

On April 21st, 2022, Max Barrows and Hasan Ko met with more than 40 self-advocates from at least 17 states to talk about mental health. This blog is based on our discussion.

People feel embarrassed and ashamed to talk about their mental health. We worry if we say something about how we feel, a person may think there is something mentally wrong with us. We can feel like the odd person out. It comes from society not accepting mental health being a fact of life. This stigma is stalking us. It is felt on our shoulders.

Some people think that we are not smart enough to benefit from therapy. When they find out we have a disability, they put us aside and do not help us with our feelings. Some people still think that people with intellectual disabilities do not have feelings. One person told us, "When I show my emotions, I get more meds."

People with disabilities are teased and put down. We are criticized and told we are not capable of doing things. Having people tell us this all the time can be overwhelming and we may experience depression because of the way we are treated.

Facing that we have a mental health issue is hard. It is confusing if you have not come to terms with having or figuring out that you have a disability. And then, you are faced with understanding mental health issues. It is hard to juggle it all.

We are reluctant to get help because of the way people see us. They blame our disability instead of finding solutions. They only see what is in front of them. Sometimes when we try to get help, a provider misunderstands and mixes up having an intellectual disability with having a mental health disability. People might think we are just looking for attention. There are situations where police are called, and they are not needed. It only escalates the problem. It is further complicated when we do not have the words to describe our feelings. And we are afraid others will say our issues are not real, that it's because we are disabled.

It can be hard to find a therapist who has experience communicating with people with disabilities. We need to have the same options as people without disabilities. Different kinds of treatment like group or individual therapy need to be accessible. When we get a list of suggestions of what to do, sometimes they do not help. We should get what works for us.

People may not know where to go for help. Disability services might be in one agency and mental health services in another agency. It can be hard if your medical insurance doesn't cover what you need. Many therapists do not accept Medicaid, so our choices could be limited.

Getting and taking medication can be tricky. You may not have the money or insurance to pay for it. Sometimes people with disabilities do not get the correct type of medication or we get too much.

We need more education so we can figure out if we are just feeling stressed out or we are dealing with a mental health crisis. We have been more isolated during Covid. Many of us have been alone when facing the loss of a loved one. We need friends in our lives who will listen. It is sad if our only option is to go to a therapist every time we want to talk something out. If we can talk about problems with a friend or a peer, we can get advice about if we need to go to a doctor. They can point us in the right direction.

Some people are shy to speak up, to say what is on their minds. They don't know how to speak up, they don't know the words. We need peer mentors to show how to speak up, then the shyness will go away. One self-advocate said, "The staff at my work activity center send people to me when they know they are having a hard time."

Providers need to listen to us when we tell them what is happening in our bodies. We need support to learn other ways to take care of our emotional needs. For example, write in a journal, listen or play music, workout in a gym. There is not one form of stress relief that helps everyone. People need different types of relief.

Keep educating people about mental health and developmental disabilities. Re-educate providers and police because they need to look past our disabilities, to see the person. We are slowly getting rid of stigma. We need to respect diverse cultural perspectives and provide support no matter where a person lives.

We need to take personal responsibility for any words or actions we use that are unfair to people with mental health issues. Terminology can create barriers to accessing needed services and supports. We should not box ourselves in with language such as "high and low functioning." It is not helpful. Teaching Diversity, Equity, and Inclusion at an early age will help dispel the myths about mental health. We need to educate ourselves to accept everyone.