

Schizophrenia and Psychosis Lexicon Guide 2023

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About NAMI

The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness.

What started as a small group of families gathered around a kitchen table in 1979 has grown into the nation's leading voice on mental health. Today, we are an association of thousands that includes state organizations, local affiliates and volunteers who raise awareness and provide advocacy, education and support in communities across the United States.

Acknowledgements

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Executive Summary

Language Matters

The language chosen to describe schizophrenia and related psychosis conditions – as well as the people who may be diagnosed with these conditions – is critical to ensure that complex information is communicated accurately, effectively, and with regard to hope and human dignity. Language matters. It matters for fostering meaningful relationships between individuals and their treatment team – including first responders – as well as between the individual and those in their personal and professional lives. It also matters for reducing prejudice and discrimination related to mental illness in news media and film. There are many elements to mental health and mental health care, and changing our language may not change the system. But by being intentional and learning from the voices of lived experience, we can change the narrative.



[P]sychosis is one of the hardest [conditions to de-stigmatize] because it's been misrepresented in movies and entertainment...I wish that these people would stop...continually linking psychosis and violence over and over and over again.

– Amy Cohen, Ph.D., SME Interview




This first edition of the NAMI Schizophrenia and Psychosis Lexicon Guide strives to represent current best practices regarding the words and terms, including clinical and plain language phrases, that are used in the assessment, diagnosis, treatment, recovery and overall

wellbeing of and respect for people with schizophrenia and related psychosis conditions. Importantly, this guide is not a glossary – it is a conversation starter.

While the guide focuses primarily on language used between individuals and their treatment team, it is intended for use by specialty clinicians, general practitioners and pharmacists, communications and public relations professionals, law enforcement and first responders, the news media, and the general public. Publication of this lexicon also coincides with the expanding demand for fact-driven news reporting on television, radio and social media, and supports improvement of communication standards and practices.

This lexicon guide includes examples of the most commonly used terms that are largely found to be acceptable, especially in a clinical setting; terms that may be acceptable depending on the circumstances; and terms that are best avoided in most cases. Any term should be used with careful exploration of its possible interpretations, and with consideration of the context in which it will be heard. Revisiting, correctly defining, and reclaiming terms that are often misapplied, or are falsely associated with violence and criminality, can reduce the prejudice and discrimination surrounding serious mental illness throughout public discourse and help lower barriers to treatment.

However, there will always be personal differences in language preferences. There is no perfect *one size fits all* language for a community composed of unique individuals. Expecting, accepting and preparing for these differences



by asking people to define their experiences in their own terms will almost always lead to more effective and respectful conversations.



[L]anguage is so culture dependent, person dependent, that my first priority would be to make sure that we're not... recommending some fixed process or fixed word, but rather a way to communicate[.]

– Lisa Dixon, M.D., MPH, SME Interview



The guide is also intended to be a living document. Language is always evolving, and this guide will be regularly reviewed and updated to reflect developments in mental health research, therapeutic protocols, culture, and the preferences and priorities of people with lived experience.

Methodology


This lexicon guide was informed by input from various NAMI partners, interviews with subject matter experts (SMEs), and focus group sessions with people who have lived experience of schizophrenia and related psychosis conditions and family members and caregivers of individuals with these conditions.

NAMI first held meetings with four industry partners to discuss project scope and request recommendations for SME interviews.

NAMI then contacted 21 SMEs with requests for interviews. Ten SMEs participated in a virtual, hour-long individual interview. Three SMEs affiliated with the same advocacy

organization participated in a virtual, hour-long group interview. One SME was not able to participate in the standard virtual interview, but did provide comment via email. Interviewee areas of expertise included clinical practice and pharmacy, academia and research, law and policy, communications, and lived experience. Interviews focused on personal and professional experiences with language related to schizophrenia and psychosis, how SMEs developed their current language practices, and overall recommendations for a schizophrenia and psychosis lexicon guide.

In parallel to SME interviews, NAMI also contracted with research and communications firm The Hannon Group to conduct online focus groups of people with a mental health condition that includes psychosis and caregivers of individuals with a mental health condition that includes psychosis. Participants represented various mental health conditions and experiences with psychosis, ages, insurance statuses, races and ethnicities, gender and sexual identities, and other demographic characteristics. All participants were over the age of 18. Six 90-minute online focus groups were conducted in August 2023, with about 10 participants per group. Two groups recruited only individuals aged 18-34 and only caregivers of individuals aged 18-34, respectively, to identify potential generational differences in language preferences. Participants were asked about specific terminology that could be used to describe conditions that include psychosis, individuals with conditions that include psychosis, and other related terminology. Participants were also asked about education and informational resources related to psychosis, and the individuals or organizations they might trust to provide that information. NAMI received the final focus group report in September 2023.



Throughout this guide, quotes from focus group participants – including people with lived experience and caregivers – and subject matter experts will be provided to illustrate recommendations as well as the varied perceptions of individual terms.

Key Findings

The language chosen by a treatment professional to communicate research, assessment findings, diagnoses, prognoses, and treatments with respect to schizophrenia and related psychosis conditions will depend on the context in which the professional is speaking or writing.

When speaking with their professional colleagues, a clinician’s language will likely include terms learned from training, continuing education, and professional gatherings and publications. This formal vocabulary is useful because it is held in common understanding with fellow clinicians to encompass a range of complex ideas efficiently. In the context of communicating with colleagues, a shared lexicon not only conveys ideas clearly, but can also foster collaboration, optimal sharing of findings, and an accelerated evolution of treatments.

When these formal terms are introduced by a treatment professional into work with people who have schizophrenia and related psychosis conditions, it can be helpful to the treatment process. These terms convey the authority of an existing body of knowledge created in service of the individual’s condition. This could offer hope that there are medications and psychotherapeutic treatment modalities already in place to help the individual, and that there is a name for the symptoms a person has been experiencing.

That said, there can also be drawbacks to only using formal diagnostic terminology. Due to the prejudice and discrimination often associated with these types of conditions, someone may not want to be “labeled” with a diagnosis. These terms are often misunderstood or misapplied by the general public, and can sometimes feel too broad or technical to the person experiencing symptoms. Any one of these factors can ultimately weaken the therapeutic alliance, or the active cooperation between the individual and members of their treatment team, which can be a barrier to effective treatment.

There may come a time in the treatment process when formal terms are useful, and even healing, for the person. However, especially early on, the sense of legitimacy intended by formal language may be outweighed in treatment efficacy by descriptors chosen by the person themselves. The rapport between a treatment professional and their patient or client is often strengthened by meeting the person where they are with respect to the language they use when discussing their lived experience.

The treatment professional is essentially exploring the individual’s personal *reference preference*. How does the individual prefer to have their condition and symptoms referred to? Are they most comfortable with language rooted in their personal lived experience? Or do they prefer more clinical terminology? Different people will offer different sets of preferred terms. Accommodating, and even embracing, a lack of uniformity among individuals is important. Beginning a clinical relationship with active listening for, and the intentional adoption of, the terms used by the person about themselves can be an important first step in meaningful treatment engagement.



It's not just the words, but how we think about things. And to me, the ultimate goal of a lexicon is to improve communication. And the way you improve communication is by providing people with the tools to be open to listening and understanding what another person is communicating.

– Alice Medalia, Ph.D., SME Interview



For **clinicians**, the application of this lexicon will enhance the treatment experience of the individual, focusing on their own real-world experiences rather than administrative labels. The clinician's sensitivity to language will foster an empathetic, compassionate relationship with the individual, maintaining their sense of dignity and humanity and supporting them in their treatment and recovery journey.

For others, this guide offers an opportunity to more appropriately balance accuracy and sensitivity when engaging with or relaying information about psychosis and individuals who experience it. Examples of non-clinical groups who can benefit from the information in this lexicon include:

- **Law enforcement and first responders:** individuals experiencing a crisis may not be in a place to hear clinical terminology and may benefit from a focus on their own perceptions and perspectives when circumstances allow.
- **Communications professionals and the news media:** diagnostic terminology should only be used when a person has officially received a diagnosis; not as a generalization for apparent symptoms or behaviors.
- **General public (including family and care partners):** while every person who has experienced psychosis is different, they all deserve the right to be defined as they choose – with or without labels.



[T]hink in terms of who's speaking... think in terms of who the audience is... to find where the common denominator goes.

– Media and Communications Professional, SME Interview



SECTION 1: Recommended Terminology

SCHIZOPHRENIA

Definition

According to the fifth edition text revision of the Diagnostic and Statistical Manual of Mental Disorders, a diagnosis of **schizophrenia** requires the presence of at least two out of five key symptoms for a significant portion of one month. Key symptoms include:

- “Positive” symptoms (those in which a characteristic or experience is present) such as delusions and hallucinations
- “Negative” symptoms (those in which a characteristic or experience is absent) such as diminished emotional expression or diminished motivation
- Disorganized or catatonic behavior

Related Terms

Schizoaffective Disorder, Psychosis Spectrum Disorder, Schizophrenia Spectrum Disorder

Recommendation

The term **schizophrenia**, when used along with a clinical definition of the term, conveys that a person is referring to a vetted body of knowledge, which can be comforting to the individual and is best used in a clinical setting by medical professionals. This use of the term schizophrenia can also be instructive to other audiences, particularly in media, where its misapplication can be associated with slang and offensive stereotypes that are inappropriate when discussing the specific diagnosis.

Schizoaffective disorder, psychosis spectrum disorder and **schizophrenia spectrum disorder** are related, but different, terms. While schizoaffective disorder refers to a condition that includes similar symptoms of schizophrenia but with the addition of mood symptoms, psychosis spectrum disorder or schizophrenia spectrum disorder refers to the entire category of conditions that may involve psychosis, including schizophrenia, schizoaffective disorder, and bipolar disorder or depression with psychosis. What ties these terms together is that they are specific, clinical, diagnostic terms. They mean something based on the most accurate, currently available clinical research, and should not be used as generalizations for a certain type of observed behavior. Psychosis spectrum disorder may be especially useful, as it conveys that there is a range of varying types and degrees of symptomology on a spectrum.

Although these diagnostic terms can provide clarity in a clinical setting, it is important to remember that they are not perfect descriptors for every person’s experience with psychosis, and that they are each highly stereotyped and associated with prejudice and discrimination. Some people may prefer to avoid them or use other terms instead.

PSYCHOSIS

Definition

The American Psychiatric Association defines the term **psychosis** as a disruption or impairment in an individual's ability to differentiate between their perceptions and reality. This may include an inability to identify boundaries between real and unreal experiences and disruption to cognitive processing, as evidenced by delusions, hallucinations, and significantly disorganized speech.

Related Terms

N/A

Recommendation

While schizophrenia, schizoaffective disorder, and psychosis spectrum disorder all describe mental health conditions, **psychosis** is one symptom of those conditions. As with the terms that describe conditions, psychosis has a specific definition in clinical terminology, and is useful when being used in that context. The term should not be used as a general descriptor of a person's behavior without an understanding of the clinical definition. For treatment professionals, explaining with clinical accuracy the definition of terms like psychosis can empower an individual with information that demystifies stereotypes and other forms of misinformation.

However, the term psychosis is also associated with prejudice and discrimination and can feel negative due to stereotypes associated with the term. In a clinical setting, it can be helpful for the treatment professional to mirror the terminology used by the person to describe their experiences first, and then incorporate the use of clinical terminology at a later point in the treatment journey if it makes sense to do so.

PERSON WITH SCHIZOPHRENIA

Definition

Person with schizophrenia is a term of reference that is commonly accepted in psychotherapeutic and patient communities. This phrasing is also known as “person-first” due to its emphasis on the individual before describing their condition. Though its use carries less association with prejudice and discrimination than other language explored here, people may still experience any use of the term schizophrenia as problematic in some situations.

Related Terms

Person Diagnosed with Schizophrenia (or another psychosis spectrum disorder), **Person Living with Schizophrenia** (or another psychosis spectrum disorder), **Person Experiencing Schizophrenia** (or another psychosis spectrum disorder), **Person Receiving Treatment/Services, Patient, Client**

Recommendation

When a treatment professional uses person-first terminology, it humanizes the person by distinguishing them from the condition. They are not the illness – they are a person experiencing the illness. No one would ever consider saying “that person is cancerous,” but all too frequently the phrase, “that person is schizophrenic” is used. By recognizing the components of a person outside their diagnosis, a treatment professional emphasizes the person’s agency and provides an opening for meaningful partnership in the treatment process.

Similarly, the term **person diagnosed with schizophrenia** is accepted. It distinguishes the person from the illness, but also acknowledges that a treatment process has begun. This phrasing is also helpful in regard to the misdiagnosis of schizophrenia, a relatively common occurrence (particularly early on in the course of an individual’s treatment journey) and one which disproportionately affects Black and other minoritized communities. If a person has been misdiagnosed, specifying that they have been “diagnosed with” a condition rather than that they “have” the condition allows room for the diagnosis to be incorrect or at least revisited in the future, instead of a label that will remain unchanged for the duration of a person’s life.

PERSON WITH SCHIZOPHRENIA

Recommendation, continued

Other terms, including **person living with schizophrenia**, **person experiencing schizophrenia**, **person receiving treatment/services**, **patient**, and **client** can also be appropriate depending on the setting and the individual's preferences. For example, many people consider "living with" a condition to be more positive and empowering, while others have strong opinions in the opposite direction. The following quote is often used to illustrate a preference against "living with": "I LIVE with my wife and daughter; I HAVE a mental illness."

"[Person with schizophrenia is] [d]escriptive. It brings honesty. I am a person with this disease. It rings true."

– Individual with Lived Experience, Focus Groups

"I like [person with schizophrenia]. You are not labeling the person. You are saying that someone has schizophrenia or is diagnosed with schizophrenia. It's more positive."

– Caregiver, Focus Groups

"Ultimately, when we talk about an individual and their illness, it's seeing them as a person who's trying their best, who's trying to...be a whole person[.]"

– Amy Cohen, Ph.D., SME Interview

CAREGIVER

Definition

A **caregiver** for an individual with schizophrenia or a related psychosis condition is most often a non-professional who assists in various aspects of supporting the individual's quality of life. A caregiver may be a family member, friend, or anyone else with a strong personal interest in the ongoing wellbeing of the individual. The role of a caregiver will vary greatly depending on the symptoms and preferences of the individual they provide care for. It's all about individual needs; anything from keeping track of appointments to supporting daily medication schedules and everything in between.

Related Terms

Care Partner, Patient Advocate

Recommendation

For many people, the term **caregiver** is accepted for family and loved ones, especially for an individual whose symptoms require frequent or constant support.

The term **care partner** is also accepted, though to some it can suggest that the partner might be romantically involved with the individual. This term is not found to indicate a particular level of intensity of the care provided.

Patient advocate is accepted as a term especially for a professional engaged to interact with the medical community, insurers, pharmacies, and other elements in the care network, on behalf of the individual. Patient advocate, when referring to an unpaid caregiver, may also be the term preferred by individuals with schizophrenia who want to emphasize that they have a greater degree of independent living.

"I like the word caregiver. It is directed on more than just one aspect. It is not just dealing with people with mental illness. It is dealing with a person that just needs help dealing with that situation."

– Individual with Lived Experience, Focus Groups

"[Care partner] sounds good because it can also mean that you are part of a team...working for a patient."

– Caregiver, Focus Groups

"Advocating in my mind is another way of saying - I've got your back."

– Molly H. Wilson, MBA, SME Interview

TREATMENT ENGAGEMENT

Definition

In “Engagement: A New Standard for Mental Health Care” (2016), NAMI defines the term **treatment engagement** as referring to an individual’s trust in their treatment process and their treatment team, which is founded in mutual respect, effective communication, and recognition of how the strengths and resources of people experiencing mental illness can complement the recovery process.

Related Terms

Treatment Adherence

Recommendation

The term **treatment engagement** has been found to reflect a collaborative, constructive relationship between the treatment professional (who is providing clinical care as well as access to adjunctive services) and a proactive patient making timely use of medications and keeping appointments with the clinician and other care providers.

The term **treatment adherence** (or conversely, nonadherence) is also preferred to indicate the quality of rapport between clinician and individual relative to the treatment plan. These terms bring less prejudice, discrimination and anticipation of failure than similar terms (see Section 2, page 11) if, for example, a medication is skipped through forgetfulness or an extenuating circumstance but is resumed in a timely manner, or if an appointment is missed but reasonable accommodations for rescheduling are made.

“I think [nonadherence] is actually better than noncompliance. To me, noncompliance feels like somebody that is being combative. I feel like [nonadherence] is better, definitely.”

– Individual with Lived Experience, Focus Groups

“It is an OK term. Nonadherence is definitely more friendly [than noncompliance].”

– Caregiver, Focus Groups

I try to use the term non-adherence, although every once in a while I still say noncompliance...We talk about why it is important to take medications, stress strategies to remember to take medications, and give permission to miss doses without feeling like a failure. It's important to set expectations and use language that gives room for mistakes. We all mess up taking medications and you don't have to feel like a failure if you forget or are not always adherent.”

– Deanna L. Kelly, PharmD, BCPP

SECTION 2: Terminology that May Be Acceptable

TREATMENT COMPLIANCE

Recommendation

The term **treatment compliance** is still sometimes used in administrative and peer communications to describe the quality of a patient's engagement with their treatment plan and health care support network. While in most circumstances the terms treatment engagement or treatment adherence are preferable as discussed in Section 1, treatment compliance may be acceptable depending on the situation and preferences of the individual receiving treatment.

In clinical use, treatment compliance (or conversely, noncompliance) often implies a power dynamic in which the individual is being controlled by the treatment professional with no agency of their own; further, noncompliance suggests that the individual is departing from agreed treatment protocols through misguided willfulness, defiance, or lack of competence. If treatment noncompliance is observed by the clinician, it would be best to conduct a deeper exploration of the reasons the individual is having trouble with a treatment plan without the assumption of failure or disobedience overshadowing this dialogue. A treatment resistant condition can also be mistaken for, and thereby mischaracterized as, noncompliance.

"I think it is kind of harmful...I take my medicine...so for them to say that I have been noncompliant, I just feel it is judgmental to me, even if technically speaking, it is true."

– Individual with Lived Experience, Focus Groups

"To me, that is completely negative. Because if a person forgets to take their medicine three days in a row, they are not compliant? No, they just forget to take their medicine. Sometimes they miss appointments."

– Caregiver, Focus Groups

"We need to do more work around the idea that treatment resistant is not someone being noncompliant. We're talking about an aspect of this disorder that is sometimes, unfortunately, what some people have. And it's not their fault."

– Amy Cohen, Ph.D., SME Interview

CLINICAL TERMS FOR SYMPTOMS

Examples

Paranoid, Having Delusions, Experiencing Hallucinations

Recommendation

Describing or referring to symptoms using clinical terms may be most useful early in the assessment and diagnostic phases of treatment, in communication with other members of a support team or caregivers, and for the treatment professional's own management and administrative requirements.

This is not to say that such terms are never appropriate for use with the individual. The clinician will need to be sensitive to the person's understanding of their condition and their current experience of symptoms to determine how well they may relate to clinical terminology. The clinician can then assess whether such terminology will strengthen the therapeutic alliance and provide hope of symptom management, or will provoke anxiety or other negative responses.

In public discourse or casual conversation, the use of clinical terminology to describe symptoms, followed by a brief definition as needed, can help prevent the audience from forming negative associations with clinical terminology to describe symptoms. The term **paranoid**, for example, can be a helpful symptom descriptor when used in a specific context, but can be used in a derogatory way in casual conversations without appropriate explanation.

"[Person experiencing psychosis, disorientation, or hallucination] to me sounds okay. Because, in my head, what came up was like, 'if the shoe fits.' Like if I am experiencing that, okay. It doesn't feel positive or negative to me."

– Individual with Lived Experience, Focus Groups

"I feel like [person experiencing psychosis, disorientation, or hallucination] describes the condition very well from a medical standpoint...but the words just seem so taboo...when you hear somebody has hallucinations or that they are disoriented."

– Caregiver, Focus Groups

"I think it is important for mental health professionals and the police to know what they are dealing with before they arrive on the scene. So, to save lives ['person experiencing psychosis, disorientation, or hallucination' is a good term]."

– Individual with Lived Experience, Focus Groups

PLAIN LANGUAGE TERMS FOR SYMPTOMS

Examples

Seeing or Hearing Things That Aren't There, Hearing Voices, Unusual Feelings

Recommendation

Plain language terminology may be more intuitive or approachable for people who are unfamiliar with clinical terminology. Using plain language can help dispel the appearance of an authoritative relationship of the treatment professional's superiority over an individual, emphasizing that the patient, too, can provide expertise in conversations about their care.

The use of plain language terminology also supports the phenomenological approach to clinical practice, or the reliance on first-person descriptions of experiences to guide assessment and treatment. This approach can encourage the individual to discover their own most accurate terms and expressions that the clinician can mirror. For example, the clinician might ask, "What's different for you now?" instead of, "Are you hallucinating?" Sometimes, this language can even do a better job at describing the experience of a symptom than available clinical terminology, and provide a new, valuable perspective to a clinician. Further, using plain language allows the person to incorporate their own cultural experiences into their descriptions of symptoms.

However, sometimes plain language terminology may lack helpful specificity. For example, "hearing voices" could be interpreted as referring to a number of very different experiences. When using plain language terminology, it is critical to ask questions and take the time to fully understand what a person means or how they might interpret a particular phrase.



PLAIN LANGUAGE TERMS FOR SYMPTOMS

“It depends on the context...if someone is having an episode, maybe [using the term ‘hearing voices’] would be positive to get them help. But if it is being used all the time...then it would probably be negative.”

– Individual with Lived Experience, Focus Groups

“[Hearing voices] is pretty decent for a descriptor. There is also the kind of separate description of whether or not it sounds like it is on the outside...of your head or hearing voices inside of your head.”

– Caregiver, Focus Groups

“[P]atients will have their particular idioms or their particular ways of describing their experience that I think are both the most valuable way to then relay it back to them and to make sure you’re talking about the same thing...patients will often give me the most useful and helpful and creative ways of defining what can be these very unusual experiences that I can then use to help try to clarify with somebody new[.]”

– Rachel Talley, M.D., SME Interview

SECTION 3: Terminology to Avoid

TERMS FOR CONDITIONS

Examples

Psychotic Disorder, Brain Disease or Disorder, Split Mind

Recommendation

These examples of dated diagnostic terminology used by a treatment professional with an individual can suggest that the person has little or no hope of progress or recovery. Such negative terms remain in use in present-day media, particularly in news reporting, on social media, and in narrative film and television. Their use is especially harmful when misapplied to situations involving violence and criminality, which only makes public prejudice and discrimination of treatable mental health conditions like schizophrenia and related psychosis conditions more deeply ingrained.

These terms can also simply be inaccurate or poor descriptors of a specific experience. For example, brain disease or disorder may bring to mind other conditions, such as dementia or brain cancers, adding unhelpful complexity to a conversation. And the phrase “split mind,” which is often associated with schizophrenia, is not at all representative of the actual symptoms or experiences of the condition.

Awareness and use of clearer, less offensive terms will be more encouraging, and therefore more engaging, to the individual in their treatment process and foster a better social understanding of schizophrenia and related psychosis conditions.

“I don’t like it. It is really easy for ‘psychotic’ to be this buzzword. It is very easy to dismiss the person entirely.”

– Individual with Lived Experience, Focus Groups

“[Psychotic disorder] just has a negative connotation. I think it is one of the older terminologies [that] hopefully is starting to be phased out.”

– Caregiver, Focus Groups

“[Brain disorder] removes some of the cause of it being caused by trauma, early childhood experiences, makes it seem like you were just born with this...that is why I don’t like it.”

– Individual with Lived Experience, Focus Groups

TERMS FOR A PERSON WITH A CONDITION

Examples

Person Suffering from Schizophrenia, Schizophrenic, Psychotic, Crazy, Psycho, Schizo, Lunatic, Mentally Ill, Delusional

Recommendation

Individuals with schizophrenia and related psychosis conditions typically do not appreciate being described as **suffering** from their diagnosis. This framing brings to mind victimhood or incompetence — presenting the person as unable to achieve recovery or independence. **Schizophrenic**, when used as an adjective or as a noun in reference to a person, is likewise met with little acceptance, since it appears to superficially define the whole person by a condition which is only one facet of their life.

These terms should be avoided. The only scenario where it may be considered acceptable to use this type of terminology would be when these terms were used by the person themselves and they are being quoted. There may also be situations when a person expresses this type of terminology as their preferred language, as in the context of reclaiming a derogatory or stigmatized term to reduce its power to harm.

“[Person suffering from schizophrenia] is an automatic negative because many people can live productive lives with these illnesses. And that [term] just seems like it’s automatically a bad situation.”

– Caregiver, Focus Groups

“Suffering makes it feel like it’s a tragedy or something...I have it. I am going to have it all my life. [But] I am not always suffering. I don’t like that word.”

– Individual with Lived Experience, Focus Groups

“I think [‘someone who is psychotic’] is a negative term because it makes them sound violent and very dangerous to be around.”

– Individual with Lived Experience, Focus Groups



Closing Statement

Language matters. Best practices regarding use of terms associated with schizophrenia and related psychosis conditions must be carefully nuanced, as both explicit and implicit meanings continue to evolve over time. An awareness of an individual's current state, especially when they may be actively experiencing symptoms, as well as their general communication preferences, is vital to strengthen the treatment professional's therapeutic alliance with their patient or client. Any opportunity the clinician might have to employ the person's own descriptors of their lived experience can offer fresh, powerful language for constructive mirroring. This can also provide both clinician and person enhanced insights beyond labels, and help build an important foundation for engagement, symptom management and healing. The right language together with active listening are crucial to an effective treatment process, allowing the person to envision and realize a greater degree of meaningful recovery.

The importance of finding out how the person you are working with wants to talk about their condition and their life cannot be emphasized enough. Finding – and using – a common language with them is essential to building trust, and trust is one of the most critical elements of a therapeutic relationship.

Although the experience and use of language is not a perfect science, steps can be taken to improve how we relate to others and to foster communities where people with mental health conditions feel safe and supported. Treatment professionals, the news media, or members of the general public – thoughtful language is for all of us.