

FAMILY CAREGIVING PART II: FAMILY CAREGIVER-PROFESSIONAL COLLABORATION IN CRISIS PREVENTION AND INTERVENTION PLANNING

JOAN B. BEASLEY, M.ED., LMHC
JERI KROLL, M.DIV.

Family members are often relied upon as a primary source of community support and care for individuals dual diagnosed with mental illness and mental retardation.² However, family caregivers may be unable to handle maladaptive behavior(s) or access the support they need during periods of difficulty.^{10,20} In addition, the use of multiple service systems by people with a dual diagnosis may result in role confusion for professionals when called upon for assistance.¹² During these times, the system may experience a crisis as it is unable to meet emergency demands.³ A primary function of the mental health crisis prevention planning process is to help individuals and their family members develop strategies to prevent the need for emergency services. It is also intended to clarify professional roles and responsibilities in advance of a crisis so that individuals and their families are better able to access the support they need.

Collaboration and communication are essential to the diagnosis and treatment of individuals with a dual diagnosis of mental illness and mental retardation.^{4,9,11,13,17,18,22,24,27,28} Collaboration and active planning are also vital to the successful management of difficulties often associated with a dual diagnosis.^{5,6,7,25} As was stated in the first article of this series, family caregiver-professional collaboration enhances mental health service outcomes.² However, families who care for individuals with mental illness often complain of a lack of support when the individual they are caring for is in crisis.¹⁰ Individuals dual diagnosed with mental retardation and mental illness (MR/MI) are more likely to exhibit aberrant behaviors during periods of crisis.²⁵ In addition, they are likely to receive services from multiple systems.² The combined effects of these two factors make collaboration even less likely during periods of difficulty without careful planning and on-going communication.

Community mental health crisis prevention planning (or personal support planning as it is sometimes called) is an important collaborative process that takes place between care recipients, family members, and members of the service system. The primary function of crisis prevention planning is to map out a strategy for individuals, their families, and service providers to follow during periods of crisis. An additional function of the planning process is to clarify roles and

responsibilities within the service system to ensure ready access to needed services.

THE GOALS OF THE CRISIS PREVENTION PLANNING PROCESS

The first and perhaps most important way to handle a "crisis" is to avoid its occurrence whenever possible. Crisis service use most often follows severe maladaptive behaviors on the part of the service recipient, i.e., assault or property destruction. Crisis prevention planning can provide a strategy to assist an individual and the people who provide support to better cope in times of difficulty. There are four goals of the crisis prevention planning process to accomplish this task.

- 1) **Reaching an understanding regarding communication of needs through maladaptive behaviors.**

A primary goal of the collaborative planning process is for all concerned parties to reach consensus regarding what an individual may be communicating through maladaptive behaviors. Family caregivers and other people providing support and assistance can better introduce alternative strategies to help an individual get their needs and wishes met when they understand the "meaning" of a given maladaptive behavior. When effective, this strategy helps to prevent a crisis from occurring.

2) **Developing/improving upon coping strategies for the individual and the family caregiver.**

The crisis prevention plan outlines options for individuals and their family caregivers (and other providers of direct support) to cope with feelings or difficulties that may increase the likelihood of maladaptive behavior(s) if not addressed. For example, the plan may delineate "early warning signs" that may indicate an individual is experiencing anxiety. Based on what is known about the individual, the plan outlines relaxation techniques to assist in reducing the person's anxiety.

3) **Preventing the system from going into crisis: The delineation of roles and responsibilities for specific professionals and service providers.**

The crisis prevention plan helps service providers respond more effectively in times of crisis. It is helpful when the plan is as specific as possible in defining who should be contacted and when. The plan may also include important facts about the individual to help service providers contacted to better assist the family. To ensure that the plan is taken seriously, we recommend that each crisis plan be approved and signed by all involved parties to prevent confusion during times of difficulty.

4) **Simplifying access to services.**

It is important that access to emergency services be as easy as possible. For example, we recommend a one page phone list of services and important contacts. Families and other direct support providers should have ready access to the list in addition to the crisis prevention plan. We often find a crisis intervention phone list posted next to the phone numbers of the local fire department and police department on family refrigerators.

THE START PERSONAL SUPPORT PLAN

The **START Personal Support Plan** is one example of a crisis prevention and intervention planning format. "The Support Plan" was developed at START in Northeast Massachusetts. START (Systemic, Therapeutic, Assessment, Respite and Treatment) provides treatment, support and training to individuals dual diagnosed

with developmental disabilities and psychiatric (or behavioral) disorders, families and service providers.⁴

The purpose of the Support Plan is to assist individuals, their providers and families to access the supports necessary to live successfully in the community by:

- providing an accurate picture of who the individual is - his/her strengths, preferences or communication style;
- identifying causes of difficulty and patterns that may lead to difficulties;
- assisting team members in understanding the individual's mental health diagnosis and what that means for the individual;
- identifying people and resources that have been helpful in the past;
- pre-negotiating the roles of service providers when outside intervention is necessary.

THE SIX ELEMENTS OF A PERSONAL SUPPORT PLAN

Summarized below are six essential elements in a START Personal Support Plan.

1) **The "face sheet"**

The face sheet provides necessary demographic information about the individual as well as a description of strengths, communication style, medical and communication issues. The face sheet is formatted so that it is easy to read. The face sheet also contains an easily accessible phone list of all providers in the individuals network described earlier.

2) **General guidelines**

The general guidelines section is very important in providing a quick overview of who the person is, what his strengths and interests are, what things are problematic for the individual and interventions that have been helpful in the past. As such this section is a "mini-support plan" which summarizes the essential factors that are operative in the individual's life.

3) **Identification of a hierarchy causes and possible interventions**

This section defines the pattern of behaviors, signs and symptoms (least severe to most severe) which may lead to a crisis if left untreated. Potential causes (or reasons) for difficulties and

suggested interventions are included at each stage.

a) **Identifying a hierarchy**

In identifying the hierarchy of behaviors we do not begin with the identification of extreme maladaptive behaviors. An individual may experience difficulties long before the use of "bad" behavior. For example, an individual with a history of property destruction and assaultive behaviors, during times of crisis, may become isolative with flattened affect days or hours before maladaptive behaviors arise. Although frowning and spending time alone are not behaviors considered to be "maladaptive," in this case they may be early warning signs of depression, environmental factors or physical discomfort. If left untreated, relatively benign behaviors as those just described can be the precursor to physical aggression or property destruction.

Behaviors may be clustered to include several behaviors at each level of difficulty. The listing of less severe behaviors also suggests that the purpose of the plan is not to impose external control over an individual. While the support plan empowers family caregivers to manage problems, a good plan also empowers the individual. The purpose of the support plan is to help an individual access support they need early enough to control his/her own behavior. In addition, early interventions (necessitating identification of early signs) are the usually the "least restrictive" interventions, making them more palatable for all involved.

The individual's psychiatric diagnosis should be included in the support plan along with a description of behaviors that represent symptoms of acute mental illness. For individuals who have MR/MI it is helpful to translate symptoms of their mental health diagnosis into behavioral equivalents.^{19,21,27} For example, one of the criteria for mania is distractibility. This may manifest itself in decreased work productivity in a given individual and treatment effectiveness can be objectively measured through monitoring performance at work. The benefit of translating diagnostic criteria into behavioral equivalents is that it provides a concrete means to assess the need for further psychiatric intervention.²⁶ When this occurs, treatment is accessed and occurs much more proactively, preventing a full blown

crisis and provides specific information to caregivers.

b) **Potential reasons for behavior**

Identifying the reasons for (or meaning of) behaviors can be a difficult task. Some important factors to remember are:

- We are looking for *possible* causes, a working hypothesis.
- Tracking daily routines and behaviors is a vital part of understanding the causes of aberrant behavior.⁸
- It is essential to engage in multidisciplinary collaboration when looking for the causes of a problem behavior. A number of factors may contribute to an individual having difficulty. These include environmental, psychiatric, medical and psychosocial conditions.²⁵
- When looking for antecedents, it is often helpful to do a functional analysis of the individual's behavior. Since particular behaviors may be an indication of certain motivational considerations, it is helpful to ask: what is the message behind the behavior?; what are the consequences and benefits of the behavior?

Some common sources of non-psychiatric or non-medical difficulties to keep in mind include: an inability to communicate feelings; environmental factors such as a change in routine; unmet needs; and physical or emotional discomfort.^{15,23,25} Some of the most common reasons for difficulty that may be related are: transitions, differing expectations in different settings, family issues, feeling powerless, inability to communicate feelings, feeling blamed when things don't go smoothly, and boredom.

c) **Interventions**

Five important issues to incorporate into your intervention strategy are:

- Intervene as early as possible to prevent the escalation of difficulty.
- Begin with the least restrictive manner of intervening that is likely to be effective.
- Interventions should match the cause of the behavior. The intervention in the

situation is based on what is going on with the individual.

- Individuals along with their direct caregivers should be assisted to manage difficulties whenever possible.
- Interventions are never punitive. Maladaptive behavior is most often used because the individual has difficulty communicating his/her needs or the system is unresponsive to them. For example, if someone is using maladaptive behavior to get attention, we suggest that they receive the attention they need *before* they use maladaptive behavior. Table 1 offers some options that may be useful to consider.

TABLE 1. POSSIBLE CAUSES OF DIFFICULTY AND SUGGESTED INTERVENTIONS

CAUSE	INTERVENTION
feeling powerless	give choices
anxiety/fear of the world	offer structure (limit choices)
feeling blamed	ego enhancing statements
lack of self-esteem	provide "attention"
boredom	activity

4) Disposition recommendations

The disposition recommendations section specifies service and other options that have been most successful in the past; i.e., whether the individual does well at respite, which hospital is most desirable, etc. This is very helpful in identifying resources for a given individual.

5) The back-up protocol

The back-up protocol details how family members can access additional support if needed. Having a clear back-up plan is essential in providing families and the service providers they contact with the resources necessary to deal with potentially difficult and dangerous situations. On-call staff can have access to and familiarity with crisis prevention plans. Should the individual experience an acute crisis, families can have easy access to the emergency supports they need.

Emergency support providers (crisis teams) should have the resources they need to intervene quickly and effectively. Resource flexibility is essential, since no crisis plan can absolutely predict all future needs.

6) The signature page

The signature page is included at the end of the document. Since the support plan is a working agreement between agencies/individuals, this final element is essential in assuring the success of the plan. When everyone involved in the network of support has a clear understanding of their role, the system will not experience a crisis along with the individual in need.³

CONCLUSION

In a time of increased dependence on family caregivers and other people who provide direct support to people with disabilities who live in the community, it is important to have a mental health system in place that is respectful and responsive to the needs and requests of service users and their caregivers. During times of acute psychiatric difficulty, family caregivers may need to rely on the community mental health service system for direction and support. In addition to lack of information and education on the part of caregivers, structural barriers in the service system often interfere with the ability to respond adequately to expectations and needs as they arise.

As advocates of family support, we do not suggest sweeping policy changes in the way the community support system is currently structured. Rather, it is suggested that any community support system can work effectively when members of the system collaborate, and if planning is done on an individualized basis. In crisis prevention we suggest a process of systematic prevention and intervention planning to address the issues faced by individuals and caregivers in the context of the community support system. When a coordinated planning process between care recipients, caregivers and service providers occurs, the use of crisis services can be minimized. In addition, crisis prevention and intervention planning fosters improved competence for all involved to respond effectively during times of difficulty.

REFERENCES

1. American Psychiatric Association. **Diagnostic and Statistical Manual of Mental Disorders, ed. 4.** Washington, DC: American Psychiatric Association, 1994.
2. Beasley JB. Long-term co-resident caregiving in families of persons with a dual diagnosis (mental illness and mental retardation). **Ment Health Asp Dev Disabil** 1998;1:10-16.3.Beasley J, Kroll J. Who is in crisis, the consumer or the system? **NADD Newslett** 1992;9(6):1-5.
4. Beasley JB, Kroll J, Sovner R. Community-based crisis mental health services for persons with developmental disabilities: The START Model. **Hab Ment Healthcare Newslett** 1992;11(9):55-57.
5. Borthwick S. Maladaptive behavior among the mentally retarded: The need for reliable data. **Mental Retardation and Mental Health: Classification, Diagnosis and Treatment Services.** New York, NY: Springer-Verlag, 1988;30-40.
6. Bregman JD. Current developments in the understanding of mental retardation Part II: Psychopathology. **J Am Acad Child Adolesc Psychiatry** 1991;30:861-872.
7. Campbell M, Malone RP. Mental retardation and psychiatric disorders. **Hosp Community Psychiatry** 1991;42:374-379.
8. Carr E, Newman J, Darnell C. The clinical importance of sleep data collection: A national survey and case reports. **Ment Health Asp Dev Disabil** 1998;1:39-44.
9. Davidson P, Cain N, Sloane-Reeves J, Giesow V, Quijano L, Heyningen JV, Shoham, I. Crisis intervention for community based individuals with developmental disabilities and behavioral and psychiatric disorders. **Ment Retard** 1995;33:21-30.
10. Fisher G, Benson P, Tessler R. Family response to mental illness: Developments since deinstitutionalization. In: Greenly J (ed), **Research in Community and Mental Health.** Greenwich, CT: JAI Press, 1990;6:203-236.
11. Fletcher R, Poindexter A. Current trends in mental health care for persons with mental retardation. **J Rehabil** 1996;62(1):23-25.
12. Fletcher R. Mental illness and mental retardation in the United States: Policy and treatment challenges. **J Intellect Disabil Res** 1993;37(1):25-33.
13. Hurley A. Vocational rehabilitation counseling approaches to support adults with mental retardation. **Habil Ment Healthcare Newslett** 1996;15:29-33.
14. Jacobson JW. Problem behavior and psychiatric impairment within a developmentally disabled population I: Behavior frequency. **Appl Res Ment Retard** 1982;3:121-139.
15. Lowry M, Sovner R. The functional existence of problem behavior: A key to effective treatment. **Habil Ment Healthcare Newslett** 1991;10:59-63.
16. Menolascino FJ, Gilson SF, Levitas AS. The nature and types of mental illness in the mentally retarded. **Psychopharmacol Bull** 1986;22:1060-1071.
17. Menolascino Frank J, McCann Brian M (eds). **Mental Health & Mental Retardation: Bridging the Gap.** Baltimore, MD: University Park Press, 1983.
18. Middelhoff LA. "Case management for persons with a mental handicap and behavior and mental health problems. Results of six years of practice through cooperation of different organizations in southeast Brabant. (The Netherlands)." Paper presented at the American Association of Mental Retardation, Region IX Annual Conference, October 30, 1996.
19. Nezu CM, Nezu AM, Gill-Weiss MJ. **Psychopathology in Persons with Mental Retardation: Clinical Guidelines for Assessment and Treatment.** Champaign, IL: Research Press, 1992.
20. Pfeiffer E, Mostek M. Services for families with mental illness. **Hosp Community Psychiatry** 1991;42:262-264.
21. Phillips I, Williams N. Psychopathology and mental retardation: A study of 100 mentally retarded children. **Am J Psychiatry** 1975;132:139-145.
22. Rambow TR, Arnold M. Individualized/homogenized/cost effective service model. **NADD Newslett** 1996;13(6):1-4.
23. Silka V, Hauser M. Psychiatric assessment of persons with mental retardation. **Psychiatr Ann** 1997;27(3):162-169.
24. Smull MW. Systems issues in meeting the mental health needs of persons with mental retardation. In: Stark JA, Menolascino FJ, Albarelli MH, Gray VC (eds), **Mental Retardation and Mental Health: Classification, Diagnosis, Treatment and Services.** New York, NY: Springer-Verlag, 1988;394-398.
25. Sovner R. Limiting factors in the use of DSM-III criteria with mentally ill/mentally retarded persons. **Psychopharmacol Bull** 1986;22:1055-1059.
26. Sovner R, Hurley AD. Do the mentally retarded suffer from affective illness? **Arch Gen Psychiatry** 1983;40:61-67.
27. Sovner R, Hurley AD. Assessment tools which facilitate psychiatric evaluation and treatment. **Habil Ment Healthcare Newslett** 1990;9:91-98.
28. Woodward H. One community's response to the multi-system service needs of individuals with mental illness and developmental disabilities. **Community Ment Health J** 1993;29(4):347-351.

This is the second in a series of three articles in family caregiving. Research for the series was made possible in part by the Merck II Scholars Program through the Starr Center on Mental Retardation at the Florence Heller School of Social Policy, Brandeis University, Waltham, MA.

A copy of the S.T.A.R.T. Support Plan format may be attained by request. Write to: Joan Beasley, M.Ed., LMHC, Director, Sovner Center, 99 Rosewood Drive Suite 240, Danvers MA 01923; or e-mail at JBeasley@GLMH.ORG.

Joan Beasley, M.Ed., L.M.H.C. is Clinical Director of Greater Lynn Mental Health and Retardation Association, Inc., Lynn, MA, and Director, Robert D. Sovner Behavioral Health Center, Danvers, MA. Jeri Kroll, M.Div. is the Director and co-founder of S.T.A.R.T. Clinical Services in Danvers, MA.