



### *The purpose of this brochure*

is to help families who use or need home-based caregivers or other in-home service providers for their children with disabilities, chronic illnesses or other special needs.

### *It is natural to feel nervous*

or unsure about having someone you may not know come into your home to provide care or other services for your child with special needs.

### *To help you get a good start*

in your relationship with your child's home-based caregiver, here are some steps to take *before* services begin:

♥ Learn as much as you can about the scope or description of services to be provided, and about the agency that employs the person who will be your child's caregiver.

♥ Be open and honest about your expectations and discuss them with the agency management. Find out what the agency expects of you.

♥ Ask about your rights and options in case you are not satisfied with the care or services your child receives. You may want to ask the agency for a different caregiver or switch to another agency altogether.

### ♥ **Where to find more information:**

American Association for Homecare  
(phone: 703-836-6263) [www.aahomecare.org](http://www.aahomecare.org)

Family Caregiver Alliance/Nat'l Center on Caregiving  
(toll-free: 800-445-8106) [www.caregiver.org](http://www.caregiver.org)

National Association for Home Care  
(phone: 202-547-7424) [www.nahc.org](http://www.nahc.org)

PACER Center, Inc.  
Health Information and Advocacy Center  
(phone: 952-838-9000) [www.pacer.org](http://www.pacer.org)

Electronic Newsletters:  
[www.care-givers.com](http://www.care-givers.com) [www.caregiver.com](http://www.caregiver.com)

### ♥ **Who to contact in TENNESSEE:**

#### FAMILY VOICES *of Tennessee*

c/o Tennessee Disability Coalition  
480 Craighead Street, Suite 200  
Nashville, TN 37204  
Phone: 615-383-9442; ext. 13  
Toll-free: 1-888-643-7811  
Email: [familyvoices@tndisability.org](mailto:familyvoices@tndisability.org)  
[www.tndisability.org/familyvoices](http://www.tndisability.org/familyvoices)

#### FAMILY VOICES

3411 Candelaria N.E., Suite M  
Albuquerque, NM 87107  
Toll free: 1-888-835-5669  
Phone: 505-872-4774  
Fax: 505-872-4780  
Email: [kidshealth@familyvoices.org](mailto:kidshealth@familyvoices.org)  
[www.familyvoices.org](http://www.familyvoices.org)

# FAMILY VOICES

## Working with Caregivers in your Home

### *A Guide for Families of Children with Special Health Care Needs*



## Caregivers in your Home

There are different types of caregivers who can provide services to your child in your home. Some examples are nurses, nurse aides or technicians, personal attendants or assistants, therapists, teachers, and respite care providers or sitters.

Getting one or more of these home-based services depends upon factors such as: your child's diagnosis or disability, age, program eligibility or availability (waiting list), funding source, as well as rules and regulations specific to your state.

♥ You, the parent or guardian, should be able to interview and have final approval of any home-based caregiver for your child. You should decide if your child or other family members should participate in the interview.

## Family Rights

Families should expect the service agency that employs the caregiver to do the following:

♥ Recognize that you, the parent or guardian, are the main authority for decisions in the home.

♥ Provide fully qualified and trained personnel suitable to the job, including proof of background checks and references from previous employers.

♥ Follow through with agreed-upon arrangements for times when the regular caregiver is unavailable.

♥ Replace a caregiver who is not providing good care for your child.

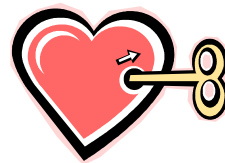
♥ Arrange for meetings with the agency supervisor, home care staff, and your family to review and resolve any problems.

♥ Maintain ongoing communication as agreed upon to discuss services and plan for future needs or changes.

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*"I treasure the loyalty, competence and reliability of my son's home health aide. She is a part of our family. I try to treat her with respect so she knows how valued and appreciated she is."*

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## Communication is Key

Keeping communication open and honest, but respectful, is the best way to maintain a positive relationship with your child's caregiver and with the agency that employs her or him.

## Family Responsibilities

Communicate your child's needs as specifically as you can and have all agreements in writing. If appropriate, talk with your child and the caregiver about what activities or situations may be decided by the child and which ones may not be negotiated.

Be clear in the beginning about any household rules, like "no smoking," but be sure your rules are reasonable. For instance, can you provide an ashcan for a caregiver who agrees only to smoke outdoors during breaks?

Families should uphold their end of any agreements and act respectfully toward caregivers. Examples:

♥ Always make sure the caregiver knows where you are, how to reach you, what time you plan to return home, and what to do in an emergency.

♥ You, and not the caregiver, are responsible for all other children or family members in the household.

*One final suggestion:* Talk with other families who use in-home caregivers and learn from their experiences.



**Acknowledgments:** Family Voices of TN; University of Illinois at Chicago Home Care Program (ph: 312-996-6380).