A Multi-disciplinary, Community Based Approach To Address The Needs Of Individuals With Developmental Disabilities And Challenging Behaviors

UW – Waisman Center
Community TIES

Introduction

The UW-Waisman Center has sustained a long term commitment to promote full inclusion for persons with developmental disabilities and their families. To this end a program was initiated in 1986 for those persons with DD who also present co-occurring mental health challenges. This program is titled Community TIES (Training Intervention and Evaluations Services). Over the past 28 years this program has grown in both size and level of expertise. The content and recommendations in this document are based on the experiences of Community TIES

Over the past year Waisman Center staff; Paul White and Axel Junker have committed to a series meetings with with a team of professionals coordinated by Amy Lorenz, Director of Crisis Services Milwaukee County Behavioral Health. The purpose is to determine what components of Community TIES model would be a good fit in Milwaukee County regarding positive behavior support and crisis response for people with DD.

This report represents our progress in working together to date. It is organized with this format:

- An overview of the Community TIES model where positive behavior supports are integrated into supported community programs.
- Description of seven approached that support the TIES model. Each approach in describes in this manner:
  - Who
  - Why
  - How

  Note – The seven approaches were written by a team so there is variation in writing style form one approach to the next.

- A description of how the Milwaukee County - Community Consultation Team (CCT) Is considering translating these approached into service delivery.

Overview

Supported life for persons with developmental disabilities is most effective when it promotes Full Community Membership and assures individual choice (Self Determination). Within this lifestyle most people lead overall meaningful, productive and healthy lifestyles.

Support to some people includes added attention to emotional, behavioral or psychological needs. Such needs, if unmet, are commonly termed “challenging behaviors”. The community team is challenged to, on behalf of the individual, understand and meet these needs.

Understanding and meeting such needs on behalf of someone else and in this case a person with cognitive, communication or mental health challenges is most often quite complex.

Challenging behaviors can be expressed overtly (tension, emotional or physical distress) or are directed inward (withdrawal or isolation). The cause or life situation that may be stimulating the challenging behavior can be wide and varied. Included here is a list of common "stress triggers" for people with developmental disabilities. These can occur individually but are often a combination of stress triggers.

When challenging behaviors occur more often or with sufficient intensity it is not uncommon for support programs to consider moving individuals to lifestyles where safety for the individual and others is better assured. This can result in more restrictive locations where community membership and choice is limited. In doing so the supported program often only serves to increase the number of stress triggers that can result in challenging behaviors. In fact, the challenging behaviors may have been occurring because the supported living program did not offer enough choice and community involvement in the first place. This is, unfortunately, a common life dilemma for people with developmental disabilities.

A better blueprint for supporting people with developmental disabilities and challenging behaviors in the community is outlined here.

- Develop a supported living model within the County that subscribes to "best practice" standards for Full Community Membership and Self Determination.
  Apply these standards to all persons with developmental disabilities, including people who present challenging behaviors. Continue to apply resources and training to this end. Practices that are essential to this model include:

  a. Person Centered Planning and a team approach
  b. Meaningful relationships
  c. Self-Directed Services
  d. Living, working and recreating in the community
  e. Living with only a few house mates
  f. Meaningful work and recreational activities
  g. Opportunities to explore spirituality

- When challenging behaviors are of concern look first and foremost to the community support program to assure that it is truly "best practice" as described above. Continually resist pressures to move individuals to, or create, more restrictive settings.

  Develop a program within the County where additional supports can be added to the existing community lifestyle and only as much as is required. Included here are examples of gradually adding behavioral supports in an effort to assure continued supported community life:

  a. Ongoing behavioral expertise within community support teams.
  b. Individualized Behavior Support Plans
  c. Training of Positive Behavior Supports and pro-active crisis prevention
  d. Intensive safety measures added to community programs
  e. Environmental adaptations and modifications

f. Psychiatry with developmental disabilities expertise
g. Crisis Response Services in the Community

An essential component to this approach described above lies within the attitude of the community support team. The providers need to believe that the community model can and will work.

** It is noted here that this model of community support to people with DD and challenging behaviors has been developed over a 25 year period. A service delivery program should expect that the process of replicating the approaches outlined here will take time.

** Additionally all the communities in Wisconsin, while similar, can also be differentiated from one another. What is been described here as effective in Madison Wisconsin may need to be altered to best fit other community DD service delivery programs.

1. Ongoing Behavior expertise within Community Teams

What:

A significant aspect of providing positive behavioral support to individuals with developmental disabilities is proactive participation in community teams. Working together as a cohesive unit can help provide insight regarding positive behavioral support. A behavior specialist would work with the team to provide insight and direction related to supporting challenging behaviors.

Why:

Teaming around an individual with challenging behaviors is important in that it helps to ensure full community membership for the person. There are several benefits to teaming which include:

- Providing a forum to proactively address issues that may arise.
- Meeting on an ongoing basis and celebrating a person's success can help the team identify and understand what is going well and why.
- By working together in a coordinated and supportive way teams are better equipped to deal with conflicts that may arise.
- Teams that meet proactively are better able to create and update individual support plans.
- Well run teams are effective in finding resources, appropriate training, and expertise to blend mental health services within existing DD supports.
- Working proactively helps assure continued participation in supported community life.

BHD Community Consultation Team (CCT)

Consultation to community providers

- The CCT will be available to community-based providers of services to adults with developmental disabilities. Potential service recipients include providers of residential services (group homes, adult family homes, etc.), providers of day program services, and Family Care MCO Interdisciplinary Teams (IDT's). The focus of this service is on assisting in the development of intervention plans to address challenging behaviors presented by Family Care enrollees. Clinicians with extensive experience in behavior modification as well as other CCT professionals are available to work with case managers, residential staff, and others to try to problem solve around client behavioral as well as mental health issues.

2. Individualized Behavior Support Plans

What:

When a number of providers are involved in the life of the individual it is important that the "team" develop a shared vision for this support. It is suggested that the team participate in regular meetings facilitated by a professional with expertise as described above. One of the outcomes of these meetings should be a written behavior support plan (BSP).

Why:

Within a supported community lifestyle it is not uncommon for a number of providers from distinct programs to support the individual across their day/week. While the various providers will want to develop their own rapport, it is also important that there is some "thread of continuity" in the manner that each will interpret and support behavioral/mental health issues. If each provider has a different notion and approach we can inadvertently create more chaos in the life of the individual. A behavior support plan can assist in assuring this united approach across providers. Additionally there is often regular turnover in providers. The behavior support plan can effectively bridge the knowledge gap for new people coming into the life of the individual.

How:

The plan should be authored in a straightforward manner so it is easily understood by direct providers and family members. The plan should be written concisely and to the point. Use of "people first" language is recommended. Also, avoid excessive use of psychiatric/psychological terms that may not be readily understood by direct providers and could stigmatize the individual.

The behaviors specialist should guide the BSP development . Assure that best practice approaches are used. The team participation will assure that the plan is individualized.

The plan should be updated on a regular basis as individuals grow emotionally or the team learns better ways to provide support. Data collection can be part of a plan and should be straightforward and not so time intensive that it would take away time from relating to the individual.

BHD Community Consultation Team

Specific services available include behavioral assessments (functional analyses) of clients, development of intervention plans, staff training on intervention plans, assessment of facility and staff needs, staff consultation and support, and serving as a liaison between stakeholders, providers, and potential providers. The CCT will maintain on-going involvement with clients in the community increasing or decreasing this as needed. Although behavioral challenges in the community can be expected, the focus of this service is on working in a preventative manner to diminish the likelihood of significant client behavioral and mental health issues.

3. Training on Positive Behavior Supports and pro-active Crisis Prevention

What:

Training activities have long been recognized as essential to promoting quality, retaining staff, providing consistency in the provision of services, communicating best or better practices, and inspiring staff to feel good about the work they do on a day-to-day basis.

Why:

Motivated and educated staff are more likely to respond better to emergency situations, make better care decisions and exhibit more confidence in the jobs they do. Staff training builds confidence and can result in a better relationship between the service provider and the consumer, as well as providing a potential pathway to a higher degree of professional responsibility.

How:

A healthy, respectful relationship between direct care professionals and consumers has been shown to reduce critical incidents, decrease unnecessary power struggles, promote good role models and, in general, build a happier household for all.

Please see Waisman Center Training and Consultation for information on upcoming training opportunities.

BHD Community Consultation Team

Staff development services
The BHD Community Consultation Team (CCT) will offer a variety of educational and support services for community providers and their staff as well as Family Care staff. One focus of this service will be a series of educational programs designed to increase staff job-related knowledge. This includes training aimed at new staff as well as "refresher" programs for more experienced staff. Specific topics covered include the nature of developmental disabilities such as intellectual disability and autistic disorders, understanding maladaptive behavior and mental illness, and basic behavior modification techniques. Other topics could be covered as needed. The focus is on providing community staff with more tools to successfully work with adults with developmental disabilities.

A second focus of the staff development services is helping direct care providers in the community to better manage the demands associated with their jobs. While working with individuals with challenging behaviors can be quite rewarding it can also be very demanding and stressful. This aspect of the service involves offering group support to providers as well as specific programming centered around stress management and personal well-being. The focus is on preventing staff burnout and turnover and facilitating staff morale and retention.

4. Intensive Safety measures added to Community Programs

What:

For some individuals with developmental disabilities, the nature of the challenging behaviors may result in aggression, destruction or self- injury. These behaviors are sometimes expressed to a level where safety for the individual and the community is a concern. Community teams are always striving to promote positive and therapeutic community life styles that address these issues in a proactive manner. Yet, despite these efforts teams can predict dangerous behaviors will still occur. Individuals with these issues may challenge teams to develop more intensive supports to the community program in order to assure safety. The approach, then, for these individuals is to offer "best practice" supported community lifestyles while simultaneously establishing an intensive crisis response for when dangerous behaviors occur.

Why:

When these programs are effective they assure the individuals grow emotionally, keep the community safe and reduce the risk of short or long stays in more restrictive settings.

How:

Some example of intensive crisis response can include:

- Training care providers in crisis intervention strategies
- Developing a "safe space" in the home for the purposes of regaining emotional control
- Use of physical intervention
- Including the police in a coordinated crisis response.

These approaches are called "Restrictive Measures". The community support team will need to use these approaches carefully and thoughtfully in order to avoid human rights violations. Also when creating more intensive supports, teams are making decisions that may impact client rights. State of Wisconsin Community Integration Specialists should be included on the team to assist with these decisions.

BHD Community Consultation Team

The CCT will be available to consult with other providers when clients are at least temporarily unable to remain in their community residence due to behavioral or mental health issues. This would include consultation with crisis or respite service providers in the community. If the client is brought to a local emergency room or crisis service CCT staff could consult with them about the client's status. If the client is in need of acute psychiatric hospitalization at a local hospital CCT staff could be available to consult with those staff and assist in transitioning the client back to the community

5. Environmental Adaptations and Modifications

What:

Environmental adaptations and modifications come in all shapes and sizes and go beyond what one might think. People often think of ramps and other modifications to make a house more accessible when discussing this topic, but there are several other modifications that can be put in place that create a safer environment for people with aggressive tendencies. Soft furniture is sometimes a good way to prevent self-injuries, sometimes door alarms are required for those who attempt to leave their homes during times of instability when they are not safe. Reinforced windows are commonly used to prevent breakage and subsequent injury, many people who are loud during times of increased anxiety and agitation risk eviction or disturb others if rooms are not soundproofed. Even a piece of tape over a clock so an individual does not obsess over time can be an environmental adaptation.

People who become violent may require a safe room in their residence; many times these rooms are unfurnished or have soft furniture items in them to keep the person safe while she/he regains control. These rooms are not used for punishment; the person enters them voluntarily because they know they are feeling out of control and unsafe. Fencing is another modification that is sometimes added to residences, particularly for those who enjoy time outdoors but have no danger or safety awareness, or who might wander off. Fencing a yard must not take the place of staff supervision however; unknown dangers can exist in all outdoor areas and without supervision, people have been known in ingest inedible items in their yards, injure themselves on swing sets and hop over fences in attempts to explore their environments.

Why:

The impact the chosen living environment has on behavior cannot be underestimated. Many people who challenge us through their behavior have difficulty sharing personal space with anyone else and may manifest this through many means; behavioral outbursts and aggression to others are common as are competing for staff attention, intruding into others' personal space or taking items that belong to others. While modifications may risk violating residents' rights, in many cases, the person will voluntarily give up his/her rights as he/she develops insight into the destructive and dangerous nature of the behavior. Safety is one of the most important reasons for modifications and adaptations. Often an individual feels safer knowing that the doors can be locked, the stove may not turn on, and the windows are reinforced; sometimes knowing that these traditional targets "won't work anymore" actually decreases the urge for property destruction and ultimately makes the person feel safer; needless to say, staff are also feeling safer.

A final reason to implement adaptations and modifications is for the community. Individuals who can become aggressive draw attention to the home. Neighbors and the community often develop a negative impression of the individual or home based on biases, ignorance, assumptions, hearsay, and perceptions; other times, these impressions are created by the presence of police cars, loud noises, yelling or observations of conflict around the home. Minimizing these negative impressions to the

degree possible is one way for adults with disabilities to be better accepted into stable neighborhoods. Soundproofing, maintaining the yard and home to the standards of the neighborhood, and teaching boundaries will all go a long way in facilitating acceptance and helping the home to blend into the existing community.

How:

Any adaptation or modification to a person's residence must be in the best interests of the resident's health and safety and must not infringe on the rights of the person nor of others in the home. Let thoughtful, person-centered thinking be your guide; include the entire team in the discussion including the persons who will be most affected by your decision. Staff convenience should never be part of these discussions. Partner with contractors who have an understanding of what the team is attempting to accomplish with Adaptations and modifications.

BHD Community Consultation Team – The Adaption and Modification program described above is under consideration. The service will need to be different due to the Family Care Model.

6. Psychiatry with Developmental Disability Expertise

What:

The role of the psychiatrist and other medical professionals within a person's team is critical. Ensuring that objective information is shared with these professionals is one responsibility team members have when gathering to discuss "how someone is doing." Medical staff are typically trained to assess progress within one-to-one verbal communications with their patients. Working with a non-verbal client or an individual with poor or unreliable communication skills therefore requires the psychiatrist to seek objective information from that person's team in order to accurately understand dysfunctional behaviors, as well as any effects of interventions that have been tried. Successful outcomes often depend on the skill the medical professional brings to the team with respect to combining treatment models that may sometimes conflict.

Why:

Team members have the responsibility to make sure information shared with medical professionals is factual. Often times, teams may use daily log books to share progress, and though this type of information is rich with content and has great value, it is often difficult for busy professionals to look through and quickly interpret. Similarly, information presented in this way is not necessarily unbiased. Teams should strive to work towards collecting information on target behaviors/psychiatric symptoms that are well defined and related to diagnosis and interventions. Data must be collected that accurately represents how the person behaves. This information should be presented in such a way that medical professionals are able to easily read and evaluate progress in a short amount of time.

How:

Presenting data in the form of a behavioral graph allows someone to make a quick assessment, and represents a simple way for team members to share "how someone is doing." Of course, including individuals who are capable of conveying their own impressions on how a particular treatment is affecting them is important, though team members need to be certain the person's statements are reliable in order to make sure medical professionals receive accurate information. Likewise, as medical professionals often prescribe medication to assist in treating behavioral concerns, it is critical that team members work with the psychiatrist or other medical professional to clearly understand the likely benefits of any medications that are prescribed, and in this way, the data that are collected can reflect those potential benefits. If the expected benefits are not observed within a reasonable amount of time, team members should work with the medical professional to decide what the next step might be, and consider discontinuing medications that are not helpful.

BHD Community Consultation Team – *The Community TIES Psychiatric Clinic http://cow.waisman.wisc.edu/clinic.html is the Waisman Center program whose principles are described above. Dr. Steve Singer is the lead psychiatrist. Dr. Singer is committed to consulting with Milwaukee County as they consider replicating this essential service.*

7. Crisis Response Services in the Community

What:

Crisis is often defined as "the experiencing of ... a situation as an intolerable difficulty ... that exceeds the person's current resources and coping mechanisms (1)." It " ... usually refers to a person's feelings of fear, shock, and distress about the disruption, not the disruption itself (2)".

Individuals with developmental disabilities often communicate feelings that overwhelm them through "challenging behaviors" which often lead to inappropriate and costly stays in more restrictive settings (psychiatric hospitals, jail, or mental health institutions). However, "crisis" in the context of developmental disabilities services, also refers to the caregiver's perception that an individual's needs and challenges exceed the caregiver's capacity to keep the individual safe.

In a medical (and more traditional mental health) model, psychiatric hospitalizations are one of the more common responses to crisis; the goal of a short term hospitalization is the stabilization of acute symptoms (through medication adjustments) in a safe and therapeutic environment. Safety refers to both the actual quality of the environment (supervision, locked doors, etc.) but also to the patient's perception/sense of feeling safe in that environment (respite effect).

Why:

Although hospitalization can be very helpful to many individuals, it can be problematic for people with developmental disabilities:

- hospital staff might have difficulties relating to individuals with DD and their unique communication strategies
- therapeutic resources cannot easily be adapted and individualized to accommodate the learning styles of individuals with DD
- individuals with DD might not be able to transfer acquired coping skills to their home environment
- the hospital routine can be disruptive for individuals who are accustomed to a rigid, very personalized routine
- individuals with DD are more at risk to be taken advantage of by other patients and are more likely to copy unsafe coping techniques from other patients
- hospitalizations can be expensive
- hospitalizations often require the individuals to give up some control (requires Dr's permission to leave).

How:

A community-based Crisis Response system for individuals with DD strives to provide an alternative to hospitalizations. It should be:

- proactive in nature (no division between pro-active and reactive supports) and part of an ongoing outreach effort to train and prepare direct care providers for crisis intervention
- individualized and person-specific (the crisis team needs to have a thorough knowledge of the person they are serving; relationships are the key!)
- positive (anchored in the principles of Positive Behavior Support)
- consumer directed: the individual and/or his/her guardian participates in the team process and directs the development of his/her crisis plan
- easy to access at all times
- work well with existing service providers.

It should offer the following service components:

- consultation on <u>positive behavior supports</u> and clients rights issues (restrictive measures)
- consultation on <u>environmental adaptations</u> & more <u>intensive supports/interventions</u>
- assistance in navigating emergency mental health services (emergency detentions) and coordinating interventions with the <u>criminal justice system</u>
- assistance with <u>health care</u> coordination
- access to community-based therapeutic resources and emergency <u>psychiatry</u>
- access to well <u>trained additional support staff</u> who can assist in the assessment process, provide <u>situational counseling,</u> provide respite and guidance to direct care staff and support the person where he/she lives/works, or plays
- short term respite in a safe, neutral environment that is modified to accommodate behavior challenges
- follow-up consultation to prevent future crises.

A functioning crisis response system will creatively and flexibly (it's more of an art than a science) piece together additional supports on a temporary basis. It should not be considered as a permanent placement option - especially in times of dwindling public funding, but can be a <u>cost-effective alternative</u> to an inappropriate and lengthy institutionalization. At best, it can help individuals and their support teams to buy time, get some breathing room and hopefully contribute some ideas and instill confidence how to tweak existing supports for the better.

Crisis interventions are highly individualized: One size does not fit all. Just as individuals are different, communities are different and a model that works in one urban setting might not work at all in a rural setting, or even another urban setting. Although the key elements of crisis response might be very similar, they might be organized in very

different ways. Successful Crisis Response programs draw from the strength of existing providers and try to expand capacity starting with the resources available.

BHD Community Consultation Team

Crisis team
The BHD Community Consultation Team (CCT) will include a mobile crisis service that will be available to assist community care providers during client behavioral crises. The crisis team will be staffed with clinicians experienced in addressing behavioral issues and other staff experienced in crisis intervention. The team will work with providers to try to diffuse the crisis or help arrange for temporary alternate services (for example, respite services), if available, based upon the current needs of the client.

The crisis team is just one component of an integrated crisis system available to help address the needs of adults with developmental disabilities who are in behavioral or mental health crises. Others crisis services that may be utilized include crisis respite homes, a crisis line, BHD's Psychiatric Crisis Service (PCS) or other hospital emergency rooms, and BHD's Observation Unit. CCT crisis team staff will remain involved with the client as they transition through these various services and return to his or her community residence.

CCT staff will also be available to work with local law enforcement agencies. The focus of such involvement is on education regarding this population as well as helping officers to assist in a supportive manner when called for crisis situations in the community arising from a client's behavior.