Family Support Services for Grandparents and Other Relative Caregivers for Children of Substance Abusing and HIV-Positive Women

Yale University Child Study Center Final Report 9/30/97 to 9/29/01

I. Major Activities

The overall purpose of the Yale Support Program for Family Caregivers has been to apply the knowledge derived from clinical experience, theory and research to increase the likelihood of stable, nurturing and long term intra-familial caregiver relationships for drug or HIV affected children whose biological parents have died or have been unable to meet their every day needs consistently. The program has provided home- and community-based supportive mental health and case management services for relative caregivers and assist them to access additional health, mental health, legal, financial, welfare and educational services in the community in the service of maintaining permanency for the children in their care. Our work over the past four years has also emphasized the importance of legislative advocacy and systems work to address the unique needs of relative caregivers.

A. In-Home Family Support

Since its inception, the Yale Caregiver’s Program has accepted referrals from an array of community and state agencies. Referral sources have increased over time as our networking in the community has grown and information about the program has been made available. Relative caregivers affected by substance abuse or HIV are eligible for in-home services. Typically families referred to the program are caregivers who have presented within the community as overwhelmed by the task of raising their relative’s children. Presenting problems have included an array of concrete needs such as housing or financial support as well as the specialized needs of the children in their care. Services provided in the home have included, home-based psychotherapy, family support, assessments, treatment planning, case management and advocacy. Concrete assistance has included transportation, escorts to medical appointments, referrals to community services and assistance with apartment/house hunting.

Since 1997, The Yale Caregivers Program has served 23 families who provided for 58 children. Families typically were provided intensive home-based services that included a clinician and a family support worker. Frequency of visits was dependent on the needs of the family. During critical times, families saw their team two to three times a week. Consistent visitation coupled with availability during emergencies set the stage for caregivers to establish a trusting relationship with the team. The development of a trusting relationship with staff has enabled caregivers to confront troubling issues, gain the information and support that was essential to maintaining the child placed with them and make effective use of the community resources available to them.
Support Groups

Support Groups are able to provide a psychologically safe and stable environment that helps caregivers increase their socialization and coping skills and decrease their feelings of anger, shame and disappointment. The Yale Caregiver’s program has made group support available by facilitating a caregiver’s group within the community. A local church as well a senior center donated space for the bi-weekly meetings. Lunch and transportation were provided by the program. Caregivers articulated that they preferred respite time away from their child care role, therefore on-site daycare was not provided.

Two short term children’s groups were also facilitated within the community. Again, a local church and a community center donated space. Transportation funds were provided by grant funded from the Connecticut Health Foundation. The groups were attended by children between the ages of five to nine. The Program for HIV-Affected Children and Families has offered two long-term groups for children ages eleven to sixteen.

C. Advocacy

A steering committee co-chaired by Sandra Gossart-Walker, MSW and Janice Currier-Ezepchick, MSW was developed as part of the implementation process of the Yale Caregivers Program. The committee members included representatives of state and community agencies as well as relative caregivers. The committee dealt with issues such as staff hiring, identification of problems unique to relative caregivers and the timely dissemination of information to the community/agencies involved in the work in New Haven. Steering committee members helped to frame the issues that were most relevant for relative caregivers. The relative caregivers on the committee shared not only their own needs of psychological support, they were able to provide meaningful feedback regarding the more concrete programmatic issues. Committee members were able to explore some of the complicated clinical and concrete dynamics of relative caregivers cases by addressing the barriers that threatened to prevent a grandmother caring for five children from securing appropriate housing. Even the data collection processes and programs evaluation were agenda items that received useful input from committee members. Initially, this committee met monthly. Over time, as the implementation phase ended and systems for the program were in place, the committee met less frequently. As our knowledge of the relative caregiving increased it was important to share our experiences with a larger group of providers and caregivers. Debra Horvath, a clinician in the program has become an active participant in both the statewide meetings of the Grandparents as Parents (GAPS) and a local initiative started by the New Haven Public Schools. Ms Horvath was part of the planning committee for a caregiver’s conference held in September of 2001. The conference provided opportunities for programs to share information with caregivers and validate the importance of their parenting role.

In collaboration with Connecticut Voices for Children and other community agencies, the Caregivers Program and the Program for HIV-Affected Children and Families have been
active participates in educational and advocacy efforts with state legislators. A principal issue for caregivers has been the subsidized guardianship legislation enacted in 1997. There has continued to be yearly efforts to increase the numbers of caregivers eligible for this financial support and reduce the barriers preventing caregivers from accessing this assistance. Although caregivers who initiated proceedings in the Probate Court remain ineligible for subsidized guardianship, a yearly stipend has been made available for these caregivers.

2. Problems

No significant problems to report regarding the implementation of the grant.

3. Significant Findings and Events

Families have been enrolled in the program for periods of time varying between three months and three years. Data collected reveals that the program was successful in achieving the goals of maintaining the care of the children within biologic families and ensuring permanency of care. No child was removed permanently outside the home. Forty-six children remained with the original caregiver, while five moved to the house of another relative and two were reunified with a parent. Caregivers were assisted in achieving permanency of care through the court system. During the period of the program, 16 caregivers obtained guardianship, six transferred guardianship to another relative and two others initiated obtaining guardianship.

Data collected has revealed that relative caregivers are parenting under enormous stress. Thirty six (36%) of the caregivers reported physical health problems, twenty (20%) had diagnosed mental health problems and eight (8%) had their own substance abuse issues. These vulnerabilities coupled with the children's special needs often challenge the coping abilities of many relative caregivers. Children served by the Yale Program ranged in age from infancy to sixteen. Eleven had diagnosed health problems, seven with mental health needs, fifteen with reported behavioral problems and two with a known drug or alcohol problem. General neglect by their own biological parent was the primary reason for their placement with a relative. The home-based interventions reflected these needs. Treatment planning with relative caregivers required a delicate balance of support to caregivers while providing service to the children in the home. The therapeutic alliance established with caregivers was imperative to ensure that the developmental needs of the children were kept in mind by relatives struggling with their own emotional and physical needs.

Ambivalence, as well as unresolved anger towards biological parents, remain key dynamics in the clinical work with caregivers. Caregivers affected by substance abuse are frequently frustrated by the uncertainty of the recovery process. Many times caregivers enter this parenting arrangement with the belief that it is a short term solution to an immediate crisis. It is not uncommon for caregivers to express disbelief that the removal of children from a parents’ care is not enough to motivate them into sobriety. Unprepared for a long term arrangement, caregivers may remain ambivalent regarding permanency planning for the children in their care. Similarly, biological parents struggle with their own limitations and a child’s need for permanency. False promises to children...
and caregivers become a set-up for disappointment and anger. Mediation between parents, caretakers and children attempt to address these issues aimed towards preserving positive relationships between family members.

Both data collected and our own clinical observations over the past years has taught us that interventions developed for relative caregivers need to be sustained over time. Grandparents and other relatives need support and assistance during times of normative transitions. Caregiver's needs change over time as children enter new developmental stages. Grandparents themselves ranked support, advocacy and counseling as their most pressing needs. We look forward to incorporating our knowledge and the lessons learned over the past ten years into the programming for the next grant period.

4. Dissemination Activities

