Speak Up: Person-Centered Language Drives Equity for Individuals with Mental Health and Substance Use Challenges

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Disclaimer

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Learning Objectives

Attendees will:

• Be able to identify different levels of stigma and how to address each

• Be introduced to person-centered language to talk to and about people with mental health and/or substance use challenges—including serious mental illness and serious emotional disturbance

• Hear stories of people with lived experience that demonstrate how harmful language negatively impacts the recovery journey

• Realize the importance of moving from mental health awareness towards acceptance to work towards a world where people with lived experience achieve equity in their workplaces, schools, and communities
Presenters

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Community Relations Specialist
National Disability Rights Network

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Founder
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Panel Discussion Moderated by:
Lynda Gargan, PhD
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Person-Centered Language

Language that maintains a person's identity as someone with strengths and the power to recover. It conveys respect and acceptance by emphasizing the fact that people with behavioral, mental health, and/or substance use challenges are first and foremost people. This often involves using language which puts the person before their diagnosis, disability, or other characteristics. Person-centered language also means deferring to the terminology expressed by individuals with lived experience.

There is one exception: how people choose to self-identify or define themselves. For example, a person in recovery from substance use may refer to themself as an “addict” or “alcoholic.” This does not imply permission for others to use that terminology.

(NFSTAC, Glossary of Terms, ND)
What Person-Centered Language Looks Like

- Schizophrenic
- Person with schizophrenia

- Suffering from a mental illness
- Experiencing a mental illness

- Addict/Drug abuser/Alcoholic
- Person with substance use challenges

- Committed suicide
- Died by suicide

(NFSTAC, Reframing Language, ND)
How to Take a Person-Centered Approach

- Treat people with dignity and respect.
- Encourage growth out of a person’s existing strengths and talents.
- Support a person to engage in their community and build meaningful relationships.
- Listen to and take action based on what the person says are their goals.
- Make a strong effort to understand the person, what’s unique about them (e.g., culture, religion, sexual orientation, self-worth).
- Learn what the person truly thinks is most important to them when planning to achieve goals.

(Adapted from Wright-Martin et al., Clinical Tip: How Person Centered is My Practice?, 2020)

Acknowledge historical and system factors/influences.

Suggested by SAMHSA’s “Guide to Equity Terminology: promoting Behavioral Health Equity through the Words We Use” ( Cafaro, 2023)
Eliminating the Stigma of Mental Health and Substance Use Disorder: A Grand Challenge

Seth Kahan, Grand Challenge Lead
Seth@VisionaryLeadership.com
Eliminating Stigma

• **NASEM 2016 Report** *Ending Discrimination Against People with Mental and Substance Use Disorders:*
  • “Need for a coordinated and sustained effort over two or more decades to reduce the stigma associated with mental and substance use disorders.”

• Mental health is a complicated, multisystem issue!

• Rather, our focus is on *eliminating the stigma*

• Why? Because stigma *kills.*
  • It prevents care and yet…
  • Is changeable
How Does Mental Health Stigma Manifest? Three Levels

1. **Structural**
   - Laws (e.g., housing, employment, restrictions, treatment)
   - Policies in schools, workplaces, health care systems, criminal justice systems

2. **Social**
   - How people behave in groups: families, workplace, places of worship, healthcare environments, bars, coffee shops, event gatherings, etc
   - Stereotypes
   - Isolation
How Does Mental Health Stigma Manifest? Three Levels (Continued)

3. Individual

- Internal dialog
- Shame and isolation
- “Why try?”

The Grand Challenge targets all three levels – together and separately
Video 1
Video 2
Grand Challenge Structure

1. Huntsman Mental Health Institute – the “Backbone Organization”
2. Executive Committee
3. National Leadership Steering Team
4. Working groups
   • Metrics
   • Financial Strategies
5. Ad Council
6. 100s of Partner Organizations
7. Task Forces & Communities of Practice
8. National Summit on Stigma: June 24-26, 2024 – Salt Lake City, Utah

300-400 Mental Health service leaders, advanced knowledge sharing
OUR NATIONAL LEADERSHIP STEERING TEAM
Task Forces & Communities of Practice

Up and Running:
1. Workplaces
2. Rural America
3. Journalism and News
4. Entertainment & Media
5. Children/Youth/Family
   Oct 2023 NYC kickoff
6. Policy

In the Works:
1. Criminal justice system
2. Social Media
3. Counties
4. Veterans
5. Faith communities
STOP STIGMA Together

NATIONAL SUMMIT ON STIGMA

June 24 - 26, 2024

Salt Lake City, Utah | The Grand America Hotel
Prepare to be inspired! Join us for an unforgettable annual meeting in Salt Lake City, Utah. Here is why you simply won’t want to miss it:

- You will be joined by the nation’s top leading experts in mental health.
- Interactive workshops.
- The voice of the advocates will be heard.
Save-the-Date & Submit to Present!

June 24-26, 2024

STOP STIGMA
Together

• We will de-silo the efforts of the medical, psychiatric, therapeutic, and social groups.

• We will emerge with a landscape of solutions that we ourselves have built.

• We will take big steps in destigmatizing mental health and substance use disorders as a national movement!
STRENGTHENING OUR COMMUNITY WITH PERSON-CENTERED LANGUAGE

Raquel Rosa, NDRN
Community Relations Specialist
May 9, 2024
FACILITATING ADVOCACY

Legislative days

- Topics important to & for the mental health community
- The value of person-centered language
- Moving away from diagnoses & treatment

Peer mentors
INCLUDING THE MOST MARGINALIZED

Underrecognized communities – often considered unsavory – are (un)intentionally excluded from the advocacy work

- Incarcerated
- Institutionalized
- People of Color
- Socioeconomic disadvantages
- Language & other cultural "barriers"
BUILDING COALITIONS

School events / meetings

Collaborations with local grassroots & other allies

Cross-pollination with other advocacy / activist groups
Speak Up: Person-Centered Language Drives Equity for Individuals with Mental Health and Substance Use Challenges

Dr. Zipporah Levi-Shackleford, PBSF
Why is This Topic So Important to Me?

- I have a younger brother with a mental illness
- I have 2 children with severe anxiety and depression
- I am a person with severe anxiety and depression
- I am a Behavior Specialist and work with hundreds of people who have Intellectual/Developmental Disorders (IDD) and mental health diagnoses
- I live in a community where Black students with disabilities and mental illness disproportionately face disciplinary consequences
- I live in a community where Black people with disabilities and mental illness are disproportionately incarcerated and less likely to be diagnosed as having a mental illness (Pope, 2019).
So, What does This Mean?

- I have worked with a lot of mental health professionals (psychologists, psychiatrists, therapists, nurses, case managers, etc.) over the years. The language is AWFUL!

- I am a part of a population that has had extremely traumatic experiences with the medical and mental health professions/fields.

- I am aware of how language can misinform individuals to the point that they suffer instead of getting help.

- I am aware of how language can influence others to see a person as a threat or monster which prevents that individual from getting quality support.

- I am aware of how language can lead to a life of harmful legal consequences.
What does this look like?
5 reasons mental health is not discussed in a positive way in the Black community

**Reason 1**
Used for experiments in the medical field without their permission and consideration of them being humans with feelings.

**Reason 2**
Medical practices used on them was not intended to heal but, 1). prove they were less and 2). save the lives of white individuals.

**Reason 3**
When medical resources were/are shared in Black communities they are often a lower quality and are therefore ineffective.

**Reason 4**
Mental illness in the black community resulted in incarceration or institutionalization.

**Reason 5**
Mental illness in the black community is associated with engaging in inappropriate behaviors.
What Does This Look Like?

• **Stigma**: Referring to mental health issues as "crazy," "weakness," or "craziness"

• **Denial**: Dismissing mental health concerns as something that only affects "other people" or refusing to acknowledge the importance of seeking professional help. “There is nothing wrong with you. We are not like other people.” “There is nothing wrong with that child they just need more discipline.”

• **Shame**: Feeling ashamed or embarrassed about experiencing mental health challenges, leading to reluctance to talk about or seek support for these issues. “I am strong I don’t need help. I can figure this out by myself.”

• **Cultural Mistrust**: Distrust of mental health professionals or the mental health system due to historical mistreatment, discrimination, or lack of representation of Black individuals in mental health spaces. “My aunt went to the doctor cause she was having a hard time and all they did was lock her up.”

• **Religious or Spiritual Beliefs**: Relying solely on prayer or spiritual practices to address mental health concerns, without considering the potential benefits of therapy or medication. “You are not believing in the Lord enough. You need to pray harder. That’s just the devil.”

• **Toxic Masculinity**: Expectations for Black men to be strong and stoic, leading to reluctance to express emotions or seek help for mental health issues due to fear of appearing weak. “You sound like a girl whining about your feelings. Toughen up Black man!”
What are some of the barriers to person-centered language towards Black clients in the professional community?

**Reason 1**
Base practices on research that either excluded the Black community or was used to try to label them as inferior. Are these accurate for us?

**Reason 2**
Personal bias based on stereotypes leads to hesitation in treatment. “They are drug seekers” “Can’t be stressed because living off the system” “They are not trying hard enough”

**Reason 3**
Black people are not represented in the leadership areas of medical research and guidance making it harder to connect us with needing quality supports.

**Reason 4**
Frustrations from lower compensation from government funded insurance programs.

**Reason 5**
Cultural competency instruction still includes harmful and false information like “having a higher tolerance for pain” “Being noncompliant with treatment”

Racial Disparities in Mental Health and Criminal Justice (Pope, 2019)
How to Make a Change
In the Black community

• Black medical professionals provide/share education resources with the community.
• Share success stories
• Have honest discussions about concerns
• Support each other with finding support/attending appointments
• Openly share your own experiences
• Get involved with organizations and committees to share your voice and experiences
• Consider joining the field for more representation
In the medical/mental health community

- Take time to reflect on your beliefs and practices and identify areas in need of change....then CHANGE.
- Reach out to Black organizations to collaborate and share your info.
- Speak up when leadership is not diverse
- Take time to speak with Black clients to learn more about their specific needs.
- Educate yourself (Madness: Race and Insanity in a Jim Crow Asylum - Antonia Hylton, Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present - Harriet Washington)
• Work with your team to create protocols that need to be followed when working with clients to increase all clients receiving the same quality of care.
• Promote professional development to learn about supporting diverse groups led by that group. Follow up with surveys to provide to clients to get feedback and adjust accordingly.
Thank You!

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COVERING YOUR A'S

PRESENTED BY:
MURIEL JONES BANKS
PARENT & EXECUTIVE DIRECTOR OF FEDERATION OF FAMILIES OF CENTRAL FLORIDA

Substance Abuse and Mental Health Services Administration * National Federation of Families * National Disability Rights Network
COVERING YOUR A’s (Continued)

• ACCEPTANCE

• ADVOCACY

• ACTION
ACCEPTANCE

• Awareness\(^1\)

• Acceptance\(^2\)

Transitioning from mental health awareness to mental health acceptance involves a shift towards acknowledging, understanding, and embracing the realities of your loved one's mental health journey.

\(^1\)The quality or state of being aware: knowledge and understanding that something is happening or exist (Merriam-Webster Dictionary, n.d.)

\(^2\)The act of accepting something or someone: the fact of being accepted; acceptance of responsibility (Merriam-Webster Dictionary, n.d.)
ACCEPTANCE INSTEAD OF AWARENESS

WHY ACCEPTANCE INSTEAD OF AWARENESS?

• **To eliminate stigma:** Acceptance helps break down stereotypes and encourages open conversations about mental health.

• **To encourage support-seeking behavior:** When acceptance is promoted, individuals feel more comfortable seeking support.

• **To improve overall well-being:** Acceptance leads to a healthier and more supportive community, benefiting everyone's mental health.
ACCEPTANCE INSTEAD OF AWARENESS (Continued)

• Research has shown that acceptance is also a process of identity development that involves moving past stigma (Mizock & Russinova, 2016). Why would you accept a mental health problem if you feel society might shun you for having one? Stigma needs to be disputed to allow for a new sense of self to emerge.

• Acceptance demands we advocate and act to change attitudes, behaviors, and systems. Acceptance is a crucial first step on the path to social justice (National Federation of Families, 2024).
Prepare to advocate **effectively** for your loved one:

- Remove your emotions
  - What? How do I do that?
- Build relationships
  - Where? With Whom?
- Hold people accountable
  - How do I do that?
  - You are not just a pronoun – you are a Proper Noun!
- Document, document, document

YOU ARE YOUR LOVED ONE’S BEST ADVOCATE!
ACTION

Put your emotions in check:
• Move forward from being silent into being heard
• Be specific about your ask
• Do not stifle your passion
• Play nice in the sandbox
• Research
• Build your advocacy toolbox by continuing to educate yourself through webinars, conferences, workshops, etc.
CONTACT INFORMATION

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THANK You!
REFERENCES


SAMHSA Sponsored Webinar Series: 
Person-Centered, Family-Driven Mental Health and 
Substance Use Support – 
A Path Towards Equity

Mental Health and Substance Use Challenges: Overcoming Challenges to Access for Families

Presenters: Paolo del Vecchio, MSW, Stephen Loyd, MD, and Lynda Gargan, PhD

In Partnership with:

JULY 30th
1:30-3 p.m. ET

Informal and Formal Family Peer Support: 
The Impact and Evidence

Presenters: Raegan and Connie Osborne, Rikki Harris, Teri Brister, PhD, LPC, Kimberly Hoagwood, PhD, and Lynda Gargan, PhD

In Partnership with:

JULY 9th
1:30-3 p.m. ET

Mental Health and Substance Use Challenge Prevention, Crisis Intervention, and Recovery: Poverty as an Equity Issue

Presenters: Kimberly Myers, Lynda Gargan, PhD, and Rebecca Roth

Register for 7/9

Register for 7/30

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Thank you!

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