

EMPOWERING THE VOICE OF THE USERS

Empoderando a Voz do Usuário

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ABSTRACT: The article describes the creation, implementation and first year outcomes of the Speaking up community; "Telling Our Stories" program in Sao Paulo, Santa Maria, RS and Rio de Janeiro. The article shows how the program grew out of a call for more lived experiences of recovery among user in Brasil and how Richard Weingarten adapted a similar North American program for Brazilian culture. The aims of the CDF are to inform the public about the real lived experiences of mental disorders while at the same time eliminate the prejudice and discrimination often targeted at Brazilian users and their families. The article contains commentary by the various audiences that have participated in the CDF (medical schools, nursing programs, hospitals CAPs, family associations, etc.) as well as testimonials by users who have presented the program.

Keywords: User. Recovery. Empowerment. Mission. Speaking up community. "Telling Our Stories".

RESUMO: O artigo relata a criação, implementação e resultados do primeiro ano do programa Comunidade de Fala em São Paulo, Santa Maria, Rio Grande do Sul e Rio de Janeiro. O artigo descreve como o programa surgiu e como ele expandiu trazendo novos usuários para relatar a sua experiência de vida e o seu processo de recovery. O programa Comunidade de Fala é uma adaptação de um programa norte-mericano para a cultura brasileira desenvolvido por Richard Weingarten. Os objetivos da Comunidade de Fala são informar ao público sobre

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as vivências reais de transtornos mentais, ao mesmo tempo em que eliminam o preconceito e a discriminação freqüentemente direcionados aos usuários brasileiros e suas famílias. O artigo contém comentários dos diversos públicos que participaram da CDF (escolas médicas, enfermagem, CAPs, associações familiares, etc.), bem como testemunhos de usuários que apresentaram o programa.

Palavras-Chave: Usuário. Recovery. Empoderamento. Missão. Comunidade de Fala.

1 INTRODUCTION

This article tells the story of how Richard Weingarten found a mission collecting the narratives of mental illness and recovery from Brazilian users. Based on his previous work collecting recovery narratives in the United States and Brazil, Richard trained three teams of Brazilian users to write up and then tell their stories to community groups in Sao Paulo, Rio de Janeiro and Santa Maria, RS. The article also quotes from the various audiences that participated in this Comunidade de fala: Contando Nossas Historias (“Speaking up community;” Telling Our Stories”) program and also from testimonials by two users who relate their experience in the program after the first year.

I found that users in Brazil are eager to tell their stories but have had their voices suppressed and marginalized by the mental health system and the media. Having had experience in the USA empowering American users to tell their stories, I adapted a North American program to Brazilian culture and my own knowledge of the recovery process in Brazil. Since 2015 teams of users in the Comunidade de fala program in three cities have been enjoying great success. The article ends by quotes from the audiences that participated in the Comunidade de fala presentations and with testimonies from two users presenters.

2 RICHARD’S HISTORY WITH MENTAL ILLNESS: How He Stays Symptom-Free

Well, I’m a user Americano who’s been in recovery since 1986. (People with mental illness in Brazil are called users in Portuguese.) I consider my recovery complete because my illness doesn’t interfere with my life anymore.

However, for 12 years I struggled with seven psychotic episodes where I had persecutory delusions, five of which I had to be hospitalized, three severe depressions that lasted for several months, a dysthymia (low grade depression) for 19 years, plus the stigma, discrimination, incarceration and social marginalization (isolation) that goes hand in hand with being a person with a psychiatric disability,

Currently, I lead a disciplined life to stay symptom-free. I take two medications, an anti-depressive and an anti-psychotic every night. I also have incorporated healthy habits in my daily life such as adequate sleep and rest, regular exercise, three nutritious meals, a social support network of friends, spirituality, work or meaningful activity, etc. I see a therapist every other week for personal growth and support. His support helps me deal with longterm issues i.e. family relationships that haunt current relationships.

2.1 How Richard Was Empowered to Launch His Recovery

Empowerment interests me because I know how empowerment works when you're trying to move your life forward. According to Judi Chamberlin, in a much-sighted article,(1977), "A Functional Definition of Empowerment," Chamberlin(1997), identifies The key elements of empowerment: access to information and/or resources, ability to make choices, power to be assertive and to improve self esteem. I was empowered in all these ways when I got involved in a user self help group that was putting together a discharge handbook for users coming out of a Cleveland, Ohio mental hospital. This empowering experience helped me start my recovery and create a new narrative for my life.

My previous employment as a high school teacher ended disastrously when I revealed to a colleague that I had a chronic mental illness and the teaching staff shunned me for the rest of the school year. On the handbook project, using my skills as a reporter my consumer colleagues and I were able to create a handbook that helped users and their families access mental health services and programs in the Cleveland area. My self confidence and self esteem was restored during the eight months I worked on this project. In wanting to contribute to my community, I don't think I'm that different from most users in recovery. I felt like a productive citizen again.

The staff at Hill House, a public mental health agency in Cleveland, Ohio, where this consumer group and project was based was very empowering and welcoming. The head of their research department, Dr. Mieko Smith, showed all of us great respect and affection. She set me up with a desk, typewriter and telephone at the agency and invited me to work on this project whenever I was able. (She empowered me with resources. It was my choice whether to come into work or not.) There was no schedule and I went into the agency one or two hours a day two or three times a week when I wasn't depressed. Twice a morning Mieko would walk by my desk and ask, ""Is everything alright?" "Do you need anything/" If I worked around the lunch hour, Mieko would invite me to have lunch with her and her staff. If I wasn't up for joining them, they asked what they could bring back for me. Their caring manner helped me feel more valued and included. Having been devalued by having the label of mental illness and being unemployed, I appreciated their attention and inclusive manner very much

The director of the agency, Henry T. Tanaka, — everyone called him Hank — had “open door” policy. Anyone could talk to Hank in his office without an appointment. I went to talk with him when I felt up to it. Hank told me stories of consumers who had worked at Hill House and then gone on to do great things in mental health. He told me about the national consumer movement. (The consumer movement was involved in advocating more humane treatment in psychiatric hospitals, sponsoring self help groups and consumer-run businesses, national and regional conferences, and much more. Since I saw myself as a member of the “60s generation,” I was quite interested in what the consumer movement, which was another civil rights movement, was trying to gain i.e. equal rights and better treatment for people with mental illness, an oppressed and stigmatized minority. Hank encouraged me to attend a regional mental health conference in the nearby state of Michigan. I participated in the conference and saw the work and influence of the consumer movement. I began to see a role for myself in the consumer movement. Thus, my life began to take on a new narrative, another element in my empowerment process. Between the respectful and inclusive treatment I received from Mieko and Hank and their staff while working on the handbook, I saw the product of my labor contributing to the mental health community in Cleveland. I felt proud of this work and valued again. And I saw a new role for my life as a militant in the consumer movement.

2.2 Richard Makes Better Decisions in Recovery

During the eight months I worked on this handbook project, I started to make better decisions for myself and got out of my apartment more. I joined a spiritual community where I made new friends, and got involved in their social action projects. I began a romantic relationship. I joined a peer support group for consumers with mood disorders. I took a leadership position in a self help group that was opening a drop in center for consumers in the evenings and on the weekends. With all this activity and contact with consumer and other friends, my life normalized and I accepted my illness now that my illness didn't define me and I could see a way forward. I even found part-time work by the time I finished working on the handbook project. I had made many new friends and felt a social person again i.e. I stopped being reclusive and wanted to leave my apartment to go out with my new friends and engage in new activities. With this empowering Handbook project I launched my recovery. I saw myself as an active and productive person again.

One more development was taking on the valued role of "information giver" that a former therapist suggested to me when I sent him a copy of the handbook. Thus, I started to write articles and speak out about my illness and recovery. With the part-time job as a "(mental health) outreach worker" at a social service agency, and my new role as an "Information giver," my life took on new meaning and purpose, and my recovery was launched.

In the four years following the handbook project, I entered a new phase in my recovery. I took "personal responsibility" for finding employment that would 1) give me an income I needed to live on and 2) be meaningful and consistent with my values. At the end of this search, after working as a "outreach worker" in mental health, after that working as a staff writer for a suburban newspaper and later as a college instructor teaching undergraduates and adults Brazilian culture and Portuguese, I found a full time position or "meaningful role in society" as Director of Peer Support at a large mental health center in New Haven, Connecticut. Thus, my recovery was complete. I worked as a Director of Peer Support in New Haven for the next ten years.

2.3 Richard's History in Brazil: How He Discovered Brazilian Users Overcoming Their Illnesses

So why does recovery in Brazil interest me? I served in the Peace Corps in Brazil in the late 1960s, fell in love with Brazilian culture and learned to speak Portuguese. I began coming to Brazil for mental health conferences and programs in the late 1990s. I met many users, primarily in Rio de Janeiro. Each year I'd see many of the same users and I noticed how their lives were changing. Some had gotten jobs, others were taking classes, some were even getting married. They had learned to manage their illnesses and were reclaiming new lives for themselves like I had done. They're in recovery I told myself and my Brazilian colleagues. So in 2000, I made a proposal to collect recovery stories with Projeto Transversoes where Professor Eduardo Vasconcelos was director, and with the Franco Basaglia Institute in Rio. They liked and approved of my proposal and in 2001 I made two trips to Brazil where I interviewed about 30 users from all over Brazil. I asked them to tell me their recovery stories and how things got better for them.

In 2006 Professor Vasconcelos and Richard published a book of 17 recovery stories, "Reinventando a Vida; Narrativas de Recuperacao e Convivencia com Transtorno Mental" The book has been very successful. I later learned that it has been taught in colleges and universities around Brazil and that associations of families and user met to discuss it. In 2010, when I was in Brasilia, participating in the Fourth National Mental Health Conference I was thrilled to see my book being sold at the Conference literature table. "Wow," I said to myself. "Did I really do that?"

2.4 Richard Finds His Mission: Collecting Recovery Narratives in Brazil:

Now let us fast forward to May 2014 when I attended a Symposium of Recovery and Rehabilitation in Campinas, SP. One afternoon the large group of primarily mental health professionals at the Symposium discussed the subject of Recovery and Rehabilitation. I remember that they couldn't reach a consensus because as one person put it, "We do not know enough about recovery in Brazil because we have not seen enough recovery experiences by Brazilian users." Hearing that, a light bulb went on in my head. I saw a new mission for myself collecting recovery narratives by Brazilian users.

So I went back to New Haven, Connecticut, my home in the States, and started thinking of ways I could collect Brazilian recovery narratives. After speaking with American and Brazilian colleagues, I came up with a plan. Back in 2003, in Connecticut, I had introduced a video program called “In Our Own Voice” (“Em Nossa Propria Voz” in Portuguese) in which American users tell their stories of illness and recovery. “In Our Own Voice” (Em Nossa Propria Voz) was developed and sponsored by NAMI, the National (family) Association on Mental Illness. The video program is organized in five segments. Each video segment is followed by two American users telling their story in conjunction with the segment. The audience has an opportunity to ask questions and make comments after each segment. By the end of the program each user has told his/her own narrative. The users loved doing it, and the public was very grateful to learn about the lived experiences of the users’ recovery. The first year my team and I presented the video program to more than 100 diverse audiences. I received an award for this work in 2003. The NAMI office in Connecticut had to hire an user to coordinate the new user-run program.

So thinking about the 2014 Symposium in Campinas, I thought to myself, “Why can’t I adapt Em Nossa Propria Voz: Contando Nossas Historias (‘In Our Own Voice’) for Brazilian audiences taking into account Brazilian culture and the experiences of illness and recovery of Brazilian users?” I showed my adaptation to my Brazilian friend, Dr. Mark Costa, who was in New Haven working at Yale University’s Department of Psychiatry. Mark liked the Brazilian adaptation, in which I created six segments beginning with segment one, “Difficult Days,” then to “Acceptance,” then “Treatment: What Helped in Treatment and What Hurt,” on to “Coping the Daily Problems Related to My Illness,” then “I Am the Subject of My Own Story” and finally, “Successes, Hopes and Dreams.” The trajectory of these segments is like a moving train, with each new segment (wagon) pulling the train forward. It goes from the difficult to treatment, to coping to success to a glance at the future.

3 TRAINING THE COMUNIDADE DE FALA TEAMS IN SÃO PAULO AND SANTA MARIA, RS

I then sent a proposal to the CDF program, with the adaptation, to Cecilia Villares, an occupational therapist whom I’d met at the 2014 Campinas Symposium. Cecilia impressed me at the Symposium by her openness to new ideas. I traveled to Sao Paulo in March 2014 to

introduce the program with Cecilia acting as supervisor. Cecilia, affectionately called Cica by everyone, had a very nice way of working with users and was a joy to work with.

Cecilia and I recruited and selected ten talented users from the Sao Paulo area. With Cica's assistance I gave the four-day training to the users. The rest is history. The Sao Paulo team has done 50 or more presentations of the CDF to a wide range of audiences. They have presented at medical schools (to staff and students), to nursing students, psychology students, CAPS (day treatment centers), associations of users and families, hospital staffs, and other groups. They even presented to the City Council of Sao Paulo! I introduced that program myself!

After training the team of presenters in Sao Paulo, in April 2015, I went to Santa Maria, RS where I was invited to introduce the program by Dr. Martha de Noal, a dynamic psychiatrist who co-founded the Associacao de Families and Users that have Bipolar illness (AFAB). Martha and I recruited and trained nine very capable users to present the CDF in and around Santa Maria. In the past year they have also presented to a similarly wide variety of audiences, including at regional conferences and in public high schools.

3.1 Why the Comunidade de Fala Found Success in Brazil: Empowering User Voice

You might be asking yourself why has the CDF been so successful? I think the answer rests on a suppressed wish on the part of the users to speak out, to tell people about their experience as they see it. Except in a few instances and locations the voice of the user has not been welcomed. The mental health system in Brazil does not empower the user voice. It ignores it, if it doesn't suppress it altogether. The first opposing voice is the psychiatrist's voice. This voice telling the diagnosis, symptoms, prescription of medications, etc. is loud and clear and highly respected in Brazil. A second powerful voice is that of the clinician or mental health worker. The clinician or worker takes what the psychiatrist has given and identifies problems and weaknesses of the user as areas to work on. Family members often express a third voice by enforcing what the doctor prescribes. If the user doesn't cooperate, he or she is labeled a "bad patient" or "bad boy or girl". In this powerful chorus, the user voice is lost or disregarded. And I have not mentioned another strong voice, and perhaps the loudest voice of all, that of the media. The media often stigmatizes the user by instilling false stereotypes or attributes that people with mental illness are seen as violent, dangerous, unpredictable and incompetent. To

see more papers newspapers commonly sensationalize acts of violence attributed to “psychopaths” or former mental patients. The usual result of these powerful voices is the marginalization of the user, often resulting in his/her silence and isolation. In the face of these loud voices, the user’s voice is lost or goes unheard.

Yet users want to talk about their lives, their realities. How do I know this? I saw it with my own eyes back in Connecticut with the In Our Own Voice program. I heard it in the interviews we did in our book of Brazilian recovery stories. I heard it in Campinas when I interviewed users about their recoveries. And I heard it again from users wanting to be chosen for the CDF program. When asked, “Why do you want to work with us in the Comunidade de fala?,” we got the following answers, repeatedly: — I want to help others. — I want to tell my truth, my experiences. — I want to give back to the world a little of what was given me. (They have been given help and support and now wanted to return the favor in helpful ways to other users.)

When I began the project I thought each CDF program would run about 60 to 90 minutes as it does in the USA. But as the users relaxed and learned more of what their audiences were interested in, they expanded their talks. I should also point out that after each segment the audience has a few minutes to ask questions and make comments. This conversation between the presenters and the audience is really the heart of the program. These exchanges are where the most education and sharing take place. So now a typical program is likely to go on for two to three hours. After the program there is applause, expressed emotions, and hugging when the public goes up to the presenters to thank them personally for sharing their stories.

3.2 Why Audiences Love the Comunidade de Fala

What do the audiences get from this program? What do they think of after hearing the program? At the beginning of each program, we pass out evaluations to the members of the audience. They fill out the evaluations after the program telling who they are, what they liked about the program and what impact the program has on them, if any. Here are a few of their remarks about the program they just heard. — They help to understand the lived realities of the users. — This is the first time I’ve heard accounts from patients. Their stories are richer than what you read in text books. — Knowledge (of lived experience), is of additional value to the

psychology profession. — The point of view of the users provides a new perspective for the process of recovery.

Some comments are related to stigma: — It reduced a little of the stigma that persons with mental illness don't do normal activities in their daily lives. And the capacity of the presenters was evident. (In Brazil, a harsh, widespread stigma holds that users are incompetent or incapable once they are diagnosed with a mental illness.)

Other comments relate to recovery or, as it is often termed in Brazil, the “overcoming” (superacao) of the illness, and things related to the illness. — Through their personal experiences (one can see) their process of overcoming. — Hearing from the person him/herself who lives the problem and who speaks of his/ her course is worth more than hearing experts that know the subject theoretically.

Here's what one professional said: — The discussion of the patient's relationship with therapeutic support is important. It increases the responsibility of the professional to establish a good bond (with the patient). One student had this to say: — We students only have contact with the illnesses through theories. It was enriching to hear the experiences of people that go through these difficult situations.

Family members would sometimes come back to the CDF presentations two or three times because each program had two different users telling their unique experiences. Their stories give hope to family members. One family member said the following: — As a family member it is important to know that it's possible to lead a productive and happy life even with so many difficulties. Finally, yes, it's possible to grow old with a mental illness.

3.3 Impact of the Comunidade de Fala on Presenters

You may be wondering what impact the program has had on the user presenters. I asked myself the same question and asked the users in Sao Paulo to write a brief testimony telling what they got out of the first year of the program. Here are two of the testimonies:

— For me, the past year with the CDF has been a year in which I saw the hope for a better future (for myself). I was hospitalized four times, and for a long time, but it was only at

Proesq (the outpatient clinic attached to the Department of Psychiatry at the Federal University of Sao Paulo that was where the CDF had their training, meetings and some presentations.) and with the CDF that I came to develop friendships with other users. This diminished my solitude. But beyond this, to give lectures is a very gratifying activity. Not only for reducing stigma, the return goes way beyond this. The sensation of being applauded, of feeling important, it's a pleasure that I hadn't had before. I thank everyone for this opportunity. Joao's parents are retired university professors.

Jose Alberto Orsi, one of two coordinators of the CDF in Sao Paulo, wrote: — In the 12 months that we've been together I had the opportunity to see casual friends sharing a journey become lifelong friends. I noted that sharing special moments, like combating stigma, each speaker spoke brilliantly in his/her own way. I also noted that each one in their own manner developed a rich presentation of stories and experiences that moved our audiences. It's with much pride that I'm part of this team that has made such a difference in my life and that has given me hope for the future.

Did you notice that both Joao and Jose mentioned seeing a better future for themselves as a result of this program. By seeing a future for themselves, and believing it, they are debunking the myth that mental illness is a death sentence, that there is no life after one is diagnosed. Both men were afflicted with a life-altering illness, but instead of accepting a dark destiny, they have put their experiences and lives into a living story — and there's more to come!

4 CONCLUSION

To conclude, the article revealed that Brazilian users, like their North American counterparts, are overcoming or moving beyond their psychiatric disabilities to reclaim new lives for themselves in recovery. Users in Brazil and the USA have shown a strong desire to tell people about their lived experiences. The *Comunidade de fala: Contando Nossas Historias* program in Brazil, developed by Richard Weingarten, gives users the opportunity to tell their stories of illness and recovery to community groups. Brazilian audiences gain clarity of the lived experience of illness and recovery and come away from the programs better informed about mental illness and recovery and feel more hopeful about the life prospects of the users.

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