



Respite Care for Children with Developmental and/or Physical Disabilities A Parent's Perspective

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Introduction

Over the past fifteen years, parents have increasingly made the choice to keep their families together. Children with developmental or physical disabilities are no longer routinely placed in institutional care. As a result, the need for respite care (temporary child care) services has increased. Until recently, respite care has been either unavailable or unaffordable in many states. Personal care through the Title XIX Medicaid program and grants through the "Temporary Child Care for Children with Disabilities and Crisis Nurseries Act of 1986" (as amended), have enabled families to receive respite care for free, or at a reduced, reasonable cost. Forty-six states have some form of respite programs for children with disabilities (Knoll, et al., 1990). States and/or agencies that administer respite care projects have realized the need to provide other supports to families which are flexible and meet the need of the whole family, not just the person with a disability. Respite care services form the basis for many state family support programs.

Purpose

For years families caring for a child with medical or physical involvements have been reluctant to allow others to provide care for their child in their own home. The two most common reasons stated by parents are (1) concerns about the caregiver's training; and (2) feelings that no one can take care of their child as well as they can. Babysitters, in general, do not have the skills needed to provide the kind of support required to care for children with medical or physical disabilities. Respite care programs for families who have children with developmental and/or physical disabilities provide trained respite care providers for in-home or out-of-home "free" time (respite) for families.

Respite Programs

Highlighting the strengths and needs of the entire family, and not just the needs of the individual with a disability, has been a common thread in exemplary programs. Providing respite care for children with developmental or physical disabilities is not unlike providing respite for any other child. The respite provider needs to know the kinds of behaviors the child is likely to exhibit and be prepared to deal with any unusual needs of the child. This is true of any child. The behaviors and needs of children with disabilities may be more acute, but ascertaining them should be done in the same manner.

For the sake of those programs considering starting a respite program for families with children with developmental or physical disabilities, the following outline is designed to give an idea of the kinds of training and attitudes that are required to provide a quality program.

The Keys to a Successful Respite Program

- Help families feel comfortable and build trust. Spend enough time with the family to develop a level of trust that will allow a free flow of information.
- Provide a flexible structure. The agency should provide as many options as possible to meet the needs of the family, rather than fitting the family into the service available.
- Be family-focused. Empower families to make decisions for themselves. Discuss the strengths and needs of the whole family.
- Provide support. The administering agency and respite care providers must be available to field questions and concerns of parents that may be outside the realm of respite care. This might include linkage and referrals to other agencies or services.
- Allow families to train providers. Be sure to include families in the process of designing the child-specific portion of the provider's training.

Training

Because of the concern that families have about the specialized needs of their children, respite providers should be trained in first aid, CPR, disability awareness issues, specific medical conditions, behavior management, and individual "hands-on" training with the child for whom they will provide care. Many states and local programs have developed respite training manuals which are available to train local providers. (The ARCH Information Center has copies of many of these manuals.)

Building *trust* is probably the key ingredient in a successful respite program. Training respite workers is only one step in this process. Establishing close working relationships with the family and ensuring close supervision are other important parts of a successful program.

The Basics — These areas can be taught in a classroom setting using professional staff.

- CPR and First Aid
- Philosophy of family empowerment
- "How to speak DD" — introduction to developmental disability terminology
- "Don't Panic" — introduction to medical and environmental emergencies

The Details — These units should be presented in at least two different forums. The first, as a parent panel with discussion of some personal stories in each of the areas mentioned. The second, as a clinical approach to care, to include a speech therapist, an occupational therapist, and a physical therapist.

- Communication sensitivity — how to communicate with someone who does not talk very well, if at all
- Eating etiquette — good table manners (skills) when working with someone who needs assistance
- The comfort factor, or "how would you feel sitting in the same position all day?"

"Hands On" — This section should take place in the families' homes, and/or, the setting where the respite will actually occur.

- Meet the family and get to know the child
- Trainee asks parents about specific assistance he or she may need to provide
- Parents demonstrate how they assist their child to move, eat, and go to the bathroom
- Trainee works with the child on each of the specific skills parents request until parents are comfortable in how the trainee performs

Conclusion

Successful programs from around the country report that, once these key requirements are met, families will enthusiastically participate in respite services. Programs also report that this process takes some time. The trust that families need does not occur overnight. Allow a considerable amount of time for the program to be fully operational.

This can be one of the most rewarding programs to operate. Families and staff report many heartwarming tales of the benefits that respite has provided.

References

Knoll, J., et al. (1990). *Family Support Services in the United States: An End of Decade Status Report*. Cambridge, MA; Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140.

National Commission on Children (1991). *Beyond Rhetoric: a New American Agenda for Children and Families* (Summary). Washington DC; National Commission on children, 1111 18th Street, N.W., Suite 810, Washington, DC 20036.

Resources

Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, DC 20016. (202) 244-1801. The Association provides information and support on family-centered care for children with special health care needs.

Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140. (617) 876-0426. The Institute has compiled extensive information on respite and other family support services throughout the United States and has numerous documents available.

Family Support Bulletin, produced by United Cerebral Palsy Association, Community Services Division, 1522 K Street, N.W., Suite 1112, Washington, DC 20005. The Bulletin is free of charge and provides excellent information concerning new and upcoming programs nationwide.

Exceptional Parent Magazine, P.O. Box 3000, Dept. EP, Denville, NJ 07834. This is an excellent resource for families and professionals on a wide range of issues concerning children with disabilities.

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