THE CONSUMER PERSPECTIVE

By Lori Yates

INTRODUCTION

Hi everyone, I'm Lori Yates. I am both a mental health consumer and a licensed independent clinical social worker. I was first diagnosed in my early twenties and court committed to the Wichita Falls State Hospital in Texas, where I was treated.

My experiences of treatment and hospitalization are overall positive and have clearly shaped both my clinical practice and my role as an advocate.

In preparing for this presentation, I asked many different consumers to review this work and then incorporated their various feedback into this presentation. While there is no way to capture all consumers’ voices, I feel confident that this presentation captures the essence of many consumer voices as well as reflecting my own voice.

MAKE SURE YOU REALLY WANT TO WORK WITH US

It is essential that before you make the choice to work with people with mental illness that you really want to work with us. We know when others truly want to work with us, and we respond much better to those people. When we are faced with a person who we sense does not want to work with us, it evokes anxiety and fear and we are very likely to react out of a need to feel safe.

Many people with mental illness have had bad if not traumatic experiences in the mental health system and sometimes even a hint of negativity; frustration, sarcasm, or even joking around can trigger a serious reaction from us.

People with mental illness have a heightened sense of awareness about others. We are very attuned to body language, mood, tone of voice, attitude, smell, touch, and energy. This is a survival mechanism. We can’t always put into words what we are feeling or even thinking, but we can sense intuitively and react accordingly.
It is important to remember that we did not ask to have a mental illness. Every day is a challenge to figure out. People who have not experienced symptoms, really don’t fully understand how frustrating, confusing, painful, difficult and challenging life can be. It is better that you don’t tell us “I understand how you feel”, you don’t!

Sometimes life and everyone in it can pose a threat. Other times, hallucinations, especially voices, are funny, and they keep us company and we don’t see anything wrong with talking to the voices or for that matter having symptoms. If the symptoms are not interfering with our lives or others, it is fine to leave well enough alone.

It takes time to make sense of what is happening around us. And again, this can be difficult for others to understand.

**FORCED TREATMENT**

Forced treatment is a difficult topic to discuss, but is central to the issue of safety.

Many people with mental illness are terrified about being committed and being forced in to treatment. For some people with mental illness, they have truly had **bad past, if not traumatic** experiences.

Many have been abused, neglected, assaulted, or taken advantage embarrassed or humiliated during the course of treatment, unnecessarily restrained or subdued, given medications that really don’t work, have bad side-effects or required more medications to manage side effects.

Many times we have not really been asked what we want, or what we think will work. Sometimes, we have just been put into groups or therapies that really don’t interest us, or meet our needs. We have not really been heard, our input has not been considered or validated and instead we are only told what to do. When we are in a no win situation, many people with mental illness will make sure that No One Wins.
Many times, the nature of the illness is such that we really don’t see, believe or understand that we are as sick as we are being told we are. In fact, sometimes the symptoms make us believe that everyone around is the enemy and out to hurt us and we may fight with a fierceness that is intended to protect us from “the enemy”.

For some people with mental illness, being placed in treatment is a welcome relief to the mental pain and suffering they have been experiencing.

Resistance is not always about not wanting treatment, sometimes the symptoms are such that we really cannot see that treatment is needed, sometimes past experiences have been so traumatizing that we will do anything to keep from going back. When you work with us, understand that it feels like we must fight for our lives.

Partnering with us makes all the difference in both the short and long run.

**VIOLENCE AND THE MENTALLY ILL**

Not all people with mental illness are violent.

Research has shown that people with mental illness are no more violent than the general public and that people with mental illness are more often victimized rather than perpetrators of violent crime. Unfortunately, the media often portrays people with mental illness as violent when in fact their illness may be the cause of criminal acts.

**PERCEPTION and DIGNITY**

It is important to see people with mental illness first and foremost as a person. We are not a diagnosis. We have names, faces, families, jobs and occupations. We have value and we matter to other people in our lives.

Please maintain our sense of dignity by talking to us, not over us or about us like we are invisible or deaf. Please do not talk to us or interact with us like we are children, unless we really are children.
We hear what you say even if we are not responding back to you. Sometimes our brains are slow to take in what you are saying to us. Sometimes, too many people are talking at the same time and all of the words, sounds and noises can be confusing and stressful and downright scary. Sometimes we are too afraid or embarrassed to speak. Sometimes, we are just being stubborn and have no plans to talk to you or are just too angry or frustrated to speak.

**WHAT IS HELPFUL**

Please have only one person at a time talk. Give us time to take in what you are saying and time to respond. Don’t run up on us like we are going to fight, give us some space to make the choice to come with you. It is really embarrassing and at times humiliating to have the police or mental health professionals showing up. People are watching and we often feel vulnerable and exposed.

Treat us with kindness, dignity and respect. We may not like the situation or even you in that moment; however, we do remember kindness, dignity and respect just as we remember rudeness, roughness and hostility.

Please stay honest when talking to us. Yes, it is likely we could get angry, rude or even threatening and hostile, but knowing the truth helps us in the end, even though we will most likely like agree with you in that moment, or even later.

If you have to use force to manage us safely or because we are trying to hurt you, please give us the chance to reconnect with you in a positive way once we have been able to calm down.

Sometimes we say and do things that are embarrassing and that we are ashamed of. Allowing us a moment of your time once we have settled down, gotten medications, and regained composure, allows us that chance to apologize if we hurt you.
THE IMPORTANCE OF THE STAFF

The psychiatrist is seen as the leader. You set the tone for the working relationship. In the first few words you make it clear as to your openness to collaboration.

The therapist is seen as the lighthouse on the bay, the lifeguard in the water. Your consistency, honesty, and trust is a critical piece of recovery. We need you to show up every time you are suppose to be at our appointments. When you are gone and we don’t have time to prepare, it is scary, so please do your best to take care of yourself so you can go the distance with us.

When you take the time to really listen and hear what we say, it makes a huge difference in our willingness to listen and hear what you say.

When you say we have to take medications, sometimes it feels like a death sentence, like there is no hope of recovery from this mental illness. Your sense of hope, your honesty and your willingness to stay open to alternatives we might bring to the session help us to have a sense of control over our own lives.

Some people who have just been diagnosed with a mental illness, have never taken medications before and to be told that you have to take medications, can be a shocker, especially to young adults.

It is also important to remember that medications are not the silver bullet and that other evidenced-based practices are important to consider and use in conjunction with medications.

Cultural considerations are also important to remember. Some cultures, medications are not readily accepted, so it is important to find ways to partner with us, learn about our culture, traditions and beliefs.

Be patient with us over the medications. Sometimes it just takes some time to buy into the whole “value of medications”.
Sometimes we are not as interested in our well being as you are, however, it is important that we know that you are not giving up on us.

Take time to talk to the other members of the team that work with us. Nothing is scarier to us than the people who are in charge of our mental health care, not knowing what is going on in our treatment.

When we come to the clinic or center, it makes a difference when the receptionist remembers our name, acknowledges us when we come to the counter and does not wave us on because she is on the phone. A warm smile goes a long way. It also makes it nice when the receptionist makes a call right then and there to let the therapist or doctor know we are waiting and if there is going to be a delay, it is nice to be told that up front. We do have a life and things to do as well. Our time is also valuable.

Take time to really listen to how we are doing and to acknowledge all that we are doing right. We get that everyone is in a hurry; however, you are here because we need your help and support. Remember, we are not just a number that you get to count for funding.

**USE OUR EXPERTISE**

We have a great deal to offer mental health programs, agencies, and organizations. No one understands mental illness as fully as someone who lives with it, and no one fully understands recovery like a person with mental illness who is in the recovery journey.

We need to have active voices on boards, program development, going out on evaluations, and we need to be hired in staff roles as well as clinical roles. We are best suited to educate others about mental illness, stigma, recovery, treatment, and everything else there is to know about working with us.

Please do not place us on as the “token consumer”, listen to what we are saying. Like you, every consumer will have a different perspective about everything depending on their personal experiences and those diverse experiences will serve to strengthen your program.
I look forward to many future opportunities to collaborate with you all as we continue to work together to provide safe, quality, and recovery focused work in the mental health field.

CLOSING

I am alive today in part because of the courageous and dedicated efforts of friends, family and the mental health system. I did not want nor did I believe I needed treatment and I fought against it, however, many people saw how bad a shape I was in and fought on my behalf and as a result, I received excellent care and treatment at the state hospital and got my life back. I have nothing but gratefulness to all those who invested in my treatment and recovery.

It was my former psychiatrist Dr. Wassel Lewis who first saw the value of having a former patient on staff at the hospital. His encouragement, advocacy, vision and forethought launched my career in the mental health system both as a clinician and as a consumer voice and advocate.

My life has completely changed because of mental illness. Living life takes on a whole new meaning. My clinical work and my advocacy work are shaped by both my prior and current experiences in the mental health system and I am thankful for the opportunities to use both experiences.

Thank you for the opportunity to be the consumer voice for this training. I understand that this training comes out of tragedy and for this I am sadden. It is my hope that healing will come from this work.

Thank you.