Donita Diamata Nicholas Emlen Sonia and Hector Fajardo Kevin Fitts Wendy Garfield Darla Ghanat Anne Graham Sheila Hamilton Mike Hlebechuk Julie Huneycutt Yana Jacobs, MFT Aaron Jacobs-Smith Caleb Jacobs-Smith Lee Macht. MD John Mendez **Billy Muer** Mr. & Mrs. Nelson Gina Nikkel, PhD Laysha Ostrow A mate on twitch xxs4rg3xx "Girl on a Hot Tin Roof" Kara

In Memory of

Barbara Cohen Leonard Dedrickson Lucas James Finnegan Karl Frohnen David Hardy Christopher Hickey Walter and Evelyn Hudson Anna Huneycutt Our son Ian Susan Kelly Lee Macht Corbett Monica Loren Mosher Alan Roy Mountain John M. "Mickey" Nardo, MD Deb Parker Ellen Pasav Lynn Payer Paul Peacock Kazadi Salwa Ryan M. Soper **Robert Medford Wagner**

Keep it going

Your giving changes lives.

Online

Support a range of priorities by giving online: Mental-Health-Excellence. NetworkforGood.com

Establish a Fund

It is simple to arrange for a donor-advised or endowment fund at Excellence, enabling you to manage your philanthropy with the degree of involvement you prefer and without having to establish or manage a private foundation. Please contact:

Gina Nikkel

President & CEO Email Gina@MentalHealthExcellence.org Phone 503.930.0349

Bequests

Build a caring legacy and inspire your family with a tradition of giving back. Estate planning options including charitable bequests, charitable lead or remainder trusts and donations of retirement assets or insurance policies.

Contact

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Recovery

: a person is successful and satisfied in the living, working, learning, and social environments of their choice.



FOUNDATION FOR EXCELLENCE IN MENTAL HEALTH CARE

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