ENGAGEMENT

A New Standard for Mental Health Care

nami
National Alliance on Mental Illness

NAMI
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About NAMI

NAMI, the National Alliance on Mental Illness, 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 blossomed into the nation's leading voice on mental health. Today, we are an association of thousands of state organizations, local affiliates and volunteers who raise awareness and provide advocacy, education and support in communities across the United States.

Acknowledgments

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DISENGAGED—
TODAY'S STATUS QUO

As an organization of individuals with mental health conditions and their families, NAMI knows that the U.S. system of mental health care is failing to engage people who seek help. The facts say it all: **many people who seek mental health care drop out. 70% that drop out do so after their first or second visit.**[1]

The first moments of interaction between a service provider and a person seeking care for a mental health condition can set the tone and course of treatment. This first interaction can start a journey to recovery and a satisfying life—or it can leave a person unsure or even hopeless about their future and unwilling to go back a second time. The same is true about interactions with others in the community; a person who has been told that people with mental illness are scary, weak or unable to care for themselves may not seek help or may avoid telling others the full extent of what they are experiencing.

> *"My son's first break was when he was most open to the idea of engagement. He was scared and didn't know what was going on. He voluntarily went to see a psychiatrist, but the manner in which he was treated really closed the door at that opportune moment. The psychiatrist was proud of being the kind of doctor who tells it like it is. He told my son, 'you have a mental illness and are going to be on medications for the rest of your life. They'll probably cause you to gain significant weight, and you probably won't be able to work in a regular job. If you don't take the medications, you are going to end up homeless, in jail or dead.' My son's reaction was to reject that and to close the door on treatment."*
>
> —PETE EARLEY

This story of lost opportunity for engagement is far from an isolated experience. NAMI hears such stories repeatedly—and they often end with tragic consequences.

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1   Mark Olfson, M.D., M.P.H., Ramin Mojtabai, M.D., Ph.D., Nancy A. Sampson, B.A., Irving Hwang, M.A., and Ronald C. Kessler, Ph.D. *Psychiatric Services*, 2009 Jul; 60(7): 898–907.
Patrick Corrigan, Benjamin Druss, Deborah Perlick. *Psychological Science in the Public Interest*, Oct 2014, vol. 15 no. 2: 37–70.

Such stories illustrate the need for a shift in the culture of our country's mental health system.

Recovery is possible and achieved by many, but for countless others, a mental health diagnosis leads to needless trauma, losses and shortened lives. When the door is shut on engagement, too many people leave school, lose jobs, get arrested, become home-less or attempt suicide.

While there are many reasons people do not engage in mental health services and supports, including in some cases lack of insight, this report focuses on the foun-dation: the relationships between people with mental illness and service providers, families and the broader community. Trusting and respectful relationships are the basis for recovery.

SPOTLIGHT ON
NEV JONES, PH.D.
Building a Relationship of Trust

"When you have a really strong relationship with a therapist, in a sense everything they do is about engagement—about winning and keeping your trust and expressing, in subtle and not-so-subtle ways, that they care about you and are invested in you. It goes beyond a financial transaction. My therapist was an amazing person. When I was first enrolled in the program and had to get meds, she took me to the pharmacy and walked me through the whole process. It wasn't a covert adherence strategy; it was her recognition that I was struggling and terrified of going to the pharmacy, of going anywhere. These kinds of things showed me that she cared about me, that she wasn't just doing her job."

Nev Jones, Ph.D., is the Director of Research and Evaluation at the Felton Institute in San Francisco, CA. Nev believes that a genuine interest in the individual's experience is essential for creating a connection, including a willingness to explore uncomfortable symptoms of psychosis.

NAMI'S INITIATIVE ON ENGAGEMENT

To explore how the quality of relationships and interactions affect outcomes for people with mental illness and their families, NAMI worked to better understand the process of engagement in mental health care. We asked, "How can providers and health systems better serve people with mental health conditions who are not engaged in care?"

Our goal was to hear diverse perspectives on the most important factors contributing to effective engagement in mental health care. Our inquiry focused on a continuum—from engagement of people when they first experience symptoms to engagement of people who have lived with mental health conditions over the course of years and with varying degrees of severity.

We started with a listening session. NAMI gathered the voices and expertise of individuals representing diverse perspectives for an in-depth look at engagement, including:

- Individuals living with a mental health condition;
- Family members;
- Peer support specialists;
- Mental health therapists and psychiatrists;
- Researchers and academics;
- Mental health system and program administrators;
- Criminal justice service agencies; and
- Housing and homeless service programs.

After listening to a rich discussion among these experts for two days, NAMI interviewed additional key informants with perspectives important to the topic of engagement. Appendix A includes a list of the listening session participants and key informants.

The Need for a Culture Shift

Although participants in the listening session had various perspectives and experiences, one theme frequently emerged: if we want to improve the lives of people with mental illness and their families, we must shift to a culture that embraces engagement as a new standard of care.

MAGGIE
Individualized Care and Encouragement

"Don't generalize about people based on their symptoms and mental health issues. Figure out what their goals are and what they want to do in life. Then… cheer them on and tell them that it is possible. Listen to their whole story and cheer them on."

Maggie experienced a first episode of psychosis during her sophomore year in high school. After her first hospitalization, she entered an intensive day program that was not right for her. She was the only one hearing voices and felt isolated.

Maggie left the day program and found a first-episode psychosis (FEP) program that made a positive difference in her life.

"The program cared about me as a person and cheered me on. They went above and beyond to help me. Because they were putting in the extra effort, I felt like I really needed to try, too, because they were trying and I didn't want to disappoint them. They cared about me getting my life back on track, getting back to school and work and keeping my goals in reach."

Maggie's engagement with the FEP program allowed her to focus on her life goals, including enrolling in nursing school.

When her psychiatrist was away, Maggie saw another doctor who wanted to significantly increase her medication. The doctor recommended that she leave school because it would be too stressful. Maggie defended her existing treatment plan and life goals. She understood the importance of negotiating with this new psychiatrist to maintain her current treatment because it was working for her. "If I hadn't had that experience in the FEP program, I probably would have quit school. I think the new doctor respected me for standing up to him!"

Maggie is a nursing student.

If we want to improve the lives of individuals with mental illness and their families, we must shift to a culture that embraces engagement as a new standard of care.

The task of defining "engagement" sparked lively conversation. Participants shared a strong interest in not placing the burden of success or failure of engagement on people with mental health conditions or their family or supporters. Instead, they saw engagement as a two-way process that includes a determination never to give up on the person.

Participants agreed that engagement has multiple dimensions and must embrace the whole person in the context of family, language, culture and community. Engagement goes beyond traditional medical goals of symptom reduction and functioning to include wellness and connection to family, friends, community, faith, school and work.

"The problem may not be that I have bipolar disorder but that I have had to quit school or quit my job."

—Oscar Jimenez Solomon

Out of this discussion emerged the following **working definition:**

Engagement is the strengths-based process through which individuals with mental health conditions form a healing connection with people that support their recovery and wellness within the context of family, culture and community.

Engagement expands on the concepts of person-centered care and therapeutic alliance. Successful engagement enables people to pursue recovery and life goals across multiple areas—home, school, work and community. Engagement is built and sustained on the foundation of hope, mutual trust, respect, effective communication and recognition of the strengths and resources that people experiencing mental illness bring to their recovery.

This report captures principles of this needed culture shift. It incorporates the wisdom and personal experiences of experts and key informants. In addition, it highlights effective strategies and approaches to achieve a culture of engagement.

MARK RAGINS, M.D.
"Do you like us enough to fill out this elaborate paperwork?"

Every person we see in the program The Village is an engagement challenge. We consider ourselves successful if over the first six months we can get people to like the program enough to come back. The enrollment paperwork takes over an hour, with individuals signing 20 different forms. They can become suspicious about someone asking so many questions. It usually comes down to this: did we get you to like us enough to sit and fill out this elaborate paperwork, and do you think we can help you?

We started working with a woman who had been doing pretty well in life. She worked in aerospace and sales until she got paranoid. She had a problem with a person living above her in her apartment building, so she had been living in a car for 10 years. She felt she had to dodge and hide from plots. She moved around a lot to keep away from imagined persecutors. She wouldn't walk into the program's building or leave messages. To build a connection, staff had been meeting her for months in a commercial parking lot. She needed help with her state disability paperwork so she could keep getting money, so that gave the program a way to be useful.

Many people with serious mental illnesses have gone beyond normal experiences, beyond family structures, beyond social roles. They are isolated, alone and confused in a strange land. If we want to connect with them, we have to get to that strange land.

Mark Ragins, M.D., is the medical director and founding member of MHA Village in Long Beach, Calif. He is a leading psychiatrist and a nationally recognized leader in the recovery movement.

Welcoming People with Mental Illness in the Community

Listening session participants stressed the importance of the community's role in welcoming, connecting with and supporting people with mental illnesses. Connecting people to treatment that works for them is a powerful outcome of engagement but so too is helping them feel valued and included at home, at work, in school and in the community—whether or not they stick with a treatment plan.

Engagement is Not Compliance

The term "engagement" has not been widely used in mental health; "compliance" is more commonly used. Temporary compliance can be achieved in various ways. An important question is whether mere compliance makes a person better off in the long term. Does compliance help a person regain a sense of purpose and personhood?

Engagement is a broader concept than compliance. It involves the participation of people who both deliver and seek services. With effective engagement, the likelihood of ongoing participation in services and supports increases. When care is respectful, compassionate and centered on an individual's life goals, the likelihood of recovery is sharply increased.

"People experiencing psychosis need friends and mentors. They need to be able to just sit with a neighbor. How do we get others not to be afraid of them—to be willing to sit, listen deeply and care?"
—NEV JONES

Social inclusion is an important engagement outcome. This is especially true for individuals experiencing psychosis. An individual may refuse services and may exhibit behaviors that seem bizarre or disturbing, but communities still need to engage and support a person experiencing psychosis. These individuals are more likely to respond when treated with respect and kindness.

"People don't engage with the woman on the street [who is] hearing voices. They don't know that they can engage with her."
—SYLVIA PEARSON

OSCAR JIMENEZ-SOLOMON, M.P.H.
Holding Hope for One Another

Oscar Jimenez-Solomon grew up in Peru in a family of business and political leaders, including the first congresswoman, two ministers, a political writer and the first Peruvian scientist in Antarctica. The implicit expectation was that everyone had a gift and was obligated to share it.

"I worked hard since I was a teenager to find my purpose. I excelled academically, and, in college, I started feeling that I was finding my way. But at the age of 22, when I was about to finish college, I had a major breakdown. I started medicating my depression and anxiety with alcohol and other substances. I started seeing a psychiatrist, but I didn't feel that he understood me. He wanted me to stop doing my work and research and go into inpatient treatment for a year. He and my family did not seem to understand what they were asking me to do—to give up my dreams."

Oscar realized his dream of going to graduate school and continuing his research. Although he continued to struggle, he attended school and worked in New York, but he was terrified that he would not do well. He saw a psychiatrist and took medications, but because he was still experiencing symptoms, he returned to alcohol and drugs. After months of this, the psychiatrist told him, "Oscar, I am a psychiatrist, and I have training in the symptoms you are dealing with. But I cannot help you stop abusing substances." The doctor gave him a phone number and said, "These people can help you because I cannot." The number was to a peer support program.

Oscar believes that, "in engagement, a good clinician recognizes his or her limitations. We try hard to keep people connected to us, but the other side of the story is taking a risk to tell people what they need to know to be part of the decision. It is also a way of saying, 'I think highly enough of you to tell you this.' This type of vulnerability is what builds trust."

Oscar called the number and started attending a peer support group.

"One of the things I heard there was that I had to put my recovery first, before everything else. For two years, I went to at least one peer support meeting a day. But every month or two my symptoms would feel like too much and I would turn back to alcohol and other substances. As time passed, I was starting to lose hope. I would think, 'what is wrong with me? Why can't I get sober? I want to, but I can't. There must be something wrong with me.'

Everyone in the peer group was very supportive, but I especially recall a very caring older woman who would say to me time and again, 'please don't stop coming to our group. We will love you until you are able to love yourself.' That support kept me coming back. At the time I was also in individual and group therapy, and I had a psychiatrist, but what kept me engaged was the unconditional love and support I felt from my peer group."

Oscar did very well in graduate school. When he graduated, he was offered a research job, but his depression and anxiety were getting worse. "Really strong internal voices were telling me that I was a loser and worthless, and that I did not deserve to have the job I had," he says. "A year later, I was on a business trip in a foreign country and the self-defeating voices were worse than ever. I felt I had to numb the pain, and I relapsed on alcohol and other substances. I disappeared for two days and lost the research career I had been working toward for 10 years. When that happened, I thought I could no longer live—like a door had been shut forever."

After considering suicide, Oscar was hospitalized for several weeks. He stayed away from New York until his one-year anniversary of being sober, then came back to visit friends and people in the peer group he attended before. "I ran into the caring woman who had been so supportive. She looked at me with love and smiles and said it was wonderful to see me again. She said to me, 'For the two years that you were coming here and sharing with us, I would ask myself, 'Why is it not working for Oscar? But now I see you, alive, in recovery and well, and I ask myself, who am I to say that something is not working for someone else?'"

To Oscar "this is a story about the unpredictability of recovery, and the importance of holding hope for one another. At times, it may not seem that our best efforts are working. It takes great vulnerability to not walk away from those who are struggling." He wonders how we can address on a broader level the basic principles of engagement and services— taking risks, embracing vulnerability and letting go of our need to predict outcomes. He believes that we need options between "you cannot do this for yourself, so we are going to commit you" and "go ahead and kill yourself."

Oscar wasn't willing to go into a hospital, but was willing to show up at a psychiatrist's office. He wasn't willing to stop his studies, but was willing to attend peer support meetings. "Readiness can develop over time. My level of readiness kept advancing, in part because of the growing pain, but also because of the risks many took to keep me engaged."

Oscar Jimenez-Solomon is a research scientist and research coordinator at the New York State Center of Excellence for Cultural Competence at the New York State Psychiatric Institute at Columbia University Medical Center and senior research staff associate at the Columbia University Department of Psychiatry. Oscar is also an Adjunct Instructor at Rutgers University Department of Psychiatric Rehabilitation. He has been sober and in mental health recovery for twelve years.

BARRIERS TO ENGAGEMENT

The concept of engagement has implications for health and mental health systems, payers, providers, individuals and families. It requires rethinking how systems are designed, how services are paid for and how providers are trained, supervised and evaluated. Doing so is essential to improving mental health care—and the lives of millions who live with mental illness.

> *"There may be some people that it is not possible to reach and [engage] in treatment. But the fact is that we don't know. I'm glad that we've had the recovery and empowerment movements. We would never blame anyone who has cancer for dying, and yet we look upon someone who doesn't get engaged and doesn't get better and assume that he is being obstinate or making a choice.*
>
> *We would much rather provide support after a person reaches a position of desperation than we would in the beginning when it is most helpful. If you fall far enough, you will eventually get help, but as you go down that slippery slope, it is hard to get help. That must change."*
>
> **—Pete Earley**

Today, outdated policies and practices are significant barriers to engagement in mental health services and supports. Overcrowded hospitals, large caseloads, time constraints imposed by payers, lack of training and lack of coordination across systems are some challenges that impede providers, programs and systems from engaging individuals and families.

But barriers to engagement extend far beyond systemic problems. The reality is that at times when compassion and understanding are most needed, people experiencing mental health crises are often treated in ways that create mistrust and drive them away from accepting help. A person experiencing a cardiac crisis typically gets concern and compassion in an emergency room setting. A person experiencing a psychotic crisis is frequently put in shackles and placed in a segregated, locked ward or transported to a holding cell at a jail.

Mental health systems of care are often designed in ways that fail to meet the needs of the people being served. Directly or indirectly, policies, procedures and practices exist that distance individuals with mental health conditions and their families and disregard opportunities for engagement. Listening session participants shared experiences that illustrate common barriers and offer insight into ways to improve the delivery of mental health care.

One participant described how, in her first experience with involuntary hospitalization, her personal items were taken away. They took away her clothes, school books and notes. She was essentially stripped of everything and anything familiar, of anything that would keep her calm. The hospital focused on rigid rules and procedures rather than on her needs and what she was experiencing as a terrified young woman. There was no attempt to engage her in care.

When people first experience psychosis or other serious mental illness, there is a critical opportunity to engage them in recovery. The failure to effectively engage a person early can cause the person to turn away from mental health services and supports. Lack of effective engagement can have serious consequences when a condition gets worse: hospitalization, incarceration, homelessness and early death. The failure to get timely, effective help often also harms relationships and traumatizes families. Watching a loved one spiral downward leaves those left on the sidelines feeling helpless, powerless and terrified.

Provider Barriers

The participants contributing to this report acknowledged the challenges that many mental health care providers face every day. People enter the field with good intentions and many perform exemplary work. Personal qualities such as warmth, empathy, compassion, caring and humility characterize these providers. In contrast, the following characteristics create barriers to engagement:

- Inability or unwillingness to use creative and innovative approaches to engagement;
- Deficits-based rather than strengths-based orientation;
- Inability to work effectively within and across diverse cultures;
- Rigid adherence to program rules and regulations;
- Lack of respect for individuals and families; and
- Inability to convey a sense of hope for recovery and achieving life goals.

One listening session participant shared this experience to illustrate the impact of a lack of empathy and sensitivity at a vulnerable time:

"I'd never been to a [psychiatric facility] until a friend took me in. I could hear people screaming on other floors. It was frightening. Everything was medicalized, with a band on my wrist and a lock-down protocol. It all made me nervous and uneasy. I wasn't talking, so my friend talked for me. The woman doing the intake told my friend, 'I'm not the one who does the formal diagnosis, but I've seen a lot of these people, and I can tell you right now that in my opinion she is a schizo.' It was a horrible experience! She was acting like I was not in the room, like I couldn't understand what was happening. Everything about that place made me want to escape."

Provider systems are currently regulated and funded in ways that often pressure front line staff to adhere to procedures, time frames and reporting requirements. Many staff have unrealistically high caseloads that do not leave room for the discretion and time needed to employ the art and science of healing. Over time, many providers experience "compassion fatigue" and burnout.

A family member shared her son's experience during the intake process for hospitalization. The focus was on the paperwork and protocol rather than on a vulnerable young man in crisis. For four hours, she and her son sat on hard chairs in a small, cold intake room. During the intake process, the staff criticized her son for not remembering information for their paperwork. This parent commented on how they were treated, the atmosphere and the environment, all of which mattered a great deal. At a time of vulnerability, the detached attitudes of providers and unwelcoming environments can negatively impact the willingness of individuals to engage in treatment and services.

If the U.S. is to fix the severe mental health workforce shortage, policymakers and insurers must make it possible for providers to do satisfying work. The best and brightest will be attracted to the mental health field when financial incentives and documentation requirements promote high-quality, compassionate, person-centered care starting with the moment of engagement.

Integrating Engagement into the Mental Health Workforce

"Until providers understand the reality of mental illness—until they understand how it looks from the perspective of the person and family—they cannot change and do the good job they want to do."
—Joyce Burland, Ph.D.

"Familiarity breeds engagement, and this population needs skilled providers who are going to stick around. But the system considers providers to be interchangeable."
—Jackie Feldman, M.D.

"Retraining and re-sensitizing the mental health workforce is vitally important. Every contact matters when someone is experiencing serious mental illness. Providers need to know and care about the person in front of them—moment to moment. Families and loved ones also need training so they know how to ask questions, get their messages across and maximize their capacity to encourage engagement."
—Adrienne Kennedy, M.A.

KENNETH MINKOFF, M.D.
People Who Need Us the Most are Pushed Away

After decades of working as a community psychiatrist, Dr. Minkoff began helping mental health and substance use systems reorganize so that the needs, hopes and experiences of the people they serve would be at the center of the system design. In his view, "this is not rocket science" and can be done with existing resources. Hotels, restaurants and retail stores do it every day, so why not mental health and addiction services?

When customers are at the center of the mental health system, complexity is an expectation, rather than an exception. That means that individuals with co-occurring mental illness and addiction disorders and other complex needs should be a priority. Instead, the opposite is often true.

People with co-occurring conditions, such as mental health and substance use or mental health and cognitive challenges, and other complex needs are more likely to have poorer outcomes and higher costs in multiple domains. For this reason, they should clearly be a priority for engagement and service at every level of the system. However, they often feel like "misfits" in current services and are pushed away from services rather than welcomed and inspired by hope.

Given the vast number of people with co-occurring conditions, complexity is an expectation, not an exception. Welcoming the needs and inspiring the hopes of people and families with co-occurring needs cannot be addressed simply by creating a few special programs or hiring a few special clinicians.

"We need to build the capacity to welcome the needs, inspire the hopes and provide engagement in integrated services for people and families with complexity in everything we do. Every program, every process, every person providing help, every policy, procedure, practice and piece of paperwork—with every penny available—needs to be welcoming and engaging the needs and inspiring the hopes of individuals and families with multiple challenges who need help."

Kenneth Minkoff, M.D., is a clinical assistant professor of psychiatry at Harvard Medical School. He is a national leader and expert in integrated treatment for individuals with co-occurring psychiatric and substance use disorders and in developing integrated systems of care.

CONCLUSION

A CULTURE OF ENGAGEMENT AS A NEW STANDARD FOR MENTAL HEALTH CARE

The systemic indifference of the mental health system would not be tolerated in the treatment of other conditions; people with other serious illnesses are treated with respect and care. They and their families are supported in care and recovery.

Many people with mental illness are handcuffed during psychiatric crises, discharged to parking lots, jailed, turned away from services and left to live on the streets. Many never experience what should be the most basic standard of care in the mental health system: a healing connection with a mental health professional, dignity, respect and a sense of hope.

The U.S. mental health system needs to promote more effective engagement. As the stories in this report indicate effective engagement should be the foundation of mental health services, not merely an aspiration.

> *There is an assumption that mental health treatment is good. Are we asking people to engage in bad mental health treatment?*
> —Ann-Marie Louison, MSW

A fundamental shift in the culture of mental health care delivery is critical. Now is the time to act. NAMI calls on providers, payers and health systems to take the following steps to promote a culture of engagement:

- **Adopt 12 principles for advancing a culture of engagement:**
    1. Make successful engagement a priority at every level of the mental health care system. Train for it. Pay for it. Support it. Measure it.
    2. Communicate hope. For those who feel hopeless, hold hope for them until they experience it themselves.
    3. Share information and decision-making. Support individuals as active participants in their care.
    4. Treat people with respect and dignity. Look beyond the person's condition to see the whole person.
    5. Use a strengths-based approach to assessment and services. Recognize the strengths and inner resources of individuals and families.

6. Shape services and supports around life goals and interests. A person's sense of wellness and connection may be more vital than reducing symptoms.
7. Take risks and be adaptable to meet individuals where they are.
8. Provide opportunities for individuals to include family and other close supporters as essential partners in their recovery.
9. Recognize the role of community, culture, faith, sexual orientation and gender identity, age, language and economic status in recovery.
10. Provide robust, meaningful peer and family involvement in system design, clinical care and provider education and training.
11. Add peer support services for individuals and families as an essential element of mental health care.
12. Promote collaboration among a wide range of systems and providers, including primary care, emergency services, law enforcement, housing providers and others.

I have seen the magic that happens when people can talk openly and deeply with a peer supporter while they are in the hospital.
—KEVIN HUCKSHORN, PH.D.

- **Require training for mental health professionals on the lived experience of mental illness, focusing on the following areas of engagement:**
    1. Motivational interviewing;
    2. Shared decision-making;
    3. Strengths-based assessment; and
    4. Including natural supports (e.g., supportive family and friends).

Training should be culturally sensitive and competent to effectively meet the needs of individuals and families in diverse communities.

- **Invest in research on effective engagement with a focus in the following areas:**
    1. Training on engagement for health care and mental health professionals.
    2. The experiences of individuals and families receiving mental health services and supports.
    3. Retention and dropout rates for individuals receiving mental health care, with a focus on achieving life and recovery goals.

The culture shift embodied in the steps and principles above may appear simple and intuitive, but it has significant implications. Adopting a culture of engagement requires a reorientation of how we provide and pay for mental health services. Moreover, it requires a fundamental change in how we view mental illness and people who live with mental health conditions. This culture shift is essential to promoting connection to care and the hope of recovery for Americans who live with mental health conditions—from those who are experiencing first symptoms to those who have struggled with severe and complex conditions for decades.

Appendix B includes promising engagement practices and programs. They offer hope and shining examples of the impact of effective engagement. As we create a new standard for mental health care, effective engagement should transcend specialty programs and exist wherever individuals access mental health services and supports.

> *We need to speak a powerful message that reaches into the darkness and lets people know what is happening in the light …*
> *People need to see the tangible thing that is recovery.*
>
> —BILL CARRUTHERS, CPS

APPENDIX A
LISTENING SESSION PARTICIPANTS AND KEY INFORMANTS

Listening Session Participants:

- **Bill Carruthers**, C.P.S. (Certified Peer Specialist), Director, Chatham Peer Program, Gateway Behavioral Health Services, Savannah, Ga.
- **Larry Davidson**, Ph.D., Professor of Psychology, Yale School of Medicine Department of Psychiatry, New Haven, Conn.
- **Leon Evans**, President and CEO, Center for Health Care Services, Bexar County Mental Health and Substance Abuse Authority, San Antonio, Texas
- **Ruth Gerson**, M.D., Director, Children's Comprehensive Psychiatric Emergency Program, Bellevue Hospital Center, NYU School of Medicine, New York
- **Kevin Huckshorn,** Ph.D., R.N., M.S.N., CADC, ICRC, President and CEO, Kevin Huckshorn and Associates, Inc.
- **Oscar Jimenez–Solomon**, M.P.H., Research Scientist and Research Coordinator, New York State Center of Excellence for Cultural Competence, New York State Psychiatry Institute at Columbia University Medical Center, New York
- **Nev Jones**, Ph.D., Director, Research and Evaluation, Felton Institute, San Francisco
- **Amanda Lipp**, Owner, Lipp & Associates, Consultant, Public Speaker, and Multi-Media Artist, NAMI Young Adult Advisory Group, Board of Directors, NAMI California
- **Ann-Marie Louison**, M.S.W., Co-Director of Adult Behavioral Health Programs, CASES, New York
- **Sylvia Pearson**, Executive Director, The Extra Mile Southeast Louisiana, Metairie, La.
- **Christy Respress**, M.S.W., Executive Director, Pathways to Housing DC, Washington, D.C.
- **Tamara Sale**, M.A., Director, Early Assessment and Support Alliance Center for Excellence, Portland State University Graduate School of Social Work Regional Research Institute, Portland, Ore.

- **Robert Weisman**, D.O., Associate Professor, Department of Psychiatry, University of Rochester Medical Center, Rochester, N.Y.
- **Nancy Wolf**, J.D., Founder and Facilitator, Parents of Young Adults Who Struggle, Writer, Speaker and Advisor on College-Related Mental Health Challenges, Bethesda, Md.

NAMI Board of Directors:

- **Lacey Berumen**, Ph.D., MNM, CAC III, Board of Directors, Engagement Workgroup
- **Joyce Burland**, Ph.D., Board of Directors, Engagement Workgroup
- **Dana Foglesong**, Board of Directors, Engagement Workgroup
- **Adrienne Kennedy**, M.A., Board of Directors, Engagement Workgroup
- **Gary Mihelish**, D.M.D., Board of Directors, Engagement Workgroup Chair
- **Mike Weaver**, M.S.Ed., Board of Directors, Policy Committee Chair and Engagement Workgroup

Key Informants:

- **Pete Earley**, Journalist, author of 17 books, among them *Crazy: A Father's Search Through America's Mental Health Madness*
- **Jacqueline Feldman**, M.D., Professor Emerita, Department of Psychiatry, University of Alabama Birmingham School of Medicine, Birmingham, Ala.
- **Maggie**, Nursing Student
- **Kenneth Minkoff**, M.D., Clinical Assistant Professor, Harvard Medical School, Zia Partners, Inc., San Rafael, Calif., and Acton, Mass.
- **Mark Ragins**, M.D., Medical Director, MHA Village Integrated Service Agency, Mental Health America, Los Angeles

PROMISING ENGAGEMENT PRACTICES AND PROGRAMS

While barriers to engagement are common, listening session participants also provided inspiring examples of programs that effectively engage individuals and families. This report highlights six programs as examples of the kind of culture shift that is needed and that achieve positive outcomes for people living with mental health conditions. However, listening session participants emphasized that a culture of engagement should not be present only in select programs; instead, engagement should be part of the entire mental health delivery system.

Housing First

PATHWAYSTOHOUSING.ORG/HOUSING-FIRST-MODEL

The Housing First model emphasizes placing people into permanent housing as quickly as possible then linking them with supportive services. People are not required to participate in treatment as a pre-condition for housing.

Housing First has successfully engaged homeless people with serious mental illness in services. The Pathways to Housing program, originally established in New York and now operating in Washington, D.C., Philadelphia, and Vermont, is recognized for its success. This has led to the adoption of hundreds of Housing First programs in communities across the country.

The philosophy of Housing First programs is that, once people have stable housing, they are more willing to seek and accept treatment and supportive services. For those who accept services, multidisciplinary Assertive Community Treatment teams provide treatment, services and supports. Residents in Housing First programs also have access to peer supports, case management and assistance in obtaining benefits.

Research shows that Housing First helps people who were formerly homeless and diagnosed with serious mental illness and substance use disorders retain stable housing for a year or more. More research is needed to determine whether and how Housing First affects the severity of pre-existing psychiatric symptoms.

Opening Doors to Recovery

Opening Doors to Recovery in Southeast Georgia is designed to increase community integration for individuals with serious mental illness and reduce the cycle of hospitalization, incarceration and homelessness. NAMI Georgia developed the service model with a diverse group of stakeholders, including people with mental health conditions and their families.

A navigation team works with program participants to develop a "meaningful day," which typically involves school, work, volunteering or a related community activity. The team also ensures access to treatment and stable housing and supports community integration through relationships, work and education. Each navigation team includes a licensed mental health professional, a trained peer specialist and a family member.

Program participants are assigned a peer navigator who is their point of contact and primary resource for intensive wraparound services. When a participant has an encounter with the police, the navigator is contacted to pick up the person anytime, day or night. This interrupts the cycle that previously resulted in a trip to the hospital emergency department or jail.

Initial evaluation of the program is promising with individuals experiencing these outcomes:

- Increased insight;
- Satisfaction with mental health services;
- Improved quality of life;
- Improved community adjustment;
- Improved ability to navigate the system; and
- Increased living skills.

Opening Doors includes engagement by recognizing the importance of peer support, the value of family navigators and the positive outcomes that come from giving people a meaningful day as an important motivating factor for remaining engaged in the program and working toward recovery.

MHALA Village

In 1990, the California Department of Mental Health chose Mental Health America (MHA) in Los Angeles to create an innovative program using an integrated services "one-stop shop" approach. This led to the creation of MHALA Village, a model program in comprehensive care for individuals with mental health conditions who are homeless, repeatedly hospitalized, or leaving jail or institutionalization.

MHALA Village provides comprehensive, traditional mental health care consisting of treatment, rehabilitation, self-help and family and community involvement. It differs from traditional mental health care in its focus on choice, equality between staff and the people they serve, a focus on continued growth and a highly supportive, emotionally vibrant environment. The Village sees the goal of recovery as full integration into all aspects of community life. The program identifies quality of life outcomes that measure independent living, work, education, finance and social goals in measuring effectiveness and accountability.

Village clients choose the services they want based on their goals, and the chosen services include customized personal service plans. Clients also choose the staff members they want to work with. Paraprofessional and professional staff—including individuals who have recovered from mental illness—have expertise in psychiatric care, employment, money management, community involvement and substance abuse recovery. All staff are viewed as recovery workers. Instead of illness services, the program promotes quality of life services. Instead of coercion, the program welcomes, engages and collaborates. Clients are involved in every aspect of their treatment and recovery.

The Village uses a collaborative approach to psychiatric care that emphasizes choice and puts individuals in control of their condition as they learn about medication and symptoms. Substance abuse services seek to reduce the harm caused by use while helping clients gain motivation for sobriety and recovery by recognizing how their life goals are affected by substance use.

The Village is widely recognized for its quality and excellence. It has received multiple awards and recognition in excellence at the state and national levels. Effective engagement is used throughout the program in addressing the needs of individuals with serious mental health conditions.

Laura's Law in San Francisco

There has been much debate about assisted outpatient treatment (AOT), which is often associated with compulsory and potentially coercive care. However, others argue that AOT can be, at its best, a form of engagement. AOT programs are relevant to the discussion of engagement to the extent that programs allow individuals to connect with services that help them move toward recovery and independence. One example is in San Francisco, where a form of AOT is being implemented that encourages voluntary participation in services and seeks to involve individuals meaningfully in decisions about services and supports.

In San Francisco, people participating in AOT are assigned to community-based mobile multidisciplinary mental health teams. These teams have client-to-staff ratios of no more than 10 to 1. Teams include a forensic psychologist, peer specialist and family liaison.

The program focuses on wellness, recovery and establishing a partnership among individuals, treatment team, and when appropriate, the person's family and natural support system. An array of services and supports are offered to individuals, including assistance with housing and employment, which are highly valued as supporting recovery.

If a court orders an individual to meet with an AOT team and the individual declines, then providers decide whether to proceed with a 72-hour emergency hold for further assessment or to accept the person's decision not to participate in treatment. Failure to comply with an AOT court order alone is not grounds for involuntary commitment.

San Francisco estimates that fewer than 100 people per year are likely to participate in the AOT program. Program implementation is in the early stages, so data are not yet available to assess the program's effectiveness. Those implementing the program believe this new approach to AOT will have a positive impact in engaging people in services and supports who historically have been difficult to reach.

We need to build engagement into managed care and other insurance arrangements. We do not have anything near parity, and that matters if we are going to make engagement stick in a bottom-line driven system. Engagement must be understood as an absolutely essential aspect of care! And when the engagement imperative doesn't work—when the level of disability is very high—there is a point when I believe that assisted outpatient treatment is required.
—ADRIENNE KENNEDY

Early Assessment and Support Alliance (EASA)

Early and first episode psychosis programs improve young lives and provide the services and supports that people need to get on with life. Outreach and engagement are core components of these programs. EASA is a nationally recognized early and first-episode psychosis program. EASA programs are offered statewide in Oregon. EASA recognizes the importance of getting engagement right in working with youth and young adults experiencing psychosis.

EASA places high value on training professionals to focus on the strengths, interests and goals of youth and young adults in developing a service plan for those in the early phase of psychosis. The program also prioritizes outreach and engagement. When a person refuses to leave his or her home or refuses to participate in mental health services and supports due to symptoms, the program does not give up. Staff will repeatedly visit a person where they are at and slowly build rapport. This approach takes persistence, patience and willingness to listen and hear youth and young adults experiencing psychosis. At the same time, EASA works closely with family members and others who are supportive of those experiencing early psychosis.

EASA provides effective services and supports that offer youth and young adults the skills and care they need to lead healthy, satisfying lives. EASA uses shared decision-making in delivering services. The program provides support and encouragement even when doing so is not easy.

Peer support is highly valued by EASA program participants, especially because services and supports are provided at a time in life when social interaction with peers plays a significant role. Professionals working in EASA programs recognize the importance of hope and empathy in delivering services and supports to those experiencing early and first-episode psychosis. This approach to delivering care is also true for other early and first-episode psychosis programs around the country.

Rochester-Forensic Assertive Community Treatment Program (R-FACT)

Assertive Community Treatment (ACT) is one of the most effective approaches for engaging people with schizophrenia and other serious illnesses in services and supports. Many individuals who participate in ACT have co-occurring substance use disorders and a history of hospitalizations, homelessness and involvement with criminal justice systems.

ACT is an intensive approach to providing community-based mental health services characterized by the following:

- Small caseload sizes;
- Integration of multiple services such as housing, mental health and substance use disorder treatment, supported employment and peer supports under one administrative structure;
- Mobile crisis response teams available 24/7; and
- Engaging people wherever they live or wherever they prefer to connect with services and supports.

In 1994, the University of Rochester (NY) created an ACT program. After a few years of implementation, the directors of the program realized that, although their program was achieving positive results in reducing hospitalizations, the results were not as favorable in reducing arrests and incarceration.

They decided to create a specialized program for individuals most at risk of criminal justice involvement. This program, called R-FACT, combines all elements of ACT with a criminal justice component. People served by FACT teams are generally referred to the program by the courts. Teams include representatives from the district attorney's office, the public defender service, and the parole and probation system, all of whom become part of the team dedicated to engaging individuals in services and supports.

R-FACT's emphasis on engagement and a more individualized, flexible approach has had positive results in reducing arrests and recidivism and fostering recovery, even among people with long arrest records.

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