

The Diagnostic Debate: Voices From the Street  
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I've been talking to strangers for 40 years. That's as long as I've had a PhD. I've spoken to many many 1000s, maybe even a million, New Yorkers on the streets and at their doors. I've petitioned for candidates, invited people to participate in privately funded innovative youth programs and international conferences, and conducted surveys on many topics—what people expect from their therapists, how they play, what they think their communities need, what kind of schools they would like to see, and more. For the past four years, I and my colleagues and students have been on the streets talking to people about how they feel about the current mental health system.

I don't talk to strangers by myself. There's always a team. And we don't only *talk to strangers* but we invite and train others—students, clients, professional colleagues, volunteers and staff—to go out on the streets and create conversation with whoever will stop and talk with them. We give people lots of support to succeed—improv and ensemble building exercises, role-plays—and a good basic script.

This kind of community organizing is hard work and energizing at the same time. It's humbling—both being ignored and connecting with someone are two ways it puts you in touch with our humanity. It's incredibly informative—and challenging of assumptions about people you didn't even know you had. And it's a great antidote to cynicism—the overall experience is how grateful people are that someone wants to talk *to them* about these kinds of issues. I realize that I could have devoted this presentation entirely to this kind of community organizing—as a methodology of human and community development research and practice. Maybe next year. But for this symposium, let me turn to the issue at hand—diagnosis and alternatives to it.

My focus today is two-fold: our 2013 and 2014 street surveys, and the online version we launched two months ago. [Survey on Emotional Distress and Mental Health Diagnoses](http://goo.gl/forms/pMJdbRBxzf) <http://goo.gl/forms/pMJdbRBxzf>.

#### Who launched the surveys?

Two New York City based organizations that are proponents and practitioners of non-medical model understandings and practices:

East Side Institute for Group and Short Term Psychotherapy  
Social Therapy Group

The Institute is training, education and research center that develops a performatory, postmodern, group approach to human and community development and learning, and promotes other relational, cultural and critical approaches. The Institute has trained 100s of psychologists, counselors, educators, social workers and performing arts activists from dozens of countries in social therapeutics.

The Social Therapy Group ([socialtherapygroup.com](http://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 other cities. Social Therapy is a non-diagnostic group approach that focuses on continued emotional development.

#### Reasons for the Surveys—A Brief History

— Our long-standing opposition to the medical model and diagnosis coupled with our 35-year practice of an effective non-diagnostic cultural-relational approach to therapy, training and supervision.

— Our commitment to community building as essential to emotional development and the involvement of 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.

— An increased concern when in 2003 New York State legislated licensing requirements for therapists. Subsequent legislation was enacted restricting sites allowable for students and new practitioners to be supervised and get their hours. This resulted in a narrowing of treatment options—as well as understandings of emotional distress—available to the public

— The revision of the DSM generated significant controversy and was a hot topic among professionals and in the media. Informed and/or activist consumers, especially parents of children with a diagnosis of autism or Asperger’s, took to the blogosphere. However, there’s been little opportunity for the broader public to participate in this important dialogue. We know that in the past, efforts to change or eliminate the medicalization of specific “disorders” were successful because grassroots support was mobilized, as in the case of homosexuality.

— The biases of opinion polls. The few published public opinion studies I could find are forced choice and presume a medical model. Our surveys are open-ended. We want to learn from ordinary people—in their own words—how they are being impacted upon by the pervasiveness of the biologically-based diagnostic model—the bombardment by media and ad campaigns of the pharmaceutical companies, and the attempt to reduce stigma with a “mental problems are an illness” public service campaign—not to mention their visits to their physicians and local clinics, and meetings with the teachers, counselors and social workers at their neighborhood schools. What do they think they need? What would be effective ways to involve people in learning about alternatives and, for those who wanted more choices, in shaping new approaches in collaboration with us and other like-minded professionals?

#### The Street Surveys

The surveys were conducted at two annual NYC street fairs attended by millions of people: Harlem Week and Atlantic Antic. These fairs were chosen as locations with a strong and steady flow of traffic of people browsing and eager to see what the next booth would bring. In addition, we were seeking 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 Social Therapy Group shared a booth that displayed literature, books and fliers. The booth was staffed by 5-6 people who fanned out and stopped walkers by and asked them to talk. Conversations lasted from five to over ten minutes each. In all, 143 people participated in the survey in 2013 and 149 in 2014. They ranged in age from 15-80, with most being between 35-55. Roughly half were African Americans.

### Results of the 2013 survey

The majority of people (60%) felt that diagnosis could be valuable, especially in providing relief to know “what’s wrong.”

90% of those who said diagnosis could be helpful had serious reservations—only sometimes, danger of misdiagnosis, the racism of diagnosis, stigma, leads to over-medication. These were the same kinds of things the 40% who said diagnosis *wasn't* helpful said. There was a particular vehemence against drugs for children.

“Medication makes you act out. My grandson was hyperactive, not ADHD and they wanted to put him on Ritalin – I told them no.”

“Kids get told in 1<sup>st</sup> grade they’re crazy—then it becomes a self-fulfilling prophecy.”

### The 2014 Survey

In 2014, we tried to go a little deeper and see if we could help people explore the apparent conflict around diagnosis, i.e., its value and its dangers. We also wanted to learn what they thought about the *necessity* and *mandate* of diagnosis.

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 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.

Across the board (whether they said diagnosis was needed or not), people again expressed concerns about diagnosis—the stigma, the dangers of misdiagnosis, and over-medication.

“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.”

Three months later in December 2014, we held a public event, “Do Diagnostic Labels Determine Who We Are?” Forty people attended the event, including some we had met doing the surveys. The conversation lasted two hours and the mostly working class adults who participated shared experiences and opinions about drug companies, the school system and mental health clinics; how they felt about having this kind of conversation; and responses to hearing from the facilitator about alternative ways to understand and deal with emotional pain and ways to relate to diagnosis.

We had a written exit poll at the end of the forum. All forty participants 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.”

Participants were enthusiastic and asked for more events like this one. Thirteen of the forty participants asked to volunteer as future survey takers.

The success of our pilot street surveys and the positive response to a written report on it from colleagues within the DxSummit and beyond spurred us on to tweak the survey and make it available to anyone who wanted to use it and take it—by posting it online and inviting others to post it, print it out, spread the word across the globe.

### The Survey on Emotional Distress and Mental Health Diagnosis—Early Results and What We’re Learning

The survey was put on line in late May of this year. It consists of seven open-ended questions and requests for demographic information.

As of now, it has been sent to the 10,000 people in the Institute's and Social Therapy Group's data base, the Future of Mental Health data base, posted on Dx Summit, Mad in America, my blog at Psychology Today, dozens of Facebook, Twitter, LinkedIn accounts, and postings by individuals. It's been translated into Portuguese and Spanish by colleagues in Brazil and NYC.

### What We've Got

As of Aug 2, 404 people completed surveys online.

They are overwhelmingly from the US but we have surveys from 21 other countries. They range in age from teens through the 80s, with 60% in their 30s to 60s. They are mostly urban and female. 68% are white. We were surprised at how many of them asked to be contacted for a follow-up conversation—62%.

At this point, we've done some basic coding of a little more than half the surveys. From these preliminary results, response look similar to the street surveys. More than half said diagnosis isn't needed. More than half said diagnosis was both harmful and helpful and 25% said it was harmful. This comment sums it up:

“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.”

Both online and on the street we also asked people about alternatives to diagnosis. To the question, “What do you think are ways to help people in emotional pain?” people had a lot to say—from talking to people (friends, family and therapists) to social or community building activities like volunteering, dance, art, to exercise, meditation, yoga. One person said this:

“What we need is more facilities where people can walk in and say 'Hey, I'm feeling really down today. Can I just be here for a while and see what could be a contribution to me and make me feel better?' I think this is true for most people but especially young people.”

In response to the question, “Are you aware of approaches or professionals that don't use diagnosis?” 75% said no (which means we have our work cut out for us).

Our last question could be the most relevant to you here today. We asked, “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?”

Here's what people, both on the streets and online, had to say:  
There were dozens of versions of the following—

Treat people with respect  
Stop with the pharmaceutical “fixes”  
Everyone is different  
Context matters  
Keep it up!

And a few choice quotes:

“Don't be constrained by what is. So many breakthroughs in human history are the result of folks cutting against the grain of what is. Dare to question established wisdom and convention”.

“Don't come up with another way to label.”

“Find away to create a culture where talking about emotional upheaval and emotional problems is accepted and open outside of diagnosis.”

“Play with diagnosis if you must have diagnosis. But don't believe that it is 'truth'.”

“We should be making the range of 'normal' bigger—not smaller.”

And perhaps the most telling comment:

“Keep including us.”

Next weekend my teams and I will be on the streets talking to strangers. How moralizing it would be if I can report from APA that psychologists from across the US and Canada are including them. I hope you make that possible.



## Survey on emotional distress and mental health diagnoses

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.

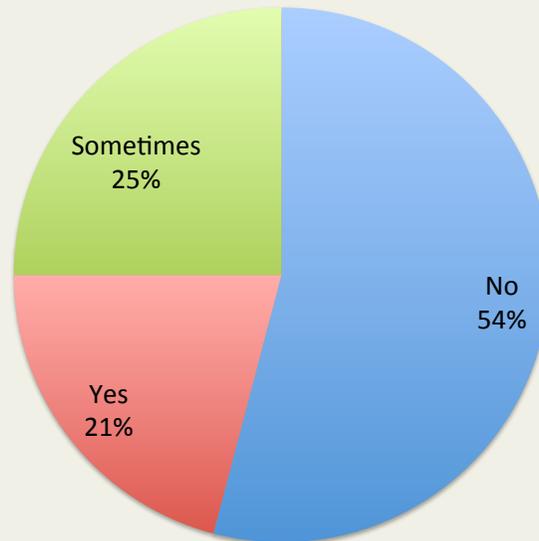
These discussions are primarily among professionals. We think this very important conversation needs the community's voice.

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.

\* Required

**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?**



**N=229**

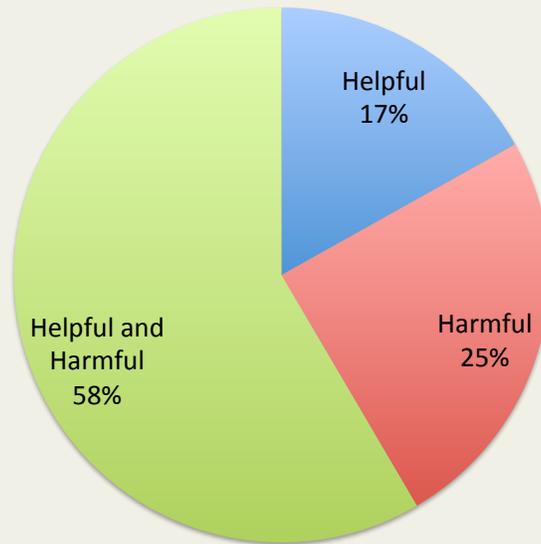
Some quotes:

“NO! That is ridiculous. Diagnosis was invented by and for the insurance and pharmaceutical companies not for the people who are in emotional pain.”

“I think I do - in order to provide treatment, it makes sense that it relate to a diagnosis. I would hope that the diagnosis could include "signs of depression" or "feelings of anxiety" - this doesn't require a clinical label, but acknowledges an unhealthy mental state that can be further addressed through counseling..”

“No, I don't agree at all. There is over diagnosing in this country to pad the pockets of the healthcare system. For example a lot of African-American children are diagnosed with ADHD and then placed in self-contained classrooms where they fail even more, when in fact there could have been many different ways to intervene on why the child could not stay still in class.”

**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?**



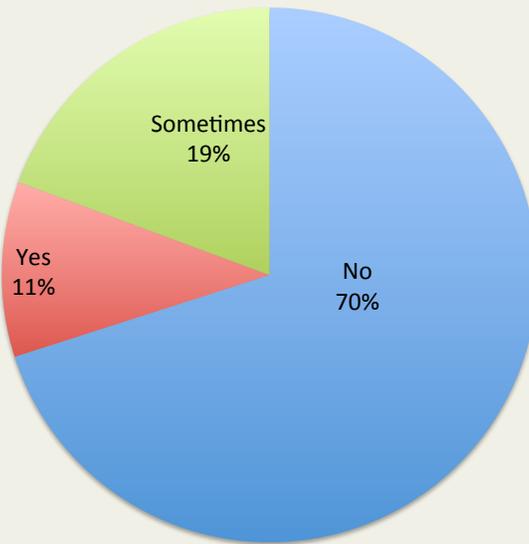
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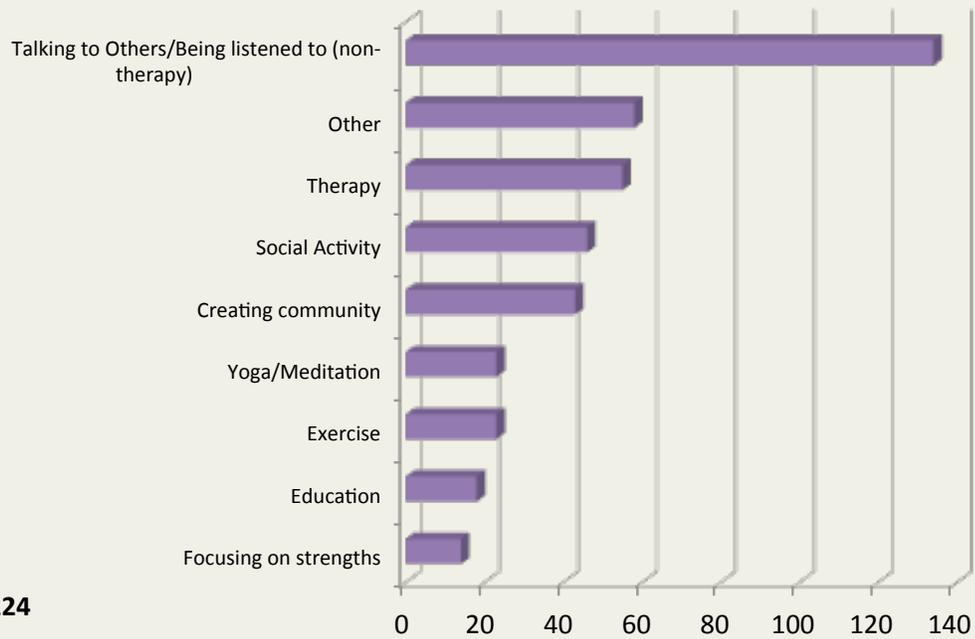
“It might be helpful, but it might also be harmful. Really depends on the full context. The client/consumer should get a say in it. Unfortunately, the way our society is currently structured, getting away from this kind of labeling is almost impossible.”

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



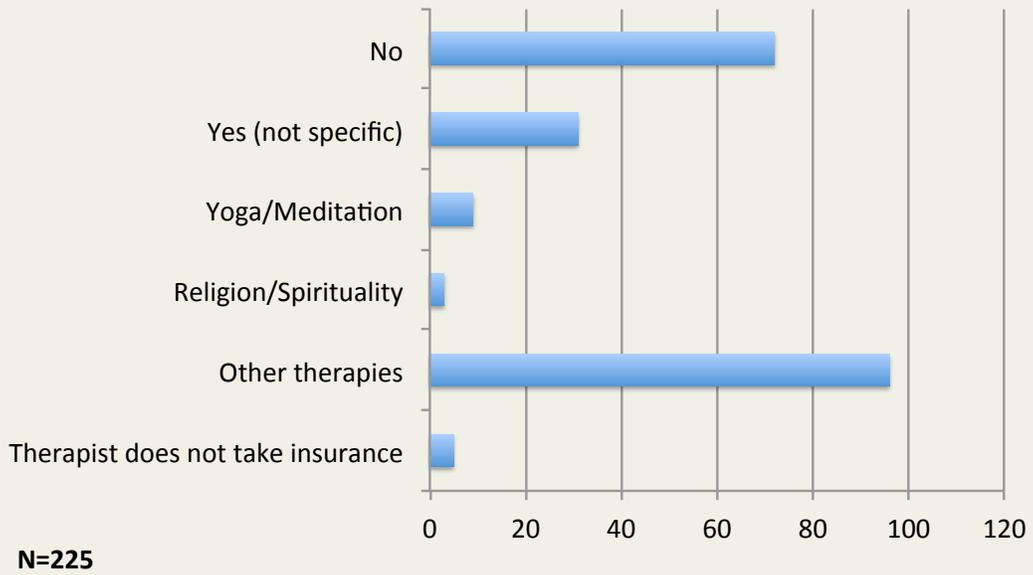
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## Are there other ways to support people emotionally? What do you think could help them?



**N=224**

Are you aware of any therapeutic approaches or mental health professionals who don't use diagnosis? If so, what are they?



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