Providing Respite at Conferences for Children with Special Needs

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Background

For many families with children, arranging to attend a two- or three-day conference can be difficult. Making arrangements for child care may be particularly challenging if the child(ren) has a developmental disability or emotional disturbance. Having respite available at conferences may make the difference between attending and not attending the conference for some families.

Conference organizers are beginning to recognize the importance of offering on-site respite programs which provide all parents and caregivers the opportunity to attend parent gatherings, conferences, and other special events. These events, ranging from parent-to-parent conferences to foster parent gatherings, provide important opportunities for parents and caregivers to share experiences, exchange information, and support each other.

Parents can usually arrange respite locally when meetings are regularly scheduled within the community, but events in distant locations complicate care options. By providing respite at a conference or special event, caregivers are able to attend educational sessions while still being able to check on their children and participate in caregiving. Respite programs which offer children a place to play, eat, and nap enhance the parent/caregivers' ability to relax and enjoy the conference.

Respite programs benefit children, providers, and the community. Children are able to form new friendships, participate in new activities, and learn to celebrate the diversity that exists among them and their peers. Providers, who may range from home health care workers to student volunteers to child care personnel, have the opportunity to gain experience working with children with special needs and will be exposed to inclusive child care. The program may also provide opportunities for community education through the visibility of the program in the hotel or event center in which it is housed and in local media spots.

Program Considerations

Is a respite program feasible?

If a respite program is to be provided as part of a larger conference or event, it is essential that it be considered in the beginning of the planning process. It is important to determine early on whether there is a need for a respite program (Are people coming in from out of town? Has there been a need for such care at similar events in the past?), whether the coordinating agency wants to coordinate respite, and whether agency support for the program will allow respite to be incorporated into the rest of the conference events. As one parent said following the respite program at a recent national conference, "Child care...should be a building block of the conference." If it cannot be, sponsoring agencies should consider offering stipends to families to obtain respite within their local communities. In this way, parents and caregivers are given financial assistance which may enable them to attend an out-of-town conference.

Logistical Concerns
Choosing a good location for an on-site respite program is essential and should, ideally, be a key criteria in choosing a site for the larger conference or event. When choosing a location for a respite program, there are a number of characteristics to consider. The location should:

- Be large enough to accommodate the children and providers comfortably and within recommended government guidelines, which vary by state
- Meet all local building, sanitation, and fire code requirements
- Be close to the conference activities so parents can come and go freely
- Be free of furniture other than work tables and chairs
- Have a room for infants and several rooms or spaces for older children to participate in different activities
- Be equipped with a sink, refrigerator, and microwave oven
- Have a check-in/check-out area equipped with a telephone
- Have bathroom facilities and an area to change and dispose of diapers
- Have a locked/limited access cabinet for medications
- Have a nearby break room for providers
- Be wheelchair accessible
- Be carpet-free or have a place suitable for snacks, arts and crafts, and other messy activities

**Risk Management**

When organizing any respite service, liability is always a fundamental concern. As with any child care program, it is most important to minimize risk to the children in care by providing adequate and experienced personnel, a safe environment, and back-up emergency planning.

Prevention is the best strategy for risk management. However, it is also important to have adequate protection should some unforeseeable event occur. The hotel or conference facility may have liability insurance that will cover the respite program. It is important to make sure hotel insurance does not exclude child care activities. In addition, if a home health agency is involved in providing care, it will likely carry some form of liability insurance. Finally, it is always advisable to have all parents and caregivers sign a waiver of responsibility.

**Hours**

There are advantages to parents if respite is provided during all sessions of the conference, but there is the potential that the quality of care could decrease if providers are strained by long hours. For example, it may be desirable to provide respite for daytime activities, and create evening conference activities that are family-centered and enjoyable for both children and adults.

**Food**

State and local laws may require food to be provided in child care settings. Respite coordinators must decide early in the planning process whether meals will be included in registration fees, or whether parents will need to bring meals with them.

If meals are to be provided by the respite program, parents should be sent menus (including ingredients) in advance with instructions to supply their own meals when those provided are not appropriate for their children. It may also be appropriate to require parents to be present at mealtimes, since many children require one-on-one assistance while eating.

In planning meals, it is important to consider food for respite providers. If the respite program is housed in a hotel, food costs may be prohibitively high, especially if providers are working on a volunteer basis. Consider providing snacks for all respite providers and meals for those who work long shifts.
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Staffing

A quality staff is the most important aspect of the respite program. Not surprisingly, recruiting and screening staff is one of the most time-consuming aspects of the planning process. Recruitment should begin as early as possible in order to guarantee a staff-to-child ratio of no more than one to three. Whether the ratio will need to be lower than that will depend on the specific needs of the children enrolled in the program, the skill level of workers, and the schedule.

The medical needs of children enrolled in the program will determine the number of certified workers, such as registered nurses and certified nursing assistants. While most respite can be provided by uncertified staff, it is important to have a nurse on duty to give medications (if they will be provided) and to attend to emergencies. Many home health agencies have a doctor on call. If this is not the case, it may be appropriate to recruit a doctor, perhaps even a conference participant, who is able to be on call during the event should any questions arise. In any case, a pre-planned emergency response procedure is essential.

Among the best sources for temporary respite workers are local parent-to-parent networks, respite programs, child care agencies, residential facilities, home health agencies, hospitals, colleges and universities, local spiritual organizations, and service agencies. Volunteers from the conference are also a great source of help but are only accessible if the respite program is fully incorporated into the conference planning. By coordinating efforts, for example, conference planners may require recipients of conference scholarships to donate time providing respite.

By maintaining a flexible approach to staffing, the cost can be minimized. Some volunteers may be interested in exchanging services for room and board. If notified early in the academic semester, professors may encourage their students to provide care as a partial fulfillment of course requirements. Home health agencies or respite agencies may be willing to give a discount on service rates if a minimum number of hours are contracted with them.

Registration

There are several stages of the registration process. The first, pre-conference publicity, consists largely of the forms and paperwork parents need to complete in order to register for the respite program. Establish a cutoff date for respite requests so that arrangements can be completed. Early publicity should clearly delineate the closing date for registration, meal arrangements at the respite program, policies concerning medications, and any requirements for parents, such as meeting with providers to explain the special needs of their children. Forms should be designed so that there will be clear and complete information on each child.

Once registrations are received, it is important to enter child-specific information into a database or file system that will be easily accessible during the respite program. Consider situations such as parents and children having different last names, which could make retrieving medical information during respite complicated. It may be advantageous to create a notebook of child-specific information and emergency procedures that can be used by any respite provider.

At the respite facility, it is important to have a comprehensive check-in/check-out system to insure a secure program. Suggested registration activities include

- Verifying enrollment, payment, meal status, and parent signatures on consent forms
- Verifying medical needs of the children, including instructions for medication
- Completing daily parent schedules and discussing the procedure to be used in case of emergency
- Assigning children to particular providers and holding parent meetings with those providers

Activities and Supplies

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From the moment the first child arrives to the minute the last child leaves, there should be a carefully planned schedule of activities. This schedule should take into consideration the different ages and developmental levels of
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children by providing a variety of activities in separate spaces. As indicated in the National Respite Guidelines, how children are divided into groups is important. They should not be grouped or labeled based on their disability and/or presenting diagnosis. Further, regardless of their ages, siblings should remain together or have access to one another if needed.

Suggested activities for respite include

- activity centers, supervised by respite providers, for arts and crafts, reading, and board games
- outdoor games, activities, and walks
- free play areas in which children are able to choose their own activities
- demonstrations and presentations by local musicians, clowns, martial arts experts, and dancers
- storytelling, singing, and puppet shows

The supplies needed for a respite program include everything from child gates and toys to rubber gloves for changing diapers. In order to decrease expenditures, significant effort should be put into finding donations for the respite program. Agencies and businesses to approach include

- local day care agencies, which may loan mats and toys, especially on weekends
- local businesses, which may donate anything from crayons to diapers
- a local "scrap exchange" that recycles industrial waste such as bags of foam, tubes, paper, and plastic pieces that are great for arts and crafts
- the hotel or conference center in which the respite program is located, especially for things like child gates and microwave ovens

Budget Issues

Respite is likely to be a far greater expense than anticipated. For example, respite for approximately seventy children required nearly ten percent of the budget for a conference of two thousand persons. Careful budgeting will be crucial if the safety and security of the children in care is to be ensured.

Costs

Personnel expenses are likely to make up the greatest percentage of costs. In order to elicit the interest of certified medical personnel in the program, salaries will need to be competitive. Other personnel costs can be reduced by enlisting volunteers and by using alternative funding arrangements, such as exchanging work for conference registration fees. Significant costs also include space rental, meals, and truck rental (if necessary to transport equipment and supplies).

Sources of Revenue

Registration fees will only cover a portion of the total respite budget. Other sources of revenue may include donations, sale of raffle tickets or other money raisers, and grants. Planning early for a conference-related respite program will allow more time to solicit funds from foundations, local and state agencies, local chapters of nonprofits, service organizations, professional organizations, and religious communities.

Evaluation

The importance of evaluating a conference-related respite program lies primarily in the ability it lends toward improving the program in progress and after its completion. Process evaluation, conducted during the respite program, may consist of informal interviews with parents, providers, and children, as well as an objective examination of the program, staff ratios, food, medical care, and other aspects of the program.

Outcome evaluation, conducted after the completion of the program, may be very important to the sponsoring organization if it will be hosting similar events in the future. Regardless of how extensive the survey is, the
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evaluation will be limited by the fact that it is likely to be difficult for parents to thoughtfully complete a form when they are picking up their children. It may be worthwhile to offer a small gift for completing a survey, or to give parents an evaluation form early in the event and repeatedly encourage them to note their positive and negative reactions to the respite program. Similarly, it may be difficult to get providers to complete evaluations unless their salary includes time to complete a survey or respond to a telephone interview.

Summary

Respite is an increasingly recognized need at conferences, parent gatherings, and other special events. By incorporating a respite program into a conference, a greater number of parents are able to attend, temporary respite providers gain experience working with children with special needs, and children have the opportunity to meet and play with each other. A quality program, however, depends on early planning and full incorporation into the larger event.

References


Resources

ARCH National Resource Center for Respite and Crisis Care Services, Chapel Hill Training-Outreach Program, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514, (800) 473-1727.

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