Chapter 3: Emergency Mental Health Services for People with Developmental Disabilities

Prevalence and Need

Efforts directed at crisis intervention when serving individuals who have both a developmental disability and a co-existing mental health condition have taken on increased attention in recent years, both nationally as well as within the state of Wisconsin. Most developmentally disabled users of crisis services are people with co-existing disorders. It has been estimated that of those persons with a developmental disability, anywhere from 30 to 70 percent [1] will experience the effects of a mental health condition at some point within their life time. In Wisconsin there are over 75,000 people with a diagnosed developmental disability, so even if only 30 percent of these individuals experience a mental illness, this still means roughly 22,500 people will be affected directly at some point in their lives.

In 2004, a multi-state study was conducted by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) regarding strategies for supporting individuals with developmental disability and mental health needs. Nearly 70 percent of the survey respondents identified the difficulty of finding trained staff as a hindrance to coordinated service delivery. Additionally, accessibility of crisis intervention and support services was identified by 56 percent of the respondents as a major barrier, and the availability of clinical consultation and treatment services was identified as a barrier by 49 percent of the respondents.

Mental health crisis services are desperately needed for this population. Coordinated team approaches involving collaborative meetings with relevant agencies, providers, and consumers are needed. However, research has shown that policy barriers are all too often a major impediment to implementing services for people with co-existing disorders. Many excellent crisis prevention and response systems do exist around the country, and to the extent practitioners throughout Wisconsin can incorporate their successes, individuals with developmental disabilities across the state, as well as their families and the professionals that serve them, will benefit.

Cross System Collaboration

A critical component of many successful crisis models is an increase in collaboration between professionals in developmental disabilities and mental health. Collaboration is based on the assumption that "the majority of negative outcomes in organizations result from faulty systems, rather than ineffective people [2]. " The research literature illustrates several social/organizational factors that are necessary for effective collaboration, including: 1) a recognition of the need for collaboration brought about by changes in organization, communication, and funding; 2) strong leaders who believe in and have a long-term commitment to collaboration; 3) an emphasis on the

[1] Szymanski, L., Madow, L., Mallory, G., et al. (1990). Psychiatric services to adult mentally retarded and developmentally disabled persons. Report of APA Task Force #30. Washington, DC: American Psychiatric Association.

[2] Green, R.L., & Etheridge, C.P. (2001). Collaboration to establish standards and accountability: Lessons learned about systemic change. Education, 121(4): 821.

importance of professional relationships including staff exchanges, and 4) the recognition or establishment of mutual goals to promote cooperation.

One relatively common collaborative effort between developmental disability and mental health agencies is the creation of client specific information packets on individuals previously identified as susceptible to crisis events. These packets may include behavior treatment and crisis plans, documentation of known antecedent events and effective de-escalation methods, a picture of the individual, and a list of designated agency contacts. Other cross-system collaborative efforts have been directed at creating integrated multidisciplinary training opportunities on topics ranging from behavior treatment plan creation, functional behavior assessment and analysis, clarity of diagnostic functioning, medication effects and side-effects, de-escalation and physical intervention methods, sex offender treatment, communication skill development, and replacement behavior strategies, among others.

Best Practices

Wisconsin's Emergency Mental Health rule provides authority, responsibility and Medicaid funding through a certified plan. The rule includes individual-specific options such as crisis plan development and stabilization services that that can be individually developed for a person who requires crisis support. Crisis plans are preventive in nature, and typically identify a continuum of services and supports to avoid or reduce the negative consequences of a crisis. While avoiding a costly hospitalization is one goal (though not always possible), this becomes more probable when combined with other supports. For some developmentally disabled persons it is helpful to use a wrap around or Assertive Community Treatment (ACT) model which provides needed services on a "24/7" basis from staff familiar with the individual who are able to communicate the person's needs. Recognized as an evidenced based treatment by the Substance Abuse and Mental Health Services Administration (SAMHSA), ACT began in Wisconsin and is available to all counties as an optional service. Known as a Community Support Program, counties may elect to develop a CSP under Medicaid certification. Both emergency mental health services and the ability to provide wrap around support are available and are of proven benefit. Barriers including the lack of cross-trained providers and the absence of integrated services across funding silos and target groups remain obstacles which prevent the use of these rules to the benefit of the developmentally disabled individual with a mental illness. CSP services may be provided, for example, to an individual with services funded under a Home and Community Based Waiver.

Use of Evidence-Based Practices

Best practices in both developmental disabilities and mental health work requires the implementation of evidence-based practices. Evidence-based practices are interventions for which there exists consistent scientific evidence demonstrating improved client outcomes. While there exists extensive evidence of effective mental health practices, research demonstrates that many mental health programs do not deliver evidence-based practices to the great majority of their clients [3]. Drawing on the research literature available for developmental disabilities, a 1988 article (predating the current push for evidence-based practices) by Van Houten et al [4] proposes

[3] Leff, H.S., Mulkern, V, Lieberman, M, & Raab, B. (1994). The effects of capitation on service access, adequacy, and appropriateness. *Administration and Policy in Mental Health, 21*, 141-160.

[4] Van Houten, R., Axelrod, S., Bailey, J.S., Favell, J.E., Foxx, R.M., Iwata, B.A., & Lovaas, O.I. (1988). The right to effective behavioral treatment. *Journal of Applied Behavior Analysis, 21*, 381-384.

that individuals who receive services designed to change behavior have the right to a therapeutic environment, services which focus on personal welfare, treatment by a competent behavior analyst, programs which emphasize the development of functional skills, behavioral assessment and ongoing evaluation, and the *most effective treatment procedures available.*

One discipline devoted to the use of evidence-based practices is that of the behavior analyst. Behavior analysts have an obligation to use only those techniques that have been demonstrated by research to be effective, to acquaint consumers and the public with the advantages and disadvantages of these techniques, and to search continuously for the most optimal means of changing behavior. Although behavior analysts work with a wide variety of populations, individuals with developmental disabilities are one of the groups where much of their effort has been focused. Increasingly, behavior analysts are also working with mental health populations, and much of this research is being published.

In reviewing the use of evidence-based practices in both mental health and developmentally disabled populations, there clearly exists a need to emphasize the role of evidence-based practices as applied to individuals with co-existing disorders. The inherent danger in not doing so represents what Osborne [5] warns us of when he declares non-evidence based procedures a "faux fixe," – little data to support their use, little evidence of their success, and little interest in their evaluation.

Crisis Support Planning

There are three key components in working with people with co-existing disorders: prevention efforts, intervention efforts, and crisis stabilization efforts. Often these three headings are put together in a treatment and stabilization plan. More details follow:

<u>Prevention</u>

Quality efforts in the area of prevention services primarily involve the use of proactive strategies designed to reliably predict those circumstances under which any particular individual might experience environmental stressors of significant enough magnitude to elicit challenging behavior. Clearly this is an oversimplification of the efforts required, however, the key element in such a strategy is the identification of known/suspected antecedents and manipulation of the environment to avoid such stressors.

Perhaps one of the disciplines best suited to such a task in developmental disability services is that of the behavior analyst. Behavior analysts focus on crisis prevention through the manipulation of antecedent strategies, whereas all too often traditional interventions have emphasized crisis management, which is a reactive strategy focused on manipulation of consequent events. Behavior analysts also work to understand the underlying motivations (i.e., behavioral "functions") of challenging behaviors, while simultaneously working to teach new, more appropriate behavior to replace the challenging behavior.

[5] Osborne, J.G. (2005). Person-centered planning: A faux fixe in the service of humanism. In Jacobson, J.W., Foxx, R.M., & Mulick, J.A. (Eds). (2005). Controversial therapies for developmental disabilities: Fad, fashion, and science in professional practice. Mahwah, NJ: Lawrence Erlbaum Associates.

One of the difficulties Wisconsin faces is the availability of qualified behavior analysts and competent behavior specialists. Many county developmental disability case managers certainly possess the skills required to provide this service, and there are also a number of competent behavioral practitioners working in residential agencies, vocational programs, and other human service settings. With the ongoing movement toward downsizing institutional settings throughout the state, the number of individuals with co-existing disorders in the community is increasing, thus prompting the need for even more qualified practitioners.

There exist many good web sites which assist in guiding those with less experience through the process of developing appropriate behavior treatment and support plans, and these can easily be found through internet search engines. Efforts are also underway throughout the state to increase the number of competent behavioral practitioners skilled in developing these plans, though admittedly this is a long term objective.

A similar though more difficult hurdle is the absence of qualified and interested psychiatrists who are knowledgeable of mental health issues in individuals with developmental disabilities, and (perhaps most importantly) who are willing to work as an integral member with teams who help support these individuals. While it is often recommended that every team have access to a psychiatrist, it is also understood that this is not always feasible. Some areas throughout the country are using telemedicine to conduct psychiatric consults in areas where psychiatrists are not available, and others are working to ensure psychiatrists without specialized training in developmental disabilities are offered training relative to this group of individuals.

Intervention

For individuals with co-existing disorders, there is a need for more than medication reviews, medication changes, and therapy groups. Cross-trained staff skilled in working with people who have both developmental and mental health needs should provide skill development opportunities in anger management, activities of daily living, coping and relaxation skills, social and vocational skill development, appropriate sexual behavior, and the development of recreational skills and interests, among other areas - the emphasis is on functional skill development across a wide variety of skill areas.

Training and information is available in Wisconsin from a variety of sources, and some of these are listed towards the end of this document. Below are suggestions around issues which ought to be considered in the provision of adequate intervention services:

Diagnosis and Assessment

Proper diagnosis is critical, and extremely difficult in many cases. Typical behaviors often targeted for pharmacologic and behavioral intervention include self-injury, physical aggression and property destruction, impulsivity, social withdrawal, verbal abuse, and sexual deviation. Common hurdles include: 1) as the level of disability becomes more profound, accurate diagnosis becomes more difficult; 2) diagnosis may be arrived at from behavioral symptoms; 3) a functional behavior assessment should, but often does not, occur, and 4) clinicians should also explore potential stressors, such as a recent loss, social or communication skill deficits, as well as environmental, transition, and health-related concerns.

Treatment Issues

Several components within an intervention need be in place to define a wrap-around support plan, to stabilize the immediate crisis, and prevent future crises to the extent possible. These include: 1) the availability and knowledge of an individual's team; 2) an environment structured to meet the person's needs; 3) access to comprehensive care; 4) enhanced skill acquisition opportunities; 5) treatment focused on behavioral function using replacement behavior strategies; 6) use of evidence-based mental health treatment as suggested for the condition; 7) control of sleep problems, through good sleep hygiene procedures, and 8) weight maintenance, which is often difficult due to the side effects of medications used in the treatment of mental health conditions.

Medication Use

The prescribing physician will ensure that health is good, and that the person's age and other environmental factors are considered relative to adding or changing medication. Keeping the medication regimen as simple as possible with as few medications as possible is important. Key points include avoiding frequent drug and dose changes; collecting good baseline and treatment data; identifying and tracking specific behaviors to evaluate medication efficacy; monitoring for side effects, weight changes, and tardive dyskinesia; reviewing blood levels periodically, and contacting the psychiatrist for assistance when acute psychotic symptoms arise.

Collection and Use of Behavioral Data

Data relative to the behaviors of concern needs to be taken, summarized and reviewed frequently to assess the impact of all interventions. When interventions are shown to not be effective, the team should review these strategies and make appropriate changes promptly. Additionally, team members are obliged to summarize these data into a format that can be easily read by psychiatrists and other consultative team members – this can easily be done via graphing and spreadsheet programs.

<u>Crisis Stabilization</u>

The emergency room is often a safe and secure environment, where stabilization takes place, sedation can be delivered if needed, and evaluations occur. Several general guidelines apply when working with people with co-existing disorders in emergency room settings:

- Do not threaten the individual with the prospect of going to the emergency room (or calling the police) as a method of control or to force compliance.
- Conduct evaluations promptly and efficiently. Waiting will often cause additional disruption/upset - even minimal amounts of time.
- Ensure privacy to the maximum extent feasible, including both visual <u>and</u> auditory privacy. Allowing someone to have an audience will cause some individuals to further act out in an effort to gain attention.
- Explain procedures simply and clearly. If you do not know if a person understands you, repeat it in several different ways to assess the validity of the person's response – ask caregivers if necessary. When it is not possible to provide choices to the person, do not request consent from the individual as the person may say "no."
- Understand that while the individual may be calm at the time of an emergency assessment, that person's caregivers recently encountered a very different person and everyone is scared. While emergency room staff may want to send the person back to his/her home, it is critical

that all concerns be evaluated in order to assess the potential for reoccurrence of the problems upon discharge.

Consideration of whether to hospitalize an individual or to provide care in the community is complex, and considers many factors including the health and safety of the person in crisis, as well as community members. When individuals with co-existing disorders are hospitalized, too often there is a lack of understanding on what approaches are helpful. Those systems which typically focus on patients who are able to speak for themselves and reliably communicate their own needs also would benefit from training regarding working with individuals with co-existing disorders, while systems who work with developmentally disabled clients are not always equipped to work with people with significant mental health needs.

Ten Considerations for Future Efforts in Wisconsin

1. Create specially trained teams to serve as clinical resources for the diagnosis, assessment, planning, and treatment of psychiatric disorders in persons with developmental disabilities. Such teams could serve as local and regional resources for families, human service agencies, providers and schools, and provide outreach to all communities.
2. Regional teams could maintain lists of "high-risk" individuals with information on effective strategies for local crisis and emergency services. Such teams could assist in the development of individual "risk profiles" to assist case managers and residential/vocational providers in predicting and intervening at early stages of potential behavioral crises.
3. Comprehensive assessments for individuals with co-existing disorders should consist of:
    - A thorough review of all pertinent historical documents.
    - At least one visit with the individual in his/her home as well as with the people who work closely with the person.
    - Suggestions for interventions which are founded in values and evidence-based beliefs.
    - A review of past and current medications.
    - A review and discussion of medical conditions which might be causing the symptoms of concern.
    - A review of behavioral data.
    - An assessment of treatment plan effectiveness based on the data.
    - Recommendations for alterations in the treatment plan if needed, including environmental changes.
    - Recommendations for other consultations (OT, Speech, etc).
4. Clinical outreach services could be provided by university-based psychology intern programs, including training and technical assistance. These services could also provide assistance in transitioning people to the community and in community-based behavioral services for people who demonstrate behaviors that threaten their placements.
5. Telemedicine has been effectively incorporated into some rural locations and its use should continue to increase where feasible.
6. Educational advancement opportunities should be created for direct care level staff to promote retention in the field. Similarly, state-level Behavior Analyst/Specialist positions should be created to promote more competent services for individuals with co-existing disorders.
7. Problems should be viewed as *crisis in support*, and not *crisis in the individual*. Such a shift ensures systems issues remain the focus of intervention efforts.

8. Interventions should look at the environment, the type of work or day program that occurs, communication and skill development strategies, community integration opportunities, and a host of personal factors such as who the person spends time with, and the adequacy of staff training efforts.
9. Form cross-system committees comprised of individuals within developmental disability services, mental health services, and residential/vocational provider agencies. Legal and educational advocates, parents, county and state-level staff and others might also be part of such committees. Meetings should be held with a focus on behavioral, psychiatric, and crisis issues, and the goal of these committees should be to collaborate and train each other.
10. Improving treatment services is likely best achieved through education of current professionals, as well as those new to the field, who have an interest in better serving individuals with co-existing disorders.

Developing Treatment Plans

- Center for Effective Collaboration and Practice website at http://cecp.air.org/fba/default.asp

Select Training Contacts

- DHFS Community Integration Initiative at http://dhfs.wisconsin.gov/cii
- Waisman Center Community Outreach Program at http://cow.waisman.wisc.edu/traincon.html
- DD Network at http://www.ddnetworkinc.org
- Milwaukee Area Developmental Disabilities Service Association at http://www.maddsa.org/events/training.htm