

## ABSTRACT - TENNESSEE RESPITE COALITION GRANT

I. PURPOSE OF PROJECT AND RELATIONSHIP TO SSA TITLE V MATERNAL AND CHILD HEALTH (MCH) PROGRAMS: The major purpose of this project has been to improve the availability and accessibility of respite in Tennessee through the development of the Tennessee Respite Coalition (TRC), and through the TRC's development of and advocacy for a plan for a comprehensive respite service system in Tennessee. The Tennessee Respite Coalition (TRC) functions to coordinate respite activities, to identify and work to fill gaps in respite services, and to develop and advocate for a plan for a comprehensive system of respite services to parents of children with special needs. The CISS/COG grants have as a purpose the development of coalitions to improve the capacity of communities to better address their system integration needs. This grant project has directly addressed this need.

II. GOALS AND OBJECTIVES: Goal 1: to enhance and diversify TRC membership by increasing the numbers of parents of children with special needs and minorities, and agencies not yet involved in the Coalition. Objectives: hiring a Coordinator for the TRC, increasing the number of parents/caregiver grandparents of children with special needs in Coalition activities, increasing the number of minorities participating in Coalition activities, and increasing the diversity of agencies in the TRC by bringing to the table agencies not yet involved with the Coalition. Goal 2: to increase access to and availability of respite services by developing and advocating for a plan for a comprehensive respite service system. Objectives: generating a comprehensive respite needs assessment to identify gaps and overlaps in respite services; networking to coordinate existing respite

services; developing a plan to increase access to and availability of non-categorical respite services statewide; and advocating for this plan.

III. METHODOLOGY: To address Goal 1, the Coordinator made outreach efforts to recruit and enable minorities and parents with special needs children to join as active members of the TRC, and to draw new in respite stakeholder agencies. To address Goal 2, the Coordinator worked with Coalition members to develop a comprehensive respite needs assessment, identify gaps in respite services, coordinate existing respite services, and develop and advocate for a plan for a statewide respite service system.

IV. EVALUATION: System level descriptive data was gathered to provide an analysis of changes needed in the respite care system, and a description of the referral and funding sources in place and needed. A Network Analysis was performed to determine the level of communication among group members, and to examine the structure/pattern of relationships among TRC members. The growth of TRC membership was tracked and analyzed for total as well as minority and caregiver membership.

V. RESULTS/OUTCOMES (POSITIVE & NEGATIVE): This grant was focused on the development of a community integrated service system in Tennessee – specifically, a Respite Coalition which could function to improve a vital service to families of special needs children. The TRC has built a consortium of all the individuals and agencies in Tennessee with an interest in respite. This coalition group formulated a plan for a statewide respite service system, and is working toward implementation of that plan. The TRC has emerged as a major voice for respite services dedicated to families with special needs children. The conversion of the TRC from a voluntary association of consortium members to a 501-c-3 (with the same consortium membership) enables it to function

more effectively as this voice, and as a conduit for respite services to our target population. This will strengthen the MCH Services Block Grant Programs in Tennessee by developing respite options for families served by these programs. TRC membership has grown from 25 to 917 members across the state. The number of parents/caregiver grandparents of children with special needs grew from 65 in 2001 to 231 in 2004. The number of minorities participating in the TRC has increased from 32 to 185. The TRC has established seven regional groups to address respite on a more local level as well as to form a statewide grassroots constituency. The TRC has identified respite needs in Tennessee, coordinates respite activities, and is working to fill gaps in respite services. The principal investigator of this grant served as the point person to coordinate and facilitate Year 2000 Annual Respite Networking and Coalition Building Conference.

VI. PUBLICATIONS/PRODUCTS: A brochure was developed and has been disseminated statewide. The Coordinator has published and disseminated a monthly TRC Newsletter. The brochure and two samples of the monthly newsletters are attached in Appendix A. The Respite Needs Surveys are attached in Appendix B.

VII. DISSEMINATION/UTILIZATION OF RESULTS: Survey results have been shared nationally at the ARCH National Respite Conference 2001. Each year, TRC progress is shared at the annual National Respite Coalition meeting. Progress and setbacks are shared with TRC members across the state through newsletters, emails, and meetings. This final grant report will be available statewide and nationally, upon request. The statewide respite service system plan developed will be used in future to try to secure funding for such a system. The TRC is implementing a pilot respite subsidy program in Memphis, TN, providing opportunities for Respite Care to our target population.

VIII. FUTURE PLANS/FOLLOWUP: The development of the Tennessee Respite Coalition as an inclusive and powerful voice for respite will help to promote the concept and implementation of respite in Tennessee through a coordinated approach to the development of a statewide system for respite care services. The short term impact is that the TRC, now a 501-c-3 agency, will continue the coordination and advocacy activities initiated by the project. In Memphis, the TRC will continue a respite care subsidy program. Funding for administration (operating funds) is a new struggle that the TRC faces. Although state dollars are tightly restricted at this time, making an entire respite care system difficult to develop, the TRC plans to work to secure funding for pilot programs in each region. The long term impact is that this grant has enabled the TRC to function as an entity capable of advocacy for respite services, planning for the collaborative statewide development of a respite service system, and administering respite programs. This project will benefit parents of children with special needs in Tennessee by increasing the availability and accessibility of respite services in the future.

IX. TYPE/AMOUNT OF SUPPORT AND RESOURCES NEEDED TO REPLICATE:

The model of coalition building demonstrated in this grant is adaptable to other states. A key to growth of the TRC was to have strong support from the TRC Coordinator for volunteer members in regional areas. In replicating this project, devoting more resources for staff and travel might be helpful. In Tennessee, due to the size of the state East to West, additional part time Coalition staff in the far regions would have been helpful.

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## ANNOTATION AND KEY WORDS LIST

- ANNOTATION

The purpose of this project was to improve the availability and accessibility of respite in Tennessee through development of a Tennessee Respite Coalition (TRC). Respite services were not readily available to parents of children with special needs. The goals were to increase and diversify TRC membership, and to increase access to and availability of respite services by developing and advocating for a plan for a comprehensive respite service system. Total TRC membership was increased, as was membership of minorities and parents/caregivers, and a comprehensive respite service system plan was developed. The development of the TRC as an inclusive and powerful voice for respite has benefited parents of children with special needs in Tennessee by increasing the availability and accessibility of respite services, and by promoting the concept and implementation of respite in Tennessee through an inclusive and coordinated approach to the development of a statewide system for respite services.

- KEY WORDS

Key Words: Respite, Caregivers, Children with Special Health Needs, Family Support Services, Family Professional Collaboration, Interagency Cooperation, Networking, Parent Support Services, Service Coordination, Specialized Child Care Services, State Systems Development Initiative

