

Establishing Residential Services
for Individuals with
Developmental Disabilities and Challenging
Behaviors

Sponsored by:
Tuscarawas County Board of Developmental Disabilities

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Introduction

Tuscarawas County Board of Developmental Disabilities in eastern Ohio was faced with a problem. An individual with a history of challenging behaviors (including sexually offending) needed residential services. Realizing the unique residential needs required to serve this population and the lack of residential options, the decision was made to establish a residential program in Tuscarawas County for individuals with unique behavioral challenges. Natalie Lupi, the Superintendent, knew the need for specialized residential programs was not unique to Tuscarawas County. She decided to do something. She invited representatives from the other counties in Region V to form a Creative Options Committee. The purpose of this committee was to form an alliance where counties in the region could assist one another replicate what Tuscarawas County had accomplished. The development of this manual is part of the process.

Overview

While the majority of individuals with intellectual disabilities are life-long law abiding citizens, a small percentage of this population may find themselves engaged in behaviors that puts them in an “at risk” situation for involvement in the criminal justice system. This population can be a very challenging population with which to deal. These individuals frequently demonstrate needs that require the services of a variety of social service systems. It is estimated that approximately 12-13% of youth in the criminal justice system have some type of developmental disability, as compared to approximately 3% of the general population. The prevalence of conditions such as intellectual disabilities, learning disabilities and emotional disturbance is three to five times higher in the prison population than the rate of these conditions in the general population.

Of particular challenge in working with this population are individuals with dual diagnosis (mental health and intellectual disability) who also have a history of engaging in sexualizing victimizing behaviors. Although individuals with intellectual disability represent 3% of the population, they commit 10 – 15% of sexual offenses.

In many cases individuals with behavioral challenges who also have intellectual disabilities have a mental health diagnoses which may include ADHA, Turret’s syndrome, Autism, Bipolar Disorder, Post Traumatic Stress Disorder (PTSD), Schizophrenia, Depression or other mood disorder. The results of these co-occurring disorders may include impulsivity, difficulty identifying and expressing feeling, memory issues and processing information issues all of which may have an influence on the individual engaging in antisocial behaviors. Another mitigating factor that may effect behavioral issues is abuse of alcohol or other prescription or non-prescription drug.

In providing service to this population there appears to be a lack of communication between the various systems, both mandated and voluntary agencies, providing services to this population. Each service system has a different philosophical approach to the unique needs of this population. Some systems mandated by law to address the needs of

this population attempt to use a “one-size-fits-all” model of treatment, disregarding the unique needs of this population. Other systems involved with these individuals may tend to dismiss the legal ramifications of the individual’s behavior because of their disability and not hold them responsible for their actions, thereby denying them the opportunity for treatment. This confusion among the service providers exacerbates the lack of involvement of families and advocates.

The initial concept and driving force behind the development of this type of home is to provide an environment that prepares an individual to become a law abiding and contributing member of society. The home is not intended to be just another “housing unit”. All individuals and agencies involved with the inception of this type of program need to agree on the philosophical perspective and expectations of the home. These factors need to be identified and agreed upon early in the development in order that they can be incorporated into the training and orientation standards for the home staff.

Operating themes including respect and responsibility have been identified as key elements in the implementation of programming for this population. Respect, defined as treating others as you would wish to be treated is an overriding factor that effects all interactions between staff and residents in the home, staff with other staff and residents with peers. Failure to show proper respect has consequences and those consequences should be consistently enforced. In addition to respect, all individuals, including staff, involved with this home need to take responsibility and/or be held responsible for their all of their actions both from a positive as well as a negative perspective..

Tenacity and consistency and are also important factors. Tenacity is simply the commitment to work with these individuals as long as it takes in order to facilitate the necessary changes needing to be made. Simply put, there are no time limits with this project. How long it will take to achieve the desired outcomes can not be predicted.

There need to be a consistency in the manner in which all staff implement the various aspects of the program. This includes staff reaction to behaviors each and every time the

behavior occurs regardless of how many times the behavior occurs or which participant in the program exhibited the behavior, all individuals have to be treated in a similar manner. Favoritism or acts of special tolerance are extremely damaging to the program. Consequences for issues that warrant them are consistent. Consistency also plays into other aspects of the homes' operation. Consistency helps to develop a sense of stability that may facilitate a sense of trust. Staff arrives at consistent times. Food is served at a consistent time. Laundry and other chore activities are done on consistent days. Individuals are consistently given options regarding choices that affect them in the home and community. Trust helps to provide an environment in which people may be willing to try new ways of thinking and behaving.

Ideally, organizations opting to provide residential services for these individuals should have a history of working with individuals with behavioral challenges, mental health issues and/or individuals with developmental disabilities. Of these three issues, working with individuals with developmental disabilities is probably the least important, and in some cases may be a detriment to providing services. Experience has shown that agencies that identify the behaviors as the primary handicapping condition tend to demonstrate a better prognosis for changing these behaviors than agencies that identify mental retardation as the primary handicapping condition. While mental retardation may present unique issues when addressing the maladaptive behaviors, it is not an excuse for one individual to victimize another.

It is imperative that there is a good working relationship between the County Board of DD and provider. In order for this to occur it is important that both the County Board of DD and the provider have a good understanding of the expectations of each other. This includes the unique needs of the DD system concerning documentation, behavior supports and client rights and general adherence to the requirements of Developmental Disabilities system. It is also important that professionals in the Developmental Disabilities system understand and adhere to the requirements of other professional systems. Additionally, the County Board of Developmental Disabilities needs to understand, agree and respect the therapeutic process identified by the provider. Among

all agencies involved, open and consistent communication is imperative if the individuals participating in the program are going to be successful.

If we are going to expect changes in behaviors, we must empower participants in the program to take responsibility for their behaviors. All behaviors have a purpose and are based on choices. If there is choice then there must be a decision making process. If there is a decision making process, then the individual must admit that they were responsible for their own behaviors, both positive and negative. Mental retardation is not an excuse to victimize another individual. Again, it is imperative that staff working with residents in the program also take responsibility for their own behaviors.

The Facility

Now that the decision has been made to establish a specialized residential program and a provider has been identified, the next step is to identify an appropriate facility in which to house the program. Several issues need to be taken into consideration. The first question is where the home will be located. If the home is to be utilized to house individuals with a history of sexual offending there may be legal requirements concerning the home's distance from schools, playgrounds etc. Some communities have their own ordinances regarding these issues and it is best to check with local authorities. Another related issues are notification statutes for convicted sex offenders and how will members of the local community react when they are notified of a convicted sex offender moving into their community. The home must also be able to meet state mandated requirements.

The type of community in which the home is to be located is very important. In an ideal situation the community would understand the need for this type on program and be supportive. This is not always the case. Some communities can be openly hostile and harass the individuals living in the home. If the home is to serve individuals with a sex offender conviction there is a probability that notification requirements will inform the neighbors of the purpose of the home and result in negative publicity and political ramifications for both the provider as well as the county board. On the other hand, the

home should not be located in a neighborhood where the residents may have easy access to prostitutes and drug dealers on the neighborhood walks.

Ideally the home will be located on a large enough lot that will allow privacy for the residents and their behaviors will not be disruptive to the neighborhood. In searching for a home, check to see if there are toys or a swing set in the neighboring household that might indicate the presence of children in the neighborhood. Will residents in the home be able to look out their windows into the windows of the house next door? Is there adequate space in the yard to allow for some recreational activities? Is there a covered porch or patio for individuals who may smoke? If located in an urban setting, is there public transportation available?

The home must allow each member of the household to have his or her own private bedroom. This will promote in the individual a sense of ownership. Room décor and furniture placement should be the domain of the individual, within health and safety standards. The individual is to be encouraged to decorate the room to his/her liking, to make that room their own. Individualizing bedrooms also fosters a sense of responsibility related to room care. Ideally all bedrooms are on the same floor and can be easily monitored to assure one resident can not enter into another's bedroom without staff being aware.

The best case scenario would be to have two separate living rooms or living room and den with each living space having a TV, DVD, etc. Individuals will need to have the opportunity to get away from each other when issues arise between roommates. Having two living rooms allows this separation to take place without denying or interfering with access to TV, DVD, etc. By giving participants in the program the opportunity to remove themselves from a potentially risky situation, it promotes self awareness, self monitoring and encourages self control. Ideally, staff would be able to observe both living rooms from one location.

Concerning bathrooms, the home can not have too many bathrooms. A minimum of two and a half bathrooms would be ideal. Each resident should be assigned a specific bathroom for supervision reasons as well as giving staff the ability to hold individuals responsible regarding room care. Both resident bathrooms should be equipped with a shower. The half bath should be reserved for staff usage and not available to residents. The kitchen should be large enough to allow for at least one resident and staff to easily function in at the same time, participants need to be able to assist with meal preparation. Eating food that peers have prepared promotes a sense of fellowship and family. Having others eat food that you have prepared promotes self-esteem. A kitchen/dinning room combination makes monitoring easier. There needs to be laundry facilities preferable on the main floor, again to facilitate staff supervision.

All windows and external doors should be tied to a central alarm system that will alert staff whenever a window or door is opened. Smoke and CO2 detectors should be hardwired into the home. External security lights are also recommended. Motion detectors on internal doors may be utilized depending on the level of supervision required for each individual. Air conditioning is required. There should be no reason for opening any of the windows in the home, especially bedroom windows without staff knowledge and approval. Electric vs. gas stoves are preferred because of the frequent history of sex offenders to also have a history of fire starting. It may be necessary to remove rods from closets if individuals have a history of mental health issues and/or suicide attempts. It may also be advisable to remove bedroom and bathroom door locks.

Staffing

The key to a successful program for individuals with challenging behavior is the direct care staff. From the very beginning, direct care staff needs to understand that this is not a typical program for individuals with developmental disabilities and that their role in working with this population is not the typical DD direct care staff role. While the primary role of all direct care staff is to maintain health and safety of the individual and their community, staff working in this type of program needs to understand that they are also to be agents of change. The goal of staff is to assist the residents living in the home

to change their philosophical perspective of the world around them and consequently the way they interact with others. Staff needs to facilitate an environment in which residents in the program are able to learn new ways of thinking and behaving that do not put themselves or others at risk of harm. Their roll is to be friendly but not to be a friend, to be positive and supportive. Staff needs to be able to set and maintain clear and concrete limits and maintain structure. All staff need know what the behavioral boundaries of the program are, be consistent in maintaining these boundaries and be consistent in addressing the behaviors of the residents in the program.

It is the attitude and behavior of the staff that will determine the success of the program. Above the basic qualifications that all staff must be able to meet, have a high school education or equivalent, have the ability to pass a criminal background check and be over the age of 18 to work as direct care staff with individuals with developmental disabilities, there are additional qualities one should look for in selecting staff to work with this population. A lengthy history of direct care service within the DD system may not be the most beneficial. Some professional with an extensive history in the DD field may have difficulty with the premise that it is the maladaptive behavior that is the primary handicapping condition and not the developmental disability. Direct care staff with a background in mental health or corrections may be more beneficial especially if they have any type of training in these areas.

In hiring staff to work with sex offenders, it is important that successful candidates have resolved issues to their own victimization. Assuming approximately 25% of the job applicants interviewed have been sexually victimized in some manner prior to their eighteenth birthday, it is important that staff working with sex offenders have resolved any issues related to their victimization prior to working with individuals who have a history of sexually victimizing others. Gender of the staff is less of a concern than attitude.

Staff need to know their limits and to understand their role is not to parent or control the participants in the program unless there is a concern about the health and safety of the

individual or their surroundings, but to allow natural consequences to occur whenever possible. Staff needs to be able remain calm at all times. Staff should not take the actions of the individuals they serve personally even though staff may become a target for resident aggression or other maladaptive behaviors. Staff needs to be able to identify their “buttons” because the residents in the program will soon know staff “buttons” and attempt to push these buttons in order to get a reaction out of the staff or to attempt to manipulate a situation. Staff also needs to be able to recognize when they need assistance and not be afraid to help when needed. Staff must to be able to set an example at all times and be good role models for the individuals they serve. Frequently, individuals with developmental disabilities will look at staff as being the “ideal” and will role model themselves after staff. Consequently, staff must be consistent in the role they present to residents and that role must present socially appropriate behaviors and image at ALL times. Staff can never “let their guard down” in front of the individuals they serve.

After staff has been hired, appropriate and adequate training is the next key element. In addition to the required training for all direct care staff working with individuals with developmental disabilities, there needs to be training specifically addressing the supervision of individuals with a history of offending behaviors and sex offender specific training if appropriate. Since the majority of these individuals with behavioral challenges also have mental health concerns, training related to specific mental health diagnosis as well as how these diagnosis may effect the individual’s perceptions of reality and how this their perception of reality may effect their behavior may also be beneficial. Additionally, staff needs to be educated regarding how best to interact with these individuals that may reduce the likelihood of maladaptive behaviors occurring.

Team building activities also needs to be a part of the initial train process and on going as new staff are added. The direct care staff needs to work as a team to be most effective and the team is only as strong as its weakest link. Teamwork encourages consistency in how staff interacts with participants in the program. Team work facilitates communication to assure that the treatment team has a comprehensive picture of the individual being served and reduces the opportunity for individuals in the program to

manipulate staff. Team work reduces stress and staff burnout. Working with this population can be extremely stressful. Staff must be constantly vigilant in supervising the individuals they serve.

Staff needs to understand that while they are expected to be friendly with the participants they are not there to be friends of the participants. Clear and concrete guidelines need to be established related to expectations placed on the staff. These guidelines may include how staff is to interact with residents, physical contact between staff and residents as well as expectations related to appropriate dress and hygiene for the staff. For example, requiring participants in the program refer to staff by Mr. or Ms. Plus their last name, limiting physical contact between staff and program participants to “high-fives” or handshakes or establishing a dress code in which staff are not permitted to wear clothing that contains images of alcohol related products or clothing that might appear provocative. Along these lines supervision of direct care staff holding them to these expectations is extremely important. Just as we hold the participants in the program responsible for their behaviors, we must also hold the staff responsible for their behaviors. Additionally, direct care staff needs to feel supported and free to hold one another responsible for their behaviors. On going, regularly scheduled, staff meetings need to be held to assure good communication and consistency in the implementation of all aspects of the program. These team meetings should also include regularly scheduled reviews of each of the individuals served in the home to assure that all staff is aware of the status of each individual in the home as well as any issues that have risen.

Program

Basic Assumptions

- All individuals, regardless of intellectual functioning have the right to access treatment.
- All individuals have the ability to change maladaptive behaviors.
- All programming should be provided in the least restrictive environment.
- All programming should enhance one’s self esteem.
- Individual is more than their behaviors.

- An individual's success must be celebrated.

Milieu: For programming to be most effective it is important to establish a therapeutic milieu. This is best accomplished by utilizing the concepts of a Positive Culture in which participant in the program feel safe and secure as well as valued as human beings. The first step in this process is to provide a working environment in which the staff feels safe, secure and valued. This may best be accomplished by clear and concrete job descriptions, identifying concrete behavioral expectations for staff, educating and training staff related to the issues of the population they are to serve, provide adequate compensation for the work required and provide supervision from a coaching perspective. It will be difficult for staff to facilitate an environment where the participants in the program feel safe and valued if, in fact, the staff itself does not feel that also.

To establish this type of environment for the individuals served it is necessary to separate the individual from his or her behavior. Participants in the program need to understand that they are more than their behaviors and that while we may disapprove of their maladaptive behaviors we still value them as people. The program needs to empower the participants with the right to make choices. However, participants also need to understand that behaviors have ramification, both positive and negative, and that we all need to be held responsible for our behaviors. The goal of staff is to encourage socially appropriate behaviors while discouraging maladaptive behaviors. Staff needs to view maladaptive behaviors from the residents as “teaching moments” rather than opportunities to correct behavior.

The environment needs to enable the participants to feel safe in attempting and practicing new ways of thinking and behaving. Staff needs to provide nonjudgmental feedback to the residents related to the effectiveness as well as the ramifications of these new behaviors. This requires the residents in the program to trust staff and trust is based on predictability. All staff must be consistent in the expectations they place on the participants in the program and must be consistent in recognizing the consequences of

behaviors. As role models, staff must be willing to take the consequences of their own maladaptive behaviors and keep their “attitudes in check”.

In allowing participants in the program to make choices, staff needs to avoid getting into power struggles with individuals served. This, however, does not apply if issues of health and safety are concerned. Staff needs to recognize their role is not to parent or control but to facilitate change allowing natural consequences to occur whenever possible.

Therapeutic Model: The therapeutic model that appears to be most effective in facilitating long term change is a Cognitive – Behavioral Approach that address both the behaviors as well as the thinking process that leads to the behavior. Behavior does not occur in a vacuum. It is precipitated by motivation. It is directed by a thought process. If we are going to effect a long term change in an individual’s maladaptive behavior we must assist that individual to understand how their thinking pattern promotes their maladaptive behaviors and how their behaviors impact on themselves as well as those around them. In addition, individuals needs to learn and have the opportunity to practice in a safe environment new ways of thinking and behaving that do not harm themselves or others. This is not a quick and easy process.

Change for many individuals is not a comfortable process. This may be particularly true for individuals with intellectual limitations. Frequently, these individuals may attempt to sabotage themselves in order to avoid being held responsible for their behaviors or being required to confront their own personal issues. Particularly for individuals that have a history of multiple placements, these maladaptive behaviors have been functional in the past and frequently resulted in a change of placement.

Positive Culture: An important component of an effective residential treatment program is the establishment of an environment in which participants feel safe in practicing new ways of thinking and behaving. The purpose of a residential treatment is to facilitate changes in the ways individuals participating in the program think and act. Change for

many individuals, particularly for those individuals with developmental disabilities, may be difficult. For example, an individual has developed a practice of using physical aggression as a means of dealing with frustration and/or anger, when things do not go their way they have historically hit the wall or another person. This has been an affective way for them to release their stress. Now all of a sudden, they are expected to talk about their feelings rather than act them out. This may be very threatening for them. They may feel that they do not possess the necessary verbal skills or they are afraid that someone may make fun of them or use the information against them.

In a positive peer culture there is a separation between staff and residents. Residents need to understand that as a result of their victimizing behaviors there is a lack of trust, and because of this lack of trust they are not peers with staff on a first name basis. This separation of staff and residents in the program may be artificially facilitated by requiring resident to refer to staff by their sir names such as Mr. Smith or Ms. Jones.

Residents: Of primary importance is the selection of the individuals that will participate in these programs. Ideally there will be a similarity in the individuals that are placed in a particular unit. Those similarities should include gender, level of functioning, and required level of supervision. It may be helpful to segregate individuals with a history of sexually victimizing others in a separate unit. Realizing that assessment is an ongoing process, the key to programming for this population, particularly for sex offenders is a good assessment prior to admission. The assessment process should be completed by a professional that has experience in working with this population. The results of the assessment process should include the level of risk the individual presents to themselves and the community, the required level of supervision in order to maintain community safety, identification of mental health issues, treatment recommendations as well as strengths and potential treatment challenges. For individuals with a history of sexual offending the treatment team needs to know the number and profile of typical victims.

Other factors to assist the team in developing a treatment plan is vocational / educational history, social history including family background, history of agencies involved in the past and medical history.