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Respite Care for Families with Children with Serious Emotional Disorders: Promising Practices in Systems of Care

In surveys of the needs of families whose children have serious emotional disorders, respite care has been consistently mentioned as one of the most needed but least available services (Butler & Friesen, 1988; U.S. General Accounting Office, 1990). As one of the services to be offered in systems of care for children with serious emotional disorders and their families, there is growing interest in respite care and respite services are being developed in many areas of the country. In this presentation, the research team reported on a study of promising practices in respite care for children and families at six System of Care sites.

METHODS

The study was one of the "Promising Practices" series funded by the Center for Mental Health Services to identify and disseminate information about innovative practices emerging at community-based Systems of Care. The purpose of this study was to identify and describe promising practices in respite care in these grant communities funded by the Center for Mental Health Services through the Comprehensive Community Mental Health Services for Children and their Families Program. Through a process of self-nomination, systems of care around the country were identified as providing "promising" programs of respite care services. Seeking to represent geographic and socio-cultural diversity, the researchers decided to focus on six sites, five of them grant communities, and one a non-grant community. Data collection was through in-depth semi-structured interviews with program administrators, staff, respite providers, parents, and children. Questions focused on the goals

and types of respite care, the organization and administration of respite services, financing, recruitment, training, matching, and family involvement in planning and decision-making. Some data collection occurred through face-to-face interviews during site visits, while other interviews were by telephone. The research team also reviewed program documents such as recruitment and training materials provided by program administrators and staff. Face-to-face interviews were taped and transcribed and detailed notes were taken during telephone interviews. Data were analyzed qualitatively and themes were identified and reported in detail in a research publication, which is in production at the time of this writing (Jivanjee, Simpson, & Garcia). In this conference presentation, an overview of the approaches to providing respite care services at each of the systems of care was given and promising practices were identified.

FINDINGS

Five of the six sites included in the study were funded by the Center for Mental Health Services; the sixth site was the statewide respite program of Oklahoma, which was nominated for its innovative family empowerment model of lifespan respite services. A brief description of respite care services and the promising features of respite care at each site are presented below in alphabetical order:

Children and Families in Common, King County, Washington

In King County, several types of respite care services were primarily provided to children and families in crisis, with a primary goal to prevent long-term hospitalization. Respite services were accessed through a single point of entry, the Children's Crisis Response Team. In the community, respite services included case aides who visited the family home, crisis respite in the home or a community setting, and next-day appointments to provide immediate access to mental health support and services. Other respite options included foster care respite, hospital diversion, and short-term residential beds, all of which had goals to avert crises, give families a break, stabilize family relationships, and provide short-term intensive

therapeutic intervention. Promising practices observed in respite services in King County were the range of respite options available to families in crisis and the collaborative relationships among child-serving agencies and community mental health agencies, which support access to respite services.

Nashville Connection, Nashville, Tennessee

At the Nashville Connection, the system of care grant community in Nashville, Tennessee, access to respite care services has been facilitated by the pre-existing respite services of the Tennessee Respite Network. Respite care was seen as an integral part of the package of wraparound services for children and families served by the system of care. Access to respite services was enhanced by the Information and Referral Service provided by the Tennessee Respite Network and subsidies of up to \$500 per year through the state Medicaid waiver program's Planned Respite. The state's respite care infrastructure also included Planned Respite Model Programs, short-term respite care and empowerment-oriented training for families to recruit their own respite provider in the community. Promising practices at the Nashville Connection were the extensive training offered to respite providers and families, and options for families to choose their own preferred form and location for respite in their home, the provider's home, or the community. In addition, the existence of the Tennessee Respite Network and availability of subsidies for eligible families facilitated families' access to respite care.

Nebraska Family Central, Region III, Nebraska

Nebraska Family Central was the System of Care grantee for 22 rural counties in Nebraska, where all families served were eligible for respite care as part of their wraparound services plan. Respite care needs of families were routinely discussed in wraparound planning meetings and families were supported to identify respite resources within their own family or social network, with payment from the System of Care grant. This model maximized the use of community resources and support networks and was respectful of families' culturally shaped preferences.

Project Relief, Tampa Hillsborough Integrated Network for Kids (THINK), Florida

Project Relief was the respite care project developed by the Tampa Hillsborough Integrated Network for Kids (THINK) Project. The development of Project Relief was planned by an advisory committee, chaired by a parent and made up of service providers, advocates, family members, and researchers. Respite program planning was guided by a logic model with clearly specified goals and outcomes, which has been a tool for accountability and evaluation efforts. The program built upon an existing therapeutic mentoring program, which ensured a high level of emphasis on therapeutic activities for the children and youth participants. At the time of the study, plans were underway to develop a community-based respite program to serve ethnically diverse communities in Tampa. The family-led program was an innovation for this area, as a new chapter of the Federation of Families for Children's Mental Health was started during the development of the respite program. Respite care was provided during Federation meetings, to enable parents to participate.

Oklahoma Respite Resource Network

Oklahoma Respite Resource Network presented a statewide model of lifespan respite care for individuals with all types of disabilities and their families, including children with serious emotional disorders. Funded through pooled funds from state-level departments and some foundation contributions, the program was administered centrally, and provided vouchers worth \$300 or \$400 (depending on family income) every three months to all eligible families. Families were free to recruit and train their own respite providers and to negotiate their own rate of payment for respite services. The principles guiding the program were that families are the best judge of whom they wish to use as a respite provider and are best equipped to train potential respite providers. Effects of this approach were low overhead costs and low rates of reimbursement, because most families used relatives or friends as respite providers. The program was therefore very cost-effective. Respite care was easily

accessible and evaluation data indicated high levels of family satisfaction.

Welcome House, With Eagle's Wings, Wind River Reservation, Wyoming

Welcome House was a respite home on the Wind River Reservation with six beds for children to stay in to give parents a break and to provide family support as part of the system of care. Welcome House offered culturally appropriate care to Northern Arapahoe children living on the reservation. Founded by a parent of a child with a serious emotional disorder, Welcome House provided respite beds on a planned or emergency basis, depending on availability. Respite care was provided at no charge to parents. Length of stay varied, with one week as the average. The central location of the home in the community led to parents, community members, and elders spending time with the children, so that it was truly a community resource.

DISCUSSION

The researchers noted that the respite care services are not available in many communities, and that the services described in the presentation were available to only limited numbers of children and families in each area. Clearly, there is a need for much more extensive development of a range of respite care services to support families and alleviate stress. The respite care programs described offered many innovative and promising strategies for supporting families. It was hoped that the ideas shared in the presentation would be of interest to conference participants from around the country who might be involved in advocacy efforts to develop or expand respite care services.

REFERENCES

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