

The Language of Mental Health

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This paper has been created to capture contributions from NEXUS partners and colleagues. In particular, it reflects conversations, research, and ideas from: Jessica Edwards, MPS; Rakesh Jain, MD, MPH; Debbie F. Plotnick, MSS, MLSP; Eric Riddle, MBA; and Hannah Zeller, MSW.





Executive Summary

This paper explores the roles of language in the many ways that mental health is understood, experienced, and cared for. It is not the goal of this paper to advocate for certain language choices, but to seek to understand how different people, communities, and stakeholder groups are making critical language decisions. Our belief is that the language of mental health will always remain dynamic and complex, and the best path forward is to commit ourselves to the task of understanding how, why, and to what ends others are selecting terminology. We frame this paper around a series of questions that, based on a wide range of expert interviews, we believe all people should ask themselves as they engage in conversations about mental health.

Introduction

From the Ivory Tower to the Blogosphere

Ahead of the publication of the DSM-V in 2013, Dr. Thomas Insel, who headed the National Institute of Mental Health (NIMH), declared that the updated version of the DSM should function as "at best, a dictionary" that "ensured that clinicians use the same terms in the same ways." Today, the American Psychiatric Association (APA) describes the DSM-V as "an authoritative volume that defines and classifies mental disorders."

The key terms offered by Dr. Insel and the APA—dictionary, define, classify—point to an enduring challenge among mental health care professionals: how to talk about mental health and mental illness and agree upon what key words mean. The World Health Organization has fueled the debate, stating that the lexicon in mental health can be "incomplete or spurious." Academics agree. A recent article in *The Journal of Substance Abuse* claims that language can "frame" how people "think about themselves" and it can "propagate stigma... depersonalizing people."

Advocates and people with lived experience fight similar battles. As one example, the website GirlBoss. com argues that we can "help end the stigma of mental illness" by making better language choices. But such choices are difficult, GirlBoss contends, because "there are more negative words than positive or neutral descriptors to choose from when referring to someone living with a mental illness."⁵

GirlBoss.com's position is representative. In researching for this paper, NEXUS hosted discussions with mental health advocacy organizations—such as the American Psychiatric Association Foundation, the Depression and Bipolar Support Alliance, Mental Health America, the National Alliance on Mental Illness, the Scattergood Foundation, the Stability Network, and more—and found that mental health advocates are looking for a better way to talk about mental health. Success has been patchy.

Across the mental health community—from the frontlines of advocacy to the highest levels of science—the difficult but urgent question persists: how should we talk about mental health?

This question is shrouded in both difficulty and urgency because of the myriad and messy ways that language choices can lead to—or deter—better care and treatment. And it demands our attention because the language we use has the power to stigmatize, alienate, and discriminate against the very people it is meant to support.

It is the goal of this paper to offer a path forward. We do not set out to define a lexicon or share a set of terms that we think are the best. Our goal is quite the opposite. In this paper, we seek to understand and share how different communities are thinking about the language of mental health—and how that thinking is guiding them to the language choices they're making.

We, as representatives of NEXUS, come to this question from different backgrounds, academic training paths, and sets of lived experiences. We recognize that we enter this dialogue with our own preferences, biases, and traditions. And while we disagree on some key points, we are united in one fundamental belief: we can improve the care and support of people with mental health challenges by encouraging ourselves to understand, respect, and accommodate the language choices that others are making.



This paper is not an exercise in picking winning terms or stamping out words we don't like. The goal is to improve our understanding, set the foundation for better dialogue across communities, and start down the path towards a future where mental health discussions lead to—rather than prevent—better health outcomes.



"I'm suffering with it and people are afraid to ask me about it."

James Meuer,

author of Damaged, a first-responder's memoir of trauma

An obvious—if imprecise—starting point is to quantify the debates about the language of mental health. One simple metric is the number of results collected through a web search:

"mental" AND "health" AND "language" AND "stigma" → 24,200,000 results

How do the 24.2 million results for mental health compare to results for heart disease and stroke, the two most common causes of death world-wide?⁶

"heart" AND "disease" AND "language" AND "stigma" \rightarrow 6,910,000 results

"stroke" AND "language" AND "stigma" → 4,690,000 results

And how does mental health compare to Alzheimer's disease?

"Alzheimer's" AND "disease" AND "language" AND "stigma" → 471,000

Though inexact, this exercise affirms an observational truth: the debates about language and stigma in mental health rage in both scope and intensity that exceed other highly prevalent health conditions. This exercise also demands that we ask the most fundamental question of all: why?

In researching this paper, we consulted with the NEXUS Advisory Council—consisting of advocates, professionals, and people with lived experience—and asked them why they think the language of mental health is such a complex and vital topic of debate. Of the many ideas that were shared, three overall themes emerged.

1. We inherit a linguistic heritage – and must therefore embrace both humility and curiosity

Each of us is an unwitting inheritor of a mental health lexicon. Professionals are taught by text-books, professors, and exams. Advocates learn and adopt the language of their organizations. People with lived experience are shaped by their own journeys and educations. Each of us, regardless of our position or stake in mental health, has

been influenced by mentors, teachers, families, and friends, as well as television, social media, and pop culture—and these influencers have passed on sets of terms that shape our thinking.

The concept of linguistic heritage is not, of course, unique to mental health. It's simply how language works. But in mental health, there is a unique and decisive distinction. More than any other branch of medicine, the discourse of mental health is structurally metaphorical. Across the spectrum of subjects—diagnosis, care, support, and even treatment—successful communication in mental health demands shared understanding of metaphors.

Spotlight on Trauma

The term "trauma" dates back to the late 17th century and was generally used to signify a flesh wound. It wasn't until the mid-1880s that the idea of trauma was linked to "hysteria" by Pierre Janet, a French pioneer of psychology. Janet contended that there was a strong connection between the "wound" of trauma and the psychological/emotional response of "hysteria."

The term "trauma" gained new currency following episodes of war. After the Civil War in America,

"trauma" was used in psychology and sociology alongside references to "soldier's heart," "nostalgia," and "traumatic stress reactions." Following the two World Wars, terms like "shell shock" and "battle fatigue" became used alongside "trauma." More recently, following the American-Vietnam War, Post-Traumatic Stress Disorder (PTSD) became a clinical diagnosis in the DSM-III

Questions about "trauma" today:

The use and meanings of "trauma" are still in flux today. A few key questions surface regarding its usage:

- When do physical and/or psychological experiences warrant the designation of the term? In other words, when and how does something—or should something—qualify as traumatic?
- How can people who have experienced trauma connect an experience and the subsequent emotions that were particular to their response?
- How can—and should—people who have lived through trauma retell their experiences?
- What are the degrees of trauma and how do varying degrees warrant different therapeutic responses?

Consider such terms such as "manic," "episode," "recovery," "stability," "competence," as well as "depression," "major depression," "bipolar," "trauma," etc. Now compare the metaphorical nature of these terms to the very non-metaphorical nature of MRI results, blood pressure readings, or glucose monitoring.

In mental health, it is language that guides diagnosis, care, and treatment, and this language is tangled up with influential metaphorical associations that cannot be unwound. And users of this language will articulate these determinative terms—and hear them—based on their unique heritage and deeply personal sets of experiences. Put another way, the language of mental health has rich connotative possibility and poor denotative specificity.

It's a problem with no solution. The vast and fascinating interplay of language will always refuse to be pinned down. One can recall Jonathan Swift's satirical episode in Gulliver's Travels when the narrator visits the Lagado Academy and witnesses their "scheme for entirely abolishing all words whatsoever." Swift is poking fun at contemporary scientific efforts to "provide a language that would be useful for the dissemination of scientific truths." As Swift suggests, language can't disseminate only scientific truths, because of its inherent connotative nature. Mental health illustrates this trap. The path forward, we would contend, is a strategy for thinking about language that prioritizes both *curiosity* and *humility*.

Curiosity gives us the power not to impose our own understanding on someone else's language, but to ask what that person might mean with their language. Curiosity demands that we pull ourselves out of our own comfort zones to meet others in their comfort zone. Curiosity forces us to listen with empathy and to stretch ourselves to

Curiosity

cu·ri·os·i·ty

gives us the power not to impose our own understanding on someone else's language, but to ask what that person might mean with their language.

Humility

hu·mil·i·ty

gives us the power not to structure a conversation on our language preferences or emotional associations, but to let a conversation build on someone else's. try to understand what someone means. Curiosity prompts the question: what is this person trying to convey to me?

Humility gives us the power not to structure a conversation on our language preferences or emotional associations, but to let a conversation build on someone else's. Humility demands us to recognize that our language isn't right or better. Humility forces us to accept that our language preferences are a complex and ultimately arbitrary interplay of inheritance, association, and cultural coding.

Humility prompts the question: why is this person choosing the terms they are sharing with me?

There is no overcoming or undercutting the challenges brought by linguistic heritage in the language of mental health. And maybe that's a good thing, because it leads us to embrace the ideas of humility and curiosity. And humility and curiosity, we would like to suggest, set the foundation not only for effective communication, but for understanding, empathy, and support.

Curiosity and Humility

RAKESH JAIN, MD, MPH PSYCHIATRIST

Language is a beautiful thing and I have been doubly, triply, or even more blessed to enjoy its wonders. English is my fifth language! I recommend keeping two things in mind when we discuss the use of language to understand and communicate about mental health issues: curiosity and humility. Curiosity is needed even if English is the primary language for both the speaker and the listener, as words have different meanings to different people and meaning is often indelibly created by our childhood experiences, and the social contacts we have as adults. Hence, having a curious and respectful mind when one listens to descriptions of mental anguish from a patient is incredibly helpful. I believe this curious mind approach leads to a deeper and more nuanced understanding of what is being conveyed to us. The second trait, humility, is also really important. Only by being truly open and humble does one truly understand what is being conveyed. After all, the only way we human beings can express our deepest fears and joys in our mind is through words, and words used with care and listened to with curiosity and humbleness truly help improve human bonds.



2. Language Is Not a Static, Fixed Code

If linguistic heritage shapes the ways that we select, associate, and deploy mental health terminology, the notion of "heritage" also posits that we must account for how things change over time. What a word means today is not what a word meant yesterday or what it'll mean tomorrow. Language evolves, adapts, and—to build on a theme introduced in the previous discussion—absorbs new connotations.

To put the matter plainly, consider the following anecdote, offered by a NEXUS advisor. It has been anonymized to protect privacy:



When I began working here, my manager and mentor was a veteran of the field, and she'd been a practicing social worker for three decades. I never doubted her good heart or good intentions, but as I was getting to know her, I found that she had a habit of saying things that made my skin crawl. She'd use certain words to describe people or events that I'd never use—and frankly she'd use words that I found offensive. I was put off. But as time went on, I realized that she was simply using the language that she'd used her whole life - and the language that she'd been trained to use. The lexicon of the community evolved while hers stayed fixed.

That's not her fault. It's just what it is.

This complexity of change cuts in multiple directions: not only across generations, as illustrated above, but also across socioeconomic lines of class, race, gender, sexuality, ethnicity, and more. It is also a complexity that intensifies as clinical and scientific terms travel into popular culture and colloquial discourse.

Pop culture, in particular, has a voracious appetite for the language of mental health. The Billboard music charts, for example, are packed with songs that use—or perhaps misuse—terms of mental health. Since the Billboard Hot 100 debuted in 1958, eleven songs have appeared on the charts with the title "Crazy," making "Crazy" as common of a song title as "Home," "Friends," and "Hallelujah," and more common than "One" and "Love Me."8

Music is hardly an aberration. Films depicting mental illness have surged in popularity in recent years. One academic study finds that "films depicting mental illness account for 15.7% of all [Academy Award] nominations and 17.2% of awards given out from 1977 to 2019."



It is not our intent to praise or criticize the adoption of mental health language and themes in music, film, or other commodities of pop culture. Our point is simply that pop culture uses the language of mental health—and its usages reach vast audiences and have profound influence. And that influence, in turn, further complicates what mental health terms communicate within clinical, educational, advocacy, and interpersonal settings.

We have previously stated that it is not our goal

in this paper to choose terms of which we do and do not approve. The "traveling" nature of words further illustrates why we made this decision. What a word means for one community at one point in time is something altogether different from what it means to another group in a different moment.

We cannot—and should not—try to fight or overcome this force. Instead, we'd refer back to the twin beliefs in curiosity and humility, as each can help us navigate the itinerant nature of language.

The Way Forward is **Empowerment**

KEN DUCKWORTH, MD

NATIONAL ALLIANCE ON MENTAL ILLNESS,
CHIEF MEDICAL OFFICER

Mental illness is difficult enough without compounding societal pressures. Stigma is a term commonly used to capture what I think is better captured by shame, prejudice and discrimination, and it is only one piece of the puzzle. The way forward is empowerment, where people feel validation that their experience is actually evidence. This lived experience will match scientific evidence. Members of the peer community can help teach each other. Experience is a different kind of evidence that we must attend to.

SHAME

is the internal experience that prevents people from seeking help.

PREJUDICE

is how other people think about those people once they know they live with a mental health condition.

DISCRIMINATION

is the reason we needed mental health parity legislation, and that battle is ongoing.

3. Stigma: The Problem to Solve or the Problem to Avoid?

To paint in very broad strokes, the mental health community's position on stigma and stigmatizing language could be plotted along a continuum. On one end are those who insist that stigma should be put at the forefront of all conversations about language. On the other end are those who contend that conversations about stigma have run their course and need to be left behind because talking about stigma only creates more stigma. Between these two poles is a vast middle-ground where many mental health stakeholders take their positions.

In researching for this paper, we heard persuasive arguments for a variety of different positions on this continuum, including that of avoiding discussion of stigma altogether. Ultimately, we conclude it belongs in this paper and in this broader project for a simple and unassailable reason: decreasing stigma remains a foremost priority for many within the mental health community, and any assessment of the language of mental health cannot ignore it. From church basements to community clinics to Capitol Hill, stigma remains a barrier to better care.

Stigma also demands our attention because of the powerful force it has on people experiencing mental health challenges. It has been described as "deep-rooted shame" and characterized as "discrimination." Stigma can operate as "self-stigma," when people stigmatize themselves for how they feel. We can see this manifest in the ways that diagnostic terminology operates grammatically.

The Great Debates

In the mental health lexicon, a few terms tend to attract the most attention and debate. Through NEXUS interviews and research, the following terms were called into question most often:

Does a person have a

"condition" or a "disorder"?

Does someone act as a

"caregiver," a "care partner," or a "supporter"?

Do people with mental health conditions face

"stigma" or "discrimination"?

Do people have

"lived experience" or are they "living with [condition]"?

Should solutions for mental health be

"patient-centered" or "person-centered"?

Does someone

"live with" or "suffer from" a mental health condition?

Does a person

"seek treatment" or "get support"? Consider, for example:

I have bipolar.

versus

I am bipolar.

In the latter construct, the "to be" verb ("am") precedes the diagnostic term ("bipolar"), setting up "bipolar" as an adjective. Adjectives, of course, are used to describe nouns (here, it's the pronoun "I"). Thus the adjective bipolar describes the "I" of the sentence.

In the former construct, the "to have" verb precedes the diagnostic term, setting up "bipolar" as a noun. Nouns, unlike adjectives, do not describe; they quantify and give shape to things. To "have" a thing is different than to "be" a thing, for just as something can be had it can also be un-had.

To be clear, we are not advocating for using "I have bipolar" as a preferable alternative to "I am bipolar." It could very well be the case that a person experiencing bipolar may find it empowering or helpful to choose the "to be" verb. If so, we would encourage such usage. Our point is simply that people can and should have the power to choose their language to avoid self-stigma. We advocate for the options to be on the table and for the user of the language to make conscious, empowering decisions. As one NEXUS advisor shared with us, "You can have the best science in the world available to someone, but it's useless if they're too ashamed to use it."

The differences between the "to be" and "to have" verbs will certainly not overcome the persistence of self-stigmatization, but it reveals a larger truth about the ways that we can choose our language to frame how we experience mental health challenges.





"What people think about the moment of discovery is really the discovery of the question."

Jonas Salk, virologist and developer of polio vaccine

In Part 1 of this paper, our goal was to outline the complexity and urgency of the debates about the language of mental health. Now, we want to begin to offer a strategy for navigating this complexity and meeting the urgency. As we have previously stated, it is not our goal to pick our favorite terms or stamp out the words and phrases we do not like. Our approach is not prescriptivist, but strategic. To that end, this paper will now outline four questions that can and should be asked as we consider how to talk about mental health.

The idea for framing this section with questions emerged from a series of expert interviews with NEXUS advisors, who, despite their very different academic and professional backgrounds, shared a spirit of curiosity and understanding. To navigate the mental health lexicon with success and compassion demands an attitude of open-mindedness and inquiry – as well as humility and curiosity.

This paper frames a series of four questions not to provide the answers, but to offer a path forward that enables each of us to choose our language dynamically, compassionately, and productively.



QUESTION 1:

How do I use language to respect people with mental illness?

When people with mental illness are spoken to in a way that does not respect them, they are forced into a position where they must make a choice. They can either "let it pass"—in which case they are forced to suffer the blow and internalize the disrespect; or they "call it out"—in which case they are forced to reveal their vulnerability and create a conflict. Both options are harmful. And they both reveal to the extent to which language has power to cause both mental and physical harm.

A solution is to build a "person-first lexicon." Advocacy organizations and others are building guidelines, handbooks, and glossaries to reach this goal. It is important work, and we advocate for its development—but we would implore the projects to be centered upon this important value of respect. It would be hard to overstate the power that language has on people with mental illness, and respect serves as a productive starting point for discussions, debates, and contemplations about language.

ERIC RIDDLE, MBA
REVEALING VOICES PODCAST

What does "healing" mean to me?

When asked a couple of years ago, my response was "restored into community."

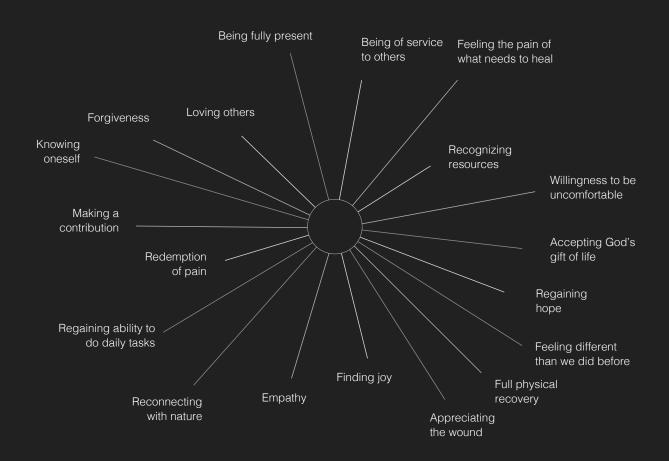
I come at the question largely from the perspective of someone who has had a psychiatric diagnosis since age 17. Much of my young adulthood was spent happily among friends, but often on the edge of isolation. As I grew into my thirties, I began to understand that self-stigma, rather than social stigma, was the root cause of my feelings of isolation. Healing from the self-stigma has been the path into fully embracing myself as a healthy member of society. I stepped away from the edge and into accepting a love of others that had always been present.

At risk of being cliché, I will say that I have learned that healing is a journey. However, I believe that healing in popular culture is often focused on the destination—grasping for the moment to say, "I have been healed". When using that paradigm, the individual will often feel shame for not reaching the destination. In my case, having the diagnosis led to a self-stigma that compounded my symptoms.

We have all experienced pain and have physical

or psychological wounds. Healing is the story that looks at parts of my life that I have perceived as negative experiences and then reframes them as opportunities to grow. It is a deeply personal story, and when I intimately share it, others join me on the healing journey.

I have had the honor of asking others, "What does healing mean to you?" There are common themes, but the nuances and experiences that led people to their perspective are deeply personal:



I appreciate the vast scope that touches on physical, mental, social, and spiritual perspectives. Healing, for me, is a journey that celebrates the diversity of actions that support my mental health.

QUESTION 2:

How can language build – and not divide – communities?



There is a common narrative about mental health journeys that goes something like this: everything was fine until it wasn't. Research conducted by the National Institute of Health finds that symptoms of psychosis often begin when a person is in their late-teens or early twenties. When parents, families, and supporters dive blind and headlong into the mental health community to find ways to offer support, they often encounter communities that are hard to penetrate. This isn't because of unwelcoming or ill-intentioned peers. It's because mental health communities—particularly support groups and parent groups—tend to develop their own lexicons filled with shorthand abbreviations and insider terminology.

There's a catch with this "insider dialogue." It both creates community among those who know the language, and it excludes outsiders and newcomers from joining in. One advocate shared with us that an online parent support group typifies this tendency. To read the online chat is to read a code that the uninitiated would struggle to comprehend.

The role of parents, families, and supporters takes on an additional complexity when we consider how language operates within power structures. People in power – parents, teachers, police officers, HCPs – mark themselves as "safe" or "unsafe" with the language they use. They "build" or "divide" a community with the person with mental illness with their language choices. The "right" language can open community between the person and power and the person with a mental health condition; the "wrong" can do the opposite.

Again, there is no prescriptivist approach here, and there are no answers. But—like respect—we'd contend that strategies for choosing language must consider the idea of building and cultivating community.

Mental health communities—particularly support groups and parent groups—tend to develop their own lexicons filled with shorthand abbreviations and insider terminology.



QUESTION 3:

What is the balance between professional specificity and person-centricity?

It can be argued that a "person-centered lexicon" loses value when it obstructs a professional from diagnosing, caring for, and treating disease. For example, if it is determined that the healthcare provider should not use the term "schizophrenia" or "post-traumatic stress disorder" with the person experiencing the condition because such usage will stigmatize and cause harm, then the provider confronts a new problem. How can she ensure the right care paths are constructed and followed if she is avoiding the diagnostic terminology?

Conversely, if a person with mental illness has come to his own lexicon about his condition—and he avoids diagnostic terminology, such as schizophrenia or PTSD because he finds these terms to be self-stigmatizing—the HCP

confronts a different problem. How can she, the HCP, ensure that she's understanding what the "patient" is trying to say? If the diagnostic term is avoided and idiosyncratic synonyms take its place, misunderstanding will arise.

A solution is to put the lexicon on the table. Talk through clinical terms and walk through what they mean. Approach clinical terms as arbitrary linguistic constructs, not as absolute truths. Recognize the strengths and weakness of terms and explore their nuances. Treat language as a system of codes that "patients" and "doctors" must use in order to share ideas, but let the person-to-person dialogue own the language instead of the language owning the dialogue.

A SOLUTION IS:

Put the lexicon on the table.

Who's the Expert?

HANNAH ZELLER, MSW

Programs Manager, Depression and Bipolar Support Alliance (DBSA)

When a patient says to a clinician, "I don't know. You are the expert", the clinician ought to pause. It might sound like a compliment, but it may be an abdication of responsibility. The distinction is important, because it marks a significant historical shift about a patient's agency in their own treatment journey. In the 1960s, the deinstitutionalization movement created monumental change as it made into law an individual's right to live in their own community. In the 1970s, advocacy organizations such as the Depression and Bipolar Support Alliance (DBSA) and National Alliance for Mental Illness (NAMI) were founded, highlighting the advancement of the rights of individuals living with mental health conditions to guide their own care. Today, patient participation in treatment and decision-making is widely studied across conditions and is shown to improve outcomes and enhance quality of life. When clinicians acknowledge that patients are the experts of their own lived experience, they are honoring a seismic shift in the health care rights that have been fought for over the last half-century.



QUESTION 4:

How can language create person-focused experiences in professional settings?



A person-centered approach to language can hit a formidable barrier in the clinical setting. Clinics are, in the end, places of business and bureaucracy, and language functions as an essential cog in the mechanism of commerce. Language determines reimbursement codes and disease classifications; in public health clinics, the lengthy intake forms that stand between entry and treatment contain a litany of foreboding diagnostic terminologies.

This creates a challenge for professionals: how can clinical experiences be person-centered while also meeting demands of coding, billing, diagnosing, prescribing, etc.?

The tension highlights the messy reality where theory and reality meet. In theory, we can imagine

a world where all the right decisions and strategies are made with the language of mental health, and we create a person-centered, respectful, humble, curious, and empowering discourse community. In reality, we have paperwork, ICD codes, and electronic health records.

Professionals in clinical settings—whether social workers, HCPs, or administrators—are stuck. But yet again, we would argue not for a single solution or answer, but for the power of the question: in this unenviable middle-ground, professionals must reflect and ask how they can balance the needs of the bureaucracy with the needs of the community they serve.

Like so much else we have discussed in this paper, there will never be a single answer or a neat solution. It's a constant interplay and negotiation, and prioritizing questions over answers, we would contend, is the most productive path forward.



Conclusion

Where do we go from here?

While it is our foremost goal that this paper be the beginning of a renewed dialogue on the language of mental health, we offer that goal with a caveat. It is the premise of NEXUS that we can move towards solutions for people with mental health challenges by bringing new people together, sharing ideas, and working across communities. We advocate for this same approach with language.

We will only get so far if doctors talk to doctors, advocates to advocates, parents to parents, people with lived experience to others with lived experience. These discussions are vital, and we do not wish to trivialize them. But if we have learned one lesson in researching this paper, it is that people throughout the mental health community are longing not only to share their perspectives, but to hear from others as well.

We frame this paper around "four questions" because we found inquiry to be at the heart of the community. The mental health community will never become un-stuck from the trappings of language. And inquiry, dialogue, and cross-community sharing will be the only path forward. Ultimately, it recalls the comment we offer at the beginning of this paper, made by Dr. Rakesh Jain: "Language has been the greatest success story of psychiatry. But also it's greatest challenge."

To write the next chapter in the story of success, we invite everyone to join our conversation and share your thoughts on the language of mental health.

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