



The Waisman TIES Clinic, a psychiatry clinic that looks at disability and mental health through a holistic lens

Posted on November 17, 2022

By Charlene N. Rivera-Bonet, Waisman Science Writer

Daniel Kliewer and his father sit in the only car parked in the lot right outside the Waisman Center TIES Clinic on Olin Ave. Daniel regularly comes to the clinic to see psychiatrist Steve Singer, MD. But it is Sunday morning and there is no one inside the clinic. For Daniel, however, this weekly routine proves to be quite therapeutic. "We drive up to the front of his office, and we shout at the front of the building so that Daniel thinks we're talking to Dr. Steve. And we pretend that Dr. Steve is telling him that he's going to see him in many days," narrates Mark Kliewer, Daniel's dad. "And then Daniel feels happy that he told Dr. Steve everything. And then we drive off."

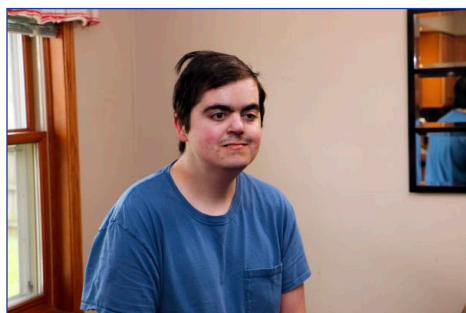


Mark Kliewer (left), and Daniel Kliewer visit the TIES Clinic at Olin Ave on a Sunday afternoon to pretend to talk to psychiatrist Steve Singer. This is therapeutic and reassuring for Daniel, who has Cornelia de Lange syndrome.

Pretending to tell Singer all about his day is very reassuring for Daniel. But this is rooted in more than a decade of working with Singer and being part of Community TIES. Community TIES (Training, Intervention, and Evaluation Services) is a UW-Waisman

Center behavioral support program that serves residents of Dane County with intellectual and developmental disabilities and their families. The Waisman Center TIES Clinic is a part of TIES that provides psychiatric care and consultation to Dane County residents with intellectual and developmental disabilities.

Once every few months, Daniel has an official session in the TIES clinic which actually includes Singer.



Daniel Kliewer at the regular Sunday hangout with his parents

At six months old, Daniel, who is now 33, was diagnosed with Cornelia de Lange syndrome, a rare syndrome caused by a spontaneous genetic mutation. Cornelia de Lange is characterized by slow growth and smaller stature, developmental and behavioral differences, and intellectual disabilities ranging from mild to profound. Daniel also has autism and is non-verbal but communicates through sign language. "Even though he's nonverbal, he's very chatty," says Eileen Ahearn, Daniel's mom.

The Kliewers came to Community TIES when Daniel was in junior high. In addition to the clinic, Daniel receives services through the Community TIES Behavioral Support, which is standard for every clinic participant. TIES behavioral

support specialists and the TIES clinic work closely together to help improve participant's independence and inclusion in their community.

Individuals with Cornelia de Lange syndrome can present behavioral issues that include self-injury and some aggression. At TIES, they take a holistic approach to help Daniel control his behavior, adapt to his environments including home and workplace, and participate in the world in a safe and healthy manner.

The TIES Clinic's unique and all-encompassing approach

The TIES psychiatry clinic often sees individuals who are unable to obtain psychiatric care from other providers due to their insurance, financial situation, behavioral issues, or medical complexities. They have two psychiatrists, Singer, and Lauren Bern, MD, who have extensive experience treating individuals with developmental disabilities.

A typical psychiatry session for Daniel, now done virtually, includes him, Singer, Mark and Eileen, TIES nurse and coordinator Joanne Law, Daniel's TIES behavioral support staff, his home manager, and his job coach. This covers all areas of Daniel's routines.

During the appointment, his home manager starts with describing Daniel's behavior at home, as noted by their staff. She mentions they use a white board to communicate with Daniel and help him better express himself. Parents then share medical updates and other observations, including changes that might be contributing to his behaviors.

Daniel's job coach joins too to talk about his experience at work. He works 20 hours a week doing laundry at Madison West High School. This is a new job for him, so his coach talks about how he has been adjusting. Mornings can be rough, but during the car rides home "He is as happy as a clam," his job coach says.

Singer then goes over the medication Daniel is prescribed and asks everyone their perspective on how it's working.

"It's a very holistic approach they take to both the individual with disabilities and our family. And it makes a big difference in terms of his quality of life, and his ability to be out in the world," Eileen says.

This comprehensive approach distinguishes the TIES clinic. "It's integrative. Medication is often necessary for managing mood swings, behavioral changes, frustrations, aggression, anxiety, depression, and it's wonderful to have that resource," Singer says. "But I am always confident that at TIES the management of a person's life and environment has been addressed with clarity and focus."

The half hour visit is designed to allow for the best level of understanding of the individual. Everyone's opinions and insights are welcomed in order to arrive at the most informed decisions on the course of treatment for the individual.

Law, who in addition to being a nurse also has experience in social work, is present to offer a medical perspective on the issues that might be physical, rather than behavioral or psychological. "A lot of people have medical issues that might be causing behavioral issues," Law says. Her input can be around whether they're having pain or other physical discomforts such as constipation or skin issues. "If you can identify and treat those physical issues, you might have less need for psychiatric medication," Law points out.

Catching the symptoms on time

Kristin Kilmark has been part of the Waisman Center since very early on in her life. She received occupational, physical, and speech therapy at Waisman when she was a child. So, the fact that the TIES Clinic is part of the Waisman Center was encouraging for Kristin's mom, Connie Kilmark, when looking for a new psychiatrist for her daughter, who now sees Bern.



Kristin, who is 38 years old, was diagnosed with autism as a teenager. Since then, she has been seeing different psychiatrists to work through some mental health symptoms. Once Kristin turned 26 and could no longer be on her father's insurance, Meg Little, MD, her psychiatrist before Bern, suggested TIES. "And it's just been a godsend. Trying to find a psychiatrist for somebody who's on the kinds of insurance that Kristin has is just really, really hard," Connie says.

The dependable and readily available support that Kristin has found at TIES has helped her mental health symptoms remain stable. "Dr. Bern has been helping me with so much," Kristin says. "She has taught me to catch the symptoms sooner. So, when an anxiety attack arises, I can catch it after the symptoms," Kristin says. "Because you're in good therapy," Connie tells Kristin.

A circle of trust and stability

Kristin's team at TIES is composed of Connie, Bern, her job coach, her IRIS consultant, a support broker, her future legal guardian, and Josh Lapin, MSSW, a behavioral support specialist and the director of Community TIES who has known Kristin for many years. "And we all trust each other and she trusts all of us in different ways," Connie says. The team meets more often when Kristin is going through a rough patch, but they still continue to stay in touch when she is more stable.

Connie finds comfort in being part of this team, and in the relationship they have with Bern. "Kristin and I can assertively make requests with Dr. Bern, and she is willing to be a respectful partner in thinking about interventions," Connie says.

A few years ago, Connie recalls, Kristin started experiencing mental health symptoms that made it difficult for her to work, and get out of the house. For several years, she would stay at home and not do much. "And I thought 'We're never going to recover this person. She's never going to come out again'," Connie says. "And because of all the treatment and all the skillful services and because we worked on the medication and all of that, slowly but surely she was getting ready." Per Connie's request, Bern discontinued Kristin's strongest psychotropic medication. "What is most remarkable is that with the help of her team and overall community, this was a successful undertaking," Bern says. Eventually, once Kristin was ready, she started a new job where she "just clicked." She is currently working for a janitorial service, four hours a day, four days a week.



Kristin happily shows off her stuffed animals. Her job allows her to spend money on things she likes. The stuffed animals were her choice of treat at the Henry Vilas Zoo



Lauren Bern, MD, Kristin's psychiatrist at the Waisman TIES Clinic

Her job and owning her own condo in the north side of Madison allow Kristin to live independently. Working also allows her to buy things she likes, such as her two stuffed animal friends, Artemis the owl and Imani the cheetah (pictured), which she got during a visit to the zoo. "You've really become such a dependable worker, that you have this great job that you're getting pretty well paid from," Connie tells Kristin. "So, you get more spending decisions and more power as a result of that."

A stable place to live was something Connie worried about for Kristin. So, in 2007, Connie and Kristin's father helped Kristin buy her own condo. "Which has made a huge difference because it means that Kristin is in a place that nobody can take away from her," Connie says. It is a beautiful, cohousing community surrounded by greenery, and more importantly, neighbors who are Kristin's age that act as an informal circle of support.

A longstanding community resource

The beginnings of the Waisman Center Community TIES trace back to 1986 with Paul White as the director. The clinic started shortly after with Mary Pearlman, MD, as psychiatrist. Dr. Meg Little joined soon after, and the clinic started growing significantly. Around 2009, Little left the clinic, and Singer was hired to work with teenagers and adults. At the beginning of 2010, Bern started working in the clinic with a focus on kids, and the elderly, but also attending to adults like Kristin. In 2016, Lapin became the director of TIES.

Both Singer and Bern brought expertise and decades of experience in mental health and intellectual and developmental disabilities. Singer also practices psychiatry privately, but dedicates two days a month to the TIES clinic.

Currently, the TIES Clinic is open four days a month and serves about 120 individuals, working closely with the TIES behavioral support team. "Medication plus behavior consultation might have a very positive impact on somebody's quality of life. Even with the medication, we still use the support plan, we still do the training, and we still do the behavioral consultation," Lapin says. Medication, he says, is used as a tool, but not as the answer to help behaviors. "We're always navigating and working to make sure that we can look at what is driving behaviors, and what's driving or triggering the issue."

In addition to the behavioral support staff, guardians, family members, case managers, support brokers, residential and vocational support staff, and teachers are welcomed and encouraged to attend appointments and share their observations on symptoms and treatment progress. "Just the holistic idea – the medications are acting on a person's body in the context of their own biology, and in the context of their interpersonal interactions – that kind of approach is what works for me," Bern says.



Steve Singer, MD

Adapting to unforeseen changes in the system

Funding for the clinic comes from a variety of sources including Medicare, Medicaid and private insurance (when available).

A big challenge for the TIES program arose in 2018 when state designed long-term care services were expanded to include Dane County. Funding of services for individuals with intellectual disabilities stopped being the county's responsibility. With Dane County no longer being the primary funder of TIES, they had to recreate how they operated. "We had to go out and meet new funding sources and create a mechanism to maintain the work for individuals that we had been doing," says Axel Junker, outreach program director of Community Outreach Wisconsin, the umbrella program Community TIES falls under through the Waisman Center's University Center for Excellence in Developmental Disabilities (UCEDD). They had to convince new funding entities that their services were valuable, and figure out the logistics of the billing infrastructure.

Singer credits the survival of TIES through the redesign to Junker and Lapin. "They kept us alive, and we kept the work going while it was more fragmented and it was much more difficult to provide the integrated care," Singer says. Individuals and families who are strong advocates of the program also joined the trek.

A real impact when needs are unique and resources scarce

Many individuals, such as Daniel and Kristin, and their family members, have been significantly impacted by the work done at the TIES Clinic. Their efforts to encourage and facilitate independence for individuals with intellectual and developmental disabilities through a process that integrates all of the meaningful areas of their lives allows the individual to

achieve the best outcomes.

“There’s a real kindness about the staff at the Waisman program, and a welcoming approach and flexibility. Those things go a long way when you’re struggling with a family member who’s dealing with a lot of issues and so we’re very grateful to them for their kindness and compassion and generosity,” Eileen says. “It’s hard to find that. It has to do both with the way it’s organized and the people. And the people are really just great,” she adds.

“To be looked at attentively and empathically and treated humanely is kind of fundamental,” Bern says. “I think TIES does a superb job of that.”

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