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The Use of Respite in Crisis Emergency Services: A Two Year Analysis

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Title: The Use of Respite in Crisis Emergency Services:
A Two Year Analysis

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Respite care is widely believed to be an important service for families raising a child with a disability. All caregivers need a break from time to time, and the need may be even greater when the caregiver is coping with the additional stress associated with a child's disability. A number of studies have demonstrated that respite care can improve family functioning (Cohen, 1982), reduce stress (Rimmerman, 1989; Wickler & Hanusa, 1990; Appoloni & Triest, 1983), and delay out-of-home placement (Cohen, 1982; Upshur, 1982) for families with a child who has a disability.

In 1993, the New York State Office of Mental Health began a three-year research and demonstration project to study the effectiveness of three models of intensive, short-term (4-6 weeks), in-home, emergency services for children in the Bronx, New York, who might otherwise be hospitalized due to a psychiatric crisis. Presenters provided an overview of the study which is described in detail elsewhere (Evans, 1992; Evans, Boothroyd, & Armstrong, 1997).

In two study conditions, in-home and out-of-home respite care was available to families in conjunction with intensive in-home services. Respite was available on both an emergency and planned basis. Respite workers were trained to care for children with serious emotional disturbances (SED) and selected to match the needs of the child and the family. Both English and Spanish speaking respite providers were available. Given the short-term nature of the interventions in this study, out-of-home respite stays were limited to three days per occasion. In-home respite services did not have to take place within the home, allowing respite workers to engage in recreational activities with a child such as going to the zoo, seeing a movie, or having a pizza. Respite care was not restricted to the identified child, but also was available for other children in the home.

During the first year of this study, the use of in-home and out-of-home respite fell below anticipated levels. In year one, 26% of the 70 eligible families used in-home respite. Utilization improved to 35% of 81 eligible families in year two and 70% of 20 eligible families in year three. The overall utilization rate was 35%. Out-of-home utilization never exceeded 4% of eligible families.

When in-home respite care was used by a family, it was provided an average of 10 times per family with the number of times it was used ranging from 1 to 24. On average, 42 hours of respite care was provided per family, with the number of hours ranging from 2 to 123. Respite sessions averaged 4 hours in length.

Researchers took several steps to better understand why utilization of respite fell below anticipated levels. We looked closely at characteristics of users and non-users for anything that might help us understand utilization patterns better. We examined program fidelity data collected at discharge to assess caregivers' knowledge of respite. Caregivers and professionals participated in focus groups and caregivers completed mailed surveys. In each of these activities we sought to better understand caregivers' need for respite; what professionals and caregivers see as barriers to utilization; and what are some important features of a respite program from a caregiver's perspective.

There were no differences between respite care users and non-users regarding the child's diagnosis, assessed dangerousness of the child's condition, gender, the number of children living in the home, the number of adults living in the home, or the primary caregiver's formal education level or income. Caregivers who used respite did have younger children (10.6 versus 12.7 years), had children with a greater number of assessed functional impairments (1.6 versus 1.3), reported a lower level of informal supports (average 74 versus 87), and reported greater difficulty controlling their children's behavior, understanding the problems their children were having, and identifying services that might be helpful.

At discharge, a significant percentage of caregivers reported that they were not told about the availability of in-home respite services, or did not remember whether or not they were told. The percentage of caregivers who remember having been told about respite has improved as we have stressed the importance of providing this information to all families, developed informational brochures, and discussed the need to discuss the availability of respite on more than one occasion. Nevertheless, many caregivers report that they were not told or did not remember being told about in-home respite (27%) or out-of-home respite (38%).

These and other data illustrate the importance of assessing how it is that families understand information they are being given. Clearly, some families were not informed about respite which makes it impossible for them to be partners in planning for their child. Others were informed, but the message may not have been clear to them. Furthermore, focus groups underscored the importance of cultivating an understanding by both professionals and caregivers as to how a new resource -- in this case respite -- could be helpful. Several steps were taken during the project to improve communication with families and among professionals: (1) brochures were developed; (2) the respite coordinator began to work more closely with staff to individually assess each family's need for respite; (3) providers incorporated suggestions from parents about how to talk

about respite with families who might be wary; and (4) staff were encouraged to exchange ideas about the different situations in which respite might be helpful.

Finally, presenters contrasted caregiver and professional perspectives on several issues which seemed to surface repeatedly in focus groups and in survey responses: the relevance of respite, safety, coordination of services, information, flexibility, and worker qualities. While caregivers and professionals shared many concerns, the differences in their viewpoints are important if programs are to be designed in keeping with caregiver's needs and concerns.

Among the differences in perspective noted were the following:

- 1) Caregivers were certain of the value of respite, while some professionals expressed doubts about "non-therapeutic" services.
- 2) Professionals were concerned that adding a respite worker might be overwhelming to families and worried about coordination of services. Caregivers were concerned that professionals were making decisions without their input on issues such as this where each family is different.
- 3) In terms of respite worker qualities, professionals emphasized the training of the respite worker as well as their ability to provide respite without interfering with the work of the primary service provider. Caregivers emphasized the personal qualities of the respite worker: She enjoys my child, understands my child's needs, and respects our family.

Although not the primary focus of the research and demonstration project, the respite sub-study has produced some interesting information on the use of this type of service by children with SED and their families. Few studies on respite focus on the families of children with SED. It will be important for children's mental health researchers and parents to continue to collaborate on the design and evaluation of respite care models.

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