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ABSTRACT

This fact sheet offers basic information on developing and implementing rural respite and crisis nursery programs. It first defines "respite" as temporary relief for caregivers and families of children with disabilities, chronic or terminal illnesses, and/or for children at risk of abuse and neglect. It also defines "rural" and notes unique qualities and challenges of rural areas as well as common characteristics of successful rural respite programs. Suggestions are then given for recruiting and training local care providers, for obtaining funding, for dealing with transportation issues, for building trust, and for putting it all together. (DB)

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Developing and Implementing Rural Respite and Crisis Nursery Programs

What is Respite?

Respite, temporary relief for caregivers and families, is a service in which care is provided for children with disabilities, chronic or terminal illnesses, and/or for children at risk of abuse and neglect. Respite can occur in out-of-home and in-home settings for any length of time depending on the needs of the family and available resources. Crisis nurseries are a type of respite which focuses on children at risk of abuse or neglect. As a vital part of the continuum of services for families, respite helps prevent out-of-home placements and possible abuse and neglect situations, preserves the family unit, and supports family stability.

What is Rural?

"Rural" is a term often defined by its relationship to both geography and distance. "Frontier," "isolated," and "remote" are other terms frequently interchanged with rural. The US Census Bureau defines the rural population as those people living in towns with less than 2,500 residents. At least one study has defined the distinction between rural and urban by proximity to a metropolitan area. In another study, a county is designated rural when it has fewer than six persons per square mile. According to these various definitions, different parts of the United States may have distinct rural characteristics. Contrast rural in tiny Delaware with rural in expansive Alaska. Consider what rural means in a sparsely populated state like Montana as compared to a more densely populated state. In fact, it is safe to say in almost every case, if you think you're rural, you are!

Rural Areas Have Unique Qualities

It is important to note that rural areas have unique, although not exclusive, strengths and resources particular to both people and place. A sense of community and relatedness is often heightened in small communities. Family, extended family, and shared cultural foundations frequently provide natural supports. A greater sense of independence and self-reliance may also exist. The slower pace, as well as flexibility in both schedule and choice of activity allow social service and political leaders in the community to become personally involved. The likelihood of less bureaucracy makes meeting individual needs more probable and, when it comes to providing services, the fact that a particular rural area may have only one or two families who need services can be viewed positively.

Rural Areas Have Unique Challenges

Challenges to rural service delivery are directly related to the key rural characteristics defined above. Typically, there is a sparse population spread across large land areas. In a number of states, mountainous terrain, large bodies of water, and climate (long, severe winters or summers) create isolation because travel is difficult or impossible at times. There is usually limited, if any, public transportation and often great distances between communities resulting in high travel costs, time expenditures, and limited transportation options.

In most cases, specialists such as physical/occupational and communication therapists, special education professionals, psychologists, and crisis counselors as well as respite providers tend to concentrate in urban areas. There may be a lack of

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care providers as well as other service providers with particular areas of expertise. As a result, rural programs face difficulty in recruiting and retaining qualified staff.

The biggest challenges for rural programs are as follows: 1) it is difficult to find care providers, and the difficulty increases for rural crisis nursery programs that may require providers who are not related or personally involved with the family seeking assistance; 2) because programs are small, typical funding ideas—local fundraisers, foundations, state assistance—may be unsuccessful; 3) lack of transportation affects people's choice and use of respite services; and 4) programs may be under-utilized because families are not comfortable asking for help from people they do not know.

What does a successful rural respite or crisis nursery program look like? A successful rural program builds on the strengths and resources unique to rural areas to overcome the challenges that appear to exist. Because rural areas may have a shortage of specialized therapies, counseling, and other support services, care should be taken that it is not assumed that respite can replace or supplant needed treatment, intervention, or other family services. Collaboration with existing service programs will ensure that respite is part of a continuum of services offered to families and their children.

Successful service models developed in rural areas display common features. These programs take advantage of the sense of community and capacity for relatedness that is often present in rural communities (Fewell & Vadasy, 1986).

- They make every effort to establish locally controlled, accessible services. The needs and desires of the families involved are assessed and addressed.
- They place an emphasis on home-based or neighborhood service delivery. Extensive advertising, social gatherings with both care providers and families, and active family involvement are essential to generate community participation and support.
- They rely on local paraprofessionals and professionals. Rural communities offer a wealth of very willing and knowledgeable sources of

information for the formation and implementation of a respite program. Networking and collaborating with these community resources (and individuals) is critical to provide social support as well as funding for an ongoing program.

- They show respect for every family's belief system. Cultural and community diversity is not just accepted but respected, encouraged, and even celebrated.
- They facilitate inclusion of extended family members in treatment and support services. On-site training and other responsive education methods are utilized rather than relying on training at a centralized, and often distant, site. Parents of children with disabilities may be guided to provide the bulk of respite care education and training.

Recruiting and Training Local Care Providers

Recruitment of qualified respite workers (paid providers as well as volunteers) can be accomplished through existing networks of local community resources. Many of these resources are appropriate even when the need requires finding providers who are not related to or involved with the family. Neighborhood child care and preschool programs often offer part-time and/or temporary care. Local schools may have teachers, teacher aides, and students who would be qualified to be a respite provider. Junior or community colleges frequently have teachers and students interested in helping families. Local religious organizations may have a cross-section of retired professionals and interested community-minded citizens. Volunteer organizations and service clubs may have members willing to provide care (Campfire, 4-H, FHA, FFA, Women's Clubs). Senior citizens (even if there is no local organization) may be interested and able to provide care in a number of cases. And, if available, foster parents may be used more creatively for short-term as well as long-term care.

For families of children with disabilities, friends and relatives of a particular family needing respite may be willing to assist, especially when the program allows them to be paid. One of the best examples of successful recruitment for rural re-

spite care is a program in which families who have recruited their own local respite providers become resources for families who are looking for a care provider. In many cases, this contact has led to the families themselves sharing care with one another. And, in at least one instance, a neighborhood parent coop (where care was reciprocal) met the family's need for respite.

When parents recruit, it is logical that parents also take responsibility for providing the necessary training to meet their child's needs. Other avenues of training as well as recruitment may be coordinated with local parents, the County Extension Service, local service organizations, or existing rural agencies (Tribal Health, Public Health Nurse, Health Clinic or Hospital, Child Care Resource and Referral Program).

Getting Funding

First of all, successful programs start out with a plan designed to sustain the program past the initial momentum. Typical funding solutions may not work in rural areas because of additional expenses, tight budgets, and some disinterest on the part of funding agencies. A solid funding base is most likely to be formed in conjunction with existing local community resources as well as state/local designated funding sources. In many states, respite funding is contracted by region for region-wide needs, which would reasonably include allocating adequate resources to the families residing in rural areas of the region.

The following are possible sources of rural funding. Each one should be evaluated individually in order to choose those which can best meet the program's needs now and in the future considering the unique qualities of each state and the local community* Creating a program as part of an umbrella agency in the community (or region) can offset basic costs and promote collaboration.

- Local clubs, groups, and private donations are more likely to be offered for special projects that benefit local families.
- A number of state, federal, and private foundation grants now target rural and/or underserved populations.
- State legislative requests need to address and

include the unique needs and challenges families (and children) face in getting services in rural areas.

- Special events fundraising has become a tradition in some rural communities and has been connected with local activities such as county fairs, ball games, and auctions. (See *Securing a Stable Funding Base: A Training Guide* published by the ARCH National Resource Center, April 1994 for additional examples.)

Dealing with Transportation Issues

Transportation can be a particular problem for families in rural areas who need access to planned or emergency respite services. For example, families may not have their own means of transportation, they may have to travel a long distance to receive respite, and/or their children may be difficult to transport. Methods and ways to share resources need to be developed to assist families in transportation. Successful programs make the design and support of a transportation network a priority at the outset.

Practical solutions which all types of respite programs have utilized include: reimbursing care providers and/or families for mileage to and from the respite site; employing neighborhood networks and family members as care providers for children with disabilities; arranging a centralized meeting place for the family and care provider to meet and exchange children; and linking up with other programs that provide transportation such as Head Start or Senior Citizen's Transport. In one case, the local school district transported the child directly from school to the child's care provider two days each week.

Building Trust

It may not be surprising to discover that rural programs build trust when they are responsive to families and emulate the best practices of family-centered services. These programs involve families in the formation and the implementation of the program. They make sure that families are made aware of the existence of the respite program and how they (and their children) will benefit from utilizing the services. Successful rural programs

give families options whenever possible about who provides care for their children, where the service is provided, the type of care provided, and the duration of each respite event. In addition, they emphasize the principle of maintaining confidentiality in the training and recruitment of providers.

Putting It All Together

While this factsheet focuses on respite in rural areas, the need for collaboration among agencies providing services for families in rural areas cannot be overemphasized. Providing a continuum of intervention and support services for families who need them wherever the family resides will always be a challenge. Service providers and their agencies need to adopt a "can do" attitude and stop making excuses for why families cannot be served because of where the family lives.

Summary

Developing and implementing successful respite programs in rural areas provides unique, but not impossible, challenges. Successful rural programs exist across the country. Using a variety of creative methods to meet their unique challenges, these programs have implemented services that effectively meet families' needs. With a thorough understanding of the community and a strong commitment to providing respite to families, programs can be established in any rural locale.

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