In Their Own Words: The voices of participants in Creating Community Solutions-KC

A national team selected Kansas City as one of ten lead sites for large-scale community engagement through Creating Community Solutions, launched by the Obama administration in June of 2013. The three goals:

- *Get Americans talking about mental health to break down barriers and promote recovery and healthy communities.*
- *Find innovative, community-based solutions to mental health needs, with a focus on helping young people.*
- *Develop clear steps for communities to move forward in a way that complements existing local initiatives and activities.*

> *"My son is an addict with borderline personality disorder. Insurance will only cover 30 days before discharging him, which is not nearly long enough."*

This document offers quotes from some of the 310 community members who spent September 21, 2013, talking about their personal connection to the issue of mental health, the challenges facing the community, strategies for assisting youth and young adults, and steps for action.

The people quoted use a mix of terminology that reflects their diverse experiences. The way people talk about mental health varies depending on how they connect with the issue, and the language of mental health continues to evolve. Their words provide a snapshot of how participants experience mental health and what they have at stake in the conversation. Their words are sometimes heartbreaking, but they are also inspiring and joyful and powerful.

When we opened the event on September 21, 2013, we talked about the language people use to talk about mental health. We explained that the language used is not intended to label people or to limit any person or group in their choice to self-identify. We said, "We hope that through this discussion, the language we use will continue to develop in a way that respects diverse perspectives. No matter what terms we use, the goal of Creating Community Solutions-KC is to find understanding and common ground for action." That remains our hope and our goal.

> *"I'm with the NAACP and one of our goals is to address mental illness and find solutions."*

WHY ARE YOU HERE?

- "I'm the mother of a son who has mental issues. I'm seeking information, resources, support and I want to contribute towards the betterment of the issue in KC."
- "I'm a mental health client and have been for several years, since I was 16 years old."
- "I go to school in Lawrence and am studying about screening youth for mental health concerns. I want to see how to bridge the community and research."
- "I am tired of the police murdering my friends, arresting them for minimal charges, and pointing guns. We need to do something better than just kill people."
- "I am a family member and a person with mental illness. I have no shame about my story. I want to make change."

> *"I lost a friend and co-worker to suicide. I want to be a part of the solution."*

- "My husband has struggles with PTSD from the Vietnam War, and we have a child with a mental health disability."
- "I want to help find ways to solve the mental issues that we face in creative ways."
- "I am trying to bring mental and physical health together."
- "I work in the police department in the Midtown area. I am in contact daily with people who have mental illness and I train police officers about mental illness."
- "I go to Paseo High School and I'm concerned about bullying in school and suicide."
- "I am a retired computer programmer. When I was young I was in psych ward and have struggled with mental illness."
- "I am a school counselor. I am here because I'd like to learn about different resources for my students."
- "I am in a day program at a health center. I'm in recovery from bipolar disorder, depression and anxiety, and I have a psychiatrist and case worker."
- "I'm the oldest of nine kids. Three of my brothers committed suicide, and so did my son."
- "I don't know much about mental health, but I'm interested in dialogue and want to participate in the discussion with community members."

> *"People with mental illness fail oftentimes to see their own personal potential."*

- "I am a consumer and a member of NAMI. All five members of my family have mental illness. I am here as an advocate for public education to remove stigma."
- "I am a victim of mental health fraud and I want to blow whistle on what happened to me."
- "I have worked in community mental health and seen our funding disappear."
- "I am a retired health care executive who has volunteered with teenagers. I'm concerned about young people dealing with violence."
- "My son has schizophrenia. I am a NAMI member and an advocate who goes to Jefferson City. I want to gather information to take to legislators."

- "I work for a tenant residency. We have frequent crises and I am wanting to learn how to deal with them."
- "I am the superintendent of an alternative school. I see lots of students coming in with undiagnosed concerns that lead to expulsions."
- "I am here for my son and the people who live around me. I want to work to bridge the knowledge gap for Independence, Missouri."
- "I live on the West Side and I'm here because my sister and nephews are struggling with mental illness, and because we had two suicides in my neighborhood this summer. I want to make a difference."
- "My son is an addict with borderline personality disorder. Insurance will only cover 30 days before discharging him, which is not nearly long enough. He has been to twelve rehabs."
- "I am here to speak up and tell people what they can do to improve the mental health system to help kids like me to speak up about our mental health issues. I want to help others to speak out."
- "I'm with the NAACP and one of our goals to address mental illness and find solutions."
- "I lost a friend and co-worker to suicide. I want to be a part of the solution."
- "I had one nephew who committed suicide and one who committed murder due to mental health issues."
- "I am here because I have lived it and my family does not understand."

> *"We need to educate people about how to manage emotional distress. There are more things than medication to help address mental illness."*

WHY IS MENTAL HEALTH AN IMPORTANT ISSUE TO YOU AND YOUR COMMUNITY?

- "It touches every family. All ages are affected. A crisis for one member affects all."
- "It seems that psychiatric treatment is more like an experiment too often."
- "I have tried for six years to get the Latino and Hispanic community to get the services they need."
- "We all have the right to a happy life and the ability to contribute to society. Getting the right help needed for mental health issues is so important to realizing the life we deserve."
- "It is how we transform our society, transform into a love-based society, to increase joy and love."
- "The lack of access to support and treatment for a family member, the lack of understanding... brought me awareness of the importance of early intervention, support, the need for education in the community and the need to reduce the stigma."
- "Without strong coordination of assessment, intervention, and recovery programs in the metro area, we lose valuable members of our society through loss of productivity, disruption in work and family life, or even death."
- "There's a lot of trauma in certain areas and a lot of people are unaware of how life has a significant effect on kids at a young age. The issue is not taken seriously and it should be."

> *"It's a public health issue of epidemic proportions."*

- "It's about the safety of others. I fear that someone I know may hurt someone and end up in jail."
- "People with mental illness are subject to violence for many unjust reasons."
- "Some people will not seek help because of labeling."
- "People with mental illness fail oftentimes to see their own personal potential."
- "Families need to respond to mental health issues without drugs. The effects of drugs need to be studied, the medical side effects of medicine."
- "Shootings in the community like in Aurora and Sandy Hook – communities need support to prevent them."
- "Medication is being used to manage the issue short term without long term support."
- "Early detection and prevention is important. It's cheaper to prevent and treat before a crisis situation occurs."
- "The killing of young black males – the killing cycle continues and needs to be addressed. Mental health is a factor."

"Bullying contributes to suicide, and causes self-confidence issues."

- "I was not able to obtain support for my daughter until I gave up custody. I was seeking help and the system was failing me. There is a need for more education and support for the family, and more protocols, or even temporary assistance, so it's not so hard. There is often too much red tape."
- "There is still a stigma. No one wants to talk about it or give it attention like other medical issues such as cancer or diabetes. It is easier to support other illnesses."
- "I've been in and out of prison due to my mental illness. The cognitive training in prison helped me."
- "We want to make mental illness an illness, but it is also a spiritual issue."
- "Dysfunctional homes, neighborhoods and societies affect a person's mental health."
- "Many students will go to a clinic, but not a mental health clinic. Even those with a mild depression don't see themselves as needing help."
- "We need to educate people about how to manage symptoms and emotional distress. There are more things than medication to help address mental illness."
- "Many homeless kids are diagnosed young and need medication. They may use the diagnosis as the reason not to get employment or housing because of low expectations of themselves. They develop their own stigma."

"The stigma involved makes people afraid to speak up about mental illness for fear of being different."

- "It is an economic issue."
- "The mental health issues of bullies should be investigated."
- "As a teenager I see kids that need help and don't get it. I wish they would get help. Compassion and education are needed."
- "It's a public health issue of epidemic proportions."
- "There is a lack of appropriate services within the schools. We blame the student for behaviors instead of addressing the underlying issue."

- "There is lots of denial. Parents of a mentally ill child feel like a failure, and that is a barrier to people understanding or frankly dealing with the presence of mental illness. This seems to be everywhere."
- "We talked about the cultural conversation, not just ethnic, but also socioeconomic. It seems like mental health professionals are seen as outsiders, so it is also a class issue."
- "There is racial inequality with services provided, and stigma within subcultures."
- "Peer specialists could help the community by helping a person be successful, reduce escalating symptoms, help them keep jobs, help maintain self-sufficiency and prevent the need for public assistance."
- "It is important to conduct assertive outreach. We have to reach out and partner with different agencies, entities that are not directly involved with mental health."
- "In 1968 I was hospitalized twice. I noticed abuses of people, such as electroshock and lobotomies, and recommendations to husbands to divorce wives with mental illness."
- "Bullying contributes to suicide, and causes self-confidence issues."

> *"To get services you have to have a diagnosis...and services are only available based on severity."*

WHICH OF THESE KEY CHALLENGES ARE MOST IMPORTANT TO YOUR COMMUNITY AND WHY?

- "Family suicide and the feeling of total helplessness, and the need to understand more about the signs and when to intervene."
- "In the African-American community, the daily issues of racism and poverty are simply magnified when there is mental illness. It's too much."
- "Fragmentation of services - need more coordination to best utilize limited resources."
- "Coordinating care, even within the same political or geographic boundaries. Difficult to unify treatment between agencies."
- "Youth need more people to relate to, people who will listen to the need for support instead of people telling you what you need."
- "The stigma involved makes people afraid to speak up about mental illness for fear of being different."
- "Funding for effective programs' sustainability."
- "I see families dealing with the aftermath of traumatic experiences. The kids don't seem to have ways to relieve stress from these events or environments, and the parents are not aware of the impact of their own response to trauma."

> *"Fragmentation creates a barrier and prevents outreach. There is no collaboration and the state line is a problem. How do you overcome that?"*

- "Stigma and the relationship between the person who needs services and the provider who understands your culture and where you are, and the provider being dismissive or perhaps having a lack of understanding."
- "The lack of easier access to medication that works for the patient rather than the institution."
- "The large number of mentally ill single mothers living in public housing, leaving children in a chaotic, irrational world with dysfunctional parents who are not medicated or who are self-medicated."

- "Fragmentation of services across state lines. People may have to start over or get a duplication of the diagnosis."
- "Bullying has a relationship to gang involvement and tears down self-esteem."
- "Families don't believe there's a problem, saying things like, 'you don't look bi-polar.'"
- "Schools lack the knowledge to sufficiently care for students."
- "To get services you have to have a diagnosis...and services are only available based on severity."
- "Screening for teens doesn't happen routinely. Health care providers don't always ask the right questions and then there is the lack of coordination with health care providers, part of fragmentation of services. There is not consistent programming in schools re: suicide prevention, depression."
- "Fragmentation creates a barrier and prevents outreach. There is no collaboration and the state line is a problem. Dollars are not equivalent. How do you overcome that?"
- "We have to dispel the myth is that people can't be different. In the faith community this is a real issue."

> *"Youth need more people to relate to, people who will listen to the need for support instead of people telling you what you need."*

- "Trauma. There needs to be help available immediately upon police involvement in the home."
- "The role of peers. Other students bully back from the problem child."
- "The increasing financial disparity, the dog-eat-dog attitude. Legislators who want to cut taxes and services because they don't care about us, the people. More tax cuts for wealthy; funding cuts for needy."
- "We're dealing with multigenerational issues. People get stuck in lifelong patterns that have been handed down from parent to child."
- "Not knowing what's wrong with you as a child because of a resistance to labelling, and being seen as a troubled child instead of getting treatment."
- "People who suffer from mental illness when in college need to have more help available and educate college professors about mental illness."
- "Silence and shame makes the problem grow."
- "Drugs play an important piece with mental health issues in the schools and students self-medicate as a result of their mental health issues or challenges."
- "Creating language-appropriate outreach programs for students and parents, in Spanish."
- "From a student's perspective, we do not have appropriate emotional support and services in schools. I never heard of any in my schools. We don't know where to find them."

> *"It's about the safety of others. I fear that someone I know may hurt someone and end up in jail."*

- "Caseloads are huge. The high turnover rate for professionals makes it difficult for clients to trust professionals."
- "Inadequate funding. All of the solutions in place today don't have enough funding. Is it going to possible to implement new solutions without additional dollars?"
- "Cultural bias. African-Americans rely on faith or it's not really happening. Pastors need to know when there is a need for treatment vs. a need for prayer."

- "Social workers in the schools are needed to sit down to talk with the kids. Confidentiality stays intact for the kids but they get to express what they feel before they explode or become aggressive."
- "Clinicians seeing themselves as the experts and not utilizing family members as resources. It leads to a disconnect between treatment and family members involved."
- "Family members blaming providers, community members blaming parents and family members."
- "Lack of service providers who look like the people they serve."
- "We're not using other types of therapies like CBT, EMDR, or client-centered, which that can be just as, or more, effective than medication."
- "We don't have sufficient research information about resilience and what separates people from those who deal powerfully with trauma and those who don't seem to recover."
- "Money should move with you. Your resources should move with you."
- "HIPPA laws are a barrier for young adults over the age of 18 because parents cannot participate in communicating with their treatment providers. Their hands are tied by the law."

> *"At college, we need a parent orientation on how to recognize mental illness in their kids."*

- "We don't always hear the success stories so people don't realize that recovery is possible, that there is a way out."
- "Insurance company stigma. There is a 'snake oil' attitude that insurance companies have about autism treatments. They're not paying for state of art services
- "We need more young people to speak about their recovery, more students available instead of professionals who deal with science-based interventions rather than personal needs."
- "Being a minor can be a barrier to the help you need. Parents can even stand in the way."
- "The system is so complex, there can be a lot of trial and error before real help is delivered."
- "Lack of respect. People are human beings and individuals, not labels."
- "Schools are not necessarily safe places to find students. Go where young people are."

> *"I get calls almost on a daily basis about teens who need help but have aged out. They're dealing with drug abuse, feelings of loneliness and lack of support ."*

- "Bullying. The way people treated me is the way I reacted to them. Bullying resulted in me lashing out."
- "Lack of food and shelter cause huge stressors."
- "We do not have a face for mental illness, publicly. Many other diseases have nationally recognized advocates, but this is not the case for mental illness. Nobody wants to step forward."
- "We need to provide assistance to the providers of services like police officers and teachers, who themselves are subject to trauma."
- "People don't understand the amount of money mental patients have to make to still get all of their benefits because their medications cost so much money and most people can't afford it."

ACTION STEPS

- "Act on the information given, early and often. None of these recommendations were given lightly. Please do what you can immediately and try to affect as many people as possible."
- "Make sure that everyone is represented at the table when the action plan is put together."
- "Please don't have this just be a meeting. Do something with this."
- "Consider funding several pilot programs, based on ideas from the national dialogue on mental health in OUR community."
- "There must be a discussion about Medicaid funds regarding the feds and states and how money can be allotted fairly. Look how services are funded and figure out an appropriate way to address them."
- "Understand that one solution does not fit all."
- "Have the money follow the people instead of just feeding the system."
- "Continue having these discussions. Young people need to be more represented - have groups for them where they feel more comfortable talking."

> *"We don't always hear the success stories so people don't realize that recovery is possible, that there is a way out."*

- "Be realistic about what you can provide to our community both financially and programmatically to better serve those struggling with mental health challenges."
- "Before changing interventions, talk to youth who have been successful with recovery through peer mentoring."
- "Set reasonable goals. Determine who will be doing what. Figure out the logistics. Ensure accountability on follow-through."
- "In the way of taking action, consider what has been discussed here, and not brush over it lightly. Really use this community conversation."
- "Directly contact participants from this community conversation to be some of the worker bees for committees that form as a result of this conversation."

> *"Folks at table 13 are exchanging cell phone numbers to volunteer and help each other."*

- "Honor/recognize/give weight to the recommendations that came from this forum. Have this be an on-going process with representatives from this group going out to the community."
- "People are suffering. Don't be afraid to start small and start the process. Do something."
- "Include the experts' knowledge."
- "Keep in mind that this is life-saving. This is an urgent need."
- "Include all families in discussion of mental health issues, not just families who are currently dealing with a mental health crisis."
- "Once this information is provided to the entire community then the community can truly get involved."
- "KEEP THE MOMENTUM GOING! PLEASE DON'T LET THIS DIE."
- "Take mental health services like Mental Health First Aid where people are, like bars, churches, restaurants, the shopping mall, farmers markets and libraries."
- "Normalize life experiences and discuss mental health/illness as a continuum, not opposites."

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"People are suffering. Don't be afraid to start small and start the process. Do something."

"Have a public celebration of accomplishments of people who live with mental illness. We should make it safe for them to come forward."

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