Diagnosis: A Thousand Ordinary People Speak Out

Lois Holzman and Elisabeth Genn[1]

East Side Institute, NY NY

Correspondence should be addressed to Lois Holzman, East Side Institute, 119 West 23

St, Suite 902, NY NY 10011, lholzman@eastsideinstitute.org

---

[1] Elisabeth Genn collaborated on the creation of the analytic codes, conducted the coding and created written analytic summaries of the data. Throughout the analysis process she read and re-read through the data set, looking across participants to explore the nuances of people's responses and continuously looking for commonalities and differences. She approached the analysis process as a continuation of conversations with the participants, generating questions for herself, and then returning to the data to develop some beginning answers to those questions. Her analysis and reflection is fully integrated into this article.

**Abstract**

The public is rarely asked its opinions concerning mental health issues and, as revealed by a literature search, has never been surveyed without the use of medicalized, diagnostic forced choice illness language. This article reports on an ongoing community outreach project that gave people the opportunity to reflect on and share their thoughts about the medical-mental illness-diagnostic model and its impact on their lives. Two organizations with a long-standing opposition to the individualized model of human development and the medicalized understanding of emotionality designed and conducted open-ended surveys on emotional distress and diagnosis at two NYC street fairs and online. Results from over 1000 surveys are discussed and indicate that mental illness diagnosis is viewed as a necessary evil at best, and an isolating and destructive practice at worst. The results strongly suggest that ordinary people are important allies in the fight for alternatives to diagnosis.

**Diagnosis: One Thousand Ordinary People Speak Out**

One would be hard pressed to find a person living in the US (and, increasingly, most other countries) who isn't impacted on and influenced by the medical-mental illness-diagnostic model. This way of understanding, identifying and relating to emotional distress and problems in living is ever-present in news reports in print, television and social media, advertisements and commercials, documentaries, movies, TV shows and books. Highly regarded scientific bodies such as the National Institute of Health and the Center for Disease Control announce on their websites and to the press that 20-25% of US adults have a diagnosable mental illness, as do between 13- 20% of children 8 years old and up. People seeking help with how they are feeling and relating to others are told they are ill, have a mental disorder and given a diagnosis. In an overall environment so thoroughly medicalized, do people reflect on and consider this model and what they think about it? Can they imagine an understanding other than this one? Do they have any opportunities to talk with others?

My educated guess is that such opportunities are exceedingly rare. Professionals have forums, associations, publications and conferences to discuss these issues. So do individuals and families that choose to become active because of personal experience embroiled in the mental health system. But the millions of others—the single mother who is called to school because her son is identified as having behavior problems, the returning vet who has given up trying to find a job and doesn't go out of the house, the teenage girl who secretly cuts herself, to name a few—have no such resources, and no idea that examining the model is something one can do.

This article reports on an ongoing community outreach project that intervenes on this cultural vacuum. The project was designed to give people opportunities to think and speak about their understandings and feelings about mental health, and to gather some public opinion data on emotional distress and diagnosis. The history of the project and results from over 1000 surveys conducted on the streets and online will be presented.

**History and Rationale**

The project was launched by two New York City based organizations that have, for 40 years, been promoting and practicing non-medical model understandings and practices of psychology, psychotherapy, education, and human development: the East Side Institute for Group and Short Term Psychotherapy (Institute) and the Social Therapy Group (STG). The Institute (eastsideinstitute.org) is a training, education and research center that developed and practices a performatory, postmodern group approach to human and community development and learning, and promotes other relational, cultural and critical approaches. Hundreds of psychologists, counselors, educators, social workers and performing arts activists from dozens of countries have trained in social therapeutics, its overall methodology, and social therapy, its clinical practice. The STG (socialtherapygroup.com) is a center for the practice of social therapy in Brooklyn and Manhattan with a client base of 175-200 people of all ages. There are affiliated centers in Atlanta, Boston, Philadelphia and San Francisco, and dozens of practicing social therapists, trained by the Institute, who work at other institutions or in private practice across the US and other countries. Social Therapy is a non-diagnostic group approach

that focuses on continued emotional development. (For books, articles, chapters, essays and videos on the work of the Institute, the methodology of social therapeutics and the practice of social therapy, see eastsideinstitute.org, socialtherapygroup.com and loisholzman.org.)

Both organizations have a long-standing opposition to the individualized model of human development and the medicalized understanding of emotionality. Further, they share the perspective that community building is essential to emotional development. They work in various ways to involve people of all ages and walks of life in creating new ways of relating to "mental health," "mental illness," emotionality, and the broader issues of human development and learning. They host public forums, seminars and workshops open to all at their offices and at community organizations throughout NYC. In addition, for the past decade the two organizations have been doing community outreach on mental health and education topics, often with a short survey, on the streets of New York City.

Beginning in 2013, the Institute decided to structure the NYC street community outreach into a pilot project gathering public opinion. Several factors led to this decision, as well as to the subsequent online survey begun in 2015.

1. During 2003-5 legislation requiring the licensing of professionals who practice psychotherapy or counseling went into effect in New York State. What soon followed was further legislation restricting where practitioners who were eligible for licensing could accumulate supervised practice hours. The result was a narrowing of psychotherapeutic and counseling approaches and a limiting of the kinds of institutions that practitioners can be exposed to during their training and early years of practice. This, in turn, reduced the treatment options—as well as understandings of emotional distress—

available to the public. Not only are professionals available to help those seeking help in clinics, schools and community centers becoming more restricted in what they can offer, those aspiring practitioners fresh out of school are less and less exposed to a variety of approaches. For example, Heatherington, Messer, Angus, Strauman, Friedlander and Kolden (2012) report on the narrowing of theoretical orientations for those in clinical psychology doctoral training.

We wanted to learn from ordinary people how they were being impacted upon by the pervasiveness of the biologically-based diagnostic model—broadly speaking, as with the media and ad campaigns of the pharmaceutical companies, and the attempt to reduce stigma with a "mental problems are an illness" public service campaign—and on the local level in their visits to their physicians and local clinics, and meetings with the teachers, counselors and social workers at their neighborhood schools.

2. The revision of the DSM (titled *DSM-5*) generated significant controversy and was a hotly debated topic among professionals and in the media in the years leading up to its publication in 2013. Informed and/or activist consumers, especially parents of children with a diagnosis of autism or Asperger's, took to the blogosphere. However, the broader public had little opportunity to participate in this important dialogue. We know from history that efforts to change or eliminate the medicalization of specific "disorders" were successful because grassroots support was mobilized, as in the case of homosexuality.

3. The biases of opinion polls. A literature search produced only a few published public opinion studies on mental health topics (Kuppin and Carpiano, 2006; Riedel-Heller, Matschinger and Angermeyer, 2005; Levi and Haslam, 2006; Mehta and Farina, 1997; O'Conner and Joffe, 2013; Pescosolido, Martin, Long, Medina, Phelan and Link,

2010; Seeman, Tang and Brown, 2015). Of these, there were none that did not presume a medical model, use conventional illness labels such as schizophrenia and depression and/or present people with forced choice. This was the case whether the purpose of the study was to discover correlations between lay people's beliefs about mental illness and the treatment options they favor, or to examine whether a disease view of mental disorder reduces stigma (apparently, it does not).

For example, Kuppin and Carpiano (1996) reported on a study of lay beliefs about the causes of disorders in which respondents were to choose between biological and upbringing explanations of schizophrenia and substance abuse in a hypothetical case. The choices not only presume but also perpetuate the beliefs that schizophrenia and substance abuse are universally agreed upon conditions and that they have one or the other identifiable cause. Similarly, Riedel-Heller, Matschinger and Angermeyer (2005) used a hypothetical scenario in interviewing 5000 Germans to learn their preferences in treatment for schizophrenia and depression. The options in this study cast a fairly wide net, and included natural remedies, acupuncture, relaxation, meditation/yoga in addition to psychotherapy, psychotropic drugs and ECT. Nevertheless, the choices interviewees could make were only among individualized treatments of presumed aliments.

To the extent that the existing research uses medicalized language (such as mental disorder, addiction, substance abuse, ailments, people living with mental illness) it preempts any consideration by the public of personhood, subjectivity, emotionality, social relations and social activities. It also leaves no room for opinions on the politics of such discourse and the role of the mental health institutional complex in perpetuating it and closing off the possibility of alternatives. How lay people think about these issues is

critically important to how they currently relate to mental health and how they might participate in transforming it.

In contrast to the existing literature, the Institute-STG surveys were open-ended. Participants responded in their own words to a series of questions.

## The Surveys

### Street Surveys: 2013-2014

During the summers of 2013-14 we conducted surveys on diagnosis and mental health on the streets of New York City as a form of community outreach. Having spoken to nearly 300 people, we realized that we had the makings of a pilot project designed to include the voices of ordinary people in the dialogue on alternatives to diagnosis. We did a rudimentary analysis of the survey data, wrote up the results and presented them to colleagues who were vocally critical of *DSM-5* and medicalized diagnosis more generally.

The surveys were conducted at two annual NYC street fairs attended by hundreds of thousands of people: Harlem Week and Atlantic Antic. Harlem Week is a celebration of Harlem's rich cultural, economic and political history attended by people from throughout the New York metropolitan area as well as tourists. Atlantic Antic, a one-day affair, showcases the cultural diversity of Brooklyn. Spanning four neighborhoods, it is the largest street fair in NYC. These fairs were chosen as locations with a strong and steady flow of people browsing and eager to see what the next booth would bring. In

addition, both have an ethnically diverse crowd with substantial African American and working class representation.

The surveys were conducted on Sunday afternoons. At each fair, the Institute and STG shared a booth that displayed literature, books and fliers. The booth was staffed by 5-6 people (a mixture of staff, students, clients and volunteers) who fanned out and stopped walkersby and asked them to talk. After introducing themselves and the purpose of the survey, the survey takers asked a series of open-ended questions and wrote down what people said on a separate sheet for each person. They then invited people to give their names and contact information for follow up. Conversations lasted from five to over ten minutes each. Between 140-150 people completed the survey each year. They ranged in age from 15-80, with most being 35-55.

**Results.**

The 2013 survey (Figure 1) focused on diagnosis and its impact, asking if and how diagnosis was helpful and/or harmful. The majority of people (60%) said that diagnosis could be valuable, especially in providing relief to know "what's wrong." However, 90% of those who said diagnosis could be helpful had serious reservations, including: only sometimes; danger of misdiagnosis; the racism of diagnosis; stigma; and it leads to over-medication. These concerns were the same as those voiced by respondents who said that diagnosis was not helpful.

In 2014 the survey (Figure 2) more directly addressed the necessity of diagnosis (which is the case for people who use insurance coverage when seeking help). The survey also introduced the increasingly common language of brain disorder and chemical imbalance. 60% of respondents said people did not need a diagnosis to get help with their

emotional pain. Of those who said diagnosis was needed, nearly all said this was because it was the only way to get to talk to someone. They overwhelmingly said we shouldn't consider such people as having a brain disorder or chemical imbalance. Similar to the 2013 survey results concerning whether diagnosis was helpful or harmful, people—regardless of whether they said diagnosis was needed or not—expressed the same concerns about diagnosis, e.g., stigma, dangers of misdiagnosis, over-medication and racism.

> "Once you have that label it doesn't stay at the clinic. You carry it with
> you for a long time."
>
> "People start calling you crazy. It can be a shame for the family."
>
> "Getting a diagnosis limits life experience, you're treated differently, you
> feel like an outcast."
>
> "Its good to know what's wrong, but it might make them feel worse about
> themselves and put them in a box."

Several people who had completed the surveys at the 2014 street fairs were among those who attended a public forum on "Do Diagnostic Labels Determine Who We Are?" At the forum, which was facilitated by the director of the STG, people shared experiences and opinions about drug companies, the school system and mental health clinics. They also responded to hearing from the facilitator about alternative ways to understand and deal with emotional pain and to relate to diagnosis, and shared how they felt about having this kind of conversation. Participants completed a written exit poll at the end of the forum.

Diagnosis: People Speak Out

All 40 in attendance answered yes to, "This conversation on diagnosis and labeling made me think about some things in new ways." Here's a small sample of what people wrote in response to "What's something you might share with a friend?"

> I will be sharing everything with a friend especially the importance of
>> labeling and how powerful that can be or damaging."
> "To encourage people more to speak more public about the topic of mental
>> illness and alternatives to medication and treatment."
> "The political consequences of diagnosis."
> "The importance of being social and developing as a social being with a
>> community of people."
> "Stop worrying about the diagnosis and focus on what you can create with
>> it."

**Survey on Emotional Distress and Mental Health Diagnosis: 2015-2016**

The ease with which strangers on the street and at the forum engaged in conversations on the topic of diagnosis and the wealth of things they had to say suggested that we had tapped into a need to speak about these issues. Further, the professional response from colleagues in the DxSummit and to a report posted on Mad in America (Holzman, 2014; 2015) was equally encouraging. With the advice of colleagues, we made minor changes to the 2014 survey and, in May 2015, we posted the revised "Survey on Emotional Distress and Mental Health Diagnosis" online. It was shared with the Institute and STG's

networks, targeted blogs and newsletter sites, with invitations to take the survey and share it globally.

The online survey (Figure 3) consists of seven open-ended questions and a request for demographic information. In addition, participants were asked for an email address if they wanted to be contacted for a follow-up conversation.

**Results.**

From mid-May through December 2015, 597 people took the online survey. We also enter data from 145 surveys conducted at the street fairs that year. These 742 surveys are the combined data to be discussed here. (The survey remains online and, as of June 2016, an additional 50 remain to be analyzed.)

Demographics. Survey takers came from all over the globe: 34 different countries in Africa, Asia, Australia/New Zealand, Eastern and Western Europe, and Latin and North America. However, they were overwhelmingly from the US (73%, n= 539), with only six other countries having ten or more (Canada, Norway, UK, Brazil, Denmark and Australia, in that order). The majority were from urban areas (66%), with 26% suburban and 8% rural. 73% of survey takers identified themselves as female. 60% identified as white (followed by 23% as black, 9% as Latino, 4% Asian, and the remaining as Native American, mixed and other). Survey takers ranged in age from 16 to 75+, with 75% of them evenly distributed between ages 26-65.

Coding. Online survey data were collected using Google forms and stored in Google sheets. Five research assistants entered surveys collected on the street into the same Google form and sheet. The data were then uploaded into Dedoose and sorted by survey question. Top-level codes were developed separately for each research question.

For example, for the question: "Some people say that when people get a psychiatric diagnosis, it can be helpful and others say it can be harmful. What do you think?" the top-level codes were 1) *Helpful*; 2) *Harmful;* 3) *Both Helpful and Harmful*, or 4) *Unclear/No answer*.

After the top-level codes were created, the research team read through a random selection of 50 responses for each question and used open coding to generate a list of potential analytic sub-codes for each top-level code. These codes were then applied to another set of 25 randomly selected surveys in order to choose the 3-4 sub-codes that were most useful in understanding the responses.  For example the final sub-codes for *Helpful* were 1) Allows people to get appropriate help; 2) Diagnosis is helpful for pragmatic reasons, and 3) People need explanations. Once the complete code-tree was created for each question, the research team continued coding together until they reached a level of inter-rater reliability of 95%. At the completion of the coding process, Dedoose was used to generate descriptive statistics of the top-level codes and the demographic data. [2]

The Value of Diagnosis. We probed people's opinions concerning the value of diagnosis with three different questions: was it necessary; harmful or helpful; and should it be required. Across the three questions, results were consistently against diagnosis, and most negative relative to diagnosis being required.

Table 1: Is diagnosis…?

|  | No | Sometimes/ Depends/Both | Yes |
|---|---|---|---|
| Needed | 50% | 28% | 22% |
| Helpful | 20% | 58% | 18% |
| Required | 64% | 12% | 24% |

Note in Table 1 that only 20% answered that diagnosis is harmful. On the face of it, this response looks counter to that of the other questions in being supportive of diagnosis, but a look at the content of what people said indicates otherwise. The most common reason given for diagnosis being helpful were insurance coverage, often coupled with the relief of knowing what's wrong: "Being diagnosed correctly is the most important thing in a person's life. It is harmful not to know, because knowledge is power. If you don't know, how will you get the proper help."

Reasons given for the harmfulness of diagnosis had to do with limitations, constraints, stigma, illness language, isolation, and reductionism. Several people summed up both the help and the harm in comments like this one: "I think it depends on the individual. Certainly getting a diagnosis can help a person get their insurance to pay for therapy, so that is helpful. I think some people need explanations, find it a relief, so I guess that would be helpful. One problem is that people can so easily become their diagnosis—that is harmful, and can even be stigmatized."

The majority of respondents who answered "harmful or helpful, depending" went into further depth on these issues. For example, there were comments on the myth and illusion of diagnosis. Some people wrote of their concern that a diagnosis can give the false illusion of being helpful while actually doing nothing to help the person improve their situation. One respondent called this "illusion of comfort and respectability" dangerous. Several people commented that diagnosis is a lie that, as one person put it, "is

peddled by idiots." For some, this lie can never be helpful, but at least one person wrote

that it can actually be helpful despite the fact that it's a lie. Finally, one respondent said

that our bias toward believing experts is paradoxically part of what allows a diagnosis to

be helpful.

The stigma of a diagnosis was a common explanation of the harm it can do. The

limitations it places on one's identity by both self and others was a great concern,

including comments as to broader societal stigma, such as diagnosis being used against a

person in a custody battle or in seeking employment, as well as blatant institutional

mistreatment and civil rights violations as a result of a diagnosis. Others took issue with

how diagnosis narrows one's understanding of how to live in the world, urging that we,

instead, need to learn "to live with ambiguity and uncertainty," and develop "a new

language that doesn't suggest one will be suffering from the problem forever."

Taken together, responses to the three questions about the value of diagnosis

provided rich data on the range of connections to the personal and the political that

people made in their thinking about diagnosis and emotional distress. They addressed

both the pragmatic and the ethical, sometime in conflict with each other and sometimes

not. They talked about mental health being contaminated by big money, said that "money

wins but the problems still remain," that pharmaceutical companies can dictate diagnosis,

and that the push for diagnosis is more bureaucratic than therapeutic. As one person put

it, "It exists for the "bean-counters" at the insurance companies who have to tick boxes

While some people used language that suggested they believe the system to be nefarious,

others lamented that it is broken, self-perpetuating, and just responding to the natural

incentives of all the players even though no one in it may be ill-intentioned. Many people

said that they disagree with a diagnosis being a pre-requisite to help but billing requires it, and they do not see any way around it.

Some respondents said that requiring a diagnosis was not only wrong, it was also unethical. They argued that there should be more protections for the people being diagnosed and more consciousness of the power differential between the professional and the patient. Others said that the stigma of diagnosis is an unacceptable price to impose on a person seeking the most basic relief for emotional pain. Several respondents said that labels preclude the possibility of growth and development. Many said the current system creates unacceptable barriers to people getting help and has a detrimental effect that leads to people suffering alone. One police officer and one former member of the military wrote about the stigma of mental health services among their peers and the cost of their unwillingness to seek help when they needed it.

Another subset of responses that took issue with the role of diagnosis focused on the professionals who do the diagnosing. They pointed to the absurdity of attaching something so weighty, stigmatizing, and in some ways final to a person after seeing them once. They said that the people doing the diagnosing cannot possibly do it accurately under these circumstances, Further concerns referenced broader consequences of diagnosing.  One respondent said that the system shapes the mental health professional's thinking about each patient even when he or she disagrees with that system and does it only for the billing. Similarly, another respondent pointed out that if the system encourages professionals to look for major problems, they will find them where they may not exist. Many respondents worried that even when diagnoses are given just so people

can get some kind of help, this will shape how they think about themselves and cause them to worry about problems that are non-existent.

The validity of diagnosis more broadly, regardless of when and by whom it is done, was called into question, with one respondent describing it as "pseudo-scientific garbage" and others echoing that it has no scientific validity and that the DSM has been "confessed to be scientifically invalid." Related to this, some people talked about how mental health professionals are simply unqualified to do their job, or how they never agree on the right diagnosis for someone, pointing out the subjective nature of the inquiry. One respondent said that psychiatrists make things up as they go along, and that the current system is "institutionalized abuse." Others said that emotional distress can present in complex ways with diagnoses often not matching the symptoms fully or precisely. Many said that there is a massive danger to misdiagnosis, and gave examples of wrong medications being prescribed with terrible side effects and instances of long-term ill effects of being given the wrong diagnosis.

Resignation to what was perceived as a broken system was a common sentiment, as expressed when people told us that there is no choice, the system can't be changed, and that they could not conceive of an alternative.

Brain Disorder/Chemical Imbalance. Responses to the question, "Do we need to relate to people seeking psychological help as having brain disorders or chemical imbalances?" indicated that people were familiar with this language. The idea was soundly rejected by 65% of respondents, who either related to news reports on such brain research as pseudoscientific or a negation of the fact that human beings are social and cultural beings. Among those who said, "Yes" (15%) and "Sometimes" (20%), most were

acknowledging that the brain plays a role in people's emotionality. The following

comments exemplify both the attraction and the uncertainty these people appear to feel,

as well as their suspicion about, or at least concern with, simple causation.

"I've been diagnosed in the past with depression and anxiety. I find it very

difficult to embrace the idea that I have a brain disorder or

chemical imbalance yet at the same time I understand that I react

differently to certain things than other people I know. But I sort of

wish it was enough to just say, 'Everyone deals with things

differently—some people need help, and that doesn't mean there is

something disordered about them.'"

"I think we need to educate ourselves and others to the ways that stress

affects the body—'chemicals' as simple as adrenaline and cortisol,

and endorphins operate inside us and affect the way we feel.

Understanding that gives us handles for shifting how we feel

through a variety of strategies, such as meditation and exercise, as

well as through meaningful connection to others."

"I have a lot of background in biology and chemistry, and given what we

know about brain science now, our behavior is a result of our brain

chemistry, as well as our background. I don't see it as a cop out."

"I think that when we experience psychological distress, this is reflected

by changes in brain chemistry. However, it is not clear to me

whether the changes precede or follow the distress. I don't think it

> is helpful to separate the brain from the person. I think the 'both-
>
> and' nature of thinking brain and thinking person is not easy to
>
> arrive at."

The remaining survey questions included two that asked people about alternatives to diagnosis and one that invited them to tell something to the professionals who are debating diagnosis and alternatives to it among themselves.

Alternatives. We asked people what ways (other than diagnosis) people in emotional distress might be supported and helped. It is in responding to this question that people gave the most direct expression to social and holistic understandings of emotionality. The most common ways to help people in emotional distress involved doing something with other people. "Talking to others" and "being listened to" were the most frequent (47%), with therapy (17%), creating community (12%) and social activity (11%) given as other social, relational responses. Exercise (7%) and meditation/yoga (6%) were also frequent responses. (Since the question was open-ended, people could give as many examples as they wanted.)

We also asked people if they knew of any approaches or professionals that didn't use diagnosis. Nearly half (44%) said no. Of those who said yes, 70% gave at least one example. The most common examples were types of therapy (for example, emotion-based, solution-focused, Buddhist, Reiki, expressive arts, and social therapy). A small portion of respondents said religion or spirituality.

Tell the professionals. 87% of respondents had something to say to the professionals who are "exploring alternatives to diagnosis and developing ways to help

people emotionally." The majority urged professionals to pursue specific issues that, in most cases, they had commented on in response to prior questions. The recurring themes included: an increased focus on the individual person over their diagnosis (including honoring people's own language); a greater utilization of group environments; increased honesty with patients; an improved culture free of stigma; and more education and public forums on alternatives to diagnosis.

> "Please stop with diagnosing and do the work of a 'helping' professional.
>
> Pay attention to the patient and not the pharmaceutical companies."
>
> "Don't come up with another way to label."
>
> "Find a way to create a culture where talking about emotional upheaval
>
> and emotional problems is accepted and open outside of
>
> diagnosis."
>
> "I appreciate what you're doing. Mental health sold it soul to the medical
>
> field and is paying a heavy price."
>
> "Keep including us."

In addition, respondents urged professionals to continue this work: "Keep exploring. You're fighting a worthy uphill battle."

## Implications

The street and online surveys conducted by the Institute and STG gave people the

opportunity to reflect on and socialize their understandings of and opinions about emotional distress and diagnosis. Their willingness to do so and the range of topics they spoke and wrote shed some light on the impact of the current medical-mental illness-diagnostic model on ordinary people. Of interest is the similarity of responses to both personally conducted street surveys in the NYC area and online entries from across the US and 33 other countries. There were no significant differences in the substance of responses between the two groups, other than a more direct expression of gratitude by those interviewed in person (which was not surprising, since they had established a personal connection with the interviewer.)

The following is a summary of the most salient features of what these people told us.

- Despite the fact that emotional distress is presented as diagnosable illness by nearly every institution and professional people have contact with, most of them are not buying it. At best, diagnosis is a necessary evil, required under the current system in order to have the possibility of getting some help. At worst, it is stigmatizing, limiting of possibilities, isolating and potentially physically harmful.

- There was significant awareness of the corruption of mental health services by pharmaceutical companies and, more broadly, the politics of a medicalized mental health system.

- The idea that emotional distress is caused by chemical imbalance or brain disorder was soundly rejected. The popularization of neuroscience research seems bogus to some and to others a denial of mind-body holism and human relationality. Neither view dampers the interest people have in the notion that the brain plays a role in

our emotionality.

- Sociality and mind-body unity were also apparent in the responses to how to help people in emotional distress. Talking to people, being listened to, and therapy were most frequent. Social activities of many kinds, as well as yoga and meditation, were also common responses.

- There was an understanding of and appreciation for the impact of diagnosis on mental health professionals. Some people were critical and some were sympathetic of the predicament professionals face—having to work with a model that distorts the people in front of you and is impossible to "get right" but, nevertheless, being influenced to see and relate to people in terms of that model.

- People encouraged more surveys and conversations like these. 48% of survey takers asked to be contacted for further conversation.

- People were appreciative of being included in the ongoing debate over diagnosis and alternatives to it. They wanted their voices heard, with 87% of survey takers having something to tell the professionals directly.

These results are encouraging. Despite being bombarded with medical-mental illness-diagnostic propaganda, people are skeptical and, in most cases, they shared thoughtful and insightful concerns that ranged from pragmatic to ethical, from philosophical to political. They are clearly important allies in the continuing fight for alternatives to diagnosis.

## References

Heatherington, L., Messer, S. B., Angus, L., Strauman, T. J., Friedlander, M. L. &
Kolden, G. G. (2012), The narrowing of theoretical orientations in clinical
psychology doctoral training. *Clinical Psychology: Science and Practice, 19(4)*,
364-365.

Holzman, L. (2014). A report on community outreach: Lay opinions on emotional
distress and diagnosis. http://dxsummit.org/

Holzman, L. (2015). Survey on Emotional Distress and Mental Health Diagnosis: An
international campaign to include "regular people" in the conversation.
http://www.madinamerica.com/2015/07/survey-on-emotional-distress-and-
mental-health-diagnosis-an-international-campaign-to-include-regular-people-in-
the-conversation/

Kuppin, S. & Carpiano, R.M. (2006). Public conceptions of serious mental illness and
substance abuse, Their causes and treatments: Findings from the 1996 General
Social Survey. *American Journal of Public Health, 96(10*), 1766–1771.

Levi, S. & Haslam, M. (2006). Lay explanations of mental disorder: A test of the folk
psychiatry model. *Basic and Applied Social Psychology, 27(2*), 117-125.

Mehta, S. & Farina, A. (1997). Is being 'sick' really better? Effect of the disease view of
mental disorder on stigma. *Journal of Social and Clinical Psychology, 16(4)*, 405-
419.

O'Conner, C. & Joffe, H. (2013). How has neuroscience affected lay understandings of
personhood? A review of the evidence. *Public Understanding of Science, 22(3),*

254-268.

Pescosolido, B.A., Martin, J. K, Long, J. S, Medina, T. R, Phelan, J. C. & Link, B. G. (2010). "A disease like any other"? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence. *American Journal of Psychiatry*, *Nov;167(11)*:1321-30. doi: 10.1176/appi.ajp.2010.09121743. Epub 2010 Sep 15.

Riedel-Heller, S. G, Matschinger, H. & Angermeyer, M.C. (2005). Mental disorders-- who and what might help? Help-seeking and treatment preferences of the lay public. *Social Psychiatry and Psychiatric Epidemiology, 40(2),* 167-74.

Seeman, N., Tang, S. & Brown, A. D. (2015). World survey of mental illness stigma. *Journal of affective disorders*, *190*, 115-121.

Figure 1: 2013 Survey (n=143)

<div style="border:1px solid black">

1. What do you think about the use of psychiatric diagnosis for kids? How do you think this is affecting them?
2. A very high numbers of young people of color have been diagnosed and medicated, what do you think about that?
3. Some people say that when people get a psychiatric diagnosis it can be helpful to them. What do you think?
4. Some people say that when people get a psychiatric diagnosis it can be harmful to them. What do you think?
5. How do you think being labeled impacts a person?
6. For the past 30 years the Social Therapy Group has been practicing and training counselors in an approach that helps people without labeling them. (We do that by helping people grow their emotions). What do you think about that?

</div>

Figure 2: 2014 Survey (n = 149)

<div style="border:1px solid black">

1.We all know people who have gotten very depressed when they've lost a loved one, or children who cannot sit still in school, lots of folks who are angry and demoralized about not finding a job. Do you think any of these people need to get a diagnosis in order to get help with their emotional pain? (IF THEY SAY YES, ASK THE NEXT 2 QUESTIONS):

2. Do we need to relate to them as having brain disorders? Or chemical imbalances?

3. Right now, in most settings, if you want to get help with ANY kind of emotional pain from a mental health professional, they are required to give you a diagnosis. Do you agree with that?

4. Are there other ways to support people emotionally? What do you think could help them?

5. Like me, you probably know people in your family, church, or at work who have serious emotional problems, who may have been diagnosed with major depression, bipolar or schizophrenia. Obviously people deserve and need top quality mental health care including access to medication. Do you think that even in these situations a diagnosis can limit the person, label them, and stigmatize them? If so, how?

6. From our past surveys we have found that people are conflicted about diagnosis and labels. They find it relieving to get a diagnosis and at the same time feel like the

</div>

diagnosis can stigmatize or label them. Why do you think that so many of us are conflicted about this, feel it can be both helpful and harmful?

7. As I mentioned before, diagnosis is now a requirement for accessing mental health care in many settings. And mental health professionals the world over have formed a Global Summit to challenge this. To be effective, we think the community needs to play a more active role in the conversation. We have their ear. What would you like to say to them?

Figure 3: Online Survey (n=742)

*We are conducting research on how people think about emotional distress and mental health diagnoses. We are a group of researchers and practitioners who are concerned about our mental health system. We believe that a variety of mental health approaches should be available to people from all walks of life. During the last few years more and more mental health professionals around the world are talking to each other about diagnosing people who are experiencing emotional distress. They're concerned about the impact of giving and receiving a diagnosis, and the diagnostic system that is used in clinics, hospitals and private practices.*

*These discussions are primarily among professionals. We think this very important conversation needs the community's voice. We want to hear from you! We will make use of your responses to create a more vibrant and open dialogue. Please take a moment to take our survey. Your responses are completely anonymous.*

1. We all know people who have gotten very depressed when they've lost a loved one, children who cannot sit still in school, and lots of folks who are angry and demoralized about not finding a job. Do you think any of these people need to get a diagnosis in order to get help? Why or why not?

2. Do we need to relate to people seeking psychological help as having brain disorders or chemical imbalances? Why?

3. Are there other ways to support people emotionally? What do you think could help them?

4. Right now, in order to get help in most settings (clinics, hospitals or private practices), with ANY kind of emotional distress, the mental health professional is required to give you a diagnosis. Do you agree with that? Why or why not?

5. Some people say that when people get a psychiatric diagnosis, it can be helpful and others say it can be harmful. What do you think?

6. Are you aware of any therapeutic approaches or mental health professionals who don't use diagnosis?

7. Do you have any other thoughts you would like to share with mental health professionals around the world who are exploring alternatives to diagnosis and developing ways to help people emotionally? What would like to say to them?

8. We will be contacting a sample of respondents for a follow-up conversation. Please give us your name and email address if you want to be in that sample.