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ABSTRACT

Respite care provides relief or backup emergency care for families of individuals who are developmentally disabled. In sparsely populated rural areas, center-based urban models for service delivery and provider recruitment and training may be inappropriate. Las Cumbres Learning Services has developed a model for provision of respite care services in a large rural area of north-central New Mexico. This report describes elements of this model that could be adapted to other rural areas, including needs assessment; deciding between center-based and home-based respite care; deciding between volunteers and paid providers; limited forms of respite care (on-call providers, after-school arrangements, transportation); allocating respite hours among families; waiting lists; defining emergency use; program publicity; and recruiting, approving, and training providers. Las Cumbres uses a three-tier training model to better meet the needs of families with strong cultural and family structures. Level I providers are family members who complete minimal training. Level II providers complete 40 hours of specialized training or have a bachelor's degree or 3 years of experience in the field. Level III providers meet Level II requirements and provide services to at least two families. (SV)

DEVELOPING A RESPITE PROGRAM

IN A RURAL COMMUNITY

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Respite care is a relatively new concept. It has grown out of the national movement of the 1970s to de-institutionalize and provide treatment settings for persons who are disabled which are least restrictive and which m[illegible]closely resemble standard community living. The purpose of respite care is to provide an opportunity for families of individuals who are developmentally disabled to get away for an evening, a weekend or several days; time to "recharge" or to provide backup to families in emergency situations, such as the illness or hospitalization of a family member.

There are several models for providing respite care. Most are agency-based (where an agency takes the lead in recruiting and training providers and linking families with providers) and many are urban and center based. In the urban models, providers are trained in groups and this is possible because of the larger population from which to recruit providers. In center-based models, a building or part of a building is available and staffed some or all the time so that families who need respite have easier access to the service.

In large, sparsely populated rural areas, center-based urban models for provision of respite and recruitment and training of providers is often not possible or appropriate. Many families as well as potential providers live in more isolated settings, some without electricity, telephones, indoor plumbing or heat other than wood. People do not concentrate in large numbers in one location, as they do in cities, and villages or isolated homes are often many miles apart. Transportation is often a problem. These factors make a centralized location for respite less practical and accessible. They also contribute to difficulty recruiting and training providers; newspapers, radio stations, personal and telephone contract are harder over such a scattered population; the number of providers who need training at any one time often is too small for group training; and centralized location for trainings are hard to schedule for the mutual convenience of all providers. Training needs and formats may differ, too, since providers may be family members or close friends of the family for whom they will be providing respite, thus needing less individualized training concerning each client. Many providers do not read or write and many may be Spanish speaking, with limited understanding of English even when material is presented verbally.

Yet rural families need respite from the care of their family member who is disabled at least as much as urban families do, and provider training is a critical element in the peace of mind of families when they leave their family member who is developmentally disabled in the care of another person.

Family members must feel reassured that their family member is safe and confident that the caregiver is competent to deal with their family member's particular needs.

Families also need dependable relief from the intensity of attending to the needs of their family member who is developmentally disabled. Respite care which involves paid providers, when it is available, is often limited because of funding considerations. Volunteer respite providers tend to either quickly tire and become unreliable or prove less than qualified to address care systems, to break down as caregivers, admit their problems, and demonstrate their need in order to obtain respite.

The philosophy of respite, on the other hand, is to strengthen families who keep their family members who are developmentally disabled at home through prevention of stress and crisis, when possible, and through consistent, dependable support. The purpose is to support families before there is unnecessary stress or breakdown. Families with this kind of support are more likely to remain a functional unit. A second major function of respite is to have

providers available in a crisis situation when emergency respite is necessary to reduce further stress for a family.

During 1987-88, Las Cumbres Learning Services developed a model for the provision of respite services in a large rural areas of North Central New Mexico. This model was developed through our experience with a tri-cultural population (Hispanic, Anglo and Native American) in a large rural region. Families served ranged from those who live in very isolated situations with few economic resources to upper-middle class families living in more populated communities. Input from a statewide Respite Network is also reflected in the model. Many aspects of the model may also be pertinent to respite services in non-rural areas, as well, and/or can be adapted to suit the needs of the geographic region where respite service will be started.

Any interested individual, network of individuals, or agency can begin a Respite Program in any community. Most often existing agencies serving individuals who have developmental disabilities add respite to the range of other services they provide. However, another agency or a network of parents could also begin a respite program in a local community. Clear commitments from individuals involved in the initial effort should be obtained as to who will do which step of the process. Written working agreements are helpful if several individuals and/or agencies are working together in the effort.

How to Start

Needs Assessment

The first step for anyone interested in starting respite services is to determine if there is a need in the local community for services. Starting a respite program is no easy task, and you want to be sure there is a need for such a program. Also, funding sources will want to see that a need exists before considering funding a new program in any community. Start by:

- defining the geographical region you want to serve (will it be limited to one town, county, or region?)
- defining the population you will serve (i.e., will you serve only individuals who are developmentally disabled or will you provide respite services to other types of disabilities?; families of people with mental health problems?; families of elderly stroke victims?; etc.) While the Las Cumbres model is for families with developmentally disabled members, many aspects of it could easily be adapted to other populations.

Then conduct a needs assessment for the population and within the geographic region you have defined.

A needs assessment can be conducted in one or a combination of several ways:

- a form which is widely disseminated throughout the community and collected and collated by a central person or agency. Forms can be distributed to local Associations for Retarded Citizens, special education classrooms in public schools, community based agencies serving the developmentally disabled, local churches, public health clinics, hospitals and doctor's offices, local human service agencies (such as Social Services), and/or state agencies such as Health and Environment Department or Human Services Department. Some information can be gained through the CO-OP System, Developmental Disabilities Division, Health and Environment Department, concerning who in your region is on a waiting list for respite services. If at all possible, determine who in each setting will be responsible for disseminating and collecting the form and getting it back to a specified central collating location.

Set a date for return of the form and put that date on the form. It is most effective if the form is combined with personal or phone contact for follow-up, since mail returns of forms received, even with self-addressed stamped envelopes tends to be slow. Follow-up phone calls, meetings, or personal contact will glean a wider response.

- media, articles in newspapers, spots on the radio, flyers grocery stores, schools, daycare centers

- a widely publicized meeting of interested individuals

- informal data collection from interested individuals

In all needs assessment formats, find out how many people are interested, if they have ever or are now receiving respite through some auspices; how much they project they would use respite and time periods when respite is most needed (i.e., after school, weekends, evenings, for a week at a time, etc.); and about their willingness or ability to help pay for services. You will need the name, address and phone number of the respondent so you can reach him/her and you need to know the name, age, and type of handicap (including whether or not they are ambulatory). Information about the type of care the disabled family member will need is very helpful in planning the program and recruiting and training providers and matching them with families.

It is also helpful to find out if the family knows of anyone who would provide respite or be interested in being trained as a provider, since, especially in rural regions, recruiting providers can be one of the biggest problems. Las Cumbres'needs assessment also asked what kinds of training families felt providers should have in order for families to feel comfortable leaving their disabled family member with them. This information helps with the design of provider training formats, which impacts total respite program costs.

Decide How and Where Respite Will Be Provided

There are several options for how to provide respite. You can choose one or a combination of the following choices. The ideal is to create a continuum in order to offer families as many options as possible, but often a small, sparsely populated area must choose one.

"Center-based" respite is just what it sounds like: respite care provided in a "center" or a central location. This might be accomplished in several ways.

Respite Center

Some agencies in larger towns have a building designated solely for the provision of respite care which is staffed 24 hours a day, seven days a week (or other regular, specified hours) so that respite is always available (providing there is an empty bed) to families who need it. The number of beds in a center-based respite program may vary according to the needs and the funding available.

Designated Respite Bed(s) in an Already Existing Location Unless a respite program exists in a fairly good-sized town with enough people needing respite and an adequate funding base, a center set aside solely for respite is sometimes impractical. Other center-based options can include a bed (or more) set aside in an already existing location.

One possibility is designating extra space in an existing group home as a respite bed. The advantage of this arrangement is that there is already staff at the group home who may be able to function as providers, thus averting the need to find a provider in a hurry. Other advantages are the already structured programs available in group homes and day programs, from which respite clients may benefit.

There are disadvantages to this. The respite person(s) must not make the total number of people exceed the number for which the group home is licensed. Client room requirements must be met for licensing. Another drawback is that children cannot be served in group homes for adults, so a bed in a group home would be limited to use by respite clients age 16 and up.

Home-based

Home-based respite services are sometimes called "provider based" models and are often most practical in non-urban areas where center-based services do not exist; or home-based can be combined with small center-based programs to create a wider range of options for the provision of respite. Home-based services are considered most "normalized" for the provision of respite to children. Home-based services can be provided in:

- the provider's home
- the family's home
- a combination/choice of the above

Providers can be hired as staff persons or work on a contractual basis (but usually not both, because the Department of Labor does not allow employees of agencies to also work for the agency on contract). If you are considering hiring a current employee to also do respite, check DOL regulations concerning paying individuals who work more than 40 hours a week.

Other Ideas

- Volunteer vs. paid providers. Some programs operate strictly with volunteers; others pay their providers.

- Provider on call. Some agencies hire or contract with a staff person or contracted person to be available ("on-call") in the event of an emergency respite need.

- Before/after school. Limited respite needs could be met by exploring utilization of a day care center or school facilities for before/after school respite care. Such an arrangement could be utilized on a planned basis, or if resources are available to have appropriate staff available, even on a "drop-in" basis.

- Transportation as respite. Many families, when they identify what would provide a break for them, say that the transportation of their disabled family member to programs, appointments, etc., could provide them with a lot of relief. Consider this as one option for the provision of respite. Look into legal/liability issues and providers' driving records first. Families should request and agree to this form of respite and should sign a release concerning their family member being transported by a provider. Providers who drive clients should have their own liability insurance; agencies sponsoring programs where this is an option need proof of that insurance as well as a copy of the provider's drivers license and driving record.

- Respite for individuals who are disabled. Adult and adolescent disabled individuals may need a break from their families (or the group homes in which they live) from time to time. Respite services might be used to organize social outings, find another place for the person to stay for awhile, or otherwise meet the needs of these disabled persons.

Allocate Respite Hours

While you are considering the budget, you will doubtless have in mind a total number of respite hours which you hope to and can afford to provide. Allocation of these respite hours among families needing and requesting respite can be a problem, primarily because there are never enough hours to meet all requests. To allocate hours fairly, Las Cumbres has devised a system to determine a family's need based on things such as; family structure; geographic isolation and behavioral concerns, independent living skills, and mobility of the family member with a disability.

Waiting List

When you are unable to provide requested respite services because of funding constraints, applicants must be put on a waiting list. Keeping accurate records on wait listed families and their unmet needs is an important function: you also have data which will support requests for more money to provide respite to those receiving no or limited services.

In addition to keeping internal records and entering data into statewide systems, agencies should refer waiting families to other respite resources as well as to other needed services. Las Cumbres touches base with respite waiting list families quarterly in order to update their needs and let them know the status of their position for potentially receiving respite. Emergency respite could also be offered to waiting list families in emergency situations.

Emergency Use

Emergency respite is a problem for several reasons in a rural setting. one dilemma is most geographic regions is defining "what is an emergency?". A good bit of discretion is required from the Respite Supervisor in

exercising judgement about this matter. However, we have defined some guidelines. The following factors may be considered in assessing the nature of each family's emergency request:

A. Is the client being abused or neglected?

B. Is the client at risk of abuse or neglect?

C. Does the client exhibit behavior problems that pose a threat of injuring self or others or that result in destruction of property?

D. Has an act of God occurred (fire, flood, tornado, etc.) which has resulted in disuse of primary residence of the client?

E. Is there recent hospitalization or serious illness of primary caretaker, immediate family members, family member who is disabled?

F. Is the client in danger of institutionalization or a move to a more restrictive environment?

G. Is there other extraordinary family stress (e.g., potential illness, hospitalization or other absence of primary caretaker if respite is not provided)?

Other problems are insufficient respite hours and unavailability of providers for emergency situations. Total number of respite hours available for a year are always limited and are not usually sufficient to reserve for an emergency respite fund, so unless families can afford a private pay situation, funding for emergencies is a problem. Furthermore, without a center-based model which is available all the time, a respite provider may not be available for family emergencies.

Las Cumbres has sought to deal with these problems by (a) making a bed available in a group home for emergency use when a provider can't be found or when this is the most appropriate setting for a respite client (however, remember, this is not a resource for clients under age of 16; (b) encouraging families who are or the respite program to plan respite use so that some of their allocated hours are available for emergencies, should they occur; (c) reserving a small number of HED funded respite hours for emergency respite use; and (d) encouraging providers to accept emergency respite cases.

At Las Cumbres, the emergency respite fund is available only to families who are not already on the respite program. This decision was made because there is already a growing waiting list for respite services, and families who are not already receiving some allocated respite hours in a year are likely to be most in need in the event of a true emergency. Other families' unused hours may be added to the emergency fund as the year progresses if needed. The Respite Supervisor monitors emergency hours use and the need for and availability of additional hours. If no emergency hours are available in our program and a family is truly in need, Las Cumbres looks for other resources by contacting other respite agencies in the State.

Publicize the Program

Once you have identified families who want respite, have decided what model(s) to use and know about what it will cost and where to get the money, it is time to publicize the program. If your resources are as limited as most new respite programs are, you may already have identified all the families you can serve and may want only a short newspaper article announcing the service.

However, the purpose of publicity is threefold in letting the community know the program exists to:

A. Families who need the service know it's there and how to link with it;

B. People who might be interested in being providers can be recruited; and

C. Potential funding sources (donations, etc.) can be solicited.

As you publicize the program, other groups than the one you are currently targeting who have a need for respite may also be identified and considered for service in the future. For instance, if your target population is families of developmentally disabled originally, but families

with members with other disabilities surface as a result of publicity, you may want to consider expanding your mission to serve a broader population in respite services.

Publicity can be done through:

- press releases
- radio/TV/other media announcements
- speeches to interested groups
- personal contact with families, potential providers
- flyers to be distributed in grocery stores, churches, and other places where families go
- notifying family doctors, pediatricians, and other health care professionals and through other means as well.

Recruit and Approve Providers

Providers of respite services at Las Cumbres must be at least 18 years of age, due to liability issues and the requirements of some funding sources in New Mexico. Recruitment of providers goes hand in hand with publicity, and as mentioned provider recruitment is probably one of the most important functions of a "Respite Coordinator" (agency, person) and sometimes one of the most difficult. Use of all the media, public speaking, flyers, notification of doctors, clinics and other professionals discussed under the publicity section. Word of mouth in our rural area is one of Las Cumbres' most successful methods of recruitment. Families are asked if they know of someone who might be interested in being a provider. Often, in this geographic area, extended family members become official respite providers for families, enabling a more official relationship in the family receiving respite than a "favor" situation. For example, a mother or father with a disabled son or daughter might be reluctant to ask a relative to provide respite on the spur of the moment, or for extended periods of time as a favor, but might feel more free to ask when the relatives get paid.

In our more rural counties, our greatest success in recruitment is through contacts families already have. Providers may also know other persons who would be interested in providing respite – let them know when you are looking.

Train Providers

Recognizing the importance of training of providers, Las Cumbres also considered factors specific to the regions that we serve in developing our Provider Training model. In these rural regions, providers are often extended family members only wishing to provide respite for their own relative, and not wishing to receive training to provide respite to other clients. Some providers do not read or write and many are Spanish speaking providers who do not speak or understand English fluently. Our task was how to improve the quality of respite through training while still empowering families through supporting existing cultural and family structures which were working in the provision of respite and, without which, respite could not effectively exist. Because of strong cultural values and customs, many of these families would not use respite if this required going out-side the extended family circle. Many providers would drop out of the program if extensive and/or sophisticated training were required.

Las Cumbres therefore developed a three-tier Training Model. Providers are paid differential rates based on their level of training and/or experience.

Level I providers are family members (grandmothers, siblings, aunts/uncles) who, typically, have known the family for an extended period of time and are aware of the family's needs. The pay for Level I providers is $4.00 per hour. The family will typically waive our reference checks and the negotiable training requirements for these family members. The very minimum amount of training a related provider can receive is a two-hour, 1:1 session with the Respite Supervisor and eight hours of CPR and/or First Aid. In the session with the Respite Supervisor the following topics are covered:

Purpose of Respite
Incident Reporting

- Behavior Management
- Abuse and Neglect
- Death of a Client

Medications

Annual Meeting and/or Strength and Needs

Forms
- Provider/Parent Agreement
- Vouchers
- Agreement with LCLS

Level II providers meet all Level I requirements and either complete 40 hours of provider training or have a Bachelor's degree in a related field, or have three years' experience working with people who are developmentally disabled, or have 40 hours of documented specialized training. The pay for Level II providers is $4.75 per hour.

The 40-hour LCLS Level II training includes all the topics listed under Level I training and in addition consists of the following topics:

Introduction to Development Disabilities
Behavior Management/Positive Discipline
Rights
Home Safety
Normal/Special Development
Confidentiality
Parent Panel Presentation
Body Mechanics (transfers, positioning)
CPR/First Aid
Disabling Ourselves (an experiential exercise)
Rules and Forms
Death and Dying Issues
Teaching Self-Care Issues
Guardianship
Cultural Awareness
Infant Motor Development
Language/Speech of Infants
Nutrition
Sexuality
Communication Skills
Specialized Family Training

We have approximately 70 hours of trainings available (listed above). Seventeen hours are required and the provider selects topics that interest him/her to fulfill the 40 hours required. The format for these topics includes group process, videos, reading materials and individual work with the family the provider will be providing respite for. Las Cumbres sends to all Level II and III providers notices of in-service trainings that might benefit them in their provider role.

Level III providers meet and maintain all Level II requirements and provide respite to at least two LCLS respite families. The pay for Level III providers is $5.50 per hour.

The Specialized Family Training is given to the provider directly from the family around the individualized needs of the disabled family member. The purpose of this portion of training is to minimize disruption of family/client's routines and for the provider to be able to meet any specialized needs the client may have while respite is being provided. The family arranges the time for this training. Las Cumbres staff reviews with the family during their application for respite services what specialized needs their disabled family member may have and what a respite provider will need to know about usual routines, etc. The family may also request that the provider observe their family member in his/her classroom, day program, therapies, or other setting to get a better feel for the client and how to work with him/her. This observation time is counted as part of the two-hour family training. A provider who is not related to the family must complete Family-Based Training for each family for whom s(he) provides respite.

The two hours of agency-based training must also be received by the provider prior to providing respite for the first time. This is done either one to one or in small groups and led by the Respite Supervisor.

Only while developing the model, we offered stipends ($25.00 for a half day or training) to providers who attended Level II Training. Many providers who attended this Level II Training were family members of respite clients and unwilling to provide respite for clients other than extended family members. One major incentive for their attendance seemed to be the stipends we offered for coming. While these providers are valuable resources, the pool of trained providers from which we could draw was not

significantly increased as a result of training. From this experience came the decision that to achieve Level III status, providers must provide respite to more than one family. Extended family members or one-family providers may still attend any trainings offered.

In Las Cumbres' Model, all providers were strongly encouraged to attend their respite client's annual Interdisciplinary Team Meeting (IDT) (agency based) or EA&R meeting (if the respite client is in school) or their annual Plan of Care Meeting (if the client is Medicaid Waiver funded). Providers are paid at their usual hourly rate to attend these meetings. An average of about two hours per meeting could be estimated. Respite provider attendance at this (these) meeting(s) facilitates further training of the provider in client needs and also integrates respite services into other services which the client might be receiving.

Conclusion

The information above is a small sampling of rural-specific portions of the Las Cumbres "How To Start A Respite Program" manual. The entire manual is available for $30.00 from: Las Cumbres Learning Services, Inc., Respite Program, P.O. Box 1362, Espanola, NM 87532, (505) 753-4123.

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