

Grand Resources

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



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Table of Contents

Who is included in these questions and answers?

This guide answers questions from many kinds of relatives. Know that the answer also usually applies to you if you are related in any way by blood, marriage or adoption. Many of the programs will also help you if you're a god-parent or close family friend raising the child. Whether you're included may depend on how "relative" is defined for a particular program.

Introduction	6
Where to Start	
<i>Where should I go first to get help for the grandchild I just started raising?</i>	7
<i>I think my grandchild has special challenges. How can I get him tested?</i>	7
<i>What types of services and benefits can my grandchild with disabilities and I get?</i>	8
<i>What help is available that can link my grandchild with disabilities and me to services and benefits that can help us?</i>	9
<i>I am not comfortable using a computer. Where can I go for help since so many of the resources you mention in this guide are on the Internet?</i>	10
<i>Which laws protect the rights of children with disabilities?</i>	10
Health Care	
<i>Will my health insurance cover my cousin who I'm raising?</i>	12
<i>Is there government assistance to help pay for my cousin's health care?</i>	12
<i>I heard that the new Affordable Care Act offers something called an exchange that may help provide insurance coverage to my cousin. How do I learn more?</i>	12
<i>What are some other key provisions of the Affordable Care Act that can help me meet the needs of my cousin?</i>	13
<i>I don't have legal custody or guardianship of my cousin. The doctor's office tells me I can't consent to her treatment. What do I do?</i>	13
Additional Special Help	
<i>My niece needs equipment, including a wheelchair, and I need things like a ramp into my house. Can I get help paying for these things?</i>	14
<i>I need help getting my niece with disabilities to appointments. Is any transportation help available?</i>	14
<i>I need help with things like lifting my niece to bathe and dress her. Can I get someone to come to my home and help me do these things?</i>	15
<i>Someone told me to call the public health department for help with my niece who has a disability. How can they help?</i>	15
The Supplemental Security Income (SSI) Program for Children with Disabilities	
<i>What is the Supplemental Security Income (SSI) Program?</i>	16
<i>How do I know if my grandchild is eligible for SSI?</i>	16

Where do I apply for SSI for my grandchild?16

Is my Income or the income of others in my household counted if my grandchild qualifies for SSI?17

If my grandchild returns to live with his mother, can he still get SSI?17

My adult child was getting SSI for my grandchild before he died. Can I still get SSI for my grandchild?17

Do I need to go to court to get legal custody or guardianship before I can get SSI for my grandchild?17

Can my grandchild get SSI if she is not a citizen?18

My grandchild was turned down for SSI, but I think he qualifies. What can I do?18

If I set aside money for my grandchild who has a disability, can she still get SSI and Medicaid? ...18

Other Financial Assistance, Food Help, and Tax Credits

Besides SSI, I hear there may be other financial help we can get. What are some of the programs that may increase my income so I can best meet my grandchild’s special needs?22

Can I get help paying for my grandchild’s food?22

Are there any federal tax credits that I can get now that I am raising my grandchild?23

Therapies and Educational Services for Children Ages Birth to 3

I’ve never raised children and I don’t know what is typical for different ages. Where can I get information?24

I think my two year old sister is not developing typically. What do I do?24

Who do I contact for more information about early intervention services?24

If my sister qualifies for services, what happens next?25

Do I need legal custody or guardianship to get my sister early intervention services?25

Will I have to pay for early intervention services?25

Head Start and Child Care

Are there other early childhood education programs that can help my sister?26

I need child care for my sister so I can go to work. Where do I turn for help?26

Special Education and Related Services for Children Ages 3 to 21

I just started to raise my grandchild. My neighborhood school tells me that I can’t enroll her because I don’t have legal custody or guardianship. What do I do?26

I think my grandchild needs special education. What do I do now? 27

What types of disabilities does my grandchild need to have in order to qualify for special education? 27

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? 27

What do special education and related services include? 31

Will I have to pay extra for special education and related services? 31

Do I need to get legal custody or guardianship before I can get my grandchild tested for special education? 31

My school tells me I need to go through a process to become a “surrogate parent” in order to ask for testing and participate in meetings related to my grandchild’s special education. Is this correct? 32

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”? 32

Who is on the team that develops my grandchild’s IEP? 32

What is the goal of the IEP? 32

How often should the IEP be reviewed? 33

Can someone help me get a good IEP for my grandchild? 33

What can I do if I don’t like the school’s special education plan for my grandchild? 33

My grandchild has been in a special education class, but he is not improving. What can I do to get him more help? 34

I just realized that my 10-year-old grandchild cannot read. Where can I get him help? 34

My grandchildren have received special education since third grade and are now ready for middle school, but their teacher said there is no special program for them. What can I do? 35

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? 35

The school told me that if our grandson does not start taking medication to calm him down, he can’t come to school. Can the school force me to medicate him? 36

A friend’s child has a Section 504 plan. What is that? 36

What if the school refuses to help my grandchild get a Section 504 plan? 36

My grandchild is 15 and gets special education. Is the school required to do anything to help him get ready to leave high school? 36

Are there ways to help my grandchild with a disability get accommodations in college?37

Mental Health Services

I am troubled because my nephew seems so sad all the time. What would help him?37

My nephew has diagnosed mental health problems. Where can we get more information and services to help him?38

I just started taking care of my nephew after his mother died. He seems okay, but should I have him talk with someone anyway?38

How can I get help for my nephew who has seen a lot of violence?39

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?39

Can I take time off from work to care for my grandchild who has a disability?40

Foster Care and Adoption for Children with Disabilities

I am a foster parent for my brother who has a disability. What special help can the foster care agency provide?41

Someone said I could get a lot more help for my brother if I adopted him. What are they talking about?41

I adopted my brother two years ago, and we just learned that he has a disability. Where can I get help for him?45

What if I can't adopt but need help caring permanently for my brother?45

Children with Disabilities Turning Age 18

My grandson is turning 18 next year, and will never be able to hold a job or care for himself. What planning should I do?45

My grandson was my foster child. Are there any other things I should ask about for him?46

I adopted my grandson from foster care. Can I still get adoption assistance to help meet his needs after he turns 18?47

I got legal guardianship of my grandson and have been receiving guardianship assistance payments from the state to help meet his needs. Can that assistance continue after he turns 18?47

Caregiver Checklist48

Helpful Resources50

Introduction

Are you a grandparent or other relative raising another family member's child? You are not alone. Grandfamilies – or extended family members and close family friends and the children they raise – are growing in numbers. More than 2.7 million children are being raised in grandfamilies without any parents in the home. Although we don't know how many, we believe many of the children in grandfamilies have disabilities or special needs. Often they may have disabilities because of the situations that led to them being cared for in a grandfamily. Some of them may develop disabilities if they do not receive services to help them while they are young.



The guide seeks to answer some of the most often asked questions from grandfamilies like yours who have children with disabilities. When answering, we will give basic information about the major programs that can help you and your family. For example, as a first step, you may want the child evaluated to learn more about their physical or mental health challenges so you can get help. This guide will explain that process. The guide also goes over questions concerning monthly cash payments, health insurance, and other public services that may be available to help you and the child you're raising. For example, we'll explore how to get early intervention services for children birth to age 3, and preschool and special education and related services for older children. This guide also has a resource section that tells you where you can go to find more information and get help.

Each of the programs mentioned in this guide has rules to identify which children and families can get help. The rules often vary depending on where you live. So, you must always check the program rules in your area. Some program rules are based on the kind of disability the child has. Others are based on how much money your family has. Virtually none of the programs require that you have legal custody, guardianship or have adopted the child; the guide will tell you if any of those legal relationships are necessary for a particular program. That's not to say that you won't have to prove through documents like birth certificates and income tax returns that you are raising the child full-time and/or are related in some way to the child.

Most of the programs will help you if you are related in any way by blood, marriage or adoption to the child. For that reason, we answer questions from many kinds of relatives, but know that the answer also usually applies to you if you are related in any way. Many of the programs will also help you if you're a godparent or close family friend raising the child. If this is you, ask if the program includes you. Whether you're included may depend on how "relative" is defined for a particular program.

It is probably going to take a lot of time and effort to apply for some of the programs in this guide. We think you'll find the effort to be worth it. You should get some much deserved support to help you meet the needs of the grandchild, niece, nephew, sibling or other family member who you're raising.

Where to Start

Where should I go first to get help for the grandchild I just started raising?

A good place to find help is the National Dissemination Center for Children with Disabilities (NICHCY). They have a very useful website at www.nichcy.org with information about services and programs, and contact information for each state. They also have staff to answer your questions over the telephone at 1-800-695-0285 (Toll-free, Voice/TTY).

The NICHCY website and its materials only talk about “parents.” Please know that the federal education laws define “parent” to include you. So, where you see “parent” mentioned with early intervention, special education or parental participation, just substitute your own name. You are included whether you have adopted, are a guardian or are raising your grandchild without any legal relationship at all. For other programs, the rules may differ because you are not the parent.



Photo by Rowena Scott-Johnson

The kind of help you can get for your grandchild 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 he have? How much income and resources do you have?

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

- **The child’s age.** For example, children from birth to age 3 may qualify for early intervention services, which can include speech-language, physical and occupational therapies. Youth 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 about the nature of your grandchild’s disability. For example, does he have a physical or mental health challenge or both?
- **How much money you have.** The pre-school and special education services for children with disabilities do not have income rules, so no one should ask you about your money. Other programs, like early intervention services or Head Start, may look at your income and other resources.
- **Where you live.** Where you live may affect what services you and your grandchild can get. Even within a state, each community may have different programs.

I think my grandchild has special challenges. How can I get him tested?

You can first talk with your grandchild’s doctor or other health care providers about the issues you notice. Describe your grandchild’s challenges so the health care provider can evaluate if there are medical or developmental reasons why your grandchild does not act like other children of the same age. If your grandchild is in preschool or school, you can also talk with the 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 grandchild tested will depend on his or her age.

- **If your grandchild is under age 3**, call your state’s early intervention coordinator to get him tested. The State is responsible for implementing early intervention programs for infants and toddlers. This plays out at the local level, under state supervision. You may be charged fees depending on where you live. Look at NICHCY’s State Organizations for your state to identify who to contact at <http://nichcy.org/state-organization-search-by-state> . Use the drop-down menu to select “state agencies”, and then click the box for your state. State agencies for your state will automatically display and you should look under the heading “Early Intervention.” The agency listed there is the state contact. They can give you the local contact in your community. Call them to find out more about the program and have your child screened for a disability or delay. If you don’t have a computer handy, another way to find your state’s early intervention coordinator is to call NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).
- **If your grandchild is between ages 3 and 5**, you can ask your neighborhood school to evaluate your grandchild at no cost to you. 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.” You can find the Section 619 coordinator for your state at The Early Childhood Technical Assistance Center at <http://ectacenter.org/contact/619coord.asp>.
- **If your grandchild is already in elementary school or a higher grade**, you can ask the school to evaluate him or her at no cost to you. 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 grandchild’s school principal, counselor or teacher that you want your grandchild 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. Your local Easter Seals may be able to help you find the right program. Visit www.easterseals.com/connect-locally/ to find a list of local Easter Seal offices or call 1-800-221-6827 (Toll-free) and they can give you the local number to call.

What types of services and assistance can my grandchild with disabilities get?

Children with disabilities can get free or low-cost services for many of their needs, and cash and other help to meet their needs.

- **Health insurance.** Your grandchild may qualify for health insurance through Medicaid, the Children’s Health Insurance Program (CHIP), or the new Affordable Care Act Marketplace. See pages 12-13.
- **Additional needs.** You may be able to get help with additional needs, like building a wheelchair ramp in your home. See pages 14-15.
- **Supplemental Security Income (SSI).** If your grandchild qualifies, you may be able to access a monthly cash benefit to help meet his or her needs through the Supplemental Security Income (SSI) Program. See pages 16-18.
- **Other cash benefits.** Your grandfamily may qualify for Temporary Assistance for Needy Families (TANF) family or “child-only” grants, and/or Social Security survivors, disability or work benefits. See page 22.

- **Help paying for food.** There are a few programs that may help you feed your grandchild. See pages 22-23.
- **Tax credits.** There are several tax credits that you may be able to claim. See page 23.
- **Early intervention services.** If your grandchild is age birth to 3, he or she may qualify for early intervention programs. See pages 24-25.
- **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. See page 26.
- **Special education.** Your grandchild may qualify for special education and related services, such as physical therapy, from age 3 through high school. He or she may need a Section 504 plan that provides reasonable accommodations to students with disabilities, such as a specially designed desk chair. 504 plans may continue through college or other post-secondary education. See pages 26-36.
- **Mental health services.** There are special services for mental health needs that may be available to your grandchild. See pages 37-39.
- **Respite care and family leave.** Your community may have services to give you a break from caregiving. A federal program may also be available if you need to take time off from work to care for your grandchild. See pages 39-41.
- **Foster care services.** Your state or county child welfare office will have information about services to help children with disabilities who are in foster care. See page 41.
- **Adoption assistance.** Grandfamilies may get monthly adoption assistance payments (adoption subsidies) as well as other supports if they adopt children with disabilities from the foster care system. See pages 41, 42 and 45.
- **Special things to consider as children with disabilities turn 18.** Legal authority, child support, SSI and other benefits are just a few things to consider before a child turns 18. See pages 45-47.

What help is available that can link my grandchild with disabilities and me to services and benefits that can help us?

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. The relevant agencies for each state are available on the National Dissemination Center for Children with Disabilities (NICHCY) website at <http://nichcy.org/state-organization-search-by-state> or by calling 1-800-695-0285 (Toll-free, Voice/TTY).

There are a number of other resources that may be able to help you and your grandchild find help too:

- **The AARP Foundation Benefits QuickLINK** website at www.aarp.org/quicklink can link you with programs that increase income, pay for food, and cover home and health care for older adults and children. You can input your and your grandchild's information in the QuickLINK tool and it will tell you what you may qualify for.
- **Kinship navigator programs** are another great resource, but they do not exist in all areas of the country. These initiatives can link you to the benefits and services that you or your grandchild need. Washington State and New Jersey have long standing programs. There are other programs in Connecticut, Delaware, and New York. Because of the past success of these programs, there are several federal grants for more programs around the country. To see if one exists in your area, go to www.grandfamilies.org

- **GrandFacts sheet** for your state is another resource to consult. Generations United, Children’s Defense Fund, AARP, and a number of other partners created fact sheets containing state-specific information for grandfamilies. The fact sheets are available at www.grandfactsheets.org
- **Support groups** are often great places to learn about resources and programs in your area. The Brookdale Foundation’s Relatives As Parents Program (RAPP) is a national network of support groups and services for grandfamilies. They have grantees in almost all states, Puerto Rico, and the District of Columbia. For more information and a list of programs, go to www.brookdalefoundation.org
- **The National Family Caregiver Support Program** may be able to provide you with support services through your local Area Agency on Aging if you are age 55 or older. Through this program, AAAs or community agencies they contract with can provide up to five types of supportive services. Among those services is help learning about available services and gaining access to those services, support groups, training, respite care, and supplemental services that may include legal help. Even if you are younger than 55, you should contact the AAA, because it may use other funds to help younger caregivers. For contact information for your local AAA, visit www.n4a.org/about-n4a/?fa=aaa-title-VI or call the elder-care locator at 1-800-677-1116 (Toll-free).
- **An eXtension office** in a land-grant university near you may be able to help. They also have a wealth of information on the Internet at www.extension.org/category/family_caregiving_grandparents_raising_grandchildren.

I am not comfortable using a computer. Where can I go for help since so many of the resources you mention in this guide are on the Internet?

You can visit your local library, community center or senior center. All those places should have staff that can help you find resources on the Internet. If you don’t know of a local place to go, you can call the elder care locator at 1-800-677-1116 and ask.

Many communities also have 211 phone numbers that can help connect people to services, like the resources mentioned in this guide. You can consult your phone book to find out if a local 211 exists in your area. You can also ask someone to visit www.211.org for you to see if 211 exists in your community.

Which laws protect the rights of children with disabilities?

Children who have disabilities are protected against discrimination under civil rights laws. Major civil rights laws for children with disabilities include:

- **Americans with Disabilities Act (ADA)**. This law protects access for people with disabilities to programs provided by state and local governments. It also protects access for people with disabilities to public transportation and to places of “public accommodation” like hospitals, restaurants, and nonprofit service programs.
- **Individuals with Disabilities Education Act (IDEA)**. This law guarantees free special education and related services for eligible students with disabilities ages 3 to 21. It also provides for early intervention services for birth to age 3, but that may involve looking at your income and charging you a fee.

- **Section 504 of the Rehabilitation Act. (Section 504).** This 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. For example, it requires that schools make reasonable accommodations to students with disabilities, such as additional test taking time. It also protects students against discrimination in extracurricular activities like sports.

The Office for Civil Rights in both the U.S. Department of Health and Human Services and in the U.S. Department of Education help to enforce these laws. See pages 59 and 61 for more information about how to contact them. You can also learn more about the ADA by visiting www.ada.gov or calling the ADA Information Line at 1-800-514-0301 or 1-800-514-0383 (TDD).

There are also other state and local anti-discrimination laws that are intended to protect persons with disabilities. Your local Office of Human Rights or the State Attorney General's Office will know about these laws. You can also call your state's Protection and Advocacy office and ask if they can help you. To reach this office, look at NICHCY's State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading "Protection and Advocacy." The agency listed there is the state contact. You can also call NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY) to ask for the contact information for your state agency.

Health Care

Will my health insurance cover my cousin who I'm raising?

If you or other family members are privately insured through an employer, you should check first to see if your health insurance policy will cover the cousin you are raising. You may find that you can only get additional private health coverage for your cousin if you adopt. If your cousin is eligible, ask about the specific services and treatments the policy covers for children with disabilities. Many policies cover physical, occupational, and speech-language therapies, and may even cover a private evaluation.

If your cousin is not eligible under your health insurance policy, you should check her eligibility for Medicaid or your state's Children's Health Insurance Program (CHIP). They may be called something different in your state. To find out about the Medicaid and CHIP programs in your state, visit <http://insurekidsnow.gov/> or call 1-877-KIDS-NOW.



Photo by Eder A

Is there government assistance to help pay for my cousin's health care?

Most children raised by non-parental relatives 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 the child you are raising has income that is too high to qualify for Medicaid, she 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 call Medicaid, CHIP or combined programs by different names. To find out about the Medicaid and CHIP programs in your state, visit <http://insurekidsnow.gov/> or call 1-877-KIDS-NOW.

I heard that the new Affordable Care Act offers something called an exchange that may help provide insurance coverage to my cousin. How do I learn more?

Due to the new Affordable Care Act, as of October 1, 2013, you can shop for affordable health insurance coverage through the Health Insurance Marketplace or "exchange." With one application, you can see all your cousin's health care insurance options and then enroll. You will also be able to find out if your cousin qualifies for Medicaid or CHIP.

Because of the new law, no plan can turn your cousin away or charge more because she has a disability, illness or medical condition. They must cover treatments for these needs. Coverage through the Marketplace starts as soon as January 1, 2014.

You can go to the Marketplace at www.healthcare.gov to see if either your state or the federal government is running the Marketplace for you. If your state runs the Marketplace, you'll get health coverage through your state's website. Otherwise, you go to www.healthcare.gov for application information. You can also call 1-800-318-2596 (Toll-free), 24 hours a day, 7 days a week to find out how and where to apply. If you are deaf or hard of hearing, you can use TTY at 1-855-889-4325.

What are some other key provisions of the Affordable Care Act that can help me meet the needs of my cousin?

- Since late 2010, children can stay on their “parent’s” private insurance until age 26. If they are covered under your private health insurance, rather than a parent’s, the same is true. They are covered until they turn 26.
- As of January 1, 2014, states must provide Medicaid coverage to foster care youth until they reach age 26. This applies to youth leaving foster care in 2014 and beyond. It also applies to former foster youth who have left foster care since 2006, as long as they were receiving Medicaid when they left. Unfortunately, a state is not required to provide Medicaid coverage to former foster youth who left foster care in another state. It is a state’s option whether to provide coverage to these youth.
- As of January 1, 2014, insurance companies cannot refuse to cover people based on pre-existing conditions, including illnesses and disabilities.
- As of January 1, 2014, states have the option to cover more people through Medicaid. The Affordable Care Act increased the income guidelines so more children and other non-Medicare eligible individuals under age 65 can qualify.

I don’t have legal custody or guardianship of my cousin. The doctor’s office tells me I can’t consent to her treatment, so he won’t help her. What do I do?

Your options will depend on where you live. If you are lucky enough to live in one of the 25 states with a health care “consent” law, you can just complete and sign a short form. On it, you swear that you are your cousin’s primary caregiver and sign it. You then give that form to the doctor or other health care provider, and he or she must allow you to consent to the child’s treatment. The form doesn’t help you pay for the health care, but it does give you the authority to get the child treated. To find the form, you can connect with a local organization that helps grandparents and other relatives raising children. Those organizations can be found on your state fact sheet at www.grandfactsheets.org.

As of September 2013, the 25 states with health care consent laws are: Arkansas, California, Delaware, Florida, Georgia, Hawaii, Idaho, Indiana, Kansas, Louisiana, Maryland, Mississippi, Missouri, Montana, Nevada, New Mexico, New York, North Dakota, Ohio, South Carolina, South Dakota, Texas, Utah, Virginia, and Washington.

In other states, if you can find one of the child’s parents, you can have them give you a “power of attorney”. That’s also a rather simple document, but you must have the parent sign it.

If you can’t find the parent and don’t have a consent law, your only option will probably be to go to court and get legal custody or guardianship. To do that, you may need legal help. For more information about these consent and power of attorney laws, see www.grandfamilies.org.

Additional Special Help

My niece needs equipment, including a wheelchair, and I need things like a ramp into my house. Can I get help paying for these things?

It depends. Your private insurance may pay for such equipment and modifications and you should check with them. If your niece gets Medicaid, you should ask your state Medicaid program. Visit <http://insurekidsnow.gov/> or call 1-877-KIDS-NOW to get connected to your state's Medicaid information hotline and ask them.

Some states also have special “family support” funds to help families who have children with disabilities. Your state may pay for things like a ramp into your house or 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 Developmental Disabilities office and asking if they can help you. To reach this office, look at NICHCY's State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading “Developmental Disabilities.” The agency listed there is the state contact. You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

I need help getting my niece with disabilities to appointments. Is any transportation help available?

It depends. Medicaid pays for most transportation to approved health facilities if no other transportation is available. CHIP in your state may also cover some transportation services. If your niece has either Medicaid or CHIP coverage, check with your state to see what they cover.

Your state's developmental disabilities office may also 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. Find out by calling your state's Developmental Disabilities office and asking if they can help you. To reach this office, look at NICHCY's State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading “Developmental Disabilities.” The agency listed there is the state contact. You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

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 niece 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 niece to child care, preschool or school, you need to ask for it as part of your niece's IFSP or IEP. You do not need legal custody or guardianship of

your niece to ask for these services. You can read more about how to get help under the early intervention or special education programs on pages 24-36.

I need help with things like lifting my niece to bathe and dress her. Can I get someone to come to my home and help me do these things?

It depends. If you have private insurance, check with them. If your niece has Medicaid, it lets states provide in-home services for children. This is done to help children with disabilities live at home rather than in a more costly hospital or other institution. The types of services offered depend on which state you live in. They may include the personal care services that your niece needs. To find out which in-home services your state offers, visit <http://insurekid-snow.gov/> or call 1-877-KIDS-NOW to get connected to your state Medicaid agency. Ask if your niece can get personal care services.

Someone told me to call the public health department for help with my niece who has a disability. How can they help?

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 which 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 niece is eligible for the Maternal and Child Health/Title V program in your state. Ask whether it serves children living with relative caregivers. Ask about the types of help available and how you can apply. You can get contact information for your state at www.mchb.hrsa.gov.

The Supplemental Security Income (SSI) Program for Children with Disabilities



Photo by Richard Adler

What is the Supplemental Security Income (SSI) Program?

SSI provides cash benefits to eligible adults and children with disabilities that seriously limit their activities. The federal Social Security Administration runs the program, but there are local Social Security offices that can help you apply. The average monthly SSI payment for children under age 18 in June 2013 was \$632.96. Children who get SSI should also qualify for free medical care through Medicaid. They may also qualify for assistance with food.

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 is eligible for SSI?

You can use the disability planner on the Social Security Administration website to see if your grandchild may qualify, www.ssa.gov/d&s1.htm. Your grandchild must meet both financial and disability rules. You can also call the Social Security Administration's staffed toll-free number at 1-800-722-1213. People who are deaf or hard of hearing may call the TTY number at 1-800-325-0778.

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 your grandchild gets from child support, most public benefits, and work. Resources mean savings accounts or other things your grandchild may own. The amount of money your grandchild has in his name affects whether he qualifies and how much cash he can get each month. Some resources are never counted, including the family home and a car needed by a family member to get medical care.

The disability rules to qualify for SSI require the child to have a physical or mental condition that seriously limits his or her activities; and the condition must have lasted or be expected to last at least one year or result in death. 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? Can he help you around the house with chores as others his age can? Can he play the same kinds of games as others his age can?

The state agency makes the disability decision. They review the information you give. They will also ask for information from medical and school sources and other people who know about your grandchild. If the state agency needs more information, they will arrange for an exam of your grandchild. The Social Security Administration will pay for the exam.

Where do I apply for SSI for my grandchild?

To apply for SSI, call the Social Security Administration at 1-800-772-1213 (or TTY 1-800-325-0778 if you are deaf or hard of hearing) and make an appointment to apply for SSI benefits. You can make

an appointment to apply for benefits on the telephone or in person at your local Social Security office. A representative will help you. SSI applications are not available on the Internet, because most of the forms to apply for SSI are not designed for self-completion. The representative will interview you and use a computer to complete the forms with information you give. When you call, have your child's Social Security number handy. Ask if your state has an extra SSI payment on top of the federal benefit. You should also 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 office counts the income and resources of the parents or stepparents who live with them. However, if a child lives with a grandparent or relative 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 can be very complicated. You may want to consult with a lawyer in your area. To find free or low-cost legal help, call the bar association in your area or check www.lsc.gov/local-programs/program-profiles 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 for the benefit.

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

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. 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 and vary from state to state. You should first get more information before you call your local Social Security office. The National Immigration Law Center has a useful table covering eligibility rules for SSI and other programs at www.nilc.org/table_ovrw_fedprogs.html.

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 or check www.lsc.gov/local-programs/program-profiles 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.

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 follow both state and federal rules for the SSI and Medicaid programs.

Linda Porter

Linda Porter is not the sort of person who cries “Uncle” very often. She’s affable, intelligent, and ready and willing to stand up for herself and her family. But even she found that raising a grandchild with disabilities, while challenging, is not nearly as daunting as having to fight for services – which can just about bring one to the breaking point.

Like most grandparents raising children, Porter learned that even though love can’t overcome every challenge, it does give one the sustenance to keep trying, and succeeding.

How Porter ended up raising two grandchildren is a bit complicated. Several years before the children were born, Porter had adopted their mother who was already 19-years-old and had come from a severely dysfunctional family, living in foster care and group homes until her family abandoned her as a young teen.

A few years later, the adopted daughter married and began having children of her own. Problem was, she and her husband struggled with drugs and alcohol and their home-life was unsuitable for children.

The oldest child was a girl and was just two-months-old when child welfare authorities removed the baby from her home. They contacted Porter and asked her to take the child in. She did.

Six years later, those same authorities came back to Porter, asking her to take in the little girl’s three other siblings, all boys. Porter knew raising four children was beyond her abilities both because of her age (she was 47 at the time) and because finances were already stretched. Porter turned to her sister for support and was thrilled when her sister agreed to raise two of the boys. Porter took in her 14-month-old grandson, while her sister took the two middle children.

Both sisters would soon learn that all three boys suffered to some degree from fetal alcohol exposure. Only the oldest girl had escaped that fate.

That was 10 years ago, and the challenges Porter has faced since then could fill a book. “I learned very early on that Nate suffers from a number of neurological disabilities. He has attention deficit hyperactivity disorder (ADHD), a neural-behavioral disorder, and a sensory processing disorder.



Linda, Nate, and Shay spend a little time at Kinship Family Camp, September 2012 (photo pro bono by City Lights Photography, kinship caregivers themselves).

He also suffers from post-traumatic stress disorder (PTSD) due to early childhood traumas,” Porter explains. “He is very needy, has difficulty staying on task and getting organized, and continually seeks sensory stimulation.”

Porter stops a moment and reflects on what she’s just said. “It sounds like I’m sorry I took him in, but that couldn’t be farther from the truth. I love him and his sister very much. I thought that I could just love him through all his challenges. But then I realized I needed help on a lot of levels.”

Such help was not forthcoming. Porter says she has had to fight and scratch her way through the bureaucracy to get the services her family needs.

“In spite of all his neurological problems, at first I couldn’t get the school system to qualify him for special help for developmental disabilities. Schools don’t acknowledge the tremendous role kinship caregivers play. They sort of dismiss you. It’s as if they’re thinking, ‘The apple doesn’t fall from the tree.’ So, she has to continually stay on top of the educational system to ensure he gets the support he needs.

“But it’s not just the schools that adopt this attitude; other institutions and even professionals tend to trivialize what you’re going through and don’t offer much hope or solace. Nate was exhibiting a lot of intense behaviors; some type of issue seemed to crop up every day, so I took him to a psychiatrist. The doctor looked me in the eye and said, ‘He will need constant supervision and the problems will get worse as he becomes an adult.’ That was it! Essentially the psychiatrist was telling me that my grandchild had no hope, that I might as well accept his fate and move on.

“Well I did move on, but I didn’t give up.”

Linda Porter says she knows how tough it has been for her to navigate services for her grandfamily. She offers the following tips to those who work with kinship caregivers of children and youth with disabilities:

- Communicate often with caregivers
 - Make no assumptions, no matter if you think the family should already know about resources, and especially refrain from judging (“not-far-from-the-tree”) attitudes.
 - Reach out and let them know who specifically they should contact for help.
 - Offer viable resources.
 - Show empathy; assume the caregivers are in for the long haul.
 - Ensure your professionals are well-trained in listening and navigating.
- Cut down wait lists; every day that kinship caregivers go without help just compounds the challenges they face.
- Push for more flexibility in the workplace to allow kinship caregivers to be there for their families.
- Recommend local nonprofits and cultural groups that can offer support; sometimes these leads can offer respite and other supports.

During the recent recession, Porter lost her job and ended up taking a new position that pays 42 percent less than her old job. “Finances had already been stretched thin,” Porter admits. “I have to use credit cards to purchase many of our necessities. I also had to apply for TANF and SNAP benefits in order to feed the kids. It’s bad enough having to ask for help, but then the process is so demeaning. I understand why many kinship caregivers simply give up.” Meanwhile, she volunteers on several statewide and local committees related to kinship care, working on policy development and advocacy efforts to gain support for these often overlooked families.

Today, Nate is 11-years-old and his sister is 16. Through perseverance, grit, and a never-say-die attitude, Porter and her children are in a better place. “Caregiving – especially when you’re an older adult – takes a lot out of you. Child Protective Services does not always understand this and they’re not often alert to any signs that you might be suffering burnout. You feel that if you show any signs, they’ll want to take the kids away. Just last November, after nine long years of trying to make it on my own, I found out Nate could qualify for Medicaid Personal Care hours. I happened upon this information; professionals working with my family did not seem aware of this possibility. But what a godsend! They agreed to provide seven hours of personal care twice a month for him. The person who provides the care also has ADHD and is excellent at diverting my now adopted [grand] son and keeping him happy. Those 14 hours a month are truly a gift.

“I’ve always thought I love would get my grandchildren and me through anything. It has and it will continue to open new paths for us. We have all come a long ways. We’ve learned a lot and I have hope for our future. The kids are my best teachers!”



Photo by Randy Billmeier

Other Types of Financial Assistance

Besides SSI, I hear there may be other financial help we can get. What are some of the programs that may increase my income so I can best meet my grandchild's special needs?

The Temporary Assistance for Needy Families (TANF) has as one of its primary purposes to help relatives raising children. This program exists in every state, but many states call it by a different name. The GrandFacts sheet for your state will tell you what it's called where you live and which office to contact to apply. Go to www.grandfactsheets.org for a copy of your state's fact sheet.



Photo by Shari Augins

There are basically two types of TANF grants. The “child-only” grants are for the child. These grants usually only consider the income of the child and do not require the caregiver to meet work requirements. They usually also do not have time limits on how long they can last. The problem with these grants is that they are typically not enough to meet a child's needs. The monthly rate varies from state to state, and in some states is a lot more than in others. However, the national average is only \$8 per day for one child with only slightly more for additional children.

The other type of TANF grant is known as a “family grant.” It's typically more money than the child only grants, but you may be required to work. The grant may also only last a limited time. Your state may make exemptions for you, as a relative caregiver, to these requirements and limits. You'll need to check with your state.

Your grandchild may also qualify for Social Security. Children being raised by grandparents may be eligible if the child's parent is collecting retirement or disability insurance benefits. If one of the child's parents has died and was fully insured when he or she died, your grandchild may also be eligible. You can apply for benefits on behalf of the child based on the work record of the child's parent.

Your grandchild may also qualify based on your work record. For more information straight from the Social Security Administration, see www.socialsecurity.gov or call the Social Security Administration's staffed toll-free number at 1-800-722-1213. People who are deaf or hard of hearing may call the TTY number at 1-800-325-0778. See also Generations United's fact sheet, The Benefits of Social Security for Grandfamilies, www.gu.org/OURWORK/publicpolicy/grandfa,iliespolicy.aspx

Can I get help paying for my grandchild's food?

There are programs that may help you pay for your grandchild's food:

- **The Supplemental Nutrition Assistance Program (SNAP)** – formerly known as “Food Stamps” may help you. To apply for benefits, contact your local SNAP office. You can also call your State's SNAP hotline number. Most are toll-free numbers. You can find local offices, the state hotline, and each State's application at www.fns.usda.gov/snap/applicant_recipients/apply.htm . You can also look under the state or local government pages of your phone book.
- **The Women, Infants and Children (WIC)** Program can help eligible relative caregivers meet

nutrition needs of children they raise under age 5. Children must have certain types of health conditions to qualify. To apply, start by calling your state office toll free. For those numbers, see www.fns.usda.gov/wic/Contacts/tollfreenumbers.htm. You can also look in the state or local government pages of your phone book.

- **The National School Breakfast and Lunch Programs** provide free or low-cost meals to eligible students. You can ask the child's school teacher or principal for an application.
- **The Summer Food Service Program (SFSP)** provides low-income children with nutritious meals when school is not in session. Free meals are provided to children 18 years old and under at approved SFSP sites. To find a program near you, call 1-866-3-HUNGRY or 1-877-8-HAMBRE (for Spanish speakers) and a live operator will tell you where the closest sites serving free summer meals are located. Or visit www.whyhunger.org/findfood to locate sites using an online map.

Are there any federal tax credits that I can get now that I'm raising my grandchild?

Yes, there are a number of tax credits that may help you meet the needs of your grandchild:

- **The Earned Income Tax Credit (EITC)** is refundable. That means, if you don't earn enough to pay taxes, you can get a refund check from the IRS. To qualify, your grandchild must have lived with you for more than half the year. This tax credit will apply until your grandchild turns 19 (or 24 if a full time student). If your grandchild is totally and permanently disabled, there is no age requirement. For more information, see the Internal Revenue Service's website at www.irs.gov
- **The child tax credit** if your grandchild is dependent on you and under age 17, you can claim up to \$1,000 per child. But, this is not refundable. So, if you don't owe enough taxes, you cannot claim the credit. For more information on the IRS website, see www.irs.gov
- **The additional child tax credit** may help if you don't owe enough taxes to benefit from the child tax credit. Unlike the child tax credit, this tax credit is refundable. You will get a refund check from the IRS. See www.irs.gov
- **The child and dependent tax care credit** may help you if you've hired someone to help care for the child so you could work or look for work. If so, you may be able to claim up to \$3,000 in expenses per child. If you think this credit may help you, see www.irs.gov/.
- **The adoption tax credit** can help if you have adopted your grandchild. It can give you a credit for the money you spent to adopt. The Affordable Care Act made the credit refundable for 2010 and 2011, so if you adopted during those years, you could file an amended tax return and maybe get a refund check. As of 2012, the credit is no longer refundable.

If you adopted a child from the foster care system with special needs, you may be eligible for the maximum amount of credit for the year you adopted regardless of whether you had any qualifying expenses. If you did not adopt from the foster care system, you must have qualifying expenses like legal fees. It allows adoptive parents to claim up to \$12,650 per child. For more information on this tax credit, visit www.irs.gov/taxtopics/tc607.html.

• **Additional tax benefits**

- Another tax benefit for relatives raising children with disabilities is that you do not have to claim SSI payments for either you or the child as part of your gross income. It is exempt.
- Tax credits themselves are also not counted as income. They will not be counted when you apply for financial help.

Therapies and Educational Services for Children Ages Birth to 3



Photo by Mary Windt

those ages. The checklists are available on the Centers for Disease Control and Prevention website at www.cdc.gov/ncbddd/actearly/milestones/index.html.

I've never raised children and I don't know what is typical for different ages. Where can I get information?

Easter Seals has a developmental milestones screening tool that you can use to see if the child ages birth to 5 is typically developing. It will take you about 10 to 15 minutes to complete. It's available at <http://www.easterseals.com/>.

Also, the Centers for Disease Control and Prevention (CDC) have checklists for typical milestones for children ages 2 months to 5 years old. The checklists describe the skills and behaviors of typical children at

I think my two year old sister is not developing typically. What do I do?

You can find out if your sister qualifies for early intervention services. These services can identify her challenges and provide the right treatment. Your sister 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 her. A “service coordinator” will help you keep track of your sister’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”, which is often a more general category that covers more children. Other states also serve infants and toddlers who are “at risk” for developmental delays. Also, some states charge fees for these services for children under age 3, whereas others do not.

Who do I contact for more information about early intervention services?

Call your state’s early intervention coordinator. The State is responsible for implementing early intervention programs for infants and toddlers. This plays out at the local level, under state supervision. The program for children ages 3 to 5 is often called “Section 619.” You can find the Section 619 coordinator for your state at The Early Childhood Technical Assistance Center at <http://ectacenter.org/contact/619coord.asp>. They can give you the local contact in your community. Contact them to find out more about the program and have your sister screened for a disability or delay.

If my sister qualifies for services, what happens next?

If your sister qualifies for early intervention services, she will get an Individualized Family Service Plan (IFSP). The IFSP describes the services that can help her. As her caregiver, you will develop the IFSP with a group of people who know which services can help your sister.

Do I need legal custody or guardianship to get my sister early intervention services?

No, you do not need legal custody or guardianship to help put together your sister's IFSP or to get her services.

Will I have to pay for early intervention services?

It depends on where you live. Some states charge fees for early intervention services for children younger than 3 years old based on family income. Other states will not charge you any fees regardless of your income.



Photo by Karen Peterson

Head Start and Child Care

Are there other early childhood education programs that can help my sister?

Head Start/Early Head Start is a federal program that promotes the school readiness of children ages birth to 5 from low-income families. These programs must serve children with disabilities too. Federal law requires Head Start grantees to develop a plan for serving children with disabilities. To find an Early Head Start or Head Start in your area, go to <http://eclkc.ohs.acf.hhs.gov/hslc/HeadStartOffices> or call the federal office at 1-866-763-6481 (Toll-free).



Photo by Christine Urbaniak

I need child care for my sister so I can go to work. Where do I turn for help?

The Office of Child Care in the U.S. Department of Health and Human Services administers the Child Care and Development Fund (CCDF). CCDF helps low-income families obtain child care so they can work or attend training/education. To find out if you qualify, contact the state's child care subsidy agency. For a list, see www.acf.hhs.gov/programs/ccb/

Special Education and Related Services

I just started to raise my grandchild. My neighborhood school tells me that I can't enroll her because I don't have legal custody or guardianship. What do I do?

Your options will depend on where you live. If you are lucky enough to live in one of the 14 states with an educational “consent” law, you can just complete a form. The form is short. On it, you swear that you are your cousin's primary caregiver and sign it. You can then give it to the school and they must enroll the child. To find the form, you can connect with a local organization that helps grandparents and other relatives raising children. Those organizations can be found on your state fact sheet at www.grandfactsheets.org. Sometimes, the school will also require other documents, like an electric bill with your name on it.

The fourteen states with these educational consent laws are: California, Connecticut, Delaware, Hawaii, Louisiana, Maryland, Montana, New Jersey, New Mexico, North Carolina, Ohio, Oklahoma, South Carolina, and Virginia.

In other states, if you can find one of the parents, you can have them give you a “power of attorney”. That's also a rather simple document, but you must have the parent sign it.

Other states may have other options. In a few states, you can enroll the child in school simply because they live with you. Some states have open enrollment laws; if you can find one of the parents, he or she can enroll the child in your neighborhood school if you live in the same state as the parent.

If you can't find the parent and don't have a consent law, your only option may be to get legal custody or guardianship. That process will generally require legal help and a court proceeding.

For more information about these consent and power of attorney laws, see www.grandfamilies.org/Education/EducationSummaryAnalysis.aspx

I think my grandchild needs special education. What do I do now?

If you think your grandchild needs special education, ask the school to evaluate her. Begin by calling your grandchild's teacher, school counselor or principal. If the school agrees to evaluate her, it must do so promptly and for free. It must do so because of a federal special education law, known as the Individuals with Disabilities Education act (IDEA), which requires schools to identify, locate, and evaluate all children ages 3 to 21 with disabilities who need special education and related services.

The school does not have to evaluate her just because you ask. But if it doesn't, the school 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, visit www.parentcenternetwork.org/national/aboutus.html. You can also call your state's Protection and Advocacy office and ask if they can help you. To reach this office, look at NICHCY's State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading "Protection and Advocacy." The agency listed there is the state contact. You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

What types of disabilities does my grandchild need to have in order to qualify for special education?

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.

Schools may also serve children ages 3 to 9 who have "developmental delays." Each state defines which children with developmental delays it will serve. This category of disabilities is typically more generally defined. When the child turns 9, her disability must be more specifically categorized in order to continue to qualify for special education and related services.

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.

Menjiwei, Paki, and Nya

Menjiwei Latham thought that her parenting days were over. She was 58, had adopted and raised two boys, and had been forced to retire for health reasons several years earlier.

“I had worked, raised my family, and was looking forward to some ‘me time,’” Latham recalls. “And even though I was dealing with health issues, I had big plans for my retirement.”



But life had other plans for Latham, a former school teacher who lives in Chicago. Suddenly, and without warning, she was called upon to take up a parenting role once again. Only this time, she would be parenting two young grandchildren, a boy named Paki and a girl named Nya.

“My son and his wife had children at a very young age – she was just a teenager – and their marriage only lasted a short time,” explains Latham. “My son, Paki, Sr., received custody of the two kids when he and his wife divorced and his wife didn’t show up for court. Some time later, his life started to spiral out of control and he was arrested. The children needed someone to care for them while he was away and I knew there were few other options. I was granted legal guardianship through the courts.”

When the two children came to live with Latham, Paki was five; his sister was four. Her grandson, Paki, had had difficulties at birth that resulted in developmental and behavioral issues, for which her son had sought help. Once the children were in her care full-time, Latham realized that she needed to continue to address those issues.

She enrolled both children in pre-school, just as their dad had done before he had to go away. When Paki was finally ready for kindergarten, his developmental delays and behavioral issues really came to the fore. Latham tried two neighborhood schools, but there was little progress in Paki’s development. The Board of Education had Paki tested, but due to his poor verbal skills and other issues, the board couldn’t come up with a complete diagnosis. So what was the answer?

Latham caught a lucky break one Sunday when she was talking with a fellow church member. The woman noticed Paki’s behavior and certain physical characteristics and wondered whether he had Fragile X syndrome. According to the friend, Paki displayed many symptoms of this syndrome, which can lead to intellectual disabilities and physical and behavioral issues. She recommended that Latham take Paki to a primary care doctor and ask to have her grandson undergo neurological testing.

Latham followed her friend’s advice and her doctor referred her to the University of Chicago.

Menjiwei Latham offers some good advice for other grandparents raising grandchildren with disabilities.

- Stay positive. This may not be the retirement you planned for, but it can be incredibly fulfilling and rewarding.
- Seek out support. Join a grandfamilies support group where you can share your trials and tribulations, offer ideas to others, and enjoy the camaraderie of individuals who understand what you're facing.
- Be persistent. Stand firm when others try to deter you from your goals, whether they be finding the right school, seeking the right diagnosis, or making your neighborhood a safe place for your children to thrive in.
- Take time for yourself. When you can, and the children are in school, at play, or asleep, do something you want to do, not just what you need to do.

“That first visit didn’t go very well,” Latham remembers. “The staff members were very condescending and said they didn’t think Paki had Fragile X syndrome. They were wrong. The testing showed he did suffer from Fragile X, so I had Nya tested, as well. She was negative.”

Armed now with a diagnosis, Latham began to learn everything she could about Paki’s syndrome. She contacted Fragile X organizations and a specialty medical center, and found a doctor who finally placed Paki on an effective medication that controlled many of his symptoms.

Latham also went back to school officials to find a suitable placement for Paki. The school system recommended that he begin attending the Mahalia Jackson School, which works with children who have autistic traits. It turned out to be a good fit; Paki seems to have found his place.

“A few years after he began at Mahalia Jackson, the school board wanted to close that school and a lot of others to cut expenses. I, along with others, fought like mad to keep [the Mahalia Jackson School] open – it was the only one dedicated to working with children with autism and other similar disabilities,” Latham notes. “We eventually won that battle.”

Because of Paki’s diagnosis, Latham now receives Social Security’s Supplemental Security Income (SSI) for her grandson. The SSI has been a godsend; without it, Latham doubts the three of them could survive on her benefits and buy the medication and other items grandchildren need.

Latham says she also relies on her local GRANDFamilies program. "My family has received so much support since I have joined the [group], but I never realized just how much I would grow to depend on them. When my neighborhood began to experience a rash of crimes, they helped me work with city officials to address the issue. I haven’t had a problem since. GRAND-Families has also provided presents for the kids at Christmas time. I get a lot of support and

ideas from other grandparents raising grandchildren. It's very instrumental and keeps me from feeling isolated. GRANDFamilies is just wonderful."

Today, the grandchildren are pre-teens: Paki is 11, Nya 10. Latham is now 65. And while she loves her grandchildren unconditionally, she admits that she often feels tired and overwhelmed by the enormity of caring for two young children, especially one with developmental disabilities.

"Paki is more like a six-year-old than an 11-year-old. And while he's remained very close to his dad, he doesn't seem to be as bothered by his mother's absence as Nya is," Latham says. "Their mother currently resides in Texas and has three other children living with her. Nya seems to be struggling more with the emotional issues of not having her mother around. At times, she can get upset about the situation. With help from a counselor, though, Nya has begun to adjust. She is a very intelligent child and has excelled at school."

Latham tries to keep the kids involved in activities – to the extent she can afford to. This summer they attended a day camp that the children have enjoyed immensely. They have participated in martial arts, swimming, church activities, and many family events to keep them involved and moving in a positive direction.

It may not be the retirement Latham had imagined, but she understands there is a master plan in place for her good.

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 raising children with disabilities. There may also be support groups in your community specifically for grandparents raising grandchildren. Consult the GrandFacts sheet for your state at www.grandfactsheets.org and visit the Brookdale Foundation's website at www.brookdalefoundation.org to see if a group exists in your area.

The sad truth is that children often make fun of each other whether they are different or not. While it may be hard to stop the teasing, you should notify your child's teacher or principal if it continues. It is also 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 you can help him understand how it will help him do well in school. You can also 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.

What do special education and related services include?

The federal law, known as the Individuals with Disabilities Education Act (IDEA), entitles eligible children with disabilities to get a “free and appropriate public education” (may be referred to as FAPE) and related services. These related services may include speech-language, physical and occupational therapies, and mental health services. It can also include services that help your grandchild participate in school activities, like an instructional aide.

Reasonable accommodations may also be made for your grandchild, things like priority seating close to the teacher or extra test taking time. He may also need services like assistive technology, which are special computers or learning devices, to help him in the classroom and other school activities.

Will I have to pay extra for special education and related services?

No. Students who are at least 3 years old and their families get special education and related services for free regardless of the family's 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.

My school tells me I need to go through a process to become a “surrogate parent” in order to ask for testing and participate in meetings related to my grandchild’s special education. Is this correct?

No. Federal special education law specifically provides that grandparents and others acting in the place of a parent do not need to become “surrogate parents.” The “surrogate parent” process is for children who do not have anyone acting as parent, are in the custody of the state or are unaccompanied homeless youth.

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”?

The special education and related services a student gets are described in a document called an “Individualized Education Plan” (IEP). The IEP should set annual goals that are reasonable for each child to achieve during the school year and reflect his strengths and needs. The IEP should describe specific related services, like speech-language, physical, and occupational therapies, and the minutes with each specialist that the school district will provide. It should also list services that help the child participate in school activities, like an instructional aide.

Reasonable accommodations and assistive technologies may also be included in the IEP. Reasonable accommodations may include things like priority seating close to the teacher or extra test taking time. Assistive technologies are things such as special computers or learning devices that can help students in the classroom and other school activities.

Who is on the team that develops my grandchild’s IEP?

First of all, as the person acting in the place of a parent, you have the right and responsibility 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 IEP meetings at convenient times for you. If you cannot attend in person, the school must help you participate by telephone.

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 may send someone who knows how to design educational programs for children with disabilities.

In addition, you or the school can invite other people to the IEP meeting. For example, you may want to invite your grandchild’s private speech therapist to explain the kind of help he needs in school. Children may receive these types of therapies both from the school and from providers outside the school. You may also ask a friend, your clergy or another advocate like a lawyer to come with you to the meeting.

What is the goal of the IEP?

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.

How often should the IEP be reviewed?

Every year the IEP team should review the child’s educational program to see if the goals for the child are being reached and make changes if they are needed. The IEP team also decides if any changes are needed in what is called the child’s educational “placement.” For example, if the public school district cannot meet the needs of your grandchild, you may want to ask for a private school placement. Federal law provides that schools must pay for these private placements.

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

You can talk with staff at your state’s Parent Training and Information Center before you go to your grandchild’s IEP meeting. 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 the IEP meeting. To find your state’s Parent Training and Information Center, go to www.parentcenternetwork.org/national/aboutus.html. You can also call your state’s Protection and Advocacy office and ask if they can help you. To reach this office, look at NICHCY’s State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading “Protection and Advocacy.” The agency listed there is the state contact. You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

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 you 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 you when they are thinking about making any change that may affect your grandchild’s educational services. If you do not agree with the school about what services are appropriate, you may ask for a due process hearing. That hearing is a meeting between you and the school district where each presents their opinions. A hearing officer listens and decides what should be done based on the law.

States also must make mediation available if you 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 you are not happy with the mediation, then you can file a lawsuit in court to ask for the educational services that you want. If you sue and win, the judge may order the school district to pay for your attorneys’ fees.

For help understanding this process, call your state's Parent Training and Information Center. You can find the contact information for your state at www.parentcenternetwork.org/national/aboutus.html. You can also call your state's Protection and Advocacy office and ask if they can help you. To reach this office, look at NICHCY's State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading "Protection and Advocacy." The agency listed there is the state contact. You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

Another option is to file a complaint with the U.S. Department of Education, Office for Civil Rights (OCR). To file a complaint with OCR, visit <https://wdcrobcolp01.ed.gov/CFAPPS/OCR/contactus.cfm>. On that site, you can find the contact information for the local enforcement offices and an electronic complaint form that you may complete.

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 may also 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, physical and occupational therapies and mental health services. At the IEP meeting, ask to review your grandchild's related services. Additional support services like these may help him benefit from classroom work.

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. It may also be that your grandchild has a learning disability of some sort that makes it difficult for him to read. It will be important to have appropriate testing done to determine any special needs. Some schools have reading specialists who can help check your grandchild's reading skills and help teach him to read.

If your grandchild has a medical problem, he may need what is called "assistive technology." This phrase 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.

Students can get assistive technology as part of their public education. If your grandchild does not get special education services through an IEP, call your local school district and ask to speak with the Section 504 coordinator. If he has an IEP, these types of devices can be added to that document.

If the school cannot help your grandchild, call the local Alliance for Technology Access Center. Many communities have these programs to help people with disabilities get the assistive technology devices that they need. To find an Alliance for Technology Access Center in your area, visit www.ataccess.org/index.php/reading-room/centers.

My grandchildren have received special education since third grade and are now ready for middle school, 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.

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

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 they must follow special rules.

Your grandchild's IEP team must first 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.

The rules regarding how schools can discipline students with disabilities are very complicated. Generally, students with disabilities must continue to get the educational services described in their IEPs, even if they are suspended.

If your grandchild is suspended or expelled from school, call your state's Parent Training and Information Center immediately. You can find the contact information for your state at www.parentcenternetwork.org/national/aboutus.html. You can also contact your state's Protection and Advocacy Office. To reach this office, look at NICHCY's State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading "Protection and Advocacy." You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

The school told me that if our grandson does not start taking medication to calm him down, he can't come to school. Can the school force me to medicate him?

No, they cannot force you to medicate him. Federal law is very clear that schools are prohibited from requiring students to take medications. The school cannot require it as a condition of his attending school, getting an evaluation or receiving special education and related services.

If you choose to medicate your grandson, that is your decision to make in consultation with your grandson and his health care providers. Before he begins taking any medication, make sure he gets a complete physical exam. Ask the health care providers all your questions about the medication and its possible side effects. If your grandson takes the medication, promptly tell the providers about any changes in your grandson's behaviors, like loss of appetite or trouble sleeping. If multiple medications are prescribed by multiple providers, make sure all the health care providers know about all the medications.

A friend's child has a Section 504 plan. What is that?

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 an IEP, call your local school district and ask to have him evaluated for a "504 plan." Federal law requires that all school districts have a 504 coordinator and identify all students who may qualify for assistance. Schools must also have evaluation procedures to decide who qualifies.

A 504 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.

What if the school refuses to help my grandchild get a Section 504 plan?

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. All school districts must have a grievance procedure for students and their families who are denied services or believe they are not receiving the right services.

You can also file a complaint with the U.S. Department of Education, Office for Civil Rights (OCR). To file a complaint with OCR, visit <https://wdcrobcolp01.ed.gov/CFAPPS/OCR/contactus.cfm>. On that site, you can find the contact information for the local enforcement offices and an electronic complaint form that you may complete.

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 stu-

dents 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, you may want someone 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.

Are there ways to help my grandchild with a disability get accommodations in college?

Yes. Section 504 applies to colleges and other postsecondary education institutions as well. As long as the college receives federal funds, and virtually all do, the college must provide your grandchild with accommodations, aids and services. This might include things like note taking help, assistive technologies or additional test taking time. The college, however, is not required to accommodate your grandson to the same extent his high school might have been required. Colleges and other post-secondary institutions do not have to provide accommodations that would fundamentally change the college program or impose an "undue burden" on it.

Mental Health Services

I am troubled because my nephew 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 nephew 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, learn, play with friends, and be part of your family life.



Photo by Zuhair Ahmad

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

My nephew has diagnosed mental health problems. Where can we get more information and services to help him?

The help you can get in your community may depend on your nephew's age. If he is very young, you may be able to get mental health services through a referral from his early childhood education or Head Start program. If he is already in school, there may be a school psychologist, counselor or social worker who can talk with him. Your nephew's teachers may also be able to tell you 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.

You can start by calling your state's Mental Health office and ask if they can refer you to local providers. To reach this office, look at NICHCY's State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading "Mental Health." The agency listed there is the state contact. You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

The National Mental Health Association also has information. You can call its Mental Health Information Center toll-free at 1-800-969-NMHA or visit www.mentalhealthamerica.net. Ask for information or referrals to agencies in your area.

The Federation of Families for Children's Mental Health is another helpful source. 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, visit www.ffcmh.org/find-local-chapter or you can call the national Federation office at 1-240-403-1901 (not Toll-free).

The American Academy of Child and Adolescent Psychiatry has many fact sheets called "Facts for Families" in English, Spanish and several other languages. Visit www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/Home.aspx for complete copies.

I just started taking care of my nephew after his mother died. He seems okay, but should I have him talk with someone anyway?

It is a good idea to find a mental health professional who can talk with your nephew. 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 nephew may not have said anything about his mother’s death, he most likely has feelings about it. The mental health professional also may have useful tips for you to help your nephew. You are right to act early before problems become serious and interfere with his 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 nephew may have. If there are problems, then you should get treatment right away. If your nephew qualifies for Medicaid, this assessment entitles him to receive any services necessary to treat his diagnosed problems.

How can I get help for my nephew who has 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 nephew deal with the violence he has seen, it may be very helpful for him to get some mental health counseling.

To find someone to help your nephew, you can start by calling your state’s Mental Health office and ask if they can refer you to local providers. To reach this office, look at NICHCY’s State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading “Mental Health.” The agency listed there is the state contact. You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

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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. Some states have a Lifespan Respite Care grant from the federal government to provide respite to people of all ages for a variety of different reasons. Other states may provide respite services to grandparents and other relatives raising children through the National Family Caregiver Support Program.

In some programs, 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. There are also programs such as summer camps that can provide more extended respite for children with disabilities.

Whether it is Lifespan Respite or another program, the National Respite Locator Service can help you find services in your area. Call 1-800-773-5433 or visit their website at <http://archrespite.org/search-for-respite> and click on your state. If you see an agency that is nearby, call to get more information about how they can help you. Many of these respite programs are aimed at providing respite to caregivers of older individuals, but don't get discouraged. Hopefully, you will be able to find help in your area.

Sometimes the Area Agency on Aging (AAA) in your local community provides respite to grandparents and other relatives age 55 and older raising children through the federal National Family Caregiver Support Program. For contact information for your local AAA, see www.n4a.org

The family support programs for children with developmental disabilities may be able to help you. Find out what family support programs your state has by calling your state's Developmental Disabilities office and asking if they can help you. To reach this office, look at NICHCY's State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading "Developmental Disabilities." The agency listed there is the state contact. You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

If your area has a Kinship Care Navigator Program, they may also be of assistance. Visit www.grandfamilies.org/KinshipNavigatorPrograms/KinshipNavigatorProgramsSummaryAnalysis.aspx to see if a Navigator Program exists where you live.

Finally, see the fact sheet, Respite Services to Support Grandfamilies at http://archrespite.org/images/docs/Factsheets/FS_45-Grandparents_Grandchildren.pdf. Although it is a bit outdated, we think you'll still find it useful.

Can I take time off from work to care for my grandchild who has a 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 or guardianship 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 a fact sheet about the program at www.dol.gov/whd/regs/compliance/whdfs28.htm. The National Partnership for Women and Families also has a guide on the Family and Medical Leave Act. It was updated in 2013. For a link to that guide, go to www.nationalpartnership.org/issues/work-family/fmla.html.

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 leaves is available and if you will be paid while you are out caring for your grandchild or other relative.

Foster Care and Adoption for Children with Disabilities

I am a foster parent for my brother who has a disability. 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.



Photo by Linde LeGendre

Your brother should also most likely qualify for Medicaid because he is in foster care. Medicaid will pay for most of the health care that he needs. But check with your state Medicaid contact because the services are different in each state. Also, as of January 1, 2014, because of the Affordable Care Act, youth who leave foster care can get Medicaid coverage until they turn age 26. This also applies to former foster care youth who have left the system since 2006, as long as they were covered by Medicaid when they left the system. To find out about Medicaid in your state, visit <http://insurekidsnow.gov/> or call 1-877-KIDS-NOW.

Your brother 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. Ask your brother's caseworker or call the state Developmental Disabilities office about services in your area. To reach this office, look at NICHCY's State Organizations for your state to identify who to contact. Visit <http://nichcy.org/state-organization-search-by-state> and click the box for your state. State agencies for your state will automatically display and you should look under the heading "Developmental Disabilities." The agency listed there is the state contact. You can also get your state contact information by calling NICHCY at 1-800-695-0285 (Toll-free, Voice/TTY).

Finally, children with disabilities in foster care are also eligible for early intervention and special education and related services just like any other eligible children with disabilities.

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

Federal and state laws provide help for families who adopt children with special needs from the foster care system. Although states define "special needs" in different ways, they usually include children with disabilities.

The help available may include cash payments, ongoing Medicaid coverage, and other services to help with the child's special needs. A special tax credit can also help even if a child is not part of the foster care system.

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 allows each state to 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 brother at least until he is age 18 and potentially until he is age 21.

Families, including grandparents and other relatives who adopt children with special needs from the foster care system, 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 brother'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 brother 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. Visit <http://insurekidsnow.gov/> or 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 or without special needs also qualify for an adoption tax credit. It is a credit for the money you spent to adopt your brother. The Affordable Care Act made the credit refundable for 2010 and 2011, so if you adopted during those years, you could file an amended tax return and maybe get a refund check. As of 2012, the credit is no longer refundable. If you adopted your brother from the foster care system with special needs, you may be eligible for the maximum amount of credit for the year you adopted regardless of whether you had any qualifying expenses or not. For other adoptive parents, they must have qualifying expenses, such as legal fees. The maximum credit is now \$12,650 per child. For more information on this tax credit, visit www.irs.gov/taxtopics/tc607.html.

The Child Welfare Information Gateway has information if you want to adopt or have adopted a child. The focus is on adopting children from the foster care system, but it includes other types of adoptions as well. Visit www.childwelfare.gov/adoption/

The North American Council on Adoptable Children (NACAC) has useful information on adoption too, including specific information on the adoption of children with special needs. You can learn about adoption subsidies in all the states at www.nacac.org/adoptionssubsidy/stateprofiles.html and connect with the Adoption Subsidy Administrator in your state. For additional information,

Across the nation grandparents and other relatives raising children with special needs have found support in a variety of local programs. Some are designed to serve children with disabilities living with parents and have adapted services to address the unique challenges of relative caregiving. Others address range of needs facing relatives raising children from special education to legal assistance. These are two examples of local programs. For information about additional local programs and resources visit www.grandfactsheets.org or contact one of the resource organizations at the conclusion of this guide.

Parent to Parent of Whatcom County (Bellingham, Washington)

Learning that your child has a disability or a chronic health need can be a traumatic experience. Parents have many questions and concerns when coping with their child's need and their own feelings. You are not alone. We have been there.

With these comforting words on the home page of its website, the Parent to Parent program of Whatcom County lays out the welcome mat for parents of children with developmental disabilities and chronic illness who are searching for support and information.

And as hundreds of parents have found, the program lives up to its word, providing a wide array of services, including:

- Emotional support
- Information and referrals to community resources
- Parent Matches with trained Helping Parents (veteran parents whose experiences closely match those of parents seeking support)
- Workshops and training
- Social and recreational events
- Regularly published newsletters

Working with schools and doctors, the program attempts to alert as many parents and grandfamilies as possible to the resources available. Grandfamilies receive the same services as other parents and regularly meet with a kinship care navigator.

Similar Parent to Parent programs are in place across the country and can be replicated in other communities. Learn more about the Whatcom Parent to Parent program and learn how to establish a Parent to Parent program in your community <http://www.p2pusa.org>.

Kids & Families Together (Ventura, California)

In Ventura County, California, grandparents raising grandchildren with special needs have a real ally at Kids & Families Together (K&FT). K&FT is a not-for-profit agency whose kinship support services programs are funded by contracts with Ventura County's Departments of Human Services and Behavioral Health. The agency provides mental health, education and support services for individuals and families who are in foster care, kinship care and adoption. K&FT is unique because it has established Community Coalitions in five (5) target areas of the county. These Community Coalitions focus on the issues and needs of kinship families; and are focused on reducing the stigma associated with seeking assistance. Peer mentors are available to guide families to local resources as they navigate various systems to meet the special needs of children; and, to assist families as they apply for services and assistance from community agencies and organizations.

K&FT was established in 2000 to bridge the gaps in services available to parents, guardians and grandfamilies in Ventura County. Overall, the program works to preserve families and promote the physical and mental health of children. Today this comprehensive program offers:

- Mental Health services
- Parent education programs
- Support Groups for kinship, foster and adoptive families
- Kinship Care services
- Outreach, advocacy, referral and community education regarding kinship families; including children with developmental disabilities
- community Coalitions exclusively for kinship families
- Support Groups
- Peer Mentors
- Case Management and referrals for counseling, social services & financial assistance, child care & after-school programs, educational supports, housing and legal resources for guardianship assistance
- When available; provisions for food, clothing, transportation, beds and furniture

you can contact NACAC's Adoption Subsidy Resource Center at 800-470-6665 or through e-mail at adoption.assistance@nacac.org.

I adopted my brother two years ago, and we just learned that he has a disability. Where can I get help for him?

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 special needs from the foster care system. Sometimes this help is only available if your brother has an identified need that makes him eligible for adoption assistance at the time he is adopted. You can check with the agency that arranged the adoption to find out if these benefits are available to you.

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

Some states offer ongoing monthly cash assistance to some relatives who get legal guardianship of their kin. In order to qualify in most states, you must be caring for your relative's child as a licensed foster parent within the foster care system before you become his legal guardian.

The federal Fostering Connections to Success and Increasing Adoptions Act of 2008 allows states and tribes to take an option to offer financial assistance to grandfamilies under the Guardianship Assistance Program (GAP). GAP provides monthly assistance to what are known as "Title IV-E" eligible children who exit the foster care system into a guardianship with a relative.

As of August 2013, GAP is available in 30 states, the District of Columbia, and two tribes. The majority of these jurisdictions also offer guardianship assistance to those children who are not Title IV-E eligible leaving the foster care system with relatives. Unfortunately, very few places offer similar help to those children who have not first been part of the foster care system. For more information, visit www.grandfamilies.org/SubsidizedGuardianship/SubsidizedGuardianshipSummaryAnalysis.aspx

Children with Disabilities Turning Age 18

My grandson is turning 18 next year, and will never be able to hold a job or care for himself. What planning should I do?

There are a number of things that you should do before he turns 18.

- **Decision making issues.** If you think your grandson does not have the cognitive ability to make personal and financial decisions for himself, you should consult a lawyer and determine if you need to get an adult guardianship of your grandson. If he has enough capacity, maybe a power of attorney document will be enough. That can give you the legal authority to help him. The problem with power of attorney is that your grandson can easily revoke it.
- **Child support.** If you chose to get legal custody or guardianship of your grandson at any point while raising him, you may have also gotten a court order ordering a parent to provide you with child support to help meet your grandson's needs. You can ask the court to



Photo by Susan Klawien

continue child support into your grandson's adult years if he will not be able to hold a job or care for himself. You could also go back to court and ask for that continued support. See a chart prepared by the National Conference of State Legislators for more information at <http://www.ncsl.org/issues-research/human-services/termination-of-child-support-exception-for-adult.aspx>.

- **Supplemental Security Income (SSI).** The adult rules are different than the child rules in determining eligibility for SSI. It is important to make a doctor's appointment as soon as the child turns 18 to document that the child continues to have a disability that makes him eligible for SSI. The income rules also change when your grandson turns 18. If his parent or stepparent lived with you and their income was too high to allow your grandson to receive SSI, he may now be eligible because only his income and assets will be considered.
- **Other financial assistance.** Now that your grandson is becoming an adult, you may want to look at other sources of financial support that may be available to him. Ask about TANF, nutrition programs, and the other supports mentioned in this guide.
- **High school, vocational training, and higher education.** The federal special education laws cover your grandson until he turns age 21.
- **Trusts.** If you have money that you want to set aside for the future needs of your grandson, you can set up a trust. A trust is a protected account that can help meet your grandchild's future financial needs without risking the loss of the government benefits he may now get. 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. 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.

My grandson was my foster child. Are there any other things I should ask about for him?

Yes, there are several things you should ask the foster care agency about:

- **Support to age 19, 20 or 21.** Some states provide ongoing monthly financial assistance to older youth. You'll need to check with your state.
- **Transition plan.** Federal law requires the state to work with your grandson to develop a transition plan to adulthood that is as detailed as he wants. This plan complements the independent living service plan that is required for youth age 16.
- **Chafee Independent Living (IL) services.** These services may be available to help with education, employment, financial management, housing, and emotional support for older youth in foster care. You should check with your state to see what they provide.
- **The Educational and Training Vouchers Program (ETV) for Youths Aging out of Foster Care.** This program provides vouchers of up to \$5,000 per year for eligible youth in post-secondary education and training.
- **Supervised independent living settings.** The state may provide living assistance to older foster care youth.
- **Medicaid coverage.** The Affordable Care Act requires states to provide Medicaid to foster youth who have left or are leaving foster care until they reach age 26. States have the option to cover former foster youth who left foster care in another state.
- **Health care power of attorney or proxy.** The Affordable Care Act ensures that children aging out of foster care have information about the importance of having a health care power of attorney or health care proxy. They also have the option to get help to prepare such a document.

I adopted my grandson from foster care. Can I still get adoption assistance to help meet his needs after he turns 18?

Continued adoption assistance may be available until age 21, if the state has taken that option under federal law. You should ask the agency that oversees your grandson's adoption assistance.

I got legal guardianship of my grandson and have been receiving guardianship assistance payments from the state to help meet his needs. Can that assistance continue after he turns 18?

Continued guardianship assistance may be available until age 21, if the state has taken that option under federal law. You should ask the agency that oversees your grandson's guardianship assistance.

Caregiver Checklist

Children with disabilities can get free or low-cost services for many of their needs, and cash and other help to meet their needs. Here is a checklist of things for you to consider in helping meet the needs of your grandchild or other relative:

Health insurance. Your grandchild may qualify for health insurance through:

- Medicaid
- the Children’s Health Insurance Program (CHIP)
- the new Affordable Care Act Marketplace or
- your existing private insurance coverage

See pages 12-13.

Additional needs. You may be able to get help with additional needs, like building a wheelchair ramp in your home. See pages 14-15.

Supplemental Security Income (SSI). If your grandchild qualifies, you may be able to access a monthly cash benefit to help meet his or her needs through the Supplemental Security Income (SSI) Program. See pages 16-18.

Other cash benefits. Your grandfamily may qualify for:

- Temporary Assistance for Needy Families (TANF) family or “child-only” grants, and/or
- Social Security survivors, disability or work benefits.

See page 22.

Help paying for food. There are a few programs that may help you feed your grandchild:

- The Supplemental Nutrition Assistance Program (SNAP), formerly known as “Food Stamps”
- The Women, Infants and Children (WIC) Program
- The National School Breakfast and Lunch Programs
- The Summer Food Service Program (SFSP)

See pages 22-23.

Tax credits. There are several tax credits that you may be able to claim.

- The Earned Income Tax Credit (EITC)
- The child tax credit
- The additional child tax credit
- The child and dependent tax care credit
- The adoption tax credit
- Additional tax benefits
 - Do not claim SSI payments for either you or the child as part of your gross income.
 - Tax credits themselves are also not counted as income. They will not be counted when you apply for financial help.

See page 23.

Early intervention services. If your grandchild is age birth to 3, he or she may qualify for early intervention programs and services like physical therapy. Fees may apply. See pages 24-25

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. See page 26.

Special education and related services. Your grandchild may qualify for special education and related services, such as physical therapy, from age 3 through high school. See pages 26-36.

Section 504 plan. Your grandchild may need a Section 504 plan that provides reasonable accommodations to students with disabilities, such as a specially designed desk chair. 504 plans may continue through college or other post-secondary education. See pages 36-37.

Mental health services. There are special services for mental health needs that may be available to your grandchild. See pages 37-39.

Respite care and family leave. Your community may have services to give you a break from caregiving. Family and medical leave may also be available if you need to take time off from work to care for your grandchild. See pages 39-41.

Foster care services. Your state or county child welfare office will have information about services to help children with disabilities who are in foster care. See page 41.

Adoption assistance. Grandfamilies may get monthly adoption assistance payments (adoption subsidies) as well as other supports if they adopt children with disabilities from the foster care system. See pages 41, 42 and 45.

Special things to consider as children with disabilities turn 18.

- Legal decision making issues
- Continued child support
- Supplemental Security Income (SSI) eligibility changes
- Other financial assistance
- High school, vocational training, and higher education
- Trusts

If your grandchild is in foster care with you, also ask about:

- Support to age 19, 20 or 21
- Transition plan
- Chafee Independent Living (IL) services
- The Educational and Training Vouchers Program (ETV) for Youths Aging out of Foster Care
- Supervised independent living settings
- Continued Medicaid coverage
- Health care power of attorney or proxy

If you adopted your grandson from foster care, ask about continued adoption assistance.

If you got guardianship of your grandson and receive guardianship assistance, ask if it can continue. See pages 45-47.

Helpful Resources

The groups listed below provide information or services to grandparents and other relative caregivers as well as parents raising children with disabilities. For a full list of resources, visit www.gu.org.

211 Resource Line

Internet: www.211.org

211 is a great way to find local resources in your area. They provide free and confidential information that can help with food, housing, employment, health care, counseling and more. 211 has 100% coverage in 39 states. All states have at least partial coverage. Visit www.211.org/ and type in your zip code or dial 211 on your phone for more information.

AARP – Grandparent Information Center

601 E Street, NW
Washington, DC 20049
1-888-687-2277 Toll-Free
1-877-434-7598 (TTY)
Internet: www.aarp.org/confacts/programs/gic.html
AARP QuickLinks: www.AARP.org/quicklink
GrandFacts: www.grandfactsheets.org

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

ALLIANCE National Parent Technical Assistance Center Network (NPTAC)

8161 Normandale Blvd.
Minneapolis, MN 55437
888-248-0822 Toll Free
952-838-90001
952-838-0190 (TTY)
952-838-0199 Fax
Internet: www.parentcenternetwork.org/national/resources.html

The ALLIANCE National PTAC is a project of PACER Center and provides Parent Centers, Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs), with innovative technical assistance, up-to-date information, and national and state wide resources and materials. Although they use the word “Parent”, they also include you as a grandparent or other relative caregiver.

Alliance for Technology Access Center

1119 Old Humboldt Road
Jackson, TN 38305
1-800-914-3017 Toll Free
731-554-5284 (TTY)
Fax 731-554-5283
Internet: www.ataccess.org/index.php/reading-room/centers.

Alliance Technology Centers are in many communities around the country and have programs to help people with disabilities get the assistive technology devices that they need.

American Academy of Child and Adolescent Psychiatry

3615 Wisconsin Avenue, NW
Washington, DC 20016
202-966-7300
202-966-2891 Fax
Internet: www.aacap.org

The Academy is the professional organization for child and adolescent psychiatrists. Their website has information sheets on many different mental health topics.

American Bar Association Center on Children and the Law

740 15th Street, NW
Washington, DC 20005
202-662-1000
Internet: www.americanbar.org/aba.html

The American Bar Association has resources for lawyers, publications and advocacy information. Their Center on Children and the Law is specific to children, families, education, and child welfare issues.

The Arc

1825 K Street NW, Suite 1200
Washington, DC 20006
800-433-5255 Toll Free
202-534-3700
Internet: www.thearc.org

The Arc works to promote and improve benefits, supports, and services for children and adults with intellectual and developmental disabilities 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.

ARCH National Respite Network and Resource Center (NRLS)

800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
1-800-773-5433
919-490-4905 Fax
Internet: www.respitelocator.org
Service Locator: www. chtop.com/Locator.htm

The ARCH National Respite Network provides information and resources for respite care. The National Respite Locator, helps caregivers and professionals locate respite services in their community.

The Brookdale Foundation Group

Relatives As Parents Program (RAPP)

400 Kelby St.

Ft. Lee, NJ 07024

201-346-1244

201-346-1247 Fax

Internet: www.brookdalefoundation.org

RAPP provides extensive services, primarily to relative caregivers caring for children outside the foster care system, in 44 States, the District of Columbia, and Puerto Rico. They conduct a National Orientation and Training Conference and provide technical assistance through site bulletins, a listserv, an annual newsletter, conference calls and web-chats to facilitate opportunities for networking and information exchange.

Center for Disease Control and Prevention (CDC)

1600 Clifton Rd.

Atlanta, GA 30333

800-232-4636

888-232-6348 (TTY)

Internet: www.cdc.gov/

Milestone Screening:

www.cdc.gov/ncbddd/actearly/milestones/index.html

The CDC protects America from health, safety and security threats, both foreign and in the U.S. Whether diseases start at home or abroad, are chronic or acute, curable or preventable, human error or deliberate attack, CDC fights disease and supports communities and citizens to do the same. The CDC provides a developmental milestones screening for parents and caregivers to use at home in order to make sure their children are developing properly.

Center for Mental Health Services' Knowledge Exchange Network (CMHS) Substance Abuse and Mental Health Services Center for Mental Health Services

1 Choke Cherry Road

Rockville, MD 20857

240-276-1310

240-276-1320 Fax

Internet: <http://www.samhsa.gov/>

CMHS treats mental illnesses by promoting mental health and by preventing the development or worsening of mental illness when possible. They help states improve and increase the quality and range of their treatment, rehabilitation, and support services for people with mental illness, their families, and communities. Further, they encourage a range of programs-such as systems of care-to respond to the increasing number of mental, emotional, and behavioral problems among America's children. CMHS supports outreach and case management programs for the thousands of Americans with severe mental illness who are homeless and supports the development and adoption of "models" for improving services.

Children's Defense Fund (CDF)

25 E Street, NW
Washington, DC 20001
800-233-1200 Toll Free
202-628-8787
202-662-3550 Fax
Internet: 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.

Child Welfare League of America

1726 M Street, NW, Suite 500
Washington, DC 20036
202-688-4200
202-833-1689 Fax
Internet: www.cwla.org

The Child Welfare League of America offers resources and information on issues affecting grandparents and other caregivers raising children inside and outside of the child welfare system.

Council on Developmental Disabilities (DD Councils)

1151 South Fourth Street
Louisville, KY 40214
502-584-1239
502-584-1261 Fax
Internet: www.councilondd.org

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.

Early Childhood Technical Assistance Center (ECTAC)

Campus Box 8040, UNC-CH
Chapel Hill, NC 27599
919-962-2001
919-966-7463 Fax
Internet: www.ectacenter.org
State Part C coordinators click on <http://ectacenter.org/contact/ptccoord.asp>
State Part C website: <http://ectacenter.org/contact/contacturl.asp?gc=101>
State Section 619 coordinators: <http://ectacenter.org/contact/619coord.asp>
State Section 619 websites: <http://ectacenter.org/contact/contacturl.asp?gc=102>

ECTAC provides information about the early intervention and preschool grant programs funded by the federal government. The Early Childhood Technical Assistance Center is funded by the Office of Special Education Programs to improve state early intervention and early childhood special

education service systems, increase the implementation of effective practices, and enhance the outcomes of these programs for young children and their families.

Easter Seals Inc.

233 South Wacker, Suite 2400

Chicago, IL 60606

1-800-221-6827

312-726-1494 Fax

Internet: www.easterseals.org/

Branch Locator: www.easterseals.com/connect-locally/

Developmental Milestone Screening:

http://es.easterseals.com/site/PageServer?pagename=ntlc10_mffc_homepageasq

Easter Seals provides services to children with physical and mental disabilities and other special needs. Services include early intervention, physical and occupational therapy, and speech and hearing therapy. They operate child care centers around the country that serve children with disabilities. Easter Seals also has a developmental milestone screening tool that you can use to see if a child ages birth to 5 is typically developing. It will take you about 10 to 15 minutes to complete.

eXtension

Internet: www.extension.org

Video with "words of wisdom" to grandparents raising grandchildren:

www.youtube.com/watch?v=hq7x4FHBHWY&list=SPC62A7602703246B3&index=1

eXtension is an interactive learning environment from America's land-grant colleges and universities that provides research-based information for family caregivers.

Families & Advocates Partnership For Education (FAPE)

PACER Center

8161 Normandale Blvd.

Minneapolis, MN 55437

1-888-248-0822

952-838-0190 (TTY)

952-838-0199 Fax

Internet: www.fape.org

FAPE, a PACER Center website, provides parents, educators, service providers, and policymakers with important national news and information related to improving educational outcomes for children with disabilities. The Families and Advocates Partnership for Education (FAPE) project, linked families and advocates to information about the Individuals with Disabilities Education Act (IDEA). Although the FAPE project has ended, PACER maintains this website to keep families and professionals informed of important issues related to IDEA and other relevant education topics.

Family Voices

3701 San Mateo Blvd NE, Suite 103

Albuquerque, NM 87110

1-888-835-5669

505-872-4780 Fax

Internet: www.familyvoices.org

State Chapter List: www.familyvoices.org/states

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.

Generations United

1331 H Street, NW, Suite 900

Washington, DC 20005

202-289-3979

202-289-3952 Fax

Internet: www.gu.org

Grandfamilies Information: www.gu.org/OURWORK/Grandfamilies.aspx

Generations United's National Center on Grandfamilies works to enact policies and promote programs to help grandfamilies address various challenges such as housing, education, health, legal, and financial. Generations United also produces a variety of publications and materials for grandparents and other relative caregivers.

Grandfamilies State Law and Policy Resource Center

Internet: www.grandfamilies.org

Educational consent laws:

www.grandfamilies.org/Education/EducationSummaryAnalysis.aspx

Health care consent laws: www.grandfamilies.org/Medical/MedicalSummaryAnalysis.aspx

Kinship navigator programs: <http://www.grandfamilies.org/KinshipNavigatorPrograms/KinshipNavigatorProgramsSummaryAnalysis.aspx>

The Grandfamilies State Law and Policy Resource Center is a collaboration among the American Bar Association's Center on Children and the Law, Generations United, and Casey Family Programs. The Center provides a searchable database of laws and legislation affecting grandfamilies both inside and outside the foster care system for all 50 states and the District of Columbia; summaries and comparisons of laws and legislation for twelve legal topic areas; and resources and publications.

Legal Services Corporation

3333 K Street, NW

Washington, DC 20007

202-295-1500

202-337-6797 Fax

Internet: www.lsc.gov/local-programs/program-profiles

Legal Services Corporation is a nonprofit corporation that promotes equal access to justice and provides grants for high-quality civil legal assistance to low-income Americans. They distribute more than 90 percent of their total funding to 134 independent nonprofit legal aid programs with more than 800 offices.

Mental Health America (MHA)

2000 North Beauregard Street, 6th Floor

Alexandria, VA 22311

1-800 969-6642 Toll Free

703-684-7722

800-433-5959 (TTY)

703-684-5968 Fax

Internet: www.mentalhealthAmerica.net

MHA 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 Association of Area Agencies on Aging

1730 Rhode Island Ave NW

Washington, DC 20036

202-872-0888

Internet: www.n4a.org/about-n4a/?fa=aaa-title-VI

The association supports the national network of 618 Area Agencies on Aging and 246 Native American Title VI programs.

National Association of State Directors of Developmental Disabilities Services (NASDDDS)

113 Oronoco Street

Alexandria, VA 22314

703-683-4202

703-684-1395 Fax

Internet: 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 Conference of State Legislatures (NCSL)

444 North Capitol Street, NW, Suite 515

Washington, D.C. 20001

202-624-5400

202-737-1069 Fax

Internet: www.ncsl.org

The National Conference of State Legislatures is a bipartisan organization that serves the legislators and staffs of the nation's 50 states, its commonwealths and territories. NCSL provides research, technical assistance and opportunities for policymakers to exchange ideas on the most pressing state issues. NCSL is also an advocate for the interests of state governments before Congress and federal agencies.

National Disability Rights Network (NDRN)

900 Second Street, NE, Suite 211

Washington, DC 20002

202-408-9514 ext.122

202-408-9521 (TTY)

202-408-9520 Fax

Internet: www.ndrn.org

NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). There is a P&A/CAP agency in every state and U.S. territory as well as one serving the Native American population in the four corners region. Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States.

National Dissemination Center for Children with Disabilities

1825 Connecticut Avenue, NW

Washington, DC 20009

1-800-695-0285 Toll Free

202-884-8200

202-1884-8441 Fax

Internet: www.nichcy.org

State agency locator: www.nichcy.org/state-organization-search-by-state

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. NICHCY is a source of information on disability topics, the education rights of children with disabilities, state specific agencies and organizations, and many other resources.

National Federation of Families for Children's Mental Health

9605 Medical Center Drive, Suite 280

Rockville, MD 20850

240-403-1901

240-403-1909 Fax

Internet: www.ffcmh.org

State Chapter List: www.ffcmh.org/find-local-chapter

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.

National Immigration Law Center

3435 Wilshire Boulevard, Suite 2850

Los Angeles, CA 90010

213-639-3900

213-639-3911 Fax

Internet: www.nilc.org

Immigration eligibility for SSI and other programs: www.nilc.org/table_ovrw_fedprogs.html.

The National Immigration Law Center is a national legal advocacy organization exclusively dedicated to defending and advancing the rights of low-income immigrants and their families.

National Partnership for Women & Families

1875 Connecticut Avenue, NW, Suite 650

Washington, DC 20009

202-986-2600

202-986-2539 Fax

Internet: www.nationalpartnership.org

Guide to Family Medical Leave Act: www.nationalpartnership.org/site/DocServer/FMLAGuide5thedition02.pdf?docID=958

The Partnership provides information about laws and policies for health care, work, and family issues.

National Resource Center for Permanency and Family Connections (NRCPFC)

Silberman School of Social Work at Hunter College

2180 Third Avenue, 7th Floor

New York, NY 10035

212-396-7500

212-396-7640 Fax

Internet: www.nrcpfc.org

The National Resource Center for Permanency and Family Connections at the Hunter College School of Social Work is a training, technical assistance, and information services organization dedicated to help strengthen the capacity of State, local, Tribal and other publicly administered or supported child welfare agencies to: institutionalize a safety-focused, family-centered, and community-based approach to meet the needs of children, youth and families. The NRCPFC provides on- and off-site Training and Technical Assistance (T&TA), which is customized for each request and designed to build capacity in child welfare systems and to support States, Territories and Tribes in achieving sustainable, systemic change resulting in greater safety, permanency and well-being for children, youth and families.

North American Council on Adoptable Children (NACAC)

970 Raymond Avenue, Suite 106

St. Paul, MN 55114

651-644-3036

651-644-9848 Fax

Internet: www.nacac.org/adoptionssubsidy/stateprofiles.html

NACAC provides information on specific eligibility, benefit, funding, and other characteristics of each state's adoption subsidy program.

PACER Center, Inc.

8161 Normandale Blvd.

Minneapolis, MN 55437

888.248.0822 Toll Free

952.838.0199 Fax

Internet: <http://www.pacer.org/>

Parent Advocacy Coalition for Educational Rights (PACER) expands opportunities and enhances the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents. The PACER Center was created by parents of children and youth with disabilities to help other parents and families facing similar challenges. They also help many grandparents and other relatives raising children. The center is staffed primarily by parents of children with disabilities and works in coalition with 18 disability organizations. (Visit <http://www.pacer.org/pandr/proglist.asp> for list of other programs.)

U.S. Department of Agriculture

Food and Nutrition Services
1400 Independence Ave., SW
Washington, DC 20250
202-720-2791
Internet: www.usda.gov/wps/portal/usda/usdahome
SNAP Information: www.fns.usda.gov/snap/
WIC Information: www.fns.usda.gov/wic/

Food and Nutrition Services provides resource to help eligible relative caregivers meet nutrition needs of children they raise.

U.S. Department of Education

Office for Civil Rights
Lyndon Baines Johnson Dept. of Education Bldg.
400 Maryland Avenue, SW
Washington, DC 20201
800-421-3481 Toll Free
202-453-60201
1-877-521-2172 (TDD)
202-453-6012 Fax
Internet: <https://wdcrobcolp01.ed.gov/CFAPPS/OCR/contactus.cfm>
File A Complaint: www2.ed.gov/about/offices/list/ocr/complaintprocess.html

The Office for Civil Rights of the U. S. Department of Education ensures equal access to education and promotes 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.

U.S. Department of Health & Human Services

200 Independence Avenue, SW
Washington, D.C. 20201
1-877-696-6775
Internet: www.hhs.gov/

The Department of Health and Human Services (HHS) is the United States government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves.

U.S. Department of Health and Human Services

Administration on Aging

National Family Caregiver Support Program

330 Independence Ave SW
Washington, DC 20201
202-401-4634
Internet: <http://www.aoa.gov/>

The program calls for all States, working in partnership with Area Agencies on Aging and local community-service providers, to provide basic services for family caregivers.

**U.S. Department of Health and Human Services
Administration for Children and Families
Administration on Intellectual and Developmental Disabilities (AIDD)**

370 L'Enfant Promenade, SW
Washington, D.C. 20447
202- 690-6590
202- 205-8037 Fax
Internet: <http://www.acl.gov/programs/aidd/index.aspx>

AIDD ensures that individuals with developmental disabilities and their families are able to fully participate in and contribute to all aspects of community life in the United States and its territories. In each state or territory, there is a Developmental Disabilities Network, or DD Network, that is uniquely positioned to meet the diverse needs of individuals with developmental disabilities in their state.

**U.S. Department of Health and Human Services
Administration for Children and Families
Office of Child Care**

370 L'Enfant Promenade, SW
Washington, D.C. 20447
Internet: www.acf.hhs.gov/programs/ccb/

The Office of Child Care administers the Child Care and Development Fund (CCDF). CCDF helps low-income families obtain child care so they can work or attend training/education.

**U.S. Department of Health and Human Services
Administration for Children and Families
Child Welfare Information Gateway**

370 L'Enfant Promenade, SW
Washington, D.C. 20447
800-394-3366 Toll Free
Internet: www.childwelfare.gov/adoption/

The Gateway has information for individuals who want to adopt or have adopted a child. The focus is on adopting children from the foster care system, but it includes other types of adoptions as well.

**U.S. Department of Health and Human Services
Administration for Children and Families
Head Start Bureau**

370 L'Enfant Promenade, SW
Washington, D.C. 20447
1-866-763-6481 Toll Free
Internet: www.acf.hhs.gov/programs/ohs/
Center Locator: <http://eclkc.ohs.acf.hhs.gov/hslc/HeadStartOffices>

Head Start is a federal program that promotes the school readiness of children ages birth to 5 from low-income families by enhancing their cognitive, social and emotional development.

**U.S. Department of Health and Human Services
Health Resources and Service Administration
Maternal and Child Health**

5600 Fishers Lane
Rockville, MD 20857
888-275-4772 Toll Free
877-489-4772(TTY)
Internet: www.mchb.hrsa.gov/index.html

State by State information: www.mchb.hrsa.gov/programs/titlevgrants/index.html.
Title V Maternal and Child Health Program is the Nation's oldest Federal-State partnership. Federal Title V Maternal and Child Health program provides a foundation for ensuring the health of the Nation's mothers, women, children and youth, including children and youth with special health care needs, and their families.

**U.S. Department of Health and Human Services
Insure Kids Now**

1-877-KIDS-NOW
Internet: <http://insurekidsnow.gov/>

Insure Kids Now provides information about Medicaid and CHIP services for families who need health insurance coverage. These programs are designed to be affordable for families who are not able to purchase health insurance coverage in the private market or do not have coverage available to them.

**U.S. Department of Health & Human Services
Office for Civil Rights**

Hubert H. Humphrey Building, Room 509F
200 Independence Avenue, SW
Washington, DC 20201
1-877-696-6775 Toll Free
1-800-368-1019
1-800-877-8339 (TDD)
Internet: 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 someone believes they have been discriminated against because of race, color, national origin, disability, age, and in some cases sex or religion, by those who receive funds from HHS, they may file a complaint with OCR.

**United States Department of Justice
Civil Rights Division Disability Rights Section**

950 Pennsylvania Avenue, NW
Washington, D.C. 20530
800-514-0301

800-514-0383 (TTY)
Internet: www.ada.gov

The U.S. Department of Justice enforces the law and defends the interests of the United States. The U.S. Department of Justice also provides information and technical assistance for the Americans with Disabilities Act.

U.S. Department of Labor

200 Constitution Ave NW
Washington DC 20210
(202) 693-2700
1-866-487-2365(TTD)
Internet: www.dol.gov
Family Medical Leave Act Factsheet: www.dol.gov/whd/regs/compliance/whdfs28.htm.

The Department of Labor fosters, promotes, and develops the welfare of the wage earners, job seekers, and retirees of the United States. They also oversee the implementation of the Family Medical Leave Act, which entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons.

U.S. Internal Revenue Service

1111 Constitution Ave NW
Washington, 20004
202-622-5000
Internet: www.irs.gov/
Earned Income Tax Credit (EITC): www.irs.gov/individuals/article/0,,id=96406,00.html
Child Tax Credit: www.irs.gov/newsroom/article/0%2C%2Cid=106182%2C00.html
Child and Dependent Tax Care Credit: www.irs.gov/uac/Ten-Things-to-Know-About-the-Child-and-Dependent-Care-Credit
Additional Child Tax Credit: www.irs.gov/publications/p972/aro2.html#en_US_2012_publink1-00012090
Adoption Tax Credit: www.irs.gov/taxtopics/tc607.html

The U.S. Internal Revenue Service provides tax information that may benefit grandparents and other relative caregivers raising children.

U.S. Social Security Administration

1905 9th St NE
Washington, DC 20018
1-800-772-1213 Toll Free
Internet: www.ssa.gov
Social Security Disability Planner: <http://www.ssa.gov/dibplan/index.htm#ssi>

The Social Security Administration is the federal office that Administers Social Security Benefits including Disability Benefits and Supplemental Security Income (SSI). They also have a number of resources to help users navigate the system.



Because we're stronger together®

Generations United
1331 H Street, NW
Suite 900
Washington, DC 20005

www.gu.org