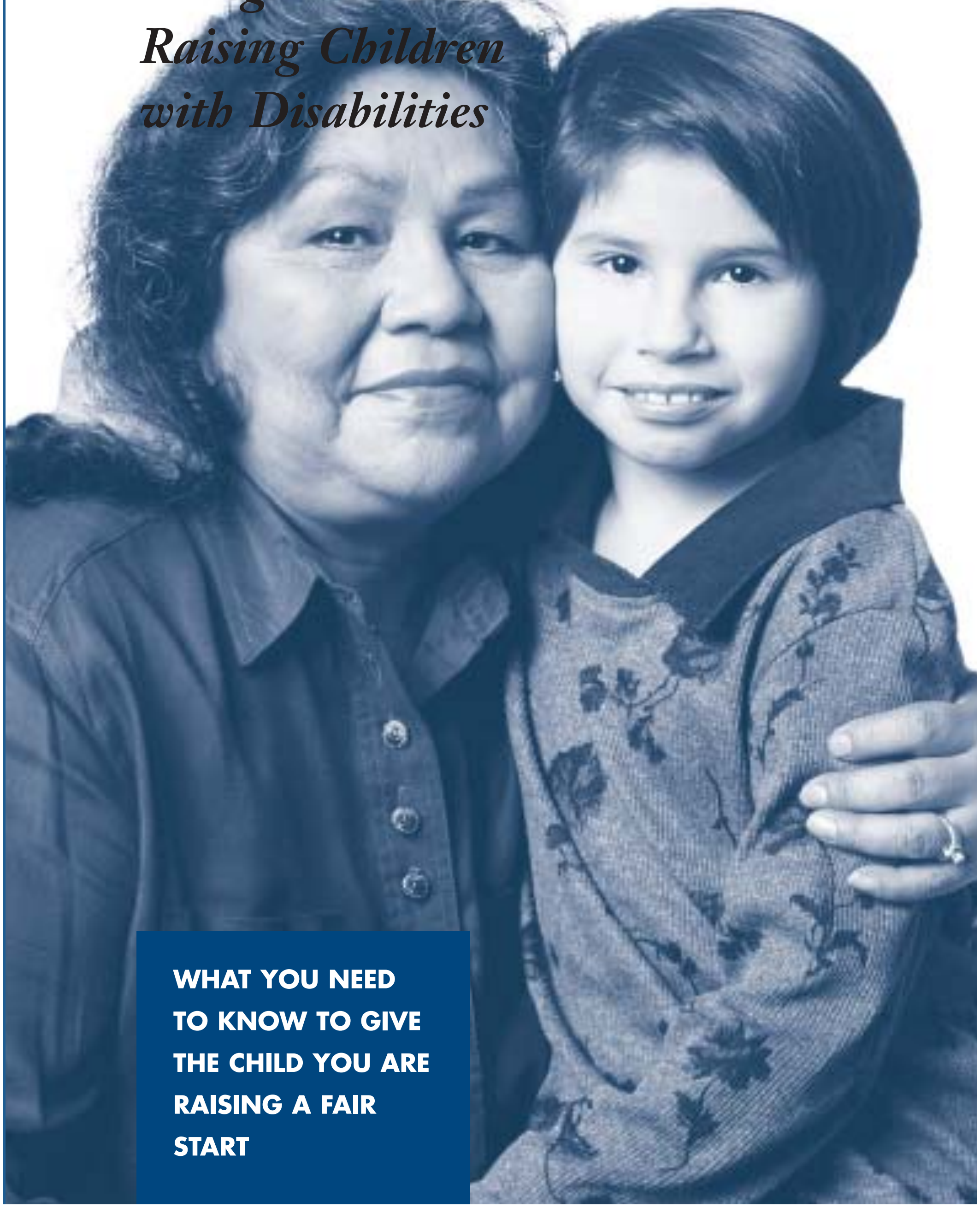
The Grandparent's and Other Relative Caregiver's Guide to Raising Children with Disabilities



WHAT YOU NEED TO KNOW TO GIVE THE CHILD YOU ARE RAISING A FAIR START

Join the Movement to Leave No Child Behind®!

Making sure that children with disabilities have access to the quality services and treatment they need is an important first step in giving them a fair start in life and the tools they need to realize their full potential. Understandably, quality services and treatment alone are not enough. Children also need quality health care, a good education, safe places to live and play, and income supports to help their families stay out of poverty.

The mission of the Children's Defense Fund (CDF) is to *Leave No Child Behind®* and to ensure every child a *Healthy Start*, a *Head Start*, a *Fair Start*, a *Safe Start*, and a *Moral Start* in life and successful passage to adulthood with the help of caring families and communities. Over the months and years ahead, CDF will be calling upon committed parents, grandparents, and other relative caregivers like you to help make this vision a reality for all American children. To get involved with other concerned individuals, children's advocacy organizations, and community and faith-based groups in the national *Movement to Leave No Child Behind®*, contact the Children's Defense Fund, 25 E Street, NW, Washington, DC 20001 or check CDF's Web site at www.childrensdefense.org.

CDF encourages you to copy and share this brochure with others.

November 2002

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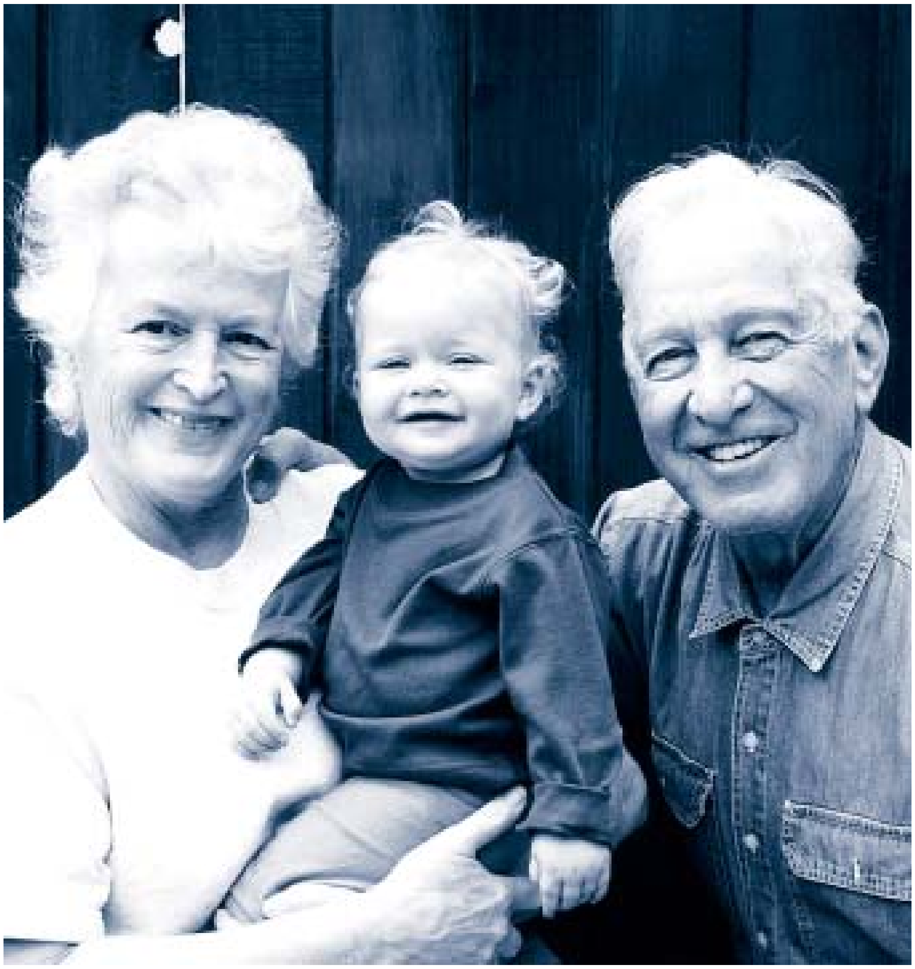

All Children Deserve a Fair Start in Life

Are you a grandparent or other relative raising another family member's child? You are not alone. Relatives are raising more than two million children whose parents cannot care for them. Many of these children may have disabilities because of various physical or mental health problems. Some of them may develop disabilities if they do not receive services to help them while they are young.

Federal, state, and local programs are available to help you raise children who have disabilities. This guide describes programs for children with disabilities that can help you in different ways. For example, you may want your grandchildren evaluated to learn more about their physical or mental health problems. You may want to find out if you qualify for a monthly cash payment to help take care of your grandchild. You may need to find out about early intervention services for your grandchildren who are under age 3. You may need to ask the local school to evaluate your grandchildren who are over age 3 to see if they qualify for special education and other services. You may need to find mental health services or programs that can give you a break from caring for your grandchildren. You may want to know how the child welfare agency can help or if you can get special adoption assistance payments if you adopt your grandchild. You also should learn about laws that protect the rights of children with disabilities.

The guide explains different federal programs. Each program has rules to identify which children and families can get help. Some rules are based on the kind of disability your grandchild has or how serious it is. Others are based on how much money your family has. Some rules are the same in all the states; others are different depending on where you live. This means that you must always check the program rules in your area.

The guide tells you where you can go to find more information to help your grandchild. Many of the resources are on the Internet. If you do not have a computer at home, go to your local public library. Most have computers you can use and someone who can show you how to use them.

Remember that it might take some time and effort to find and apply for some of the resources and programs in this guide. Sometimes that means calling more than one place for help. But don't give up. Your grandchildren are worth the effort!

We use the word "grandchildren" throughout this guide to refer to children you are raising in your home. The information is the same if you are caring for other related children such as nieces or nephews. We also sometimes refer to you and other grandparents and relatives caring for related children as kinship caregivers.

How Do I Get Help for My Grandchild with Disabilities?

I just started caring for my grandchild who has disabilities. Where should I go first to get help for her?

A good place to find help is the National Information Center for Children and Youth with Disabilities. They have fact sheets about services and programs in all the states. They have special staff to answer questions from parents and caregivers over the telephone. They also have a very useful Web site with state resource sheets listing contact names for important programs. To contact the National Information Center for Children and Youth with Disabilities, (NICHCY) see page 63.

The kind of help you can get depends on different things. Programs that serve children with disabilities likely will ask some questions about your grandchild and your family. They may ask questions such as: How old is your grandchild? What kind of disability does she have? How serious is it? How much money do you have?

They ask these questions because different programs often have different rules for various groups of children and families. The rules may look at certain things:

- **Your grandchild's age**. Children up to age 3 may get early intervention services. Early intervention services are designed to help children with special needs before their problems become more serious. Children who are ages 3 to 5 may qualify for Head

Start or other preschool programs. School-age children may qualify for special education and other services. Older children may get help as they leave high school and want to work or go to college.

- **The kind of disability**. There will be some documentation as to the nature of your grandchild's disability. For example, does she have a physical or a mental health problem or both? Will she develop a disability later if she does not get special help now?
- **The seriousness of your grandchild's disability**. Programs may define disability in different ways, sometimes based on the frequency, duration, and extent of the disability. For example, one program requires children to show what they can do compared to children of the same age who do not have disabilities.
- **How much money you have**. Some programs use federal income rules, but others use state rules. You must always check the income rules used in your state. If your income and/or earnings reach a certain level, you may no longer be eligible for help.
- **Where you live.** Where you live may affect what services your grandchild can get. Even within a state, each community may have different programs.

What benefits can my grandchild with disabilities get?

Children with disabilities can get free or low-cost help for many of their needs.

The types of help include:

- **Cash benefits.** The Social Security Administration may provide a monthly cash benefit through the Supplemental Security Income Program. See pages 20-28.
- **Early intervention services.** State or county early intervention programs may provide services for infants and toddlers. See pages 11-12.
- **Education.** Your grandchild may qualify for special education or related services in school. See pages 29-42.
- **Family support services.** Family support programs may provide services or even money to prevent children from needing residential care. See pages 16, 50-51.
- **Health insurance.** Health insurance is often available through Medicaid or the Children's Health Insurance Program. You can read more about these programs in CDF's health insurance guide for kinship care families described on pages 70-71.
- **Child care and early childhood education.** Local agencies and programs may offer child care, Early Head Start, or Head Start programs that serve children with disabilities. You can read more

about these programs in CDF's child care and early childhood education guide for kinship care families described on page 70.

- **Respite care.** Your community may have services to give you a break from your caregiving duties. See pages 50-51.
- **Foster care.** Your state or county child welfare office should have information about services to help children with disabilities who are in foster care. See page 53.
- **Adoption assistance.** Families may get special cash payments as well as health insurance and other supports if they adopt children with disabilities. See pages 54-57.

Remember that all programs have different rules and some may vary state by state. You must check the specific rules for each program in your state. Check your state Resource Sheet, which is available from the National Information Center for Children and Youth with Disabilities (NICHCY), to find the right agencies to call about services and programs. To learn how to get your state Resource Sheet, see page 63.

What laws protect the rights of children with disabilities?

Children who have disabilities are protected against discrimination under civil rights laws. These laws are written to make sure that people with disabilities are treated the same way as people who do not have disabilities. Major civil rights laws for children with disabilities include:

- **Rehabilitation Act** (often called "Section 504"). The law protects access for people with disabilities to schools, child care programs, hospitals, mental health centers, and other human service programs that get funds from the federal government.
- **Americans with Disabilities Act** (often called "ADA"). The law protects access for people with disabilities to programs provided by state and local governments. It also protects access for them to transportation and to places of "public accommodation" such as nonprofit service programs.
- **Individuals with Disabilities Education Act** (often called "IDEA"). The law guarantees special education and related services for eligible students with disabilities from ages 3 to 21.

There also are other state and local anti-discrimination laws that are intended to protect persons with disabilities.

The Office for Civil Rights in both the U.S. Department of Health and Human Services and the U.S. Department of Education help to enforce these laws. See pages 65-66 for more information about how to contact them. You can also learn more about the ADA by calling the ADA Information Line at 1-800-514-0301 or 1-800-514-0383 (TDD). If you have a computer, go to http://www.usdoj.gov and click on "Disabilities." Your local Office of Human Rights or the State Attorney General's Office will know about state or local anti-discrimination laws.

How Do I Get My Grandchild Evaluated?

It has been a long time since I raised a child and I've forgotten what is normal at different ages. Where can I get information?

The U.S. Department of Health and Human Services Maternal and Child Health Bureau has published *Bright Futures: Pocket Guide*, which can help you. The guide describes activities that are normal for different age groups of children from birth through age 21. You can get *Bright Futures: Pocket Guide* on the Internet at www.brightfutures.org, on the Family Voices Web site described on page 60 of this guide, or by calling the toll-free number 1-888-434-4625 at the National Maternal and Child Health Clearinghouse to get a free copy.

A friend told me that she thinks my grandchild is slow for her age. How can I get her tested?

You should first talk with your grandchild's doctor or other health care providers about the problems you notice. Describe her difficulties so the doctor can evaluate if there are medical or developmental reasons why she does not act like other children of the same age. If your grandchild is in preschool or school, talk with her teacher about your concerns.

Some public agencies are required by law to test children to find out if they have any developmental delays or disabilities. Where you go to get your child tested will depend on the age of your grandchild.

- **If your grandchild is under age 3,** call the state early intervention coordinator. All states are required to have an early intervention coordinator. You can get this person's name by calling the National Information Center for Children and Youth with Disabilities, Easter Seals, or by checking the Web site for the National Early Childhood Technical Assistance Center. These toll-free telephone numbers and Web sites are listed on pages 59-60, 62, and 63. You also can read more about early intervention programs in CDF's child care and early childhood education guide for kinship caregivers described on page 70.

- **If your grandchild is between ages 3 to 5,** you can ask her neighborhood school to evaluate her. Federal law requires state education agencies to identify, locate, and evaluate all children with disabilities who need special education and "related services" starting at age 3. The program for children ages 3 to 5 is often called "Section 619." All states are required to have a Section 619 coordinator. You can get this person's name by calling the National Information Center for Children and Youth with Disabilities, Easter Seals, or by checking the Web site for the National Early

Childhood Technical Assistance Center. These toll-free telephone numbers and Web sites are listed on pages 59-60, 62, and 63 of this guide. You can also read more about the program for children ages 3 to 5 in CDF's child care and early childhood education guide for kinship caregivers described on page 70.

- **If your grandchild is already in elementary school or a higher grade,** you can ask her school to evaluate her. Federal law requires state education agencies to identify, locate, and evaluate all children with disabilities who need special education and "related services" from ages 3 to 21. Tell your granddaughter's school principal or teacher that you want her evaluated for special education.

There may also be private, nonprofit organizations in your community that can help you find a place that will test your grandchild. Call the toll-free number for Easter Seals on page 59 and ask them to help you find the right program.

My daughter used drugs while she was pregnant. Where can I go to find out if her drug use hurt my grandchild?

The first thing to do is to get your grandchild evaluated. Talk with your grandchild's doctor or health care provider. Ask if he or she can tell you if there is anything wrong with your grandchild. You need to find out more about her condition to see if she qualifies for early intervention services. Early intervention services provide evaluation, treatment, and support for very young children and their families. Providing help early should prevent problems from getting worse and avoid more costly treatment later. Each state has an agency that coordinates early intervention services. Some states charge fees for these services based on the income of parents or caregivers.

Call your state's early intervention coordinator to discuss your grandchild. Get the coordinator's name by calling the National Information Center for Children and Youth with Disabilities, Easter Seals, or by checking the Web site for the National Early Childhood Technical Assistance Center. See pages 59-60, 62, and 63 for the toll-free telephone numbers and Web sites for these groups.

My 2-year-old grandchild has physical and mental health problems. Where can I go for help?

You need to find out if your grandchild qualifies for early intervention services. These services can identify his problems and provide the right treatment. Your grandchild may need occupational and physical therapy, hearing or vision services, or mental health services. Early intervention programs can also give you special training to help your grandchild. A "service coordinator" will help you keep track of your grandson's different services and appointments.

Each state's early intervention program has different eligibility rules. Generally, eligible children get early intervention services until they reach age 3. Some states serve infants and toddlers who have disabilities. Others serve children who have developmental delays. Other states also serve infants and toddlers who are "at risk" for developmental delays.

If your grandchild qualifies for early intervention services, he will get an Individualized Family Service Plan (IFSP). The IFSP describes the services that can help him and his caregivers. As his caregiver, you will develop the IFSP with a group of people who know what services can help your grandson. You do not need legal custody or guardianship of your grandchild to help put together his IFSP.

To find out about early intervention services in your area, call your state's early intervention coordinator. You can get the coordinator's name by calling the National Information Center for Children and Youth with Disabilities, Easter Seals, or by checking the Web site for the National Early Childhood Technical Assistance Center. See pages 59-60, 62, and 63 for the toll-free telephone numbers and Web sites for these groups.

Someone in my support group says my grandchild is mentally retarded. The doctor says she has a developmental disability. Is there a difference?

Yes. There are different legal definitions for "mental retardation" and "developmental disability."

- Generally, the term "mental retardation" includes children who have an IQ (intelligence quotient) below 70. (There is a test to measure intelligence that gives a child an IQ score.) These individuals have significantly limited daily living skills and have the condition before they reach age 18.

- The term "developmental disability" generally includes a broader group of children. It includes children who have a mental or physical disability that appears before age 22 and that will probably continue indefinitely. These children also have significantly limited daily living skills, and they will need services for a long time or their entire life.

It is important to know how your state defines these two conditions. Some states use the two terms to mean the same thing. The definition of your grandchild's disability may affect what services and treatment she can receive. Call your state's Mental Retardation/Developmental Disability agency or the Developmental Disability Council to find out what definitions your state uses and what services and treatments your grandchild can receive. See pages 59 and 62 about how to find these groups.

What Help Can I Get Paying for Health Care?

Will my health insurance cover the cost of my grandchild's medical treatment?

If you or other family members are privately insured through an employer, you should check first to see if your health insurance policy even covers the grandchild you are raising. You may find that you can only get additional private health coverage for your grandchild if you adopt her. If your grandchild is eligible, ask about the specific services and treatments the policy covers for children with disabilities.

If your grandchild is not eligible under your health insurance policy, you should check her eligibility for Medicaid or the Children's Health Insurance Program (CHIP). To find out about Medicaid and CHIP programs in your state, call 1-877-KIDS-NOW.

What government assistance will help pay for my grandchild's medical treatment?

Most children raised by grandparents are eligible for free or low-cost health insurance from the government through Medicaid or the Children's Health Insurance Program (CHIP). Medicaid covers the cost of all "medically necessary" services that are found in the child's preventive health check-up. This includes care for special physical and mental health needs.

If your grandchild's income is too high to qualify for Medicaid, the child may still qualify for CHIP. Each state decides which medical services for children with disabilities the CHIP program will cover. Some states cover more services than others.

In some states, the Medicaid and CHIP programs are separate. Other states combine them into one health insurance program. Sometimes, states have different names for their Medicaid and CHIP programs. When the children's health insurance programs are combined, they also cover the cost of most services for children with special needs. To find out about Medicaid and CHIP programs in your state, call 1-877-KIDS-NOW.

CDF's guide for kinship caregivers on health insurance described on page 71 also provides useful information on Medicaid and CHIP.

Where Do I Go If My Grandchild Needs Additional Special Help?

My grandchild uses a wheelchair. Can someone help pay for a ramp into my house or a lift for my van?

It depends. If your granddaughter gets Medicaid, you should first check with your state Medicaid program. Call 1-877-KIDS-NOW to get automatically connected to your state's Medicaid information hotline. Ask if the program pays for this kind of service.

Some states also have special "family support" funds to help families who have children with disabilities. Your state may pay for a ramp into your house or for a van lift. The rules and services vary from state to state. Find out what family support programs your state has by calling your state's Mental Retardation/Developmental Disabilities agency or Developmental Disabilities Council. See pages 59 and 62 for information on how to reach these groups.

I need help getting my grandchild with disabilities to a child care program. Is any transportation help available?

It depends. Your state may pay for transportation and other special services for children with disabilities. Each state selects the groups of adults and children that it will help and what it will provide them. Ask your state's Mental Retardation/Developmental Disabilities agency or Developmental Disabilities Council about what services your state has for children with disabilities. See pages 59 and 62 for information on how to contact these groups.

You may also be able to get transportation as part of early intervention (ages 0 to 3) or special education (ages 3 to 21) programs if your grandchild is eligible for them. Each child who qualifies for these programs should have a document describing the services he will get. Younger children have an Individualized Family Service Plan (IFSP). Older children have an Individualized Education Program (IEP).

If you need transportation to get your grandchild to child care, you need to ask for it as part of your grandchild's IFSP or IEP. Once it is in the IFSP or IEP you should also get help paying for it. You do not need legal custody or guardianship of your grandchild to ask for these services. You can read more about how to get help under the early intervention or special education programs on pages 29-42.

I have trouble lifting my grandchild to bathe and dress her. Can I get someone to come and help me with these activities?

It depends. The Medicaid program lets states provide in-home services for children. This is done to help children with disabilities live at home rather than in a hospital or other institution. Some states provide these services through "home and community-based waivers." Although Medicaid pays for the services, states decide who is eligible and how many families will get services. The eligible children and families get standard Medicaid benefits plus additional services and supports. States offer different in-home services. They may include the respite care or personal care services that your grandchild needs.

To find out what in-home services your state offers, call 1-877-KIDS-NOW to get connected to your state Medicaid agency. Ask what groups of children qualify for home and community-based waivers and if your grandchild can get personal care services.

Someone told me to call the public health department for help with my grandchild who has a disability. What can this department do for me?

All states get federal funds for Maternal and Child Health programs that are run by their health departments, sometimes they are called "Title V" (five) programs. They serve mothers and children, especially those who have little money or who have trouble getting health care.

States must use at least 30 percent of their Maternal and Child Health funds to provide community-based services for "children with special health care needs." Each state defines what group of children it will serve and what services it will provide. States may charge for services based on family income. Many states serve more children with physical health care needs than with mental health needs.

Check to see if your grandchild is eligible for the Maternal and Child Health/Title V program in your state. Ask whether it serves children living with grandparent caregivers. Ask about the types of help available and how you can apply. You can get the name of your state's Title V director from the NICHCY state resource sheets described on page 63. Each Title V program also has a contact for the Children with Special Health Care Needs Program. If you have a computer, go to http://www.mchb.hrsa.gov/programs/blockgrant/ directors.htm for a list of the state directors.

What Help Can My Grandchild Get from the Supplemental Security Income (SSI) Program for Children with Disabilities?

What is the Supplemental Security Income (SSI) Program?

SSI provides cash benefits to eligible adults and children with serious disabilities. The federal Social Security Administration runs the program, but there are local Social Security offices. In 2002, children who qualify for SSI may get up to $545 each month, but some states pay more.

In most states, children who get SSI also qualify for free medical care through Medicaid. They may also qualify for food stamps. You can read more about Medicaid and food stamps in CDF's guides for kinship caregivers described on pages 70-71.

As children get older, special SSI rules may allow them to work and still get cash benefits and Medicaid. They may also get long-term care services through Medicaid.

How do I know if my grandchild's disability makes him eligible for SSI?

Children with serious disabilities who need financial help are entitled to SSI benefits. You can learn if your grandchild qualifies by calling or visiting your local Social Security office to apply. SSI has both financial and disability eligibility rules.

The financial eligibility rules require that only your grandchild's income and resources be counted if he lives with you or other relatives who are not parents or stepparents. Income means money from child support, most public benefits, and work. Resources mean savings accounts or other things an applicant owns like houses or cars. Some resources are not counted, including the family home and a car needed by a family member to get medical care. The amount of money your grandchild has in his name affects whether he qualifies and how much cash he can get each month.

The disability rules to qualify for SSI require children to have very serious physical and/or mental disabilities. Generally to qualify, your grandchild must be unable to do the same things as other children his age who do not have disabilities. For example, can your grandchild dress himself like other children the same age can? Help you around the house with chores as others his age can? Play the same kinds of games as others his age can?

Where do I apply for SSI for my grandchild?

You must make an appointment to talk with someone at the Social Security Administration. You can go to a local office or speak with someone over the telephone. Call the toll-free number at 1-800-772-1213 Monday through Friday between 7:00 a.m. and 7:00 p.m. (Eastern time). If you are deaf or hard-of-hearing and need a TTY, call 1-800-325-0778 during the same hours.

These numbers are very busy early in the week and early in the month so it is best to call at other times. If you can, have your child's Social Security number handy whenever you call. When you talk with someone, ask if your state has an extra SSI payment on top of the federal benefit. You also need to ask if your grandchild automatically qualifies for Medicaid if he is eligible for SSI or if he needs to apply separately for Medicaid.

Is my income or the income of others in my household counted in deciding if my grandchild qualifies for SSI?

No, unless the child's parent or stepparent lives with you. When children under age 18 apply for SSI, the Social Security offiace counts the income and resources of the parents or stepparents who live with them. However, if a child lives with a grandparent or relatives other than parents, only the child's income and resources are counted.

The Social Security office does not count your income and resources as the grandparent. However, it does count the food and shelter that you give your grandchild as part of his "living arrangement." As a result, the Social Security office may reduce your grandchild's federal cash benefits by up to one-third because of the food and shelter you provide in your home.

The living arrangement issue is more complicated in states that pay more than the federal benefit. If your grandchild already gets SSI, you should consult a lawyer about how the Social Security office decides your grandchild's monthly benefit. To find free or low-cost legal help, call the bar association in your area. If you have a computer, you can check http://www.lsc.gov/gla/directory.html for a listing of some legal aid offices.

If my grandchild returns to live with his mother, can he still get SSI?

It depends on his mother's income. When children under age 18 apply for SSI, the Social Security office counts the income and resources of their parents or stepparents. So if his mother's income is too high, then your grandchild may no longer qualify.

My son was getting SSI for my grandchild before he died. Can I still get SSI for her?

Yes. The Social Security Administration names someone as "representative payee" to receive SSI on behalf of children under age 18 and adults who cannot care for themselves. Your son was probably the representative payee. This means that he was responsible for making sure the SSI was being used to take care of your grandchild. Call your local Social Security office as soon as possible to report your son's death. When you call, say that you are now caring for your grandchild and want to become her representative payee.

Do I need to go to court to get legal custody or guardianship before I can get SSI for my grandchild?

No. You do not need to have formal legal custody or guardianship to be your grandchild's representative payee and get his benefit checks. A representative payee must account for how he or she spends the monthly cash benefit to help care for the child.

Can my grandchild get SSI if she is not a citizen?

It depends on her immigration status and when she entered the United States. Children under age 18 who were legally living in the country on or before August 22, 1996 may qualify for SSI. If your grandchild came here after that date, she will have a harder time getting SSI.

If your grandchild is not a citizen, the rules are very complicated. You should first get more information before you call your local Social Security office. To find free or low-cost legal help, call the bar association in your area. If you have a computer, you can check http://www.lsc.gov/gla/directory.html for a listing of some legal aid offices.

My grandchild was turned down for SSI, but I think he qualifies. What can I do?

If the Social Security Administration says your grandchild is not eligible for SSI, don't give up. You have the right to question why Social Security says he does not qualify. This is called making an appeal. The appeals process has several steps. If you are not successful at any step, then you have 60 days to appeal to the next one.

The first step is called reconsideration. Go to your local Social Security office and fill out a form to request this review. If you cannot get to the office, write or call to request the form. You must return the completed reconsideration form to the Social Security Administration within 60 days after your grandchild is denied. You can provide any new information you have about your grandchild's condition when you apply for reconsideration. Often the Social Security Administration denies appeals at this step, but you are more likely to succeed at the next one.

The second step is a hearing before an Administrative Law Judge (ALJ). This is your only chance to meet with the person who will decide if your grandchild meets the disability requirements for SSI. It is worth having a hearing because the judges reverse more than half of all denials. It is a good idea to have a lawyer or other advocate help prepare your grandchild's case.

To find free or low-cost legal help, call the bar association in your area. If you have a computer, you can check http://www.lsc.gov/gla/directory. html for a listing of some legal aid offices. There are also private attorneys who may be able to help you. Call the National Organization of Social Security Claimants' Representatives at its toll-free number 1-800-431-2804 and ask if they have members in your state who take children's SSI cases. Some of them may help you for free, but others may charge a fee so be sure to ask.

If the judge denies your grandchild's appeal, there are still two more steps in the appeals process. It is essential to have a lawyer help you with the last two steps. The first of these is a review by the Appeals Council. The last step is a review by a federal court of the Appeals Council decision. See the information in the paragraph above about how to find free or low-cost legal help.

My teen-aged grandchild received SSI, but lost her benefits. Can she still get Medicaid?

It depends on why she no longer qualifies for SSI. A large number of children lost SSI benefits in 1996 when the eligibility rules changed. Many children no longer qualified as "disabled" under new rules. However, the law says this group of children can still get Medicaid. It is illegal for states to stop Medicaid for these children. If your grandchild lost her SSI in 1996 and lost her Medicaid at the same time, she should re-apply right away.

If your grandchild lost SSI for a reason other than her disability then she does not have this legal protection. However, the state Medicaid agency must decide if she qualifies for Medicaid in any other way before stopping her coverage. Because many children raised by their grandparents already qualify for Medicaid, your grandchild is probably covered.

If your grandchild has lost Medicaid, you always have the right to appeal. To find free or low-cost legal help, call the bar association in your area. If you have a computer, you can check http://www.lsc.gov/ gla/directory.html for a listing of some legal aid offices.

If I set aside money for my grandchild who has a disability, can she still get SSI and Medicaid?

Yes. There are ways for grandparents to put aside money for the future needs of their grandchildren with disabilities while the children still receive public benefits. However, it is very important that you set aside the money right away. For example, if your grandchild gets an inheritance from you, this may cause her to lose her SSI or Medicaid. To avoid this loss of benefits, you can set up a trust that follows special rules.

A trust is a protected account that you can set up to meet your grandchild's future financial needs without risking the loss of the government benefits she now gets. There are different kinds of trusts. Some you set up while you are alive and others you can set up as part of your will.

If you have the money to set up a trust, you must know what options your state allows. Setting up trusts is very complicated. It is best for families to work with a lawyer and a financial planner who know about disabilities. These people can help you select and set up a trust that works best in your state. It is very important that your trust follows both state and federal rules for the SSI and Medicaid programs.

The Arc of the United States has information about how to set up a trust for a child with disabilities. If you have a computer, go to their Web site at www.thearc.org, click on “Information” and then look at the “List of Topics” and scroll down to “Future Planning/Guardianships/Trusts.” You will find several fact sheets about future planning and trusts. You can also call your local chapter of The Arc, which may have names of lawyers who can help you. See The Arc’s Web site at http://www.thearc.org/futureplanning.html for a list of local chapters.

How Do I Make Sure My Grandchild Gets the Special Education and Related Services He Needs?

My grandchild's teacher says he needs special education. What do I do now?

A federal law, the Individuals with Disabilities Education Act (IDEA), requires eligible children with disabilities to get special services and help in school. These services are called "special education" and "related services." Children with disabilities who qualify have the right to get a "free and appropriate public education" (often called FAPE) and related services.

State education agencies must identify, locate, and evaluate all children ages 3 to 21 with disabilities who need special education and related services. State and local education agencies may also serve children ages 3 to 9 who have developmental delays. Each state defines which children with developmental delays they will serve.

To qualify for special education and related services, your grandchild must have one or more specific disabilities that negatively affect her ability to perform in school. These include: mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbances, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities.

If you think your grandchild needs special education, ask the school to evaluate her. Begin by calling your grandchild's teacher or the school principal. If the school agrees to evaluate her, it must do so promptly and for free. The school does not have to evaluate her just because you ask. But if it doesn't, it must explain in writing why it refuses to evaluate her.

A teacher may also request an evaluation if the teacher thinks a child needs special education. You must agree to the evaluation. However, if you refuse the school may still legally be able to evaluate her.

If your grandchild's school wants to evaluate her and you do not want her evaluated, contact your state's Parent Training and Information Center right away for advice about what to do. You should also call this center if you want an evaluation and cannot get it. To find your state Parent Training and Information Center, see page 66.

Will I have to pay extra for special education?

No. Students who are at least 3 years old and their families get public special education programs and related services for free. Some states charge fees for early intervention services for children younger than 3 years old based on their family income.

Do I need to get legal custody or guardianship before I can get my grandchild tested for special education?

No. You do not need legal custody or guardianship to ask the school to test your grandchild for special education or to participate in meetings related to her special education needs. The special education law allows someone to act in place of a parent, such as a grandparent.

I was told that if my grandchild's special education evaluation found that he was qualified, he would get an "IEP." What is an "IEP"?

Federal law guarantees eligible students with disabilities the right to a "free and appropriate public education." The services the student will get are described in a document called an "Individualized Education Plan" (IEP). The IEP describes the special educational program that your grandchild needs to participate in regular classroom activities designed for his age. It also describes special services that he needs to join other students in regular school activities.

Federal law requires a team of people to develop your grandchild's IEP. The team must include one or both of the child's parents or an adult acting in place of his parent(s). The team must also include at least one regular and one special education teacher who know your grandchild and someone else from his school. The school district will send someone who knows how to design educational programs for children with disabilities.

In addition, you or the school can invite other people who know what your grandchild needs to the IEP meeting. For example, you may invite your grandchild's speech therapist to explain the kind of assistance he needs in school. You may ask a friend, your clergy, or another advocate to come with you to the meeting.

The team decides if the child qualifies for special education and chooses the appropriate services and supports. Every year, the IEP team reviews the child's educational program to see if the goals for the child are being reached and makes changes if they are needed. The IEP team also decides if any changes are needed in what is called the child's educational "placement."

The IEP sets annual goals that are reasonable for each child and reflect his strengths and needs. The goals describe what the child should achieve during the school year. The IEP also describes specific support services that the school district will provide. Your grandchild should participate in the regular curriculum as much as possible. The goal is to have your grandchild learn the same things as other children who are the same age and who do not have disabilities. The IEP also lists services to help your grandchild participate in school activities outside of the classroom. You should be sure to ask your grandchild's IEP team about assistive technology, such as special computers or learning devices, to help him in the classroom and other school activities.

Can someone help me get a good IEP for my grandchild?

As a caregiver, you have the right to participate in the team meeting that develops your grandchild's IEP. You also have the right to meet with the IEP team when any changes are proposed for your grandchild's educational placement. The school must make every effort to schedule the meeting at a convenient time for you. If you cannot attend in person, the school must help you participate by telephone.

You should talk with staff at your state's Parent Training and Information Center before you go to your grandchild's IEP. They can review what the law requires in an IEP. They can help you prepare questions for the meeting. Depending on where you live, they also may send someone with you to your grandchild's IEP meeting. To find your state's Parent Training and Information Center, see page 66.

My grandchild has been in a special education class, but he is not improving. What can I do to get him more help?

If you think that your grandchild is not getting enough special help, ask for a meeting of his IEP team. While the law requires an IEP review once a year, you can ask for one at any time you think he needs it. You can attend all IEP meetings as your grandchild's acting parent. The IEP team and you will review your grandchild's progress towards his goals. If you all believe that he is not moving towards his goals, you can change his IEP to get him more help.

Your grandchild also may need more related services. These support services are part of a child's IEP along with his classroom program. Related services may include speech-language therapy, mental health services, physical and occupational therapy, or recreation. At the IEP meeting, ask to review your grandchild's related services. Additional support services like these may help him benefit from his classroom work.

My twin grandchildren have received special education since third grade and are now ready for junior high, but their teacher said there is no special program for them. What can I do?

The law requires states to provide special education and related services to all eligible children with disabilities ages 3 to 21. Schools at all levels must make every effort to teach students with disabilities in regular classrooms with students who do not have disabilities. Unless the IEPs for your grandchildren require another arrangement, they must be educated in the school they would attend if they did not have disabilities.

It is probably a good idea to get your grandchildren evaluated to ensure that they are still eligible for special education and related services. If they are, then ask their IEP teams to meet to discuss what the school district will do to ensure that they get an appropriate junior high school education.

By law, public schools that cannot meet the needs of their special education students may put them in a private school at no cost to you. The school district may decide to do this for your grandchildren. You and your grandchildren still have all the same legal rights as you would have if they were receiving special education in public school.

My grandchild is 15 and gets special education. Is the school required to do anything to help him get ready to leave high school?

Yes. There is now more attention on transition planning at an earlier age because so many students with disabilities drop out of school before they complete high school.

Federal law requires schools to provide two different types of transition statements as part of a child's IEP. Beginning at age 14, a child's IEP must include a statement of the different courses of study that will help the child prepare for what he will do after high school. It must be updated every year. This is intended to help him select classes that will motivate him and help him finish school.

Beginning at age 16 or younger, schools must also provide a statement of needed transition services that will help children with disabilities move to the next phase of their life. This can help your grandchild plan a realistic job goal, consider college, or learn how to live independently. Transition services include classroom instruction, vocational evaluation, structured work experiences, and help with adult living skills.

Planning transition services often requires help from non-school agencies. For example, it may be appropriate for a representative from the vocational rehabilitation agency to attend your grandchild's IEP meetings. All participating agencies must discuss their responsibilities to pay for the transition services that your grandchild needs. It is important that these different responsibilities be spelled out in your grandchild's IEP.

The school said it suspended my grandchild who has emotional disabilities because of his violent outbursts. He didn't have a weapon and didn't hurt anyone. Can they do that?

Yes. Schools have the authority to suspend or expel children with disabilities in certain situations. But schools must follow special rules before removing students with disabilities from school.

First, your grandchild's IEP team must review the situation. They must make sure that his IEP and placement are appropriate. They must also make sure that he is receiving the special education, related services, and behavioral help that his IEP requires. In addition, the IEP team must consider if your grandchild's emotional disabilities limit his ability to control his behavior and to understand its consequences.

Federal law has special rules for when and for how long schools can remove children with disabilities. Students with disabilities should be disciplined in the same ways as students without disabilities. Generally, students with disabilities must continue to get the educational services described in their IEPs.

The rules regarding how schools can discipline students with disabilities are very complicated. If your grandchild is suspended or expelled from school, call your state's Parent Training and Information Center immediately. They can review the situation so you know your grandchild's legal rights. To find this group, see page 66.

What can I do if I don't like the school's special education plan for my grandchild?

There are laws that protect the rights of students with disabilities when decisions are made about their education. Schools must give parents and full-time caregivers a copy of these rules. They are called "procedural safeguards." Procedural safeguards protect students and their families so that they know their educational rights. The safeguards include requirements for prior notice, due process hearing, mediation, and attorneys' fees.

"Prior notice" means that schools must tell parents and caregivers when they are thinking about making any change that may affect their child's educational services. If parents or caregivers do not agree with schools about what services are appropriate, they may ask for a "due process hearing." This hearing is a meeting between parents or caregivers and the school district where each presents their opinions. A hearing officer listens to each of them and decides what should be done based on the law.

States also must make mediation available if parents or caregivers do not want a hearing. Mediation is a way to try to settle disagreements between two groups of people. A qualified and impartial person, called a mediator, listens to each group in the dispute. Then the mediator tries to negotiate a solution to avoid going to court. Parents and caregivers often find that a mediator can help them and the school district agree about what to do for the child. If parents or caregivers are not happy with the mediation, then they can file a lawsuit in court to ask for the educational services that they want. If they sue and win, the judge may order the school district to pay for the attorneys' fees.

You can get more information about the rights of parents and caregivers under IDEA from the Family & Advocates Partnership for Education described on page 60. It has information in both English and Spanish. You can also call the state's Protection & Advocacy Agency or your state's Parent Training and Information Center for help. See pages 66 and 67 for information about how to find these groups.

My grandchild's teacher says I should have him tested for special education, but I don't want his friends to make fun of him. What can I do?

First you should find out more about why the teacher thinks that special education will help your grandchild. You may meet with the teacher to hear more about what special education can do for him. If you decide to have the school evaluate your grandchild, read more about the evaluation process on page 29.

You can learn a lot about special education by talking with other parents and grandparents whose children get these services. Most communities have parent support group meetings where you can meet parents and other grandparents. You can also get in touch with different groups to ask for their newsletters. Call the National Information Center for Children and Youth with Disabilities to get the fact sheet about your state that lists parent groups. The Center's contact information is on page 63.

The sad truth is that children often make fun of each other whether they are different or not. While there is no way to stop the teasing, it is important that you tell your grandchild how special he is—regardless of what anyone else may say.

If your grandchild qualifies for special education, then part of your job is to help him understand how it will help him succeed in school. Another part of your job is to make sure that your grandchild's special education program educates him, as much as possible, with students who do not have disabilities and who are the same age. The purpose of the special education law is to make sure that students with disabilities, whenever possible, get the help they need to participate in regular classrooms. Most children who qualify for special education and related services should be able to participate to some degree in regular classrooms using special aids and services.

Where can I go if my grandchild just needs extra help with his schoolwork?

Some children do not qualify for special education services even though it may be very difficult for them to learn. Even if your grandchild is not eligible for special education, he may qualify for special accommodations under Section 504 of the Rehabilitation Act. This law requires public schools to make sure that students with disabilities have access to appropriate services in the classroom and to other school activities.

If your grandchild does not qualify for IDEA, call your local school district and ask to have him evaluated for a "504 plan." This plan describes what accommodations and services the school will provide to help your grandchild learn with other students who do not have disabilities. For example, a 504 plan may include assistive technology such as special computer equipment that will help him participate in classroom activities or a braille typewriter to take notes on.

The law requires public schools to identify all students who may qualify for this assistance. Schools must have evaluation procedures to decide who qualifies. The law also requires all schools to provide access to the same programs that are available to students who do not have disabilities. All school districts must have a 504 coordinator and a grievance procedure for students and their families who are denied services or believe they are not receiving the right services.

If your school district does not want to help you with a 504 plan or your grandchild is evaluated and denied help, ask how you can file a complaint. You can also file a complaint with the U.S. Department of Education, Office for Civil Rights. To find out how to call or write the Office for Civil Rights, see page 65.

Whether your grandchild qualifies for 504 services or not, you may want to find him a tutor. Agencies in your community may have tutors to work with students after school or on the weekends. Check with the local recreation centers, the YMCA, YWCA, and Boys or Girls Clubs. You should also ask your grandchild's teacher about tutoring help.

I just realized that my 10-year-old grandchild cannot read. Where can I get him help?

You should first get your grandchild's vision and hearing tested by a doctor or health care provider. If he is having problems seeing or hearing, it may affect his ability to read.

If your grandchild has a medical problem, he may need what is called "assistive technology." This word covers many services and supports that help children with mental and physical disabilities learn and perform regular daily activities. It includes things that can help children improve their ability to function every day—at home, at school, and in the community. Assistive technology includes computers and special programs for computers to help students with all kinds of disabilities learn more easily.

Examples include devices that make the words bigger on the computer screen or that “read” the typed words aloud to help children who do not see well or electronic talking boards to help students who have trouble speaking.

Students can get assistive technology as part of their public education. Call your local school district and ask to speak with the Section 504 coordinator. To read more about Section 504, see pages 40-41.

Some schools also have reading specialists who can help check your child’s reading skills.

If the school cannot help your grandchild, call the local Technology Resource Center. Many communities have these programs to help people with disabilities get the assistive technology devices that they need. If you have a computer, go to www.ATAccess.org and click on “Centers” to find Technology Resource Centers in your area.

Where Do I Get Mental Health Services for My Grandchild?

I am troubled because my grandchild seems so sad all the time. What would help him?

You are right to be concerned. At some point in their lives, all children have emotions, feelings, or behaviors that cause problems for the people around them. Sometimes this is just part of the normal "ups and downs" of childhood. But sometimes your grandchild may need extra help if he has trouble expressing or controlling his emotions or behavior.

Children's mental health problems are very real, even for younger children. Sometimes they need professional mental health services to understand the problems and to get the right treatment. This help is just as necessary as the help children need when they break an arm or need treatment for their diabetes. It is very important to get help for emotional or behavioral problems before they become so serious that they interfere with a child's ability to go to school, play with friends, and be part of your family life.

Read the answer to the next question to learn how to find mental health services in your area for your grandchild.

Four grandparents in our support group have grandchildren with diagnosed mental health problems. Where can we get more information and services to help these children?

The help you can get in your community may depend on the children's ages. If they are very young, you may be able to get mental health services through their early childhood education or Head Start program. If they are already in school, there may be a school psychologist or social worker who can talk with the children. Ask the children's teachers what help the school can provide and where you can find help outside school.

Your community may also have a mental health center. Its staff often can see children for free, or they may charge a small fee based on income. Ask the children's doctor or health care provider to suggest mental health providers who can help.

If you cannot find local services, there are several places where you can get information about both diagnosed and undiagnosed mental health problems and help finding local mental health providers. Remember that children with emotional or behavioral problems may still need help even if they do not have a specific diagnosis.

The Center for Mental Health Services Knowledge Exchange Network runs a national toll-free hotline and provides information about different mental health problems and lists of agencies that can help families. When you call, you will speak with trained staff who will know about local services. Your conversations with the staff are free, private, and confidential. To find out how to reach the Knowledge Exchange Network, see pages 61-62.

The National Mental Health Association also has information. You can call its Mental Health Information Center toll-free at 1-800-969-NMHA (see pages 63-64). Ask for information or referrals to agencies in your area.

The American Academy of Child and Adolescent Psychiatry has many information fact sheets called “Facts for Families” in English and Spanish. To learn how to get the Academy’s fact sheets, see page 58.

You should also call the Federation of Families for Children’s Mental Health. The Federation is a national organization run by and for families whose children and grandchildren have mental health problems. They have chapters in most states. Chapters have staff and members who are raising children with mental, emotional, and behavioral problems. They understand what you face and can discuss ways for you to get help. To find out how to call the closest Federation chapter, see page 61.

I just started taking care of my 8-year-old grandchild after her mother died. She seems okay, but should I have her talk with someone anyway?

It is a good idea to find a mental health professional who can talk with your grandchild. It does not have to be a psychiatrist—there are other professionals, such as social workers and nurses, who are trained to speak with children about their feelings. The loss of a parent is a major event in anyone's life, especially for young children. Although your grandchild may not have said anything about her mother's death, she most likely has feelings about it. The mental health professional also may have useful tips for you to help your grandchild. You are right to act early before problems become serious and interfere with her ability to go to school, play with friends, and be part of your family life.

A mental health professional can assess any potential problems your grandchild may have. If there are problems, then you should get treatment right away. If your grandchild qualifies for Medicaid, this assessment entitles her to receive any services necessary to treat her diagnosed problems.

How can I get help for my two little grandchildren who have seen a lot of violence?

Experts agree that children who see a lot of violence often show signs of increased stress and anxiety. Sometimes they show more aggressive behavior. This is true when children see violence in their own homes, in their communities, and on television. To help your grandchildren deal with the violence they have seen, it may be very helpful for them to get some mental health counseling. To learn more about how to find mental health services, contact the National Mental Health Association's Mental Health Information Center. See pages 63-64 for more information.

How Can I Protect the Legal Rights of My Grandchildren with Disabilities?

The child care center my grandchild was attending will not let her come back because she is in a wheelchair. What can I do?

Two different federal civil rights laws should protect your grandchild from discrimination based on her disability.

One federal civil rights law is called Section 504 of the Rehabilitation Act. It forbids discrimination on the basis of disability in programs and activities that get federal funds. The law protects children with disabilities in child care programs, schools, mental health centers, hospitals, and other programs that get federal funds to operate. If the child care center gets federal funds and excludes your grandchild because of her disability, then you can file a complaint. The U.S. Department of Health and Human Services has an Office for Civil Rights that can help you. To learn how to contact the Office for Civil Rights, see pages 65-66.

A second law also protects children with disabilities. It is called the Americans with Disabilities Act (often called ADA). It applies to almost all child care centers except those run by religious groups. Call the ADA Information Line at 1-800-514-0301 or 1-800-514-0383 (TDD) for more information. If you have a computer, go to http://www.usdoj.gov and click on "Disabilities." You can read about how to file a complaint and learn more about the Americans with Disabilities Act.

You can also call your state's Protection & Advocacy office and ask if they can help you. To reach this office, see page 67. Your local Office of Human Rights or the State Attorney General's Office will also know about state or local anti-discrimination laws that can protect your grandchild.

I'm afraid if I tell the Head Start program about my grandchild's disability that they will not accept her in the program. What should I do?

Head Start programs cannot exclude children because they have a disability. In fact, Head Start programs are required to include a certain number of children who have disabilities. The law requires each program to include among their enrolled children at least 10 percent with disabilities; some programs serve more.

When you apply for your grandchild, the local program may not have space. This happens often because programs do not have enough money to serve all eligible children. The program may say that your grandchild will go on the waiting list. If so, ask if children who do not have disabilities who are applying at the same time are going on that same list. This is a good way to check if the program is treating your grandchild in a different way than other children because of her disability. You may also ask if there is a special list for children with disabilities.

If you believe that the Head Start program is treating your grandchild differently because of his disabilities, you should contact the Office for Civil Rights in the U.S. Department for Health and Human Services. To learn how to contact the Office for Civil Rights, go to pages 65-66.

To learn more about Head Start and other early childhood programs, see CDF's child care and early childhood education guide for kinship caregivers described on page 70.

What Help Can I Expect in Terms of Respite Care and Family and Medical Leave?

Can I get a break from the daily demands of caring for my grandchild who has a disability?

All caregivers need a break from raising children, especially those caring for a child with a disability. You may qualify for a service called "respite care." It provides temporary care for children with disabilities or those who have chronic or terminal illnesses. Your ability to get respite care will probably depend on what you need and what resources are available in your area.

States provide respite care in different ways. Some provide it through family support programs that are funded especially for families raising children with disabilities. In some states, certain respite caregivers are selected by the state. Other states give vouchers to families so they can find their own respite caregivers. Either way, you may get the respite care in your own home or your grandchild may go to the respite caregiver's home. Sometimes there are also programs such as summer camps that can provide more extended respite for children with disabilities.

The National Respite Locator Service can help you find services in your area. Call 1-800-773-5433. If you have a computer, you can also check to see what agencies are available in your area by going to http://www.chtop.com/

locator.htm and clicking on your state. If you see an agency that is nearby, call to get more information about how they can help you.

A list of family support programs for children with developmental disabilities is available from the National Center for Family Support. If you have a computer, go to http://www.familysupport-hsri.org and click on "Site Projects" to find information for your state. You can also ask your state's Mental Retardation/Developmental Disabilities agency or the Developmental Disabilities Council about family support programs. To learn how to find these groups, see pages 59 and 62.

Can I take time off from work to care for my grandchild who has a serious disability?

It depends. You can in certain circumstances. A federal law allows many workers to take time off for certain family and medical reasons. The law is called the Family and Medical Leave Act. It allows you to take leave to care for a child with a serious health condition. You also may get this leave if you have adopted a child or are caring for a foster child. You do not need legal custody to qualify for family and medical leave.

If you qualify, you can take up to 12 weeks of leave in a 12-month period. The law protects your job during your leave, but does not require your employer to pay you during that time.

The Family and Medical Leave Act applies only to certain workers. The U.S. Department of Labor has fact sheets about the program at http://www.dol.gov/esa/whd/fmla/. Read these to see if you qualify. The National Partnership for Women and Families also has a guide on the Family and Medical Leave Act in both English and Spanish. To get it, see page 64.

Some states have family and medical leave laws that give you more time off. Some union contracts also include family leave. You should also ask your employer what family leave is available and if you will be paid while you are out caring for your grandchild.

What Special Things Should I Know about Foster Care and Adoption for Children with Disabilities?

I am a foster parent for my grandchild who has developmental disabilities. What special help should the foster care agency provide?

Public agencies are required to develop care plans (often called case plans) for children in foster care. The care plans must outline services for both the children and their parents or other caregivers. Each state selects the services it will offer and the families it will serve. Be sure to tell your grandchild's caseworker what services you think she needs.

Your grandchild should also most likely qualify for Medicaid because she is in foster care. Medicaid pays for most of the health care that she needs. But check with your state Medicaid contact because the services are different in each state. To find out about Medicaid in your state, call 1-877-KIDS-NOW.

Your granddaughter may also get help from the state developmental disability agency. Each community has different services, but you may get respite care or help making your house or van accessible for your grandchild. Ask your grandchild's caseworker or call the state Developmental Disabilities Council about services in your area. To find out how to reach the Council, see page 59.

Someone said I could get a lot more help for my grandchild if I adopted him. What are they talking about?

Federal and state laws provide help for families who adopt children with special needs. Although states define "special needs" in different ways, they usually include children with disabilities. The help may include cash payments, health insurance, social services, and a special tax credit.

Federal and state laws provide two kinds of special cash payments for families who adopt children with special needs. Federal law offers a one-time payment for costs related to adopting a special needs child. Federal law allows up to $2,000, but lets each state decide how much it will pay up to that amount. The second payment is a monthly adoption assistance payment to help you care for your grandchild at least until he is age 18. If your grandchild has disabilities, you actually should be able to receive the monthly cash payments until he is age 21.

Families, including grandparents, who adopt children with special needs often can get an adoption assistance payment regardless of their income. You must meet with the state child welfare agency to decide how much assistance you need to take care of your grandchild's special needs. The amount you get generally will take into account the needs of the child and your income and will change in the future if your circumstances or the child's change.

If you adopt your grandchild who has special needs, the state must give him health insurance. Most states include these children in their Medicaid programs, and a few use state funds to cover them. Medicaid pays for most of the health and mental health services that he will need. However, each state offers different services for children with special needs, so check with your state Medicaid contact. Call 1-877-KIDS-NOW to find out about Medicaid in your state.

Some states have a range of social services for adoptive parents if their children have disabilities. Each state selects the services it will offer and the families it will serve. For example, you may get mental health services or transportation for your grandchild. Ask the social worker from the adoption agency what ongoing services your state has for families who adopt children with disabilities.

Families who adopt children with special needs, such as physical, emotional, or mental disabilities, also qualify for an adoption tax credit when the adoption is finalized to assist them with related expenses. Beginning in January 2003, you can claim a $10,000 tax credit when you file your annual tax form. Prior to that time, you can receive a credit of up to $10,000 for all qualifying expenses. Contact the IRS about tax exemptions and deductions that you can get when you adopt your grandchild with special needs. The IRS has helpful information on its Web site at www.irs.gov or you can call 1-800-829-3676 and ask for booklets on adoption credits. Also check with your local Office on Aging where someone may have useful information for grandparents who adopt their grandchildren with special needs.

The National Adoption Information Clearinghouse also has information if you want to adopt or have adopted a child who has special needs. If you have a computer, go to http://www.calib.com/naic and click on "Parents" and then "Introduction to Adoption." You will find a section called "Adopting a Child with Special Needs."

The North American Council on Adoptable Children has useful information on adoption too. You can learn about adoption subsidies in all the states through its National Adoption Assistance Training Resource and Information Network at 1-800- 470-6665. You can also check http://www.nacac.org/adoptionsubsidy.html to connect with the Adoption Subsidy Administrator in your state.

I adopted my grandchild two years ago, and we just learned that she has a disability. Where can I get help for her?

You should first check with the agency that originally arranged the adoption. In the answer to the question above, we describe special adoption assistance payments and services that are available for families who adopt children with disabilities. Sometimes this help is only available if your child is determined eligible for adoption assistance at the time you adopt. You need to find out if these benefits are available to you.

What if I can't adopt but need help caring permanently for my grandchildren?

Some states offer ongoing payments to grandparents who go to court to get legal guardianship of their grandchildren whether they are in foster care or not. These payments generally are offered through "subsidized guardianship" or "assisted guardianship" programs. Check with your child's caseworker to find out if your state has such a program and whether your grandchild may be eligible. The Kinship Care State Fact Sheets posted on CDF's Web site at http://www.childrensdefense.org/kincare/ ss_kin_sbsfactsh.php also highlight subsidized guardianship programs in the states. Click on your state on the map to get to your state's fact sheet. Other information on subsidized guardianship laws also is available on CDF's Web site.

Helpful Resources for Grandparents and Other Relative Caregivers Who Are Raising Children Who Have Disabilities or Are At Risk of Developing Disabilities

The groups listed below provide information or services to grandparents and other relative caregivers as well as parents raising children with disabilities.

American Academy of Child and Adolescent Psychiatry
3615 Wisconsin Avenue, NW
Washington, DC 20016-3007
202-966-7300
202-966-2891 Fax
www.aacap.org

The Academy is the professional organization for child and adolescent psychiatrists. Its Web site has information sheets on many mental health topics of interest. "Facts for Families" are available in English, Spanish, German, and French.

Children's Defense Fund (CDF)
25 E Street NW
Washington, DC 20001
202-628-8787
202-662-3550 Fax
http://www.childrensdefense.org

CDF provides information and resources on issues facing grandparents and other relative caregivers, including information on federal legislation that helps kinship care families. CDF also has a number of publications for kinship caregivers including three more guides like this one in different areas: health insurance, food and nutrition programs, and child care and early childhood education programs. See pages 70-71 for more about these publications.

Councils on Developmental Disabilities (DD Councils)
Use http://www.acf.dhhs.gov/programs/add to find
your state DD Council or call 202-690-6590.

Each state has an organization to plan and coordinate services for adults and children with developmental disabilities. Many DD Councils provide grants to nonprofit organizations that serve families. Others train people with disabilities and family members to be their own advocates through a program called Partners in Policymaking. The DD Councils provide basic information to all adults and children who have developmental disabilities and their families.

Easter Seals
230 W. Monroe Street, Suite 1800
Chicago, IL 60606
312-726-6200
312-726-4258 (TTY)
312-726-1494 Fax
1-800-221-6827 (Call weekdays 8:30 a.m. - 5:00 p.m.
Central Time. There is voice mail to leave a message.)
E-mail: info@easterseals.org
http://www.easter-seals.org/

Easter Seals provides services to children with physical and mental disabilities and other special needs. Go to the Web site and click on "Services" to find the nearest services. You can also call their national toll-free telephone number. Services include early intervention, physical and occupational therapy, and speech and hearing therapy. They also operate child care centers around the country that serve children with disabilities.

Families & Advocates Partnership for Education (FAPE)
PACER Center
8161 Normandale Blvd.
Minneapolis, MN 55437-1044
1-888-248-0822 (Call weekdays 8:00 a.m. - 5:00 p.m. Central Time. There is voice mail to leave a message.)
E-mail: fape@pacer.org
www.fape.org

The Family & Advocates Partnership for Education (FAPE) Web site has information for families and advocates about many special education issues.

Family Voices
3411 Candelaria NE, Suite M
Albuquerque, NM 87107
505-872-4774
505-872-4780 Fax
Toll-Free: 1-888-835-5669 (Call weekdays 8:00 a.m. - 5:00 p.m. Central Time. There is voice mail to leave a message.)

E-mail: kidshealth@familyvoices.org
www.familyvoices.org (Web site in English and Spanish)

Family Voices is a national grassroots network of families and friends speaking on behalf of all children with or at risk for special needs. Family Voices has chapters across the country. The Web site has a list of state chapters and provides links to other organizations in each state.

Federation of Families for Children's Mental Health
1101 King Street, Suite 420
Alexandria, VA 22314
703-684-7710
703-836-1040 Fax
E-mail: ffcmh@ffcmh.org
www.ffcmh.org (Web site in English and Spanish)

The Federation is a national parent and caregiver-run organization to address the needs of children and youth with emotional, behavioral, or mental disorders and their families. The Web site has a list of state and local chapters that you can call in your area.

Knowledge Exchange Network (KEN)
P.O. Box 42490
Washington, DC 20015
1-800-789-2647 (Call weekdays 8:30 a.m. - 5:00 p.m. Eastern Time.)
866-889-2647 (TDD)
301-984-8796 Fax
E-mail: ken@mentalhealth.org
http://www.mentalhealth.org/aboutken/

KEN provides information about a range of diagnosed and undiagnosed mental health problems and disorders. Trained staff members answer a national toll-free hotline where people can ask questions and get referrals to local service providers. There is no charge to call KEN and all conversations are private and confidential.

National Association of State Directors of Developmental Disabilities Services (NASDDDS)
113 Oronoco Street
Alexandria, VA 22314
703-683-4202
703-683-8773 or 703-684-1395 Fax
E-mail: ksnyder@nasddds.org
http://www.nasddds.org/index.shtml

NASDDDS helps state agencies develop service delivery systems and supports for people with developmental disabilities. To find your state office, go to the Web site and click on "Member State Agencies."

National Early Childhood Technical Assistance Center (NECTAC)
Campus Box 8040, UNC-CH
Chapel Hill, NC 27599-8040
919-962-2001
877-574-3194 (TDD)
919-966-7463 Fax
E-mail: nectac@unc.edu
http://www.nectac.org

NECTAC provides information about the early intervention and preschool grant programs funded by the federal government. To get a list of state Part C (early intervention) coordinators on the Web site, click on "Programs for Infants and Toddlers with Disabilities." To get a list of state Section 619 (preschool) coordinators, click on "Preschool Grants Program."

National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013
1-800-695-0285 (Voice/TTY) (Call weekdays 9:30 a.m. - 6:30 p.m. Eastern Time. There is voice mail to leave a message.)
E-mail: nichcy@aed.org
http://www.nichcy.org

NICHCY serves as a national information and referral center about disabilities for families and professionals, especially on issues for children and youth from birth to age 22. NICHCY has bilingual information specialists who can answer specific questions from parents in both English and Spanish. The Web site has "State Resource Sheets" listing groups and agencies that can help you find information and services for your child.

National Mental Health Association (NMHA)
2001 North Beauregard Street, 12th Floor
Alexandria, VA 22314-2971
703-684-7722 or
1-800 969-NMHA (6642)
800-433-5959 (TTY)
703-684-5668 Fax

Mental Health Information Center: 800-969-NMHA
(Call weekdays 8:00 a.m. - 5:00 p.m. Central Time.
There is voice mail to leave a message.)
www.nmha.org

NMHA works to improve the mental health of all Americans through advocacy, education, research, and service. It provides information and referrals for individuals seeking help for themselves, family members, or friends through the Mental Health Information Center. It has pamphlets on many topics, including children's mental health. One series of pamphlets on the mental health needs of teens covers topics such as depression and suicide, self-esteem, eating disorders, and stress.

National Partnership for Women and Families
1875 Connecticut Avenue, NW, Suite 650
Washington, DC 20009
Phone: 202-986-2600
Fax: 202-986-2539
E-mail: info@nationalpartnership.org
www.nationalpartnership.org

The Partnership provides information about laws and policies for health care, work, and family issues. Go to its Web site and click on "FMLA" to see its "Guide to the Family & Medical Leave Act" in both English and Spanish

National Respite Locator Service
1-800-773-5433 (Call weekdays 8:30 a.m. - 5:00 p.m.
Eastern Time. There is voice mail to leave a message.)
www.chtop.com/Locator.htm

The National Respite Locator Service helps caregivers find respite services in their area. If you use the Web site, click on your state to see what is available. The locator service has limited staff so it is generally faster to check the Web site than to call. You will then have to check with each agency listed to learn more about their services.

Office for Civil Rights, U.S. Department of Education
Customer Service Team
Mary E. Switzer Bldg.
330 C Street, NW
Washington, DC 20202
1-800-421-3481
1-877-521-2172 (TDD)
E-mail: OCR@ed.gov
www.ed.gov/offices/OCR/complaintprocess.html

The Office for Civil Rights of the U. S. Department of Education has as its mission to ensure equal access to education and to promote educational excellence throughout the nation through vigorous enforcement of civil rights laws. OCR enforces several federal civil rights laws that prohibit discrimination in programs or activities that receive federal financial assistance from the Department of Education. A complaint alleging discrimination on the basis of race, color, national origin, sex, disability, or age can be filed with OCR. See its Web site for details on how to file a complaint.

Office for Civil Rights, U.S. Department for Health and Human Services

Hubert H. Humphrey Building, Room 509F
200 Independence Ave, SW
Washington, DC 20202
1-800-368-1019
1-800-537-7697 (TDD)
E-mail: OCRMAIL@hhs.gov
www.hhs.gov/ocr

The Office for Civil Rights in the U.S. Department of Health and Human Services (HHS) enforces federal laws that prohibit discrimination by health care and human service providers that receive funds from HHS. If you believe you have been discriminated against because of your race, color, national origin, disability, age, and in some cases sex or religion, by those who receive funds from HHS, you may file a complaint with OCR. You may call 202-619-0403 or go to the OCR Web site to learn how to file a complaint.

Parent Training and Information (PTI) Centers

See http://www.taalliance.org/PTIs.htm for a list of centers in each state or call 1-888-248-0822.

Each state has at least one parent-run organization to help parents learn more about the needs of their children with disabilities. PTIs provide information to parents of infants, toddlers, school-aged children, and young adults with disabilities. They also work with professionals who serve these children. PTI staff members can help you talk with professionals about your child's needs. They can also help you learn how to participate in planning processes for your child's education. The centers have a lot of information about programs, services, and resources in your state.

Protection & Advocacy Agency (P&A)
See http://www.protectionandadvocacy.com to find
your state P&A or call 202-408-9514.

The state P&A provides legal and other advocacy services to adults and children with disabilities. The P&A also investigates conditions in facilities and programs that take care of people with disabilities. Many P&A agencies provide help to families so they can get education and other services for their children with disabilities. Each state P&A decides what services it will provide. Community representatives and P&A staff members make these decisions together.

The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
301-565-3842
301-565-3843 Fax
www.thearc.org

The Arc works to promote and improve benefits, supports, and services for children and adults with mental retardation and related disabilities so that they can live with their families and in the community. The Arc has state and local chapters across the country to provide basic information or refer you to other agencies.

Additional Contacts for Grandparents and Other Relative Caregivers

The following organizations may be useful to grandparents and other relative caregivers looking for additional information to help the children they are raising:

AARP – Grandparent Information Center
601 E Street NW
Washington, DC 20049
(202) 434-2296
(202) 434-6466 Fax
http://www.aarp.org/confacts/programs/gic.html

Provides an extensive range of services including a listing of local support groups for grandparents and other relatives, newsletters, and other useful publications.

Casey Family Programs National Center for Resource Family Support
1808 Eye Street NW, Fifth Floor
Washington, DC 20006
(202) 467-4441 or 1-888-295-6727
(202) 467-4499 Fax
http://www.casey.org/cnc

Provides comprehensive information about policies, programs, and practices for retaining, recruiting, and supporting foster, adoptive, and kinship care families.

Children's Defense Fund
25 E Street NW
Washington, DC 20001
(202) 628-8787
(202) 662-3550 Fax
http://www.childrensdefense.org

Provides information and resources on issues facing kinship care providers inside and outside of the child welfare system, including information on federal legislation that helps kinship care families.

Child Welfare League of America
440 First Street NW, Third Floor
Washington, DC 20001
(202) 638-2952
(202) 638-4004 Fax
http://www.cwla.org

Offers resources and information on issues affecting grandparents and other caregivers raising children inside and outside of the child welfare system and sponsors an excellent national biennial conference on kinship care.

Generations United
122 C Street, NW, Suite 820
Washington, DC 20001
(202) 638-1263
(202) 638-7555 Fax
http://www.gu.org

Offers information and advocacy materials for grandparents and other relative caregivers, including information on state and federal legislation, educational enrollment issues, subsidized guardianship, and support groups.

Children's Defense Fund's Publications for Grandparents and Other Relative Caregivers

For a copy of these publications, call the Children's Defense Fund (CDF) at 202-662-3568, fax 202-662-3550, write to CDF, Child Welfare and Mental Health Division, 25 E Street, NW, Washington, D.C. 20001, or log on to http://www.childrensdefense.org.

The Grandparent's and Other Relative Caregiver's Guides

CDF has created four helpful guides, written specifically for kinship caregivers, to answer their questions about important issues affecting the children in their care. The guides offer useful information on federal programs, eligibility requirements, and how to enroll the children they are raising. The four guides include:

- ***The Grandparent's and Other Relative Caregiver's Guide to Child Care and Early Childhood Education***
- ***The Grandparent's and Other Relative Caregiver's Guide to Food and Nutrition Programs for Children***

- ***The Grandparent's and Other Relative Caregiver's Guide to Health Insurance for Children***
- ***The Grandparent's and Other Relative Caregiver's Guide to Raising Children with Disabilities***

Kinship Caregiver Leadership Training: A Guide to Advocacy for Children

This training tool provides a curriculum for teaching kinship caregivers advanced advocacy methods to help them bring about change in their communities. The guide includes information on how to set goals; how to use the media and data to support a cause; how to build support at different levels, such as engaging the community and faith-based organizations; and fundraising basics.

Kinship Care State Fact Sheets

Many kinship caregivers are not aware of the services that their states may offer to them. CDF and seven other organizations created state-specific fact sheets so kinship caregivers can learn about their state's efforts to help children and the relatives who are raising them. These fact sheets talk about states' initiatives for offering services to kinship caregivers, the number of children living with relatives in foster care, subsidies for legal guardians when they exist, and other laws that support kinship caregivers. Not all states offer the same services so kinship caregivers can look at what is provided in their own state as well as what may be available in other states.

Resources to Help You Leave No Child Behind®

The State of Children in America's Union: A 2002 Action Guide to Leave No Child Behind®

Learn how our nation can make more just choices to truly Leave No Child Behind® and to hold society accountable for protecting children. The guide includes state tables and how states rank with other states in protecting children.

Hold My Hand: Prayers for Building a Movement to Leave No Child Behind®

This is an inspiring collection of heartfelt prayers written by CDF President Marian Wright Edelman.

For other information about the Movement to Leave No Child Behind®, visit CDF's Web site at www.childrensdefense.org.

About the Children's Defense Fund

The mission of the Children's Defense Fund is to Leave No Child Behind® and to ensure every child a *Healthy Start*, a *Head Start*, a *Fair Start*, a *Safe Start*, and a *Moral Start* in life and successful passage to adulthood with the help of caring families and communities.

CDF provides a strong, effective voice for *all* the children of America who cannot vote, lobby, or speak for themselves. We pay particular attention to the needs of poor and minority children and those with disabilities. CDF educates the nation about the needs of children and encourages preventive investments before they get sick, into trouble, drop out of school, or suffer family breakdown.

CDF began in 1973 and is a private, nonprofit organization supported by foundation and corporate grants and individual donations. We have never taken government funds.