Voices for Change

A Statewide Newsletter of the Massachusetts Mental Health Community

Spring 2013

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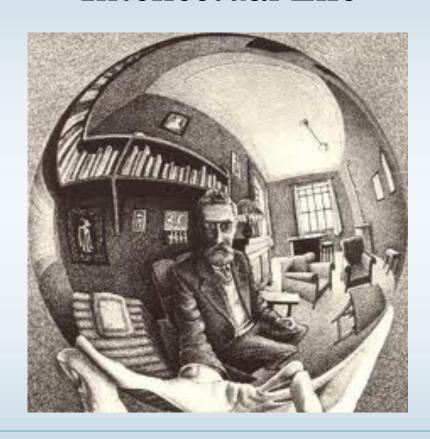
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Reclaiming Intellectual Life



With the experience of mental health struggles, many of us lose touch with our intellectual interests and activities. Peer authors write about their experience with intellectual losses and gains, we bring news from a discussion forum, and include information about retraining the brain. And news about the Transformation Center!

The Wisdom Within Us

By Amy Dahlberg-Chu

By all accounts, I'm an intellectual person. In my youth, I devoured the classics of American and English literature and developed a passion for history. In college and grad school, I studied history. I've worked in publishing, museum design, and historical tour development. And throughout my life, I've pursued a love of writing.

Intellectual pursuits, however, have never come easy. Although I consider myself intelligent and place a high value on learning and creative expression, I've always found reading and writing diffi-Challenged by low moods, negative thoughts, and anxiety, most intellectual activities take me roughly three times as long as I'd My cognitive abilities prefer. have also been affected by medications and ECT. I have to write ideas down the moment I have them or in a matter of minutes. they could be lost forever. I regularly reverse numbers and letters as well. But I'll never give up on

"...it's far more challenging and thought-provoking to discover for ourselves what we value and cherish, and live our lives by our *own* mile-markers."



 $Amy\ Dahlberg\text{-}Chu$

my intellectual pursuits; they're part of who I am.

Like so many of us, I've sustained losses during my journey with a mental health condition. In my mid-20s, after being diagnosed with bipolar disorder, I left a Ph.D. program in American History to devote my limited energies to caring for my young son. Choosing to put my family first and set aside my academic career was a painful and humbling decision for me. On one hand, I found relief in lightening my workload and making family my priority; on the other, I felt I'd let my illness get the better of me. The social expectations I'd taken upon myself weighed heavily on me. By age 21, I'd competed in a National Spelling Bee. won Regional and State Science Fair Awards, been Salutatorian of my high school class, and earned a B.A. with Honors from Harvard. My vision of success was clouded by outward achievements, making my recovery process torturous.

You see, in my 20s, I didn't see how grappling with a mental illness could help me to grow or make any special contribution to the world. I felt cheated and defeated. Why had I been handed this illness that carries with it immense stigma and often makes day -to-day life feel like mountain climbing? What had I done to deserve this fate? What was my life worth if I couldn't live up to the standards of mainstream society, let alone build a career commensurate with those of my Harvard peers? What if I didn't earn my doctorate, build a successful career, and garner a respectable salarv?

Truth be told, on my darkest days I still torture myself with these questions. Yet deep inside, I eventually came to honor my decision to leave the Ph.D. program. Abandoning my doctorate was not an ending, but a beginning for me - a pivotal turning point in my recovery. My subsequent work as a peer specialist has brought me a fulfilling sense of purpose as I work to foster hope in others, help my fellow peers see their talents and strengths, and increase awareness of mental health conditions in the wider community.

Freed from academia, I've found myself upon a philosophical and spiritual journey greater than any I've ever known. Along this wonderful and harrowing journey, I've experienced a gradual acceptance of life's inherent unfairness and an ever-deepening gratitude for life's gifts. My definition of intellectual recovery has also changed. Where before my conception of intellectual growth was inextricably wed to academia and mainstream definitions of achievement

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Wisdom Within

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"normalcy," now I see my intellectual recovery as a very personal process of inner speculation and philosophical development. I've come to measure my success by how I've given back to others, treated others with compassion and kindness, and used my experiences of illness and renewal to nurture hope in others. No, these values can't be precisely quantified, but when I hold true to my mission, it's a wonderful feeling, better than any award or salary I'll ever receive.

We know so much more than we give ourselves credit for. don't need the world to tell us what's of value, or how we should spend our talents and energies. It's easy to internalize mainstream society's definitions of success, but it's far more challenging and thought-provoking to discover for ourselves what we value and cherish, and live our lives by our own mile-markers. For me, the latter course is a work-in-progress, but the more I measure myself by my own values, beliefs, and goals, the more I find satisfaction and joy in my daily activities. And that's how I know I'm on my true path of insight and recovery.

Craig Lewis has a web site:

www.punksinrecovery.com

Go to this site for tour diaries, videos, flyers, events and more. Up the punx in recovery!

Sanity is a Full-time Job

By Craig Lewis

I am a 39 year old certified peer specialist and college student. I wear many other hats as well including being a musician, a writer and hopefully a revolutionary thinker and actor in the recovery world. I would like to think of myself as one whose brain operates and functions in an intellectual way however I spent much of my life lacking the awareness that I had much of anything to offer or contribute. I have been asked to contribute my thoughts on the topic of "intellectual recovery" and I have agreed. I am grateful for the opportunity to share and I hope help others; for I believe that is my purpose in being alive (and well).

I lived in institutional settings from age 14 through 18. Being institutionalized at such a young age, I did not have a former quality of life to reclaim. I was a gifted child who was prevented from blossoming as a result of these institutional placements and followed by more than two decades of being prescribed psychotropic medications for a disorder that I did not have. I was prescribed countless medications over the years and nothing ever worked except for successfully making me sick. On my first day in the hospital in 1988, I met a punk rocker who was also inpatient and she lent me some tapes. I related to the anger, energy and aggressiveness of the music and knew that punk rock was something that I wanted and needed in my life. Punk rock gave me an outlet with which to express myself and made it ok for me to be a freak.

For many years I lived in substandard housing surrounded by violence, drugs, dealers and filth. Due to my own abject dysfunction, the only people who would allow me to live with them were also dysfunctional and things al-

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Craig Lewis pictured with issues of punk rock zines he created.

Sanity is a Full-time Job Cont'd

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ways ended poorly. I was arrested twice and abused and humiliated by the police as I was ill. I did not have any income and I had no idea that I could get Social Security benefits or food stamps. I spent countless winters without heat and often faced the threat or reality of physical violence. However, even these extended moments of living hell were not enough to sedate the mind of a person who wanted more. I was actually succeeding in managing my dysfunctional life via my involvement in the punk rock community.

Since 1995, I have published fifteen issues of a fanzine (magazine). I became a documentarian and wrote about music and life. I always desired a better life and I was expressing these sentiments for many years before I had any idea that people with mental illness got better. This was a productive role with which to express myself and that facilitated global communication with like-minded people. These communications allowed me to experience a sense of meaning and purpose which nurtured my growth. By being engaged with others and connecting on the power of the music, ideologies and sense of community that we had in common; I was maintaining my life and ever so slowly working toward recovery and wellness although unbeknownst to me. This was intellectually stimulating for me.

My involvement in punk rock ultimately led to my involvement

in other intellectual activities. I have played in several bands and travelled throughout the USA, Canada and Mexico. Playing in bands required me to write lyrics, organize tours, answer mail and included many other related responsibilities. I became involved in show promotion and organized almost 150 concerts which required organizational and intellectual thinking. In order to successfully organize and facilitate a concert, I had many responsibilities to manage. I had to secure the venue, find bands to play, engage in the promotion of the concert, manage equipment issues, deal with security issues and handle the PA (amplification system).

I hadn't done much reading of anything unrelated to punk rock until I got a copy of Animal Farm written by George Orwell. This segued into reading more and I continue to read to this day. As a benefit of the communication that I was engaging in due to my fanzine and bands, I spent many hours writing several letters a week. It was this regular practice that taught me how to write and my confidence and ability increased over the years.

Without being involved with writing fanzines, bands and organizing shows, I may never have found a way to transcend my life of dysfunction and discover my recovery. I never want to go back to my days of dreadfulness and on the contrary, each day that the sun rises I am getting closer to becoming selfactualized and living out all my dreams and desires. I saved myself through writing and punk rock because I had nothing else; now this beautiful life is mine.



Valeria Chambers

Intellectual Recovery By Valeria Chambers

Often when people hear the term "Intellectual Recovery", there is a flash back of sorts to when they were last in school, be that a positive or negative remembrance. For me, intellectual recovery is about using the intellect to take me into the realm of the heart.

The last time I sat for an exam. it was for certification as a Peer Specialist. I loved the class, but when my supervisor asked me to take the test, I felt that familiar sick feeling in my stomach. As I began to study there was a point where I almost threw in the towel. I had the equivalent of 2 master's degrees from Harvard, yet I was truly panicked. It was so intense that I actually became fascinated by my reaction. What in the world was going on with me? Upon closer examination I was able to get to bottom of my feelings, and I discovered that that was all there was to it. Tons and tons of feelings: mostly fear and perfor-

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Intellectual Recovery cont'd

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mance anxiety. Through my yoga practice experience, I knew that if I could just tolerate the feelings, I would be good to go. Not that I didn't study! I put in many hours, utilized the study buddy system and memorized colorful note cards. Anytime the anxiety hit I'd breathe through it and keep studying a little each day. The problem really wasn't the material; the problem was managing my feelings about the material. Being out of school for so long and losing self-confidence because of the depression had really done a number on me. Belief in oneself is so, so powerful.

When I first started having problems with depression, my identity was solely that of a student. That was my "job" as my mother put it, and I took it very seriously, seeking to do my best in every subject. What I lacked in natural aptitude, I made up for with extra effort. It was somewhat comforting to look at a book and know the answers to the test were there, because all around me and inside of me there were tons of questions with few answers in sight. School work quickly became a defense mechanism that helped me shut out the pain, fear and trauma that only a part of my mind knew about. As a result, I became an excellent student at Ivory league schools but felt totally numb inside and had no idea who I was apart from my intellect.

When it was time to graduate from college and go out into "the real world", I was so overwhelmed with emotions that I went straight into graduate school for safety! But like they say: "you can run, but you can't hide". I think I would still be in academia hiding if I hadn't come down with severe depression. The little black box that I had been stuffing all the yucky stuff in was about to explode if I didn't stop and take the time deal

with it. So here I am, dealing with it piece by piece. Thank God I have a whole lot of you supporting me! Thank you, by the way;) Anyway, in the beginning of my recovery I would try to think and think and think about things, trying to solve the problem. I would spend hours obsessing about it, but I never got anywhere. Then I learned that if I wrote out the various options, let it go, and sat down to meditate with an empty mind, the answer would come later on its Now, instead of own accord. studying other people's books, I'm studying my own book. It's the book that is me, and yet is related to a huge, incredible library of others. Heart and soul: it's a book that is infinite and everlasting, whose pages never end. I have only to sit, close my eyes, and let the thoughts disappear, breathing in and out. There are so many subjects, characters and languages; each chapter leads to new insights and ideas. I'll never get bored and there will always be more!

Resources (Susan can send you any of these by email):

Mad in America website, thread on Intellectual Recovery:

http://www.madinamerica.com/forums/topic/intellectual-recovery/

Free online games for cognitive recovery:

http://www.bigfishgames.com/online-games/index.html

<u>www.SuperBetter.com</u> (recovery game)

www.coursera.org (free online courses)

www.ted.com/talks (interesting talks on different (sometimes really different)

subjects)



Cognitive Rehabilitation By Martha Barbone

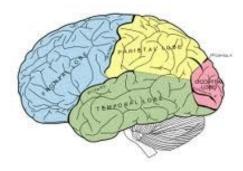
Cognitive problems may accompany some mental health conditions. In the last decade there has been interest in testing patients with depression, bipolar illness, and other mood disorders for cognitive impairment. Cognitive impairment is a key factor affecting the ability to return to work.

Common cognitive domains evaluated include memory, attention, reasoning, and problem solving. The idea that cognitive impairment may be related to brain anatomy and physiology has brought neuroscientists to research ways to train the brain to overcome deficits. Neuroplasticity is the brain's ability to reorganize itself by forming new neural connections throughout life. Neuroplasticity allows the neurons (nerve cells) in the brain to compensate for injury and disease and to adjust their activities in response to new situations or to changes in their environment.

Cognitive remediation training is exercise for the brain designed to improve the brain's structural and functional integrity via neuroplasticity. There are three key principles to follow when using neuroplasticity to improve cognitive function:

- The more one exercises, the better
- Start simple and move toward more complex
- Training must be tailored to the individual, using each person's capabilities and limitations

I have participated in a computerized cognitive remediation program. The exercises are "brain games" that exercise various cognitive domains such as memory and problem solving. The program follows the above key principles and is adapted for each individual. I found one of the most beneficial outcomes is that I can see and measure my improvement which further motivates me to do more. Cognitive remediation is used in patients recovering from stroke, brain injury, and in early dementia. It is also being used by the general public to improve memory and attention. One commercial program for "Brain Training" visit *lumosity.com*.



Editorial: Intellectual Recovery:

Definitions and Strategies

By Susan Landy

The idea for this issue came out of the Eight Dimensions of Wellness conceived by the Substance Abuse and Mental Health Service Administration (SAMHSA). You can find out more about this program by Googling "8 Dimensions of Wellness." The brief definition of intellectual wellness of-

fered by SAMHSA is: "Recognizing creative abilities and finding ways to expand knowledge and skills."

Intellectual Recovery is one part of mental health recovery. It may mean regaining faith in our ability to think and express ourselves and dialogue with others thoughtfully. It may also mean regaining faith in one's identity as a whole person. Many of us have found that after mood swings, trauma or extreme states we left behind mentallyengaging activities such as reading, listening to the news, or discussions about community or global issues. In fact, some of us have left behind large parts of our lives, so it may take a while to get to intellectual recovery (some while after financial recovery for some of us). When we get to it, we may wonder what to do about it or if it matters. Some of my thoughts on the subject:

Can I read what I used to be able to read? Will it go better as a book-on-tape or in shorter bursts? Should I get a neuropsychological evaluation? Is my difficulty with reading due to cognitive difficulty or that I'm not interested in that subject anymore? There are some subjects which I found it hard to believe I was no longer interested in. Lived experience has changed my priorities as well as my abilities.

On the Mad in America website, in the Community Forums, there is a thread,

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Editorial: Definitions Cont'd

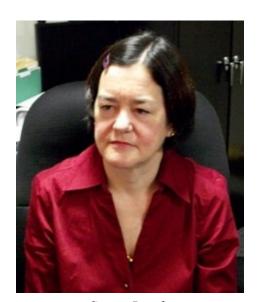
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http://www.madinamerica.com/
forums/topic/intellectual-recovery/

that discusses some of these concerns as well as solutions people have found to cognitive problems and identity. Owing perhaps to the thread's location on the Mad in America website, there were several comments that posters got cognitive powers and the sense of full humanity back after they stopped taking medication.

Several people commented that they use Zen or Mindfulness meditation. Two others mentioned exercise. Responding to comments that people had lost cognitive abilities, one commentator responded, BE PATIENT.

The writing that meant the most to me was posters' efforts to make sense of their struggles. Interestingly, they often commented on writing while they were doing this.



Susan Landy



Ruthie Poole

One poster commented that she thought her physical and mental problems were due to the intense effort her mind and body were making in their healing process. Some people raised the question of whether they ever had impairment. The far-ranging thought, depth and engagement that people brought to the Intellectual Recovery thread demonstrated the usefulness of cognitive practice that some mentioned, as well as the hopeful feelings that many brought to the discussion.

Transformation Center Staff Ruthie Poole Receives Award

On October 18, 2012, our Director of Advocacy, Ruthie Poole, received the 2012 Isaiah Uliss Award at the Massachusetts Psychiatric Rehabilitation Association annual meeting held at Holy Cross College in Worcester, MA. The Uliss Award is given every year to an individual who demonstrates exemplary ability and suc-

cess in mental health advocacy.

We at the Transformation Center are very proud of Ruthie and feel that this award calls appropriate attention to her long-standing advocacy and compassion skills. Ruthie learned about organizing by starting out as a welfare and tenant rights organizer. The award also highlights her dedication to helping oppressed people find their voice in the community.

Ruthie's acceptance speech commended her colleagues from her early mental health organizing days. She spoke with pride of several of her "heroes" from the LOVE group (Lawrence Organizing Voices for Empowerment).

"They are folks like me who have learned that it is best to Speak Truth to Power. They followed Maggie Kuhn's lesson to speak their minds no matter how much their voices shook."

Ruthie's view of speaking truth to power, however, is not always soft-hearted. She ended her speech with her favorite quote (by Fredrick Douglas), "Power concedes nothing without a demand. It never did and it never will."

Transformation Center Staff Emily Russell Gives Talk at National Conference

On October 24, 2012, the Transformation Center's Emily Russell gave a talk on Youth and Homelessness at a conference sponsored by several Massachusetts agencies, at Holy Cross College in Worcester, MA. The conference, called "In Pursuit of Ending Homelessness for Young Adults," brought together local and national experts, professionals and practitioners to identify program models and strategies to help end homelessness for Young Adults.

Emily coordinates the Healing and Self-Inflicted Violence Project at the Transformation Center. Her talk in the program was titled, "A Personal Perspective on Being Homeless at a Young Age." Emily broke the mold at once by citing Massachusetts statistics on the dramatic rise in the population of homeless youth in our state. She spoke about the difficulty of getting off the streets when you can't document who you are and where you've been. She laid particular stress on the lack of easily accessible, pocket-size information about resources for homeless youth.

Emily finished her talk by pointing out that "the whole fabric of society" is affected by allowing a large population of homeless youth to live on the streets of Boston. She mentioned that crime goes up, prisons become overcrowded, medical and mental hospitals become overcrowded and food pantries are over-burdened. The gap in services for youth aged 18-24 has added to the problem, according to Emily. She mentioned that being offered a job at



Emily Russell

the Transformation Center was what helped her to get off the street. Transformation Center leadership heard Emily speak at a function at Bay Cove Mental Health Services and were moved to offer her a job.

We at the Transformation Center are proud that Emily was asked to speak about such an important issue. We are proud of her dedication and impressed by the rational, knowledgeable view she brings to a difficult subject.

Additional Resources

Music by Erica Badu, or Thievery Corporation Search YouTube for "Top Tracks for Thievery Corporation"

So called "Brain Music": *free* http://www.youtube.com/watch?v=Z5N3vjaY2ws

Penn Sound—*free* large collection of recordings of contemporary writing:

http://writing.upenn.edu/pennsound/

Www.ubu.com

Free Contemporary film, dance, art, music & poetry

<u>Craig Lewis recommends</u>: Petrograd—all of their cd's Mano Chau—all of their cd's

Valeria Chambers recommends:
http://www.websudoku.com/
free

Transformation Center Events and News

April

Spring Forums:

Whole Health Integration: Bridging a Path to Wellness

Registration is Required

Tuesday, <u>April 23</u>, 2013 Sturbridge, MA Wednesday, <u>April 24</u>, 2013 Dedham, MA

To register by phone, call 1-877-769-7693 Or 1-617-442-4111

For more information or to register online go to the Transformation Center Home Page:

www.transformation-center.org

Look under "Latest News"

Sponsored by Mass. Behavioral Health Partnership

May

The Transformation Center presents:

2013 Massachusetts Leadership Academy

The focus will be on New Peer Leadership in Mental Health. Including training on empowering wellness practices for leaders.

Tuesday, Wednesday and Thursday

May 13-15, 2013

Framingham, MA

Sponsored by Mass. Behavioral Health Partnership Registration is required. To register or for more information, please go to:

www.transformation-center.org

June

Coming soon!

The Transformation Center and Massachusetts

Organization for Addiction Recovery (MOAR) will host a <u>policy forum</u> on eligibility, enrollment and recovery support services in Healthcare Reform. Stay tuned to our website

www.transformation-center.org

Announcement: Next Class for Peer Specialist Certification

The next Certified Peer Specialist class will be held in August in Worcester. If you're interested in applying for the course, you should download the application (which will be posted by the second week of April) and follow the instructions for requesting an interview.

We do not take mail-in applications. All applicants are required to attend an interview and bring their application with them. Full instructions will be available on page one of the applica-

All updates will be announced in the Recovery Network News, on our website, and on our Facebook Page.

Thanks,

LYN

tion.

"Hope is like a road in the country: there was never a road, but when many people walk on it, the road comes into existence."

Lin Yutang



VOICES FOR CHANGE

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Nothing about us without us!

www.transformation-center.org

the new online issue:

As you can see, we have shifted to publishing our *Voices for Change* newsletter online. This is largely because the process of bulk-mailing paper copies through the post office has become both expensive and complicated, and requires special software. In the online publication, we will be able to have added features such as video and direct links. We will still be mailing some paper copies to most clubhouses and clinics, and we will bring paper copies to conferences. As usual, we welcome your feedback and suggestions!



Second Annual Run-Walk

We are pleased to announce the Transformation Center's 2nd Annual 5K Run-Walk this Fall at Jamaica Pond on September 22, 2013.

The 5K Run-Walk (you can walk or run or both) will kick off our campaign to promote exercise as a tool in recovery and challenge ourselves and our community to take charge of our physical wellness. There is growing evidence of the benefits of exercise in mood regulation, and many people with mental health conditions talk about their workouts as central to their well-being.

As part of our event, we are seeking donations so we can continue to foster health and wellness in our community. We will gladly receive donations in any amount or gift certificates.

For more information on the 5K Run-Walk or developing a partnership with the Transformation Center, you may email us at 5kflight@transformation-center.org. Thank you in advance for supporting the health of our community!