

Finding connection and support for families navigating mental illness

By Camille Escovedo, Special to SoCoNews Apr 5, 2022 Updated Apr 5, 2022

Every family has its ups and downs, but when someone begins to struggle with a mental and behavioral health condition, treating the situation as a family affair doesn't cut it.

Tracking down resources to support a loved one with neurodiverse needs isn't easy, either, and by the time many parents reach out to Buckelew Programs, they're in crisis mode, according to Family Service Coordinator Nicole Natividad.



Buckelew Programs is a North Bay mental health services provider, offering an independent living program, supportive housing for transition-age youth, family service coordination and more in the county.

Often families are overwhelmed when Natividad speaks to them, "almost hesitant to ask for services because I think the reality is that their child may be struggling with something and they're not sure how to best support them," she said. "And so they're very scared."

Some families seek out Buckelew Programs because they have a child who's autistic, recently diagnosed with ADHD, living with a traumatic brain injury or perhaps experienced their first psychotic break and got a referral, she said.

Sometimes families notice their child acting differently and don't know if it's a chapter of development or if it warrants getting help. And a lot of families do need help.

The National Alliance on Mental Illness (NAMI) reported data from sources like the Center for Disease Control and the National Institute of Mental Health showing that in 2020, one in six youth aged 12 to 17 in the U.S. had a major depressive episode.

There was a 31% uptick in mental health-related emergency department visits for adolescents that year, and one in three U.S. young adults aged 18 to 25 experienced a mental illness. One in 10 young adults became familiar with a serious mental illness, the data revealed.

Both Buckelew Programs and the local organization NAMI Sonoma County work to support people living with mental health struggles and the people who love and live with them.

A tale of two mental health organizations and what family resources are out there

NAMI takes the position that learning about mental illness is the most powerful thing a person can do in the situation, from understanding signs of a mental condition early on to knowing what questions to ask when managing the condition and participating in treatment, said Executive Director Mary-Frances Walsh. "All of that said, resources are so limited that that's not always real," she said.

Around 80% of NAMI Sonoma County's work is with family members supporting someone with a significant mental health condition, usually bipolar, schizophrenia or major depression, Walsh said.

NAMI Sonoma County offers a free 8-week course called Family-to-Family that covers current information on mental health conditions, resources, treatment options, getting through a mental health crisis and more. Meeting other families having similar experiences is the most important piece of the course, the executive director said.

"And understanding that you are not alone, that you can share ideas, talk about your experiences without judgment — it's just so fundamental to gaining hope because you realize you're not alone in this and you don't need to be," she said. "But you need to be connected with other people who get it and resources."

The program leaders all have lived experience and must be certified with NAMI's nationally standardized training to teach a class or facilitate a support group, Walsh said. NAMI Sonoma County offers a weekly family support group, another support group for Spanish speakers, and a group that meets twice a month.

People living with mental health conditions can attend a support group that meets twice a week. "We want people to feel safe there, but they can talk about the challenges with people who get it, who get the struggle," she said. "It's a place for them to avoid isolation, which can often lead to worsening symptoms."

Back at Buckelew Programs, the family services coordination team offers peer support, education and system navigation to families for free. "That includes referring them to resources and also how they can go about getting those resources," Natividad said.

"And to be completely honest, sometimes it's not always as simple as, 'OK, this is your step-by-step on how to get services there' because sometimes it can be a little bit tricky." This means occasionally working with families on how they can work around the system to access the services that will support them the most, she said.

Like NAMI, the family services coordination team offers several family support groups, which are all online now due to COVID-19. Everyone on the team has some level of lived experience with supporting someone through mental and behavioral health challenges, the coordinator said.

The support groups are primarily aimed for adults, and while they'd like to offer support groups for siblings, Natividad said the team often recommends family counseling through other agencies.

Recently, the family services coordination team got a grant specifically for helping families and individuals who've been involved in the criminal justice team, she said. This is in addition to Buckelew

Programs' ongoing work with the county's Forensic Assertive Community Treatment (FACT) Team to provide intensive services to those in the system.

A referral from Sonoma County Behavioral Health Division is needed to access the organization's other programs for people seeking support living with mental illnesses, like medication and symptom management, finding employment, education and sometimes supportive housing, according to Natividad.

Whole family impacts and challenges

Principal to NAMI's approach to supporting mental health in Sonoma County is the understanding that one person's experience of mental illness can affect the entire family and household.

Often, Walsh said, people diagnosed with two of the three main mental health conditions NAMI Sonoma County addresses — major depression, bipolar and schizophrenia — also experience anosognosia, a condition where they are largely unaware of or unable to perceive that they are demonstrating mental illness. It's hard for people to accept treatment when they don't think they need it, she said.

Sometimes, the side effects of psychiatric medication can be so unpleasant people stop taking them even if they work. Some people may cycle through mental and behavioral health spirals, starting up medication until they feel better and then stopping because things feel more stable, until their condition escalates again.

"That is so hard on everybody, both the person and it's hard on the family," Walsh said. "And mental health crises are not always predictable, so we believe families need to know how to pick up on the triggers, what's happening that a person's behavior is beginning to escalate, how do you take steps to help early on before you get to crisis level — and if you are in a crisis, how you get help."

Paths to treatment and recovery vary with age and families can have very different views on medicating children, Natividad has observed in her role. A doctor may recommend medication for children diagnosed with ADHD or an autism spectrum disorder and "a lot of times families struggle with, 'Is my child too young to be on medication? What are going to be the side effects? Is it going to be worth it in the end to put my kid on medication?" she said.

The wait list for various treatment options can be incredibly long, even for people reporting serious mental illness, according to Walsh. "I just talked with somebody this week who said there could be a two month wait to even get started with treatment," she said.

There aren't enough mental health providers, either. "This is nationwide, but it is absolutely the case here in Sonoma County," Walsh said, adding there's also a shortage of culturally competent, Spanish-speaking providers. Same goes for affirming providers to serve the local LGBT+ community, who aren't inherently more susceptible to mental health conditions but often face many traumatic experiences that can cause anxiety and depression.

Natividad named COVID-19 as another challenge for families. "Especially right now, a lot of folks are dealing with the stress of being at home together, the confusion of going from in-person learning to distance learning back to in-person learning," she said.

Taking the pandemic further into account, NAMI collected data reporting one in five young people said the experience has had "a significant negative impact on their mental health," and "nearly half of young people with mental health concerns report a significant negative impact."

After being diagnosed with COVID-19, one in ten people younger than 18 experienced a mental health condition. Young people were also using alcohol and drugs more to treat stress in 2020, NAMI stated.

NAMI Sonoma County's executive director said hosting so many activities on Zoom is great for access, but not for people who can't easily access the internet or don't have privacy in their home. People may not feel comfortable talking in a support group if they live with someone managing a mental health condition.

And of course, the process can be painful for families, let alone for the person navigating their mental illness firsthand. Sometimes Natividad refers supportive figures to counseling themselves, she said.

"I think it can be really hard for families when they're seeing their loved one struggle. And so sometimes, I talk to a lot of families who are like, 'Okay, what's going to fix my person? What's going to fix this?' And I have to tell them there is no quick fix to anything. Everything takes time and in order to support somebody else, you have to take care of yourself as well."

Gaining stability and support often involves "trial and error," Natividad said, especially in terms of waiting for medication to become effective and starting over when it doesn't go well.

"I just try to remind them to be patient and that it's going to be a lot of ups and downs. And when you have your highs, celebrate those, and then when you have lows, you know, work on yourself and try to just be a constant in your loved ones life — as long as you're not sacrificing your own mental health," she said.

This work can mean setting boundaries, which Natividad said can be especially challenging when people are afraid something will happen to their loved one if, say, they're not allowed at the house anymore.

"We speak with many families who have somebody who has been in and out of emergency department visits, in and out of jail, in and out of very short psychiatric hospitalizations, and then it's just like revolving doors. Their long-term needs are not being met and families just don't know what to do," said Walsh.

Some families even consider conservatorship for people so unwell that they might need another person to oversee their care. "I'm talking about somebody very, very ill who is just not able to lead a normal life without support," Walsh said.

"And that is very hard to come by in this county, for good reasons, because as a country we've decided we want to protect people's rights to voluntary treatment, which is very important. But there are situations in

which people are so sick, they need help and getting help sometimes for those individuals is very difficult," she finished.

Locating hope

As much as there is for families and mental health organizations to bear, there's also great cause for hope in healing and meaningful change.

Both Walsh and Natividad voiced their hope in the ongoing progress of having more of a mental health response than a law enforcement approach when people are experiencing mental health crises. The issue hits home in Sonoma County, where in 2007, deputies killed 16-year-old Jeremiah Chass of Sebastopol as he was experiencing a major mental health episode described in some outlets as "psychotic."

"Having somebody show up with handcuffs, with a police car with flashing lights can be very frightening to somebody who's going through a mental health crisis, who's fundamentally afraid ... and that's why they may be acting out or threatening others," Walsh said. "They're feeling out of control and that's a frightening experience."

She praised new models of crisis care in Santa Rosa, Petaluma, Rohnert Park and Cotati. "People having a mental health crisis deserve a mental health response, somebody who knows how to de-escalate the situation to make sure nobody gets hurt," and maybe even resolve the crisis without hospitalization, Walsh said.

Natividad said increasing mental health responses excites her because there are families she talks to who don't trust law enforcement and hesitate to make that call. "Now, we can give them a number to call when they're in crisis and they can feel a little bit safer calling that because they know (the responders) are specifically trained for mental health crises."

Walsh said these changes aren't as far-reaching as they could be beyond some cities, however. "If you happen to live north of Windsor or if you happen to live in Bodega Bay or parts of Sonoma Valley, you're not going to get that kind of response because we just don't have enough capacity in these teams to be able to travel for long periods of time," she said.

"And it can leave families and individuals in crisis on their own, kind of scary. In that case, probably law enforcement is involved, but it doesn't always go well, kind of frightening," she added, acknowledging the shame that a law enforcement response can evoke.

According to Walsh, empathy is of the essence when it comes to the healing work ahead and staying connected to loved ones. She spoke of the book "I AM NOT SICK, I DON'T NEED HELP! How to Help Someone with Mental Illness Accept Treatment" by Xavier Amador.

In the book, the author figures out he'll never persuade his adult brother to accept treatment, "so he learned fundamentally the most important thing was to keep a relationship," she said.

"Don't close the door. Let that person know that you care. It is just so fundamentally important to develop a bond of trust and maybe, given that trust, with engagement and encouragement, you can get the person to voluntarily accept treatment," Walsh finished.

Most importantly, she said people with mental illnesses need life skills and connectedness, which is key for anyone feeling suicidal. "They need to be able to talk about their feelings. They need to not feel alone."

Natividad shared the importance of families accepting and adapting to needs they didn't anticipate. Parents can appreciate when their child is on a roll and ride the "highs of doing really well together" once they let go of how they thought things were supposed to be, she said.

"We talk a lot with families about grieving the life they thought they were going to have with their kids. It's okay to be sad and to grieve that part, but now it's kind of this shifting point of 'My kid needs help. I'm here to support them. These are the things that I can do to support them," Natividad said.

Those living with diabetes may not be able to eat everything they want, but can enjoy things in moderation, Natividad pointed out. "People are able to live normal lives with their mental health challenges and mental illness — it's just going to look a little different than maybe their parents had envisioned."

Buckelew Programs runs the North Bay Suicide Prevention hotline for Sonoma, Lake and Mendocino counties at 1-855-587-6373. Online, NAMI Sonoma County lists the county's 24/7 Crisis Stabilization Unit number as 707-576-8181, along with many other crisis resource numbers.

https://soconews.org/scn_county/finding-connection-and-support-for-families-navigating-mental-illness/article_895ffa42-b4f0-11ec-94df-0fc1e0c0d896.html