

ASK THE DOCTOR

JOAN B. BEASLEY, PH.D., LMHC¹
ANNE DESNOYERS HURLEY, PH.D.²

THE DESIGN OF COMMUNITY SUPPORTS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES AND MENTAL HEALTH NEEDS

¹Private Consultant, Chestnut Hill, MA

²Tufts University School of Medicine

Individuals with developmental disability and mental health needs can be served in the community when there is a planned continuum of supports that accommodate chronic, acute, and emergency psychiatric needs. In addition to having appropriate supports, it is essential that there is a community system of collaborators that communicate and plan services. The use of the Crisis Prevention Plan is a critical element to avert situations that pose adverse outcomes for people with developmental disabilities.

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Q. Dr. Beasley, in your work you have reviewed the community support systems in a number of states. There are common needs for people with developmental disabilities (DD) and mental illness, such as outpatient psychiatry services, acute inpatient hospitalization, long-term care, and crisis supports. Most of the available services are designed for the general population of service users. What have you learned from evaluating service outcomes for individuals with DD?

A. In many cases, people with DD can successfully be treated within the generic mental health (MH) services that are available to the general public. In some cases, however, expertise and training is needed to effectively provide necessary supports to individuals with significant cognitive disability, complex medical conditions, particular behavioral phenotypes, or behavioral disorders that are rare in the general population.³

People with severe or profound mental retardation (MR), for example, lack the ability to communicate internal feeling states.^{12,13} Most psychiatric clinicians have little experience diagnosing such individuals. Further, a general psychiatric hospital inpatient unit will not be designed with the proper extra staff, support, or resources to help these

individuals effectively. Many individuals may be presumed to have severe behavioral manifestations of a mental disorder but in fact may suffer from underlying medical conditions. Psychiatric inpatient units often overlook the fact that a target behavior such as self-injury can be related to pain or medical illness. In addition, a significant number of people with DD also have seizure disorders, necessitating increased consulting with neurology in the diagnostic formulation and treatment plan.^{1,6,10} Individuals with DD may also have a genetic condition or syndrome as the etiology of their intellectual impairment, and it may be associated with a behavioral phenotype. For example, Prader-Willi syndrome is well known for mood and psychotic symptoms, combined with overeating and continual seeking of food. These individuals typically require a different psychopharmacology regimen than that which would be used typically for a generic population, as well as a comprehensive behavioral protocol that would not be used for the majority of eating disorder patients in psychiatric treatment.

Lastly, a number of people with DD display significant self-injurious behavior that is quite different from the self-injury seen in the general population. Increase in self-injury may occur

during psychiatric crisis, and will require a comprehensive behavioral protocol based on applied behavior analysis as well as possible psychopharmacological intervention.

Q. Given the many factors you have discussed, what is one of the most serious issues in community support systems that should be addressed?

A. Probably the most significant problems come during periods of acute difficulties that may impact the health and safety of the individual or community. I often find that service systems are ill equipped to support individuals in preventing crises. Furthermore, when a crisis occurs, they often do not have good intervention procedures.²

One problem is lack of communication between caregivers and individuals with needs, and the system that is intended to support them. As a result, the system itself goes into crisis when the individual has acute needs. This results in many adverse situations, such as unnecessary hospitalizations, incarcerations, or poor psychopharmacological decisions.

Q. What is your suggested remedy to this problem?

A. Cross-systems crisis prevention and intervention planning can be a good start in solving some of the prevailing systems-related issues.⁴ It is an important collaborative process that takes place between care recipients, caregivers, and members of the service system. The primary function of the crisis prevention and intervention plan is to map out a strategy for individuals and their caregivers and service providers to follow to prevent or manage periods of crisis. In short, the crisis prevention plan serves as a person-centered working agreement between providers to assist an individual during times of impending difficulty.

By person-centered, I mean that the plan incorporates a multimodal approach,⁸ and considers all of the factors that may contribute to an individual's difficulties including medical, environmental, psychiatric, and psychological factors. It also emphasizes the use of the individual's skills and abilities to help ride out potential difficulties whenever possible. The working agreement in the plan aims to delineate

roles and responsibilities in the support system to ensure ready access to needed services.

Q. In the development of the Crisis Prevention and Intervention Plan, what remedies are typically utilized?

A. Cross-systems crisis planning is most often part of a comprehensive system of coordinated care found in many model programs throughout the U.S.^{5,7,9} In the places where cross-systems plans are currently implemented, remedies range from consultation and in-home support to out-of-home diversionary respite depending upon the presenting issues. Caregivers are directed through the planning process to consider all of the factors that may contribute to a behavioral difficulty when it occurs based on prior information and diagnostic assessment, and members of the support system are willing participants in the process. For example: a person is presenting as irritable and unwilling to cooperate with usual demands. It is determined that the person may be suffering from depression due to recently observed changes in the sleep cycle (all of these are common problems associated with mood disorders). As a result, interventions will most likely include a medication evaluation. The psychiatrist who treats the individual will be part of the cross-systems planning process and will therefore agree in advance to evaluate the individual as soon as possible. However, even when the person has symptoms of mental illness, psychiatric interventions are usually not all that are needed. Other factors that may contribute to the individual's MH difficulties should be included in the plan for consideration. For example, physical discomfort, change in routine, and changes in environment may increase the risk of MH and other difficulties and should be considered as part of the planning and intervention process. Therefore, in addition to consulting with the psychiatrist, the plan may also map out strategies that account for the other contributing factors. Residential providers, the behavioral psychologist, medical doctors, family members, etc. will also have a role in assisting the individual in overcoming his or her difficulty.

Q. What typical emergency supports might be in the plan?

A. If the person resides with a family, which is often the case, supports to the current caregiver offer a cost effective option. They empower families and individuals and allow the person to remain in his or her community. Examples include in-home and out-of-home respite and hospital diversion services.³ Mobile crisis supports are also very helpful as well as the ability to access a trained person 24 hours a day 7 days a week who is familiar with the crisis plan and the options available to consult with the family member and offer advice and support. Since the plan pre-establishes interventions, who is going to implement the interventions, and how service providers are to be contacted, the planning process allows for the system to manage difficulties more effectively and helps to prevent long waits in emergency rooms, confusion about the problems, and arduous debates about whether the problem is due to the person's MR or mental illness, during times of crisis.

To illustrate the role of proper planning, I would like to discuss a case. Mr. J was a twenty two-year-old man with moderate MR and autistic disorder. He lived with his family and received in-home staffing and out-of-home staff support through the Department of Mental Retardation. It is estimated that almost 45% of all people served through model programs live at home with their families as did Mr. J. Prior to my involvement, his family tried to access family support services for many years. Because of his unique behavioral needs which included self-injury and severe property destruction, however, he was not able to use traditional out-of-home respite services available to other service recipients. He was followed by psychiatry but medications were never thought to be effective by his family. As a result, he and his family were in a constant state of crisis as he neared adulthood. His self-abusive behavior and property destruction was so severe that he was hospitalized in psychiatric facilities on numerous occasions. However, after each admission he seemed worse to his parents. His medicines were reduced to allow Mr. J to "stay awake," but his severe behaviors would return, beginning the cycle of crisis again. Mr. J was referred to the coordinated services system and the outpatient neuropsychiatric clinic for individuals with DD. His family appeared to be in severe distress, and expressed doubt that they

could continue to manage the situation. Soon after, Mr. J and his family received a number of services through the coordinated service system and the clinic including: diagnostic and treatment planning, crisis prevention and crisis assistance planning, planned respite, parent education, psychiatry and emergency respite when he needed out-of-home crisis services. Since working with the coordinated services team, he has been diagnosed and successfully treated for OCD and bipolar disorder and his behavior has improved dramatically. He continues to receive support staffing through a state funded provider agency in the family home. Members of the coordinated services team provide on-going training and support to his direct service staff members and they help to monitor his psychiatric status. In addition, he receives out-of-home planned respite at the coordinated service's facility (a four-bedroom home in the community) for one weekend a month. After almost one year in the model service system, his parents were able to take a trip away from home without worrying about him for the first time in ten years. A coordinated services clinician continues to attend Mr. J's psychiatric appointments regularly, along with his direct support person and his parents to assist in communicating with his psychiatrist. The clinician also talks with Mr. J's day program provider regularly to ensure that everyone on his team is in communication with regard to his MH care needs. The clinician also makes home visits to assess his needs in his natural environment. This case illustrates how comprehensive programmatic support can assist people like Mr. J and his family to live successfully in the community free from the worries that have often been present for people with DD and behavioral health care needs. Mr. J continues to have on-going challenges; however, he and his family are no longer in constant distress. The system is linked, communication is active, and everyone continues to benefit from the fruits of their efforts, especially Mr. J.

Q. Coordination of services such as those you describe in the crisis planning process is rare in the United States, do you agree?

A. Unfortunately, I do agree. However, as I mention in our article, in a number of states, model programs have been developed to assist in the provision of service linkages like cross-systems crisis prevention and intervention

planning. For example, in the state of Washington, as part of the Allen lawsuit settlement agreement, a cross-systems crisis and intervention procedure has been implemented state-wide. As a result, MH and developmental disability providers meet regularly to collaborate in support of individuals with multi-service needs. They share information and expertise in order to effectively prevent crises as well as intervene in times of severe difficulty. Although this planning occurs in other venues in the United States, this is to my knowledge the only state that has made a state-wide effort.

Q. Is cross-systems crisis prevention and intervention planning expensive?

A. The message here is that ineffective services are not necessarily inexpensive.¹¹ There is much evidence that people with DD and problematic behavior are more likely to use hospital emergency rooms during times of difficulty when there are no alternatives available. The most expensive services both economically and socially are those provided in the hospital emergency room. There is also evidence that with a coordinated care system, there is a reduction in the use of emergency services.

With regard to the crisis prevention planning process, the advent of technological developments can allow members of the cross-systems team to meet together from their own sites, when time and geography prohibit people from meeting in one location. Email offers the opportunity for every member of the team to share information and review and comment on plans in a short period of time. Plans can also be modified frequently with very little effort.

Structural barriers in many states still exist, but state governments can learn from existing models. There are many cost-effective remedies that can be pursued to improve the lives of people with DD and MH needs.

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CORRESPONDENCE: Joan B. Beasley, Ph.D., LMHC, Consultation and Training Services, 184 Bonad Road, Chestnut Hill, MA 02467; tel.: 617-469-7391; email: jbbeasley@rcn.com.