

Diagnosis: A Thousand People Speak Out

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Abstract

The public is rarely asked its opinions concerning mental health issues and, as revealed by a literature search, is almost never surveyed on this topic 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 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 online and at two New York City street fairs. Results from over 1,000 surveys 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 nonmental health professionals are important allies in the fight for alternatives to diagnosis.

Keywords

diagnosis of mental disorder, public opinion, surveys, community outreach

One would be hard pressed to find a person living in the United States (and, increasingly, most other countries) who is not affected and influenced by the

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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 announced on their websites and to the press that 17% to 20% of U.S. adults have a diagnosable mental illness (National Institute of Mental Health, 2017b), as do between 13% and 20% of children 8 years old and up (National Institute of Mental Health, 2017a). People seeking help with how they are feeling and relating to others are told they are ill, have a mental disorder and given a psychiatric diagnosis. In an overall environment so thoroughly medicalized, do people reflect on and consider this model and what do they think about it? Can they imagine an understanding other than this one? Do they have any opportunities to talk with others?

Our educated guess is that such opportunities are exceedingly rare. Professionals have forums, associations, publications, and conferences to discuss these issues. Individuals and families that choose to become active because of personal experience embroiled in the mental health system also have these outlets. 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 does not go out of the house, and the teenage girl who secretly cuts herself, to name a few—have no such resources to support the examination of the mental illness model.

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 1,000 surveys conducted on the streets and online are presented.

History and Rationale

The project was launched by two New York City (NYC)-based organizations that have, for 40 years, been promoting and practicing nonmedical 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; it also 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 is a center for the practice of social therapy in Brooklyn and Manhattan with a client base of 175 to 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 United States and other countries. Social therapy is a nondiagnostic 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 psychology in which development is understood as what happens to individuals, and to the medicalized understanding of emotionality. Furthermore, 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 conducting community outreach on mental health and education topics, often with a short survey, on the streets of NYC.

Beginning in 2013, the Institute decided to structure the NYC street community outreach into a pilot project gathering public opinion. There were several factors leading to this decision, as well as to the subsequent online survey begun in 2015, as follows:

1. During 2003-2005, 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 (“Social Work Licensure,” 2008). The result was a narrowing of psychotherapeutic and counseling approaches and a limiting of the kinds of institutions to which practitioners can be exposed during their training and early years of practice. This, in turn, reduced the number of treatment options—as well as understandings of emotional distress—available to the public. Not only are professionals who are available to those seeking help in clinics, schools, and community centers becoming more restricted in what they can offer but also those aspiring practitioners fresh out of school are less and less exposed to a variety of approaches. For

- example, Heatherington et al. (2012) reported on the narrowing of theoretical orientations for those in clinical psychology doctoral training to primarily cognitive behavioral therapy.
2. The revision of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*; American Psychiatric Association, 2013) 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 (Kamens, Robbins & Flanagan, 2017, 2018; Reese, 2013; Sun, 2013). Informed and/or activist consumers, especially parents of children with a diagnosis of autism or Asperger's, took to the blogosphere (Caplan, 2011; Lane, 2011; "They Hear You," 2014). 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 (Hickey, 2011).
 3. The biases of opinion polls. A comprehensive literature search produced only a few published public opinion studies on mental health topics (Kuppin & Carpiano, 2006; Levi & Haslam, 2006; Mehta & Farina, 1997; O'Conner & Joffe, 2013; Pescosolido et al., 2010; Riedel-Heller, Matschinger & Angermeyer, 2005; Seeman, Tang, & 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 specific forced choice options from which to choose. 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.

For example, Kuppin and Carpiano (2006) reported on a study of lay beliefs about the causes of disorders in which respondents chose between biological and upbringing explanations of schizophrenia and substance abuse in a hypothetical case. These choices not only presumed but also perpetuated the beliefs that schizophrenia and substance abuse are universally agreed on conditions and that they have one or the other identifiable cause. Similarly, Riedel-Heller et al. (2005) used a hypothetical scenario in interviewing 5,000 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 electroconvulsive therapy. Nevertheless, the

choices interviewees could make were only among individualized treatments of presumed ailments.

To the extent that this existing research uses medicalized language (such as mental disorder, addiction, substance abuse, ailments, and 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 the mental health institutional complex plays in perpetuating this discourse 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 services and how they might participate in transforming them.

In the present project, we wanted to learn from ordinary people about how they were being impacted on by the pervasiveness of the biologically based diagnostic model. What is the impact of the media and ad campaigns of the pharmaceutical companies? How have attempts to reduce stigma with “mental problems are an illness” public service campaigns affected them? We also were interested in more local impact, such as their visits to their physicians and local clinics, and meetings with the teachers, counselors, and social workers at their neighborhood schools.

The Surveys

The project described in this article had a mixed-method emergent iterative design spanning 3 years and consisting of two distinct phases. The first phase took place from 2013 to 2014 and involved the collection and analysis of surveys that had been administered during street fairs in Harlem and Brooklyn, New York. The qualitative analysis of these initial data led to a redesign of the survey and a widening of its distribution to include online data collection. The second set of data were then analyzed. In the sections that follow, we will first describe the methods of the 2013-2014 surveys, followed by a reporting of the findings for that period. We will then present the methods and findings for the 2015-2016 period. At the conclusion, we will provide a discussion across all the findings.

As with all surveys, the people who responded to these surveys chose to do so. Those who completed the in-person survey at the street fairs stopped to talk. They might have been curious about the small crowd gathered around the booth or the friendly person inviting them to talk, or perhaps they noticed the booth sign which read “Ordinary people never get asked . . .” Those who completed the survey online took the time to type their responses. They could have gotten the survey announcement directly from the Institute or STG, seen it in their Facebook or Twitter feed, had it passed on to them from a friend, coworker, or family member, been handed a hard copy that someone printed

out, or any number of other ways. We did not gather data on how participants received information about the survey. We assume that some proportion of respondents had heard of or were familiar with one or both of the organizations sponsoring the survey. However, given the thousands of people at the street fairs and the spread of the online survey on social media, it is more likely that it was the issue of diagnosis, and not the organizations, that drew people to complete the survey.

Street Surveys: 2013-2014

Method. During the summers of 2013-2014, we conducted surveys on diagnosis and mental health on the streets of NYC 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 these voices 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.

Setting. 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 1-day fair, showcases the cultural diversity of Brooklyn. Spanning four neighborhoods; it is the largest street fair in NYC.

Participants. 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 five to six people (a mixture of staff, students, clients, and volunteers) who fanned out and stopped walkers-by 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 5 to over 10 minutes each. Between 140 and 150 people completed the survey each year for a total of 300 surveys. Participants ranged in age from 15 to 80 years, with most being 35 to 55 years.

Table 1. Responses to Whether Diagnosis Is Needed, Helpful, and/or Required.

	No, %	Sometimes/ depends/both, %	Yes, %
Do you think people need to get a diagnosis in order to get help?	50	28	22
Do you think diagnosis can be helpful?	20	58	18
Should be people in mental distress be required to get a diagnosis in order to receive help?	64	12	24

Analysis. Preliminary analysis of the 2013-2014 survey data consisted of organizing the responses by survey question and reading through all of the answers to each of the questions as a group. The responses to each question were then categorized by type of response (i.e., diagnosis is always helpful, diagnosis is sometimes helpful and sometimes harmful, diagnosis is always harmful). This first level of codes was analyzed using descriptive statistics. The data for each survey question in each of these broad categories (see Appendix A and Appendix B) were then reexamined in order to develop analytic codes to create a more nuanced understanding of what the participants were saying. Statistics were not conducted on these more nuanced codes; however, the total data set for each code was checked by several readers to ensure accurate representation.

Results. The 2013 survey (Appendix A) focused on diagnosis and its impact, asking if and how diagnosis was helpful and/or harmful. The majority of respondents (60%) said that diagnosis could sometimes be helpful, especially in providing relief to know “what’s wrong.” However, when analyzed further, 90% of those who said diagnosis could be helpful had serious reservations. These reservations included recognizing the danger of misdiagnosis, the racism of diagnosis, stigma attached to diagnosis, and the ways diagnosis could lead to overmedication. Interestingly these concerns were also found in the analysis of responses by those who said that diagnosis was never helpful (see Table 1).

In 2014, the survey (see Appendix B) more directly addressed the necessity of diagnosis (e.g., a diagnosis is required to be reimbursed by an insurance company). The survey also introduced the increasingly common language of brain disorder and chemical imbalance. Sixty percent of respondents said people did not need a diagnosis to get help with their emotional pain. Of those who said diagnosis was needed in order to get help, over 75% said this was because it was the only way to receive insurance reimbursements when requesting help from practitioners. Participants overwhelmingly (92%) said, we should not 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—expressed the following concerns about diagnosis: stigma, dangers of misdiagnosis, overmedication, and racism. Examples of statements that participants made about these concerns included the following:

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.

It's 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 they shared how they felt about having this kind of conversation. Participants completed a written exit poll at the end of the forum. All 40 in attendance answered *yes* to the statement, “This conversation on diagnosis and labeling made me think about some things in new ways.” Below are some examples 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. Furthermore, the professional response from colleagues in the DxSummit (a forum for discussion of diagnostic alternatives that took place online from May 2013 to February 2015 and in person in Washington, D.C., in August 2014, dxsummit.org) and to a report posted on Mad in America (Holzman, 2015a, 2015b) 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.

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

Participants. From mid-May through December 2015, 597 people took the online survey. We also entered 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.) 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 United States (73%, $n = 539$), with only six other countries having 10 or more (Canada, Norway, the United Kingdom, 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% as Asian, and the remaining as Native American, mixed and other). Survey takers ranged in age from 16 to 75+ years, with 75% of them evenly distributed between ages 26 and 65 years.

Analysis. Online survey data were collected using Google forms and stored in Google sheets. Five research assistants entered surveys collected on the street that year into the same Google form and sheet. The data were then uploaded into Dedoose and sorted by survey question. Top-level qualitative 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*. At the completion of the coding process, Dedoose was used to generate descriptive statistics of the top-level codes and the demographic data.

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 subcodes for each top-level code. These codes were then applied to another set of 25 randomly selected surveys in order to choose the 3 to 4 subcodes that were most useful in understanding the responses. For example, the final subcodes 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 interrater reliability of 95%. This level of subcoding was not analyzed statistically, but was utilized in writing up the qualitative aspects of the study.

While the coding process was very important to the process of the research, throughout the data analysis process the researchers kept reading and rereading through the data set, looking across participants to explore the nuances of people's responses and continuously looking for commonalities and differences. Even while coding, we approached the analysis process as a continuation of conversations with the participants, generating questions for ourselves, and then returning to the data to develop some beginning answers to those questions.

Findings. Once the subcodes had been applied to all the responses in a category, they were read and reread to provide a deeper understanding and a rich description of the range of responses given by participants. For each subcode, several examples were identified as representative of the group and these were utilized in the writing up of the findings.

The value of diagnosis. We probed people's opinions concerning the value of diagnosis with three different questions: "Was it necessary?" "Was it 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.

Eighteen percentage answered that diagnosis is helpful, with the most common reason (60%) given that it allowed access to insurance coverage to receive treatment. Some people felt strongly that receiving a diagnosis could produce the relief of knowing what's wrong. For example, one person shared that, "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?"

In responding to this question, people offered a variety of ways they thought diagnosis could be harmful. These included its limitations and 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.

Thirty-five percentage of the 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. More specifically, one person wrote of a concern that a diagnosis can give the "false illusion of being helpful while actually doing nothing to help the person improve their situation." Another respondent viewed this "illusion of comfort and respectability" as 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 to receive a diagnosis despite the fact that it's a lie. Finally, one respondent said that, "believing experts is paradoxically part of what allows a diagnosis to be helpful because we can give responsibility over to an 'expert' instead of having to figure it out ourselves."

Some comments pointed to the stigma of diagnosis and the harm it can do. Diagnosis was seen as "limiting people's ways of seeing themselves and others." Others told stories about 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. There were also people who 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. Several people talked about how mental health services were contaminated by "big money." This was put most succinctly by the person who said, that "money wins but the problems still remain." They shared stories about how the pharmaceutical companies can dictate diagnosis, and that diagnosis "exists for the 'bean-counters' at the insurance companies who

have to tick boxes.” While some participants used language that suggested they believe the mental health system to be “nefarious,” others lamented that “it is broken, self-perpetuating,” and “simply responding to the natural incentives of all the players even though no one in it may be ill-intentioned.”

Approximately 15% of respondents said that requiring a diagnosis was not only wrong but also unethical. These participants argued that there should be more protections for the people being diagnosed and more awareness of the power differential between the professional and the patient. One person pointed out that the stigma of diagnosis is an “unacceptable price to impose on a person seeking the most basic relief for emotional pain.” Another said that “labels preclude the possibility of growth and development.” Almost 30% 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.

Approximately 10% of respondents who took issue with the role of diagnosis focused on the professionals who do the diagnosing. These participants emphasized the absurdity of attaching a label that is so “weighty,” stigmatizing, and in some ways final to a person after only seeing them once. As one of them said, “the people doing the diagnosing cannot possibly do it accurately under these circumstances.” Further concerns referenced the broader consequences of diagnosing. One respondent said that the “psychiatric system shapes the mental health professional’s thinking about each patient, even when he or she disagrees with that system and diagnoses only for billing purposes.” Similarly, another respondent pointed out that, “if the psychiatric system encourages professionals to look for major problems, they will find them where they may not exist.” Respondents worried that even when diagnoses are given “only for the purpose of access to services, this will shape how service users think about themselves and cause them to worry about problems that are nonexistent.”

The validity of diagnosis more broadly, regardless of when and by whom it is done, was called into question, with one respondent describing diagnosis as “pseudoscientific 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 stated that mental health professionals are “simply unqualified to do their job,” or how they “often do not 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 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. Ten people implied that diagnosis was very dangerous, with one person saying that “there is a massive danger to misdiagnosis,” and another who gave examples of

mistaken medications being prescribed with “terrible side effects and instances of long-term negative effects of being given the wrong diagnosis.”

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

Brain disorder/chemical imbalance. The idea that we “need to relate to people seeking psychological help as having brain disorders or chemical imbalances” was rejected by 65% of respondents, either calling news reports conveying that as “pseudoscientific” or a negation of the fact that human beings are social and cultural beings. The following comments exemplify an acknowledgment of the importance of the brain and the uncertainty people appear to feel about the relationship between biology and psychological diagnosis, as well as their suspicion about, or at least concern with, simple causation between brain and behavior.

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.

Alternatives. 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.

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 who did not use diagnosis. Nearly half (44%) said "No." Of those who said "Yes," 70% gave at least one example. The most common examples (85%) were types of therapy (e.g., emotion-based, solution-focused, Buddhist therapy, Reiki, expressive arts, and social therapy). A small portion (4%) of respondents said religion or spirituality.

Tell the professionals. Eighty-seven percentage of respondents had something to say to the professionals who are "exploring alternatives to diagnosis and developing ways to help people emotionally." A common response was to urge professionals to relate to people as human beings instead of focusing so much on diagnosis. One person said, "Pay attention to the patient and not the pharmaceutical companies," another urged professionals, "Don't come up with another way to label," and another asked that professionals, "Please stop with diagnosing and do the work of a 'helping' professional." Other participants expressed concern with the stigma of mental illness and asked professionals to "find a way to create a culture where talking about emotional upheaval and emotional problems is accepted and open outside of diagnosis." There was a pervasive message from the participants in the survey that professionals should "keep including us" in these conversations. There was also understanding and encouragement expressed by survey participants, with one respondent saying, "I appreciate what you're doing. Mental health sold its soul to the medical field and is paying a heavy price." Another urged professionals to continue raising questions about diagnosis, "Keep exploring. You're fighting a worthy uphill battle."

Discussion

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 about 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 United States and 33 other countries. There were no meaningful 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).

A summary of the most salient features of what people told us suggests that they are emotionally and intellectually engaged and often troubled by the understanding and treatment options currently available.

- 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 of health insurers 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, however, lessens 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.
- Participants encouraged more surveys and conversations like these. Indeed, 48% of survey takers asked to be contacted for further conversation.

- Participants 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, participants were skeptical and, in most cases, they shared thoughtful and insightful concerns that ranged from pragmatic to ethical, philosophical to political. Nonprofessionals are clearly important allies in the continuing fight for alternatives to diagnosis.

The findings indicate that people from all walks of life and relationships to the mental health system are eager to discuss diagnosis and its impact on their lives. However, limited resources meant, we were only able to reach a relatively small number of people. We are eager for others to continue this work by conducting surveys and conversations like these all over the world. In addition, many of the people we spoke with expressed an interest in continuing conversations on this topic. It would be extremely interesting to follow up this survey research with focus groups which could provide more richness to the data we collected and could continue to develop the public discourse. We are currently in the process of creating such conversations in partnership with a community-based organization, and we hope this article will inspire others to do so as well.

Appendix A

2013 Survey.

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?

Appendix B

2014 Survey.

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 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?

Appendix C

Online Survey.

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 e-mail address if you want to be in that sample.

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*Credit: Kira Bucca Photography.