How Community TIES Builds Support Networks for Individuals with Disabilities

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By Emily Leclerc, Waisman Science Writer

She won't get off the couch. She refuses to move, choosing instead to wrap herself in blankets. She hasn't left the house in days. Shawn Bass knows this isn't typical behavior for her. "We know that this is a coping strategy she has and uses. A reluctance to move lets us know that something is off," Bass says. Bass, a behavioral consultant and the assistant director of Community TIES, works through a variety of possibilities to try and find the trigger for this behavior; staffing patterns, times of day, events prior, things she might be looking forward to that could increase anxiety, and numerous health factors. He spent time looking through her records as well as TIES has been an integral part of her support system for more than 15 years.

"We started problem solving," Bass says. "We found that this exact same thing happened nine years ago. We went through this same pattern." The tips, tricks, and techniques that worked nine years ago could be the answer to working through this behavior now. Some of the old techniques helped while others didn't, but it gave Bass and her support team a starting point. Her exceptionally collaborative team, which includes Bass, her parents, Wellness Inclusion Nursing services, occupational therapy, a psychiatrist, and residential and vocational support agencies, worked together closely to offer and try a variety of solutions.

With that consistent support and effort, she is doing much better. Sometimes she still likes to lay on the couch cocooned in blankets but it happens less frequently. "There are key trusted staff who she has become very willing to get out with," Bass says. "We try to capitalize on those relationships and maximize her opportunities then." Bass is a part of the talented team at Community TIES that provides behavioral support to individuals with IDDs to give them the best quality of life possible, just as he has done with this woman.

Community TIES (Training, Intervention, and Evaluation Services) opened in 1986 as a branch of the Waisman Center under the direction of Paul White, MA, with funding and support from Dane County Human Services. Their mission is to address the behavioral, psychological, and emotional needs of individuals with disabilities using therapeutic approaches that assure continued participation in supported society. "Ultimately our goal is to keep people in the community and participating as full members of their community. And I think we do that. I think we do that pretty well," says Josh Lapin, MSSW, director of Community TIES.

We all agree that individuals with disabilities have the right to be full members of society just as much as everyone else, but sometimes they just need a little extra support. The bulk of Community TIES' services come in the form of behavioral supports. Individuals with IDDs can behave differently from neurotypical individuals for a variety of reasons. At times, those behaviors can be challenging. To help people with IDDs, their families, and caregivers navigate these challenging behaviors, TIES behavioral consultants work to provide support, information, and resources to those who need it.

Challenging behaviors can take a variety of forms and be different for each individual. This does not mean every individual with an IDD will have challenging behaviors. But when they do occur, there is a range of presentations from aggression

and property destruction to self-injurious behaviors and non-compliance, among many other things. TIES meets people where they are and builds resources and support systems to meet their current needs, behavioral or otherwise. "That's the magic of TIES," Bass says.

First Meetings to Design Supports

The process of developing behavioral supports for someone begins with the crucial step of relationship building. "We really value creating therapeutic relationships and rapport with clients that we support. We spend time directly with clients, getting to know them, getting to know their strengths and their interests so that we can really capitalize on helping them be a part of their community at large," Bass says. Consultants also meet with everyone in a client's circle of support – their guardians, caregivers, teachers, residential agencies, and any other supports they have. This builds trust between client and consultant, and also gives the consultant a well-rounded picture of the individual and their life.

"We want to look at the situation from a macro level. Because when it comes to behavior it is always communication and commonly to get a need or want met. So, if we're talking about challenging behaviors we have to look at what's driving it," Bass says. "Then how do we help them get that need met or communicate their desires in a more constructive way that gets their needs met without them being harmed or others being harmed."

After the introductory period, a client's behavioral consultant, TIES psychiatry clinic (if involved, to learn more about the psychiatry clinic read story), the client, and the client's support team will meet to put together a behavioral support plan (BSP). A BSP is a comprehensive document that details everything from triggers to how to promote positive behaviors to specific steps on how to deescalate challenging behaviors to what to do in a crisis. The participation of the client in this process is crucial as the BSP describes out how the individual would like to be approached during difficult moments.

The core of a BSP is to be a resource and reference point for family, caregivers, and support personnel. "When it comes to writing support plans, it really is a collaborative process. We often feel that the person and their circle of support – be it a family member, caregiver, or teacher –may have some unique insight or developed some ways on how to help that person to manage those critical situations better," says Axel Junker, MS, outreach program director of Community Outreach Wisconsin. Community Outreach Wisconsin is the umbrella program that oversees TIES through the University Center for Excellence in Developmental Disabilities at the Waisman Center.

Collaboration is the foundation of BSPs. TIES consultants are only one part of a care team. They are one person with one view point and one perspective. And they do not spend every day with a person. Ensuring that every member of an individual's circle of support, including the individual themselves as much as possible, is crucial to creating an accurate and effective BSP. "It is very much a collaborative effort," Bass says. "That is a key tenet to TIES philosophy."

When constructing a BSP, the team puts a large emphasize on crafting proactive approaches and strategies. Understanding what could work proactively derives directly from the relationship developed between client and consultant. "The idea is that if we can put more energy in at the beginning, that hopefully it will avert a crisis later," Lapin says. "Then when there are those more negative behaviors and they do arise, what do we do to make sure that people are safe." This depth of understanding of an individual is made possible by TIES commitment to not only building personal connections with clients but the involvement of the person's already established support team.

Kristin and Connie Kilmark in Kristin cohousing community

Once written, the plans are not left to decay. They become living documents. As consultants continue to check in and work with clients as frequently or infrequently as needed, the BSPs grow and evolve with

each individual. "They're never complete," Lapin says. "As people mature, their behaviors may change. They may shift. And we want to capture that too." The depth of thought and knowledge that goes into the creation and maintenance of the BSPs is part of why so many families find them so effective – including the Kilmark family.

Behavioral Support Plans in Action

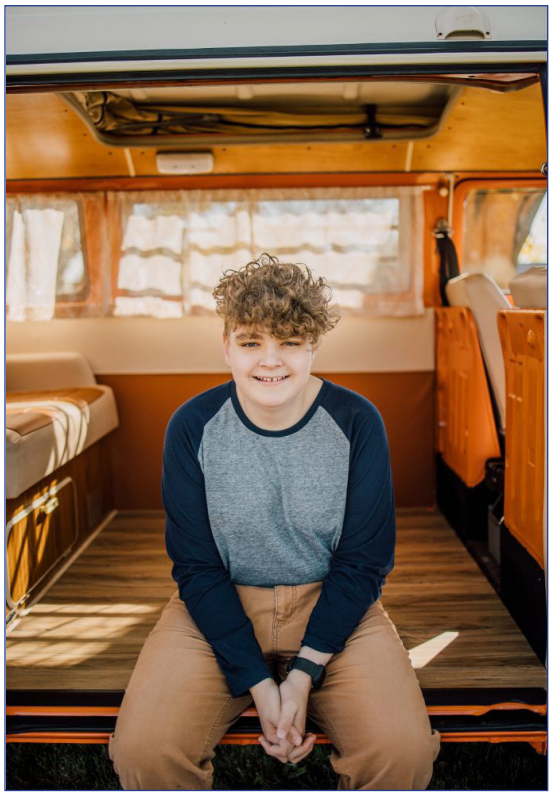
Connie Kilmark and her daughter Kristin have been a part of TIES for many years. Kristin was diagnosed with autism as a teenager and eventually joined TIES when she turned 26. Kristin loves watching airplanes, cars, the weather, talking about sports, and can struggle with some challenging behaviors. Connie knew she would need support as she transitioned into later adulthood.

Upon joining TIES, Kristin quickly bonded with Josh Lapin, her consultant. That bond allowed TIES and the Kilmarks to put together a robust and detailed BSP. Kristin's behavioral needs are intricately described along with what works for her and what doesn't. The relationship and trust Kristin has with Lapin is almost as important as the document itself – for a BSP would be nothing without the consultant behind it.

"It is that behavioral support, Josh [Lapin]'s trustworthiness, and the gorgeous rapport that he has with Kristin that allows Josh to be a person that Kristin trusts coming into her house," Connie says. TIES' consistent support and Lapin's fixed and trusted presence has enabled Kristin to become more resilient in the face of challenges.

"Kristin is in a relatively stable place at this point and that's partly because of the fact that we have unchanging supports that are dependable and available," Connie says. Lapin has been supporting Kristin for over a decade and has become a carrier of her history. Lapin and Junker have been supporting some clients for more than 25 years and have all of those records to rely on. This wealth of information can be invaluable and highlights the role of TIES as record keepers.

"A TIES consultant can be a historian as well. We might remember back in 2000 when we tried a medication that didn't work well. Or we might remember a time when we tried this intervention that was really successful, or we tried this and it was really unsuccessful," Lapin says. TIES is a lifelong service and those years of history provide useful insights for new people entering an individual's scene and even veterans who have been around since the beginning. "The behavioral support plan is like basic training for new people that are helping Kristin and it has made a world of difference," Connie says.



Owen Bradley

schools and other groups that may interact with someone on a regular basis. Danielle Bradley has found the BSP for her son Owen to be invaluable at home, at school, and in the community.

Owen Bradley is a big fan of anything mechanical and wants to be a diesel mechanic after high school. "He's always liked to tinker and to take things apart," Danielle says. He is also autistic and can exhibit some challenging behaviors at school as well as at home. Danielle homeschooled Owen for several years as the school system he was in was not equipped to support him properly. In 2018 Danielle and Owen were recommended to TIES. Danielle credits their TIES behavioral consultant Hedy Burke's support for Owen's ability to re-enter school.

Owen's BSP gives the school system a step-by-step guide on how to help him and deescalate situations as necessary. People with challenging behaviors exist in more spaces than their home and will often have

different behaviors in different environments. A BSP provides information and contingency plans for all places that a person regularly inhabits.

"The thing about TIES is that they're an intermediary between school, home, and the community. They understand that everyone in their own way is an expert in their environment and they use that information to support that behavior plan as best as we can in each environment," Danielle says.

A BSP even provides resources past the document itself. While substantial, a document cannot encompass all that a person is and unexpected behaviors can happen. Many TIES behavior consultants will make themselves available to assist as needed. "Hedy is a lifeline for both me, the school, and my son. She offers herself as a resource to the school so people know her door is always open," Danielle says. "They'll call her and say we have this new behavior; can you help provide some input on it."

It all comes back to the foundational relationships that support the BSPs and all of the care that comes afterwards. "Hedy got to know Owen and I think in some ways she knows him far greater than we do, in a way," Danielle says. "Hedy is invaluable to our family."

Tying the Community Together

BSPs and TIES' behavioral supports reach even farther than just individual families because TIES partners with several organizations in the community that work and support individuals with disabilities. Aniekan Ifediora owns Doria LLC, which is a group of 12 homes throughout Madison that house and care for individuals with IDDs.

Ifediora has worked closely with TIES to develop BSPs for several of her residents and TIES behavioral consultants have been brought on as members of some residents' care teams to ensure Ifedioria's staff can keep the residents healthy, happy, and safe. "We do support some of the more difficult residents in the county and without the involvement of Community TIES we don't think we would be able to support them," Ifediora says. "TIES consultants are the behavior specialists on teams as required and they come in and train us and write behavior support plans and help guide the staff in how to manage the behaviors that the clients or residents are challenged with."

Planning with the Police

An individual's challenging behaviors can at times extend past their immediate support circle. On occasion, the behaviors could incur law enforcement involvement – whether that be a challenging behavior that warrants a call to the police or where individuals put themselves in situations that are responded to by the police. TIES understands that this may have already happened to a client or it may potentially happen in the future and, with the individual's or guardian's consent, proactively puts plans in place for just those circumstances in the form of police plans.

The Bradley family

Police plans are a valuable addition to the BSPs. They are a one-page document that details information a police officer might need to communicate and lists successful past de-escalation techniques. Police plans are intended to provide officers with the information they need to have successful interactions with individuals and prevent

inappropriate incarceration or hospitalization. TIES works closely with the Madison Police Department (MPD) in these situations – in particular the MPD's mental health officers.

Each MPD district has a dedicated mental health officer (MHO). These officers have special training for dealing with mental health crises and are not part of general patrol. They have more leeway in how they respond to situations. "Patrol officers are call driven and are the members of our team responding to 911 calls. They are your first responders and may be getting the first contact with someone who's in a mental health crisis," says Clare Gloede, an MPD mental health officer. "MHOs are not call driven so we have a lot more flexibility in either responding a little proactively or we can do follow-up and really spend time with people." Gloede sees the police plans as cheat sheets that set everybody up for success.

Clarice Gloede

"They allow us to slow down and take into consideration what is going to work best for this person. Maybe they're sensitive to sound and loud noises or maybe they don't have the best history with police. These are things we can be conscious of in our response," Gloede says. MHOs can take the time to sit with individuals and ensure they are getting what they need before returning them home. In this way unnecessary and often unhelpful incarcerations and hospitalizations can be avoided.

"The plan says, 'oh, they like Cheetos.' Well then, we're going to get some Cheetos out here and we're going to eat Cheetos together for 20 minutes. And hopefully by that point they've calmed down enough and we can get them back home," Gloede says.

Danielle Bradley and her son Owen have a police plan in place alongside his BSP. Owen has had previous interactions with the police before joining TIES that did not have desirable outcomes. So, when he started working with TIES, his team knew he needed a police plan as a proactive measure for potential police involvement. Danielle finds that contingency comforting, knowing that it will prevent past mistakes from repeating themselves.

The police plans also contain contact information for the TIES consultants and other TIES staff that may be able to help in a situation. "I love my partners at TIES. I call on Shawn Bass all the time," says Hannah Johnson, MPD mental health officer. "A lot of the police plans are for consumers in the community that we don't really come into contact with but its always just a safeguard to know that we have all their information and a plan in place in case they do ever escalate or need to utilize 911."

Hannah Johnson

Johnson has also called consultants while on the scene with individuals. She understands that jail or the hospital may not be the best place for people and will call up TIES to ask for advice on what the best course of action may be. She will work with TIES after a situation as well to provide follow-up support and update police plans as needed.

For both Gloede and Johnson, the police plans are an exceptional resource that they make use of on a regular basis. "People call 911 because that's the only number they know to call. And a lot of times police don't have all the answers, all of the resources, all of the knowledge," Johnson says. "So, TIES is a great resource for us to have somebody who can guide us, help us, and lead us to an appropriate decision. Their open communication and support has been so valuable and has really made police contact result in a more ideal situation." Gloede too can't imagine what her job would look like without the involvement of TIES and the foundational behavioral support they provide.

An Emergency Safe Space

But despite the forethought and proactive strategies put in place with BSPs and police plans, sometimes they just are not enough to curtail a crisis. When a crisis becomes overwhelming and the individual and family need emergency support,

TIES has a program in place that facilitates accelerated access to crisis response services that are designed for individuals with IDDs.

The Crisis Response Program, developed in close partnership with Dane County Human Services, was originally run by TIES, but is now carried out in partnership with Responsive Solutions Inc. – a small nonprofit agency that TIES helped create. The program encompasses crisis coordination, access to behavioral consultation, home and workplace adaptations, additional caregiver support in the home or workplace, access to psychiatric consultation, and follow-up consultations.

Mental Health Officers

Axel Junker is the primary Community TIES liaison for the Crisis Response Program and has been overseeing it from its inception. According to Junker, Dane County Human Services started to realize that there were a number of individuals with IDDs that were experiencing crisis situations that were resulting in inappropriate, and at times prolonged, hospital stays or even arrests. "In response, the department had the idea to create and establish some resources that can be flexibly and creatively put together to avoid those inappropriate placements and if they do happen, at least shorten the time span," Junker says.

This way, when families are overwhelmed and individuals are struggling, there is something to fall back on that can help. In collaboration with Responsive Solutions Inc., Dane County, and the respective long-term care funding agency through Family Care or IRIS, the Crisis Response Program can get additional feet on the ground to assist, and quick access to additional supports. "The crisis program is just another notch up in TIES' continuum of services," Junker says. "The goal is to add more support where the individuals are at."

Responsive Solutions' Safehouse is another resource for individuals experiencing crisis or challenges to avoid inappropriate arrest or hospitalization. It offers a neural, calming environment with additional safety modifications in place and – if needed – additional support staff provided by Responsive Solutions while navigating challenges. Simply knowing that the Safehouse is available can be a comfort as well.

Connie Kilmark and her daughter Kristin faced a situation several years ago where Connie thought Kristin would need to be taken to the Safehouse. Kristin was in some distress and her care team was struggling to manage her behaviors. Luckily, Kristin ended up not needing the Safehouse but just knowing it was there was reassuring for Connie. "The availability of the Safehouse and Josh Lapin's supportiveness during that time was absolutely invaluable," Connie says.

The police are also well aware of the Safe House and like to utilize it if needed. Johnson has used the Safehouse several times when she knew that it wasn't safe to return an individual home but the hospital or jail were not good options either.

"A lot of these individuals that we come into contact with are not appropriate for jail. They won't benefit from a short hospitalization, but they can't remain safe in their home. That's where the Safehouse is key," Johnson says. "The officers love utilizing it when it's available because you never feel good taking someone to the hospital knowing they're going to be discharged in an hour and sent back home into the same situation as before. The Safehouse is a great tool."

All of the behavioral supports that Community TIES has available come with one singular purpose – to provide a solid foundation for people with intellectual and developmental disabilities to thrive as an integrated part of their larger community. Sometimes that just means they need a little extra support. TIES behavioral consultants, behavioral support plans, police plans, and the Crisis Response Program provides an added layer of support some individuals may need.

"There has been so much progress made in the lives of people with disabilities and there have been so many wonderful advocates, nationally and internationally," Josh Lapin says. "There are wonderful stories to be told. We have made a lot of progress and we just need to continue that progress."