

Family Resource Guide

A guide to benefits, supports & services for families raising children with
mental retardation and related developmental disabilities

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Updated October 2003





Table of Contents

Introduction	1
Part One: Children and Youth Through Age 21	3
<u>Income Assistance</u>	3
1. Supplemental Security Income (SSI)	3
2. Social Security Disability Insurance (SSDI).....	4
3. Trusts.....	5
4. Temporary Assistance to Needy Families (TANF)	6
5. Earned Income Tax Credit (EITC)	7
<u>Health Care & Related Services</u>	8
1. Medicaid	8
2. State Children’s Health Insurance Program (SCHIP).....	9
3. Maternal and Child Health Services (MCH or Title V)	9
4. Home and community based (HCB) waiver	10
5. TEFRA (“Katie Beckett” waiver).....	11
6. Intermediate Care Facilities for People with Mental Retardation (ICF/MR)	12
7. Tax Deduction for Medical Expenses	13
<u>Education</u>	15
<u>Family Support</u>	16
<u>Programs to Help Families Meet Other Basic Needs</u>	17
1. Food Programs - Food Stamps, WIC, School Breakfast, School Lunch	17
2. Social Services (Title XX)	19
3. Technology assistance.....	20
4. Family and medical leave.....	21
5. Child support	22
6. Tax provisions - Child Tax Credit, Child & Dependent Care Credit	22
<u>Child Welfare Services</u>	24
1. Getting services for children with mental retardation/developmental disabilities.....	24
2. Finding another home for children with mental retardation/developmental disabilities.....	25
3. Adopting children with mental retardation/developmental disabilities	25
4. Tax credit for special needs adoptions	27
5. Preventing child abuse and neglect	27



Part Two: Age Specific Services	29
<u>Services for Infants & Very Young Children</u>	29
1. Early Intervention (birth - age 3)	29
2. Pre-School Children (ages 3 - 5).....	29
3. Early Head Start/Head Start	30
4. Child care	31
<u>School Age Children</u>	32
1. Public education (ages 5 - 21).....	32
2. Special Accommodations (Section 504)	33
<u>Adolescents Making Transition to Adult Life</u>	35
1. Plan for Achieving Self-Support (PASS)	35
2. Vocational services	36
Part Three: Civil Rights Protections	37
1. Resolving conflicts between schools and parents of children with disabilities.....	37
2. Protection against discrimination	38
(a) Section 504.....	38
(b) Americans with Disabilities Act (ADA).....	39
Part Four: Where Can Families Get Help?	40
1. The Arc	40
2. State Developmental Disabilities Councils (DD Council).....	40
3. Protection & Advocacy Agency (P&A).....	41
4. University Centers for Excellence (formerly UAP)	42
5. Parent Training and Information (PTI) Centers.....	42
6. National Information Center for Children and Youth with Disabilities (NICHCY).....	43
7. National Center for Parent Support.....	43
8. The Beach Center on Families and Disabilities	44
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Introduction

To have self-determination, people need information to help them make choices and decisions.

The Family Resource Guide is written for families raising children with mental retardation and related developmental disabilities. It tells you about benefits, supports and services that might help you and your child.

Families have told us that they need this information to know what resources are available in their state and community. With this information, you can make more informed decisions about services and supports to help you raise your child. It also gives you a better understanding about choices that you can make to improve the quality of life for your child and family.

The Family Resource Guide describes many federal programs. Some programs vary by state or county depending on where you live. For each program, this guide provides you the following:

- Authority - the federal legal source for the program and the name of the agency that runs the program at the federal or state level
- Benefit/support/service - describes the benefit, support or service that the law provides
- Eligibility - explains financial and non-financial rules that decide which children or families qualify for the benefit, support or service (example: size of their income; type or severity of disability)
- For more information or how to apply - lists the state or federal office where you can apply or get more information about eligibility rules in your state.

Wherever possible, Web sites are provided where you can get more information. If you do not have a personal computer at home or at your office, go to your local public library. Most of them have computers for families to use.

This Guide was prepared especially for families raising children with mental retardation and related developmental disabilities. Here's how we define these two terms:

- "Mental retardation" includes children who have an IQ below 70-75. Their daily living skills are significantly limited and they have the condition before age 18. (Definition from the American Association on Mental Retardation, 1992 edition, Mental Retardation Definition, Classification, and Systems of Support).
- "Developmental disability" includes children who have a mental or physical disability that appears before age 22 that will probably continue indefinitely. Their daily living skills are significantly limited. They will need services for a long time or for their entire life. (Definition from the Developmental Disabilities Assistance and Bill of Rights Act of 2000).



It is important to know how your state defines both mental retardation and developmental disability. Not all states use the same definition of mental retardation. Some state programs only serve individuals with developmental disabilities, especially children under age 10. While some states refer to people with mental retardation, others say people with developmental delays. Ask your state chapter of The Arc what definitions your state uses. You can find your local chapter of The Arc by going to <http://www.thearc.org> and clicking on the "Locations" button.

All the benefits, supports and services described have rules that decide which children and families may qualify. Some rules are based on the kind or severity of the disability. Other rules are based on how much money your family earns. The financial rules often use the federal poverty guidelines. These federal guidelines change every year, usually in February. For some programs, states are allowed to set their own income eligibility based on different percentages below the federal guidelines. In 2003, the federal poverty line for a family of four was \$18,400. You can get annual numbers at <http://aspe.hhs.gov/poverty>.

The Arc would like to thank Rhoda Schulzinger, Esquire, for preparing this guide. Volunteer leaders and staff of The Arc contributed significantly by reviewing the initial drafts. This guide was prepared through a sub-contract on a grant from The Robert Wood Johnson Foundation. While this document is part of the Foundation's effort in Self Determination, the information and opinions contained here are not necessarily those of the Robert Wood Johnson Foundation.



Part One: Children and Youth Through Age 21

Income Assistance

1. Supplemental Security Income (SSI)

Authority: Social Security Act, Title XVI (Title 16)

Benefit

SSI provides cash benefits to eligible individuals with disabilities. Your child can receive up to \$552.00 as a federal payment every month in 2003. However, some states also give an extra payment. SSA increases SSI benefits every January if the cost of living increases nationally.

In most states, children who get SSI also qualify for free medical care through the Medicaid program. You can read more about Medicaid in “Health Care and Related Services” later in **Part One**. People who get SSI may also qualify for food stamps. You can read more about food stamps in “Programs to Help Families Meet Other Basic Needs” later in **Part One**.

As your child gets older, he or she may be able to work under special rules and still receive SSI and Medicaid. The child may also receive long-term care under Medicaid.

Eligibility

There are both financial and disability rules. The financial rules count the parents’ income from salary or wages. The rules also count the parents’ resources such as savings or property to decide if your child qualifies. The amount of money you have affects eligibility and how much SSI your child gets each month.

The disability rules require children to have “marked and severe” functional limitations from a physical or mental condition. This means that your child cannot do the same things that another child who is the same age, but who does not have disabilities, can do.

To apply

You can make an appointment at the nearest SSA office or speak with a service representative by telephone. Call SSA’s toll-free number at 1-800-772-1213 on Monday through Friday between 7 a.m. and 7 p.m. (Eastern time). If you are deaf or hard of hearing and need a TTY, call toll-free 1-800-325-0778 during the same hours.



These numbers are very busy early in the week and early in the month so it's best to call at other times. When you call, have your Social Security number handy. When you talk with someone, ask if your state makes an extra SSI payment and how you apply for it.

In some states, children who are eligible for SSI automatically qualify for Medicaid. This is not true in all states so ask someone at the SSA office if you need to make a separate application for Medicaid.

[In (name of state), you must apply for Medicaid separately at (say where to go; maybe welfare office in department of social or human services)].

2. Social Security Disability Insurance (SSDI)

Authority: Social Security Act, Title II (Title 2)

Benefit

SSDI provides monthly cash payments to eligible workers and **sometimes** to their dependent children. The size of the payment depends on how long the worker paid into the Social Security system. SSA increases SSDI benefits every January if the cost of living increases nationally.

Eligibility

There are financial and other rules for workers. If you are a worker who becomes disabled or blind before you retire, then you may qualify for these benefits. When you retire, become disabled or die, your dependent children **of any age** can get cash every month.

The size of your child's payment is based upon your benefit. Your child will get up to 50 percent of the benefit if you retire or become disabled and up to 75 percent if you die. There is a family maximum when both you and your child get benefits.

To apply

You can make an appointment at the nearest SSA office or speak with a service representative on the telephone. Call SSA's toll-free number at 1-800-772-1213 on Monday through Friday between 7 a.m. and 7 p.m. (Eastern time). If you are deaf or hard of hearing and need a TTY, call toll-free 1-800-325-0778 during the same hours.

These numbers are very busy early in the week and early in the month so it's best to call at other times. When you call, have your Social Security number handy.



3. Trusts

Authority: Federal and state laws allow parents to put aside money for the future needs of their children with disabilities.

Benefit

A trust can help protect your child's future needs without losing government benefits. When your child inherits money or other assets from you, this increases how much money he or she has. This affects the fee that the state may charge for any public services your child receives. [This fee is often called the "cost of care."]

An inheritance may also cause your child to lose some or all of his or her SSI cash benefits or Medicaid. To avoid affecting these benefits, you can consider making a trust that follows the SSI and Medicaid rules. There are different kinds of trusts. Some you make while you are alive and others can be set up as part of your will.

Eligibility

If you have the money to set up a trust, consider what options are available in your state. If your child receives money in his or her own name, it is also possible to set up a trust that follows the SSI and Medicaid rules.

For more information

Setting up trusts is very complicated. You should work with a lawyer and financial planner who know about disability. These people can help you select and set up the kind of trust that works best in your state. It is very important that your trust follow both state and federal rules.

Go to <http://www.thearc.org> to find more information about trusts. Click on "Information" and then look at the topic "Mental Retardation," and you will find several fact sheets about future planning and trusts. You should also contact your chapter of The Arc for names of lawyers who can help you. Go to <http://www.thearc.org> for a list of local chapters.

4. Temporary Assistance to Needy Families (TANF)

Authority: Social Security Act, Title IV-A (Title 4-A) as amended by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. This legislation is often called “welfare reform” and other laws amended it later.

Benefit

TANF replaced the Aid to Families with Dependent Children (AFDC) program. States receive TANF funds to provide cash payments, work opportunities and other services to eligible families with children.

Eligibility

If your family needs cash, you can apply for TANF. However, you must follow a number of federal and state rules. Many rules are different from state-to-state because states decide what families must do to qualify and what services families can get. Some of the most important rules are:

1. Most adults must go to work after getting TANF for two years. States may recognize “good cause” reasons why some people cannot work. Some states do not require mothers who are caring for a child with a disability to work, but this is not always true. [*In (state), (describe “good cause” exemptions)*] Also, since states define “work” in different ways, you need to know what is required where you live. Sometimes this means that you must have a job and other times it gives you time to look for a job or attend a training program or school.
2. Your family is limited to five years of TANF benefits during your entire life. This means that after getting benefits for five years in a row or over a longer time period, you cannot ever get benefits again. Your state may even have a shorter time limit. Some states excuse certain families from the time limit under “hardship” rules. You need to find out if your state includes raising children with disabilities as a “hardship.”
3. Teen parents must live with an adult and go to school or a training program to qualify for TANF.
4. When you apply, you must sign an agreement that lets the state keep any child support that is collected as long as you receive TANF. Your local child support enforcement agency is required to help you get child support if you get TANF.



To apply

Apply at your local welfare office. It may be part of your state department of social services or human services.

[In (state), apply (what welfare office is called in your area)].

5. Earned Income Tax Credit (EITC)

Authority: Internal Revenue Code, Section 32

Benefit

The Earned Income Tax Credit (EITC) is a refundable federal tax credit for eligible low- and moderate-income individuals and families who work. The EITC reduces the amount of tax you owe. It may give you a refund from the Internal Revenue Service (IRS).

Eligibility

The financial rules are based on your family income and number of children. There is a maximum amount that each family can receive. In 2001, workers who are raising more than one child in their home may apply if their incomes are under \$31,152. Workers who are raising one child may apply if their income is less than \$27,413.

Married workers must file a joint tax return to qualify. The credit is available if you have biological, adopted or foster children. You can also apply for children at any age who have "total and permanent" disabilities. Adult children who have mental retardation may automatically qualify if their physical or mental condition prevents them from working a regular job. You must have Social Security numbers for all the children you list.

To apply

Check http://www.irs.gov/ind_info/eitc4.html to find out if you qualify for the EITC. The income limits change annually and the figures above are for 2001.

You will find more information in the IRS [Publication 596](#), Earned Income Credit. You can download it and the forms you need from <http://www.irs.gov> or by calling the IRS at 1-800-829-3676.



Health Care & Related Services

1. Medicaid (sometimes called Title XIX) (Title 19)

Authority: Social Security Act, Title XIX

Benefit

Medicaid is the federal-state program that provides free medical care to children and adults. It provides both basic health and long term care services.

All children in Medicaid are eligible for “EPSDT” services. This means that states must provide Early and Periodic Screening, Diagnosis and Treatment for a child’s physical or mental condition if such services are “medically necessary” until age 21.

Eligibility

The Medicaid program has very complicated rules that vary among states. There are very broad national guidelines, but each state sets its own eligibility rules and decides the services it provides. In most states, children who receive SSI qualify for Medicaid. States can also choose to cover other groups of children based on their age or income. Many states cover all very low-income children under age 19. Other states may serve children who live in higher income families.

To read more about other ways that children with disabilities can get Medicaid, go to “Income Assistance from Social Security Administration (SSA)” in **Part One**.

To apply

See <http://www.hcfa.gov/medicaid/mcontact.htm> for a list of the state Medicaid toll-free phone numbers. When you call, ask what programs your state has to help children with disabilities. Some states have special programs to help certain groups of children.

Note: This is the Web site for HCFA (Health Care Financing Administration), the federal agency that oversees Medicaid, Medicare and SCHIP. The agency name changed to the Centers for Medicare & Medicaid Services (CMS) in 2001. The new Web address at <http://www.cms.gov> will also get you to the Medicaid information.



2. State Children’s Health Insurance Program (sometimes called Title XXI or SCHIP) (Title 21)

Authority: Social Security Act, Title XXI

Benefit

States get funds to provide health insurance for low-income children who do not qualify for Medicaid when their family income is too high. Services vary depending on where you live because states select which ones they will provide. States may have their own SCHIP program or provide the services through Medicaid.

In states that do not have a SCHIP program based on Medicaid, it is likely that children with disabilities will not get all the services they need. Make sure that your state does not put your child into SCHIP if he or she qualifies for Medicaid.

Eligibility

The states have different eligibility rules. In most states, children who are not insured and who are 18 years old and younger can qualify if their families earn up to around \$34,000 a year (for a family of four). Some states serve children whose family incomes are higher.

To apply

See <http://www.insurekidsnow.gov/> for information about your state children’s health insurance program and toll-free numbers to call to apply.

3. Maternal and Child Health Services (sometimes called Title V)

Authority: Social Security Act, Title V (Title 5)

Benefit

States receive funds to provide services to mothers and children, especially those who have little income or have trouble getting health care.

States must use at least 30 percent of these funds to serve children with special health care needs. Each state defines “children with special health care needs.” For this population, states should provide coordinated services based on the needs of each child and his or her family. The services are different in each state, but may include some specialty care or service coordination.



Eligibility

The rules vary among states. You may have to pay for services, but not if you have a low income.

To apply

See http://www.mchb.hrsa.gov/html/regional_offices.html for a list of state Title V directors. All Title V programs are in their state health departments. Each Title V program has a contact for the Children with Special Health Care Needs Program. Ask what services are provided in your state and how you can apply.

4. Home and Community-Based (HCB) waiver

Authority: Social Security Act, Title XIX, Section 1915 (c)

Service

Medicaid home and community-based waivers allow states to provide services for children with certain disabilities so they can live at home rather than in a hospital, nursing home or other institution. Although Medicaid pays for the services, states decide who is eligible and how many families will be served.

Each state designs its own waiver. Children served in HCB waiver programs receive standard Medicaid benefits plus additional services and supports. You may get respite care or in-home support services for your child.

Eligibility

There are financial and other rules that vary among states. Each state may select different groups of children who can qualify. These may include children with mental retardation and/or developmental disabilities.

To apply

You can ask your state chapter of The Arc what waivers your state offers children with disabilities. You need to know what services the state provides, what families can apply, and how you can apply.

See <http://www.hcfa.gov/medicaid/mcontact.htm> for a list of State Medicaid toll-free phone numbers to ask what groups of children can get HCB waivers. You can also get this information from your state Mental Retardation/Developmental Disabilities (MR/DD) agency or DD Council. To find your state MR/DD office, click "State Member



Agencies” at <http://www.nasddd.org/index.shtml>. To find your DD Council, see **Part Four: Where Can Families Get Help?**

Ask your case manager or service coordinator about Medicaid waiver programs in your state.

[In (state), waivers are available for (describe populations covered)] You can apply for the waiver (describe what office; sometimes families must go to the Medicaid agency for the disability eligibility and the welfare agency for the financial eligibility.]

5. TEFRA (sometimes called the “Katie Beckett” waiver)

Authority: Social Security Act, Title XIX, (Title 19) Section 1902(e)(3)

Service

States may decide if children qualify for Medicaid through TEFRA. It allows some children with disabilities to qualify for Medicaid without counting their parents’ income. The program’s nickname comes from the law called the Tax Equity and Fiscal Responsibility Act of 1982 or TEFRA. Some people refer to TEFRA as the “Katie Beckett” waiver.

Through TEFRA, children can receive Medicaid services that address their needs, but still live with their families. States can decide if they want to offer TEFRA.

Eligibility

To qualify, your child must

- (1) be under 19 years old and
- (2) meet the SSI definition of “disability” and
- (3) need the level of care provided in a hospital, nursing facility or intermediate care facility for persons with mental retardation (ICF/MR).

The cost to the Medicaid program cannot be more at home than it would be to have your child in an institution.

The state will only count your child’s income and resources for eligibility. Children who receive SSI, but lose coverage sometimes because your family income is too high may qualify for TEFRA in the months they do not receive SSI.



To apply

See <http://www.hcfa.gov/medicaid/mcontact.htm> for a list of State Medicaid toll-free phone numbers. Ask if your state offers expanded eligibility for children with disabilities.

You can also ask your state Mental Retardation/Developmental Disabilities (MR/DD) agency or DD Council if TEFRA is available for children with disabilities. To find your state MR/DD office, click on "State Member Agencies" at <http://www.nasddd.org/index.html>. To find your DD Council, see **Part Four: Where Can Families Get Help?**

Ask your case manager or service coordinator what Medicaid waivers your state has for children.

[In (state), TEFRA is available for (describe populations covered)] You can apply for it (describe what office; sometimes families must go to the Medicaid agency for the disability eligibility and the welfare agency for the financial eligibility.] OR [In (state), TEFRA is not available.]

6. Intermediate Care Facilities for People with Mental Retardation (ICF/MR)

Authority: Social Security Act, Title IX (Title 19) Section 1905(d)

Service

The program funds "institutions" for people with mental retardation and related conditions. For many years, when a family needed services, their only option was to place their child with mental retardation in an institution. Although conditions may have improved in these facilities, they do not provide the same quality of life that a child with mental retardation can have living in his or her own community.

Under the law, an "institution" has four or more beds. Currently, all states make ICF/MR services available. Some states may pay for the child to go out-of-state for the service. Most people who live in an ICF/MR have mental retardation and also other disabilities.

This is a very limited option for children, one that The Arc does not recommend. Most states are more likely to provide a Medicaid waiver so you can get the services you need to raise your child at home or in a home-like setting in your community. The ICF/MR program is rapidly diminishing as a service as other programs meet the need for 24-hour a day support more effectively.



Eligibility

There are financial and disability rules. To be placed in an ICF/MR, you must qualify financially for Medicaid. These rules vary among states, but generally your family must have very little income and few resources. However, all states will count your child as “a family of one” after he or she has lived outside your home for 30 days. This means that if your child is in a facility for over 30 days, he or she can qualify for the ICF/MR regardless of your family income.

Your child must meet the state’s definition of someone who needs this level of care.

To apply

See <http://www.hcfa.gov/medicaid/mcontact.htm> for a list of toll-free phone numbers to contact your state Medicaid program.

You can also ask your state Mental Retardation/Developmental Disabilities (MR/DD) agency or DD Council if the ICF/MR facilities in your state serve children with disabilities. To find your state MR/DD office, click on “State Member Agencies” at <http://www.nasdds.org/index.shtml>. To find your DD Council, see **Part Four: Where Can Families Get Help?**

Ask your case manager or service coordinator about ICF/MR facilities for children in your area.

[In (state), you can apply for an ICF/MR for your child by contacting (name agency)].

7. Tax Deduction for Medical Expenses

Authority: Internal Revenue Code, Section 213

Benefit

The IRS offers a tax deduction for eligible medical expenses. Families do not receive any direct cash payment. You can deduct medical expenses that you must pay to help diagnose or treat your child’s condition. You can deduct health insurance payments as well as transportation and hotel costs to get your child medical care. You can deduct what you spend to get assistive technology devices and durable medical equipment.



Eligibility

The deduction is only for unreimbursed medical expenses. You cannot receive this deduction unless you itemize and also do not take the standard deduction. You can deduct these expenses for yourself, your spouse and your children (or other dependents). The expenses must be greater than 7.5 percent of your adjusted gross income.

For more information

Read the IRS Publication 502 and Tax Topic 502, Medical and Dental Expenses. You can get them at <http://www.irs.gov> or call the IRS at 1-800-829-3676.



Education

Authority: Individuals with Disabilities Education Act Amendments of 1997 (IDEA)

Service

States get federal funds to provide appropriate education and related services to children with disabilities. Local school districts get this money to provide a “free and appropriate public education” (FAPE) and related services. All children with disabilities from age 3 to age 21 qualify. The law guarantees the right to an education for every child with a disability through an “Individualized Education Plan” (IEP).

Eligibility

There are no financial eligibility rules for public special education programs. Under the special education law, children must have certain specific disabilities to qualify. The disabilities include: mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments or specific learning disabilities.

State and local education agencies may also serve children ages 3 through 9 who have developmental delays but no specific disability diagnosis. States can define the group of children who have developmental delays that they will serve. Some states have laws to serve children with disabilities from the time they are born.

Some children with disabilities do not qualify for special education, but may get special accommodations in their classrooms or other school activities under Section 504 of the Rehabilitation Act.

For more information

Read about education services and Section 504 in **Part Two: Age Specific Services** in “Services for Infants & Very Young Children” and “School Age Children.”



Family Support

Authority: Developmental Disabilities Assistance and Bill of Rights Act of 2000, Title II (Title 2) and many state laws

Benefit

Some states have special funds to provide certain supports for families raising children with disabilities. States offer different supports and services although most provide respite care. You may also be able to get special clothing, cash payments, vehicle or home modifications, transportation, counseling, or medical services.

Eligibility

States design their own family support programs so the rules vary state-to-state.

To apply

A list of family support programs is available from the National Center for Family Support. Go to <http://www.familysupport-hsri.org> and click on "Site Projects" to find information about your state.

You can find out about family support programs through your state Mental Retardation/Developmental Disabilities (MR/DD) agency or DD Council. Go to <http://www.nasdds.org/index.html> and click on "State Member Agencies" to find your state MR/DD office. To find your DD Council, see **Part Four: Where Can Families Get Help?**

You can also call the county Department of Social Services or the local mental retardation agency about local family support programs. Your case manager or service coordinator may know about family support programs in your community.



Programs to Help Families Meet Other Basic Needs

1. Food Programs

(a) Food Stamps

Authority: Food Stamp Act

Benefit

This federal program provides monthly coupons to eligible low-income families to buy food. In most states, people now get food stamps through Electronic Benefit Transfer (EBT). All states must use EBT by October 2002.

Eligibility

There are financial and other rules. Eligibility is based on your “household” income. A household is a group of people who live together even if you are not related and who buy food and cook together.

Your household can qualify if it has very little income, at or even below the federal poverty level. You also must have very limited resources, like checking or savings accounts. Some things you own do not count, like your home and cars up to a certain value. In general, your household can only have up to \$2,000 in resources. The limit is higher if your household has at least one member age 60 or older.

To apply

Go to your State or local welfare agency office. Your local SSA office should also have applications. The program is run by the welfare agency, but the rules are written by the U.S. Department of Agriculture.

Go to <http://www.fns.usda.gov/fsp> to find out how to apply.

[In your state, apply for food stamps at (give name local office).]



(b) Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)

Authority: Child Nutrition Act of 1966, as amended

Service

The WIC program provides free food and formula to eligible women and children. It also can educate you about proper nutrition and refer you to health care providers.

Eligibility

There are two sets of rules. You must show that you are at “nutritional risk” and you must have little income. To qualify, you must be pregnant or have just had a baby. Your children can get WIC from birth until age 5. You will qualify if you get or have certain family members who get Food Stamps, Medicaid or TANF benefits.

To apply

You must go to an approved local agency that runs a WIC program. The programs are generally found at local public or nonprofit private health or welfare agencies.

Go to <http://www.fns.usda.gov/wic> to find toll-free numbers to call in your state. When you call, they will make an appointment for you to talk with someone about whether you qualify.

(c) School Breakfast Program

Authority: Child Nutrition Act of 1966, as amended

Service

All participating schools can give free and reduced price breakfast to eligible school children. The meals must meet certain standards of nutrition.

Eligibility

Any child at a school that has the School Breakfast Program may buy a meal regardless of the student’s household income. The financial rules are based on household income and size. Eligible students get free or reduced-price breakfasts.



To apply

Go to <http://www.fns.usda.gov/cnd> for information about how to apply. Ask your case manager or service coordinator about this program.

(d) School Lunch Program

Authority: National School Lunch Act, as amended

Service

All participating schools can give free or reduced price lunch to eligible school children. The meals must meet certain standards of nutrition.

Eligibility

Any child at a school that has the National School Lunch program may buy a meal regardless of the student's household income. The financial rules are based on household income and size. Eligible students get free or reduced-price lunches.

To apply

Go to <http://www.fns.usda.gov/cnd> for information about how to apply. Ask your case manager or service coordinator about this program.

2. Social Services

Authority: Social Security Act, Title XX, Social Services block grant (Title 20)

Service

States fund social service activities that they select to offer. States often fund local government and non-profit groups to provide these services to children, adults or families.

Your state may provide childcare, child welfare services, or special services for people with disabilities. You may be able to get respite care, family support or transportation. Your child may get sports activities, counseling or independent living skills training.



Eligibility

There are financial and other rules that vary among states. In general, services are provided to three groups of people: (1) low-income individuals, (2) people who may be placed in a nursing home or institution because no community services are available for them, and (3) people who are abused or neglected. Each state selects the people it will serve.

To apply

You can ask your state Mental Retardation/Developmental Disabilities (MR/DD) agency or DD Council what services the state provides for families raising children with disabilities. To find your state MR/DD office, click on “State Member Agencies” at <http://www.nasdds.org/index.shtml>. To find your DD Council, see **Part Four: Where Can Families Get Help?**

3. Technology assistance

Authority: Assistive Technology Act of 1998 (often called the “Tech Act”)

Service

Assistive technology can help children with mental and physical disabilities. The term “assistive technology” covers many services and supports. They include things that can help children improve their ability to function every day – at home, at school and in the community. Examples include computer software or videotapes that can help your child learn.

All states get funds to help meet the assistive technology needs of individuals with disabilities. Local programs can provide access to assistive technology items or services for people with disabilities and their families.

Students also can get assistive technology as part of their public education. See “School Age Children” in **Part Two: Age Specific Services**.

Eligibility

There are no financial rules. Anyone with a disability can contact a Technology Resource Center.

If your child needs services or supports from your local public school, ask what assistive technology is available. See “School Age Children” in **Part Two: Age Specific Services** to read about special education and Section 504 plans.



To apply

Go to www.ATAccess.org and click on “Centers” to find Technology Resource Centers in your area.

Ask your local special education or Section 504 coordinator about assistive technology that your child may need in school. Call your local school district and ask to speak with one of them. Every school district has coordinators for special education and Section 504.

4. Family and medical leave

Authority: Family and Medical Leave Act of 1993 (FMLA)

Benefit

The federal FMLA allows many workers to take up to 12 weeks of unpaid, job-protected leave in a 12-month period for certain family and medical reasons. You may get this leave if you give birth, adopt a child or have a foster care child. Some states offer other family and medical leave benefits.

You may also qualify if you must care for a member of your immediate family (spouse, child or parent) who has a serious health problem. You may qualify if you are unable to work because of a serious health problem.

Sometimes you may qualify for a longer period of leave. Some states have family and medical leave laws that give you more time off. Some union contracts give workers family or medical leave. The Americans with Disabilities Act (ADA) also protects workers who have a disability. Read more about the ADA in **Part Three: Civil Rights Protections**.

Eligibility

All workers are not covered by FMLA. Your employer must have 50 or more employees. Also you must have worked for your employer for at least 12 months and for at least 1,250 hours during the last year.

For more information

The U.S. Department of Labor's Employment Standards Administration, Wage and Hour Division runs the program. Go to <http://www.dol.gov/dol/esa/fmla.htm> for fact sheets that explain when you qualify for family and medical leave.

The National Partnership for Women and Families has a Guide to the Family & Medical Leave Act in both English and Spanish. Go to www.nationalpartnership.org and click on “FMLA Q&A.”



5. Child support

Authority: Social Security Act, Title IV-D (Title 4-D)

Benefit

Each state runs a child support program to ensure that parents contribute to the care of their children. Child support laws apply to all parents even if you are divorced or never married the mother or father of your children.

Eligibility

Child support services are available automatically to families who get help through TANF programs. See "Income Assistance From Other Programs" in **Part One: Children and Youth Through Age 21**.

Child support services are also available to families who do not receive TANF. These families must apply for child support services. You will receive any child support payments that the state collects on your behalf. The state may charge a fee to help you, depending on where you live.

To apply

The state child support program is in the human services department, department of revenue or district attorney's office. You can contact this office if you want help to collect child support or to locate the other parent of your children. To find your state office (and their Web site if they have one), go to <http://www.acf.dhhs.gov/program/cse>.

In [your state], the child support program is in the [name location].

6. Tax provisions

(a) Child Tax Credit

Authority: Internal Revenue Code, Section 24

Benefit

The Child Tax Credit is available to taxpayers who have dependent children. Families do not receive any direct cash payment.



Eligibility

Single parents with incomes up to \$75,000 and married parents with incomes up to \$110,000 are eligible. The most credit you can receive is \$500 per child.

Your children must be under age 17 and you must claim them as dependents on your federal tax return. You can claim the credit for a son, daughter, grandson, granddaughter, stepson, stepdaughter or an eligible foster child. If your family income is so low that you owe no income tax, you generally do not qualify unless you have three or more children. Then you may qualify for the "Additional Child Tax Credit."

To apply

See IRS Publication 17, "Your Federal Income Tax," to read more about the child tax credit. You can download it from www.irs.gov, but it is a very long publication so you may want to call for it, 1-800-829-3676. The worksheet to help you claim this credit comes with instructions for IRS Form 1040 and 1040A.

If you have three or more children, you must fill out IRS Form 8812, the "Additional Child Tax Credit" to see if you qualify for an extra credit. You can get all these forms at <http://www.irs.gov> or call IRS at the number above to request them.

(b) Child and Dependent Care Credit

Authority: Internal Revenue Code, Section 21

Benefit

The Child and Dependent Care Credit is a tax benefit for all families who need this type of care to go to or look for work. If you do not owe taxes, then this credit can give you back some or all of the federal taxes that were taken out of your paycheck during the year. If you owe taxes at the end of the year, this credit can lower what you must pay to the IRS.

The size of your credit varies by family. It is based on the number of your children (or dependents), your family income and how much you pay for childcare during the year. There is a limit to what you can request. Families with one child or dependent can claim up to \$2,400. Families with more than one child or dependent can claim up to \$4,800.

Over half the states have refundable child and dependent care tax credits. To find out what credits your state has, call the state department of revenue.



Eligibility

The credit is available if you pay federal income tax and list children (or others) as dependents on your tax return. There are special rules if you are divorced or separated.

To apply

See IRS Publication 503 and Tax Topic 602 to read more about the child and dependent care credit. You must file federal income taxes with Form 1040 or 1040A. You must also fill out Form 2441 to get this credit. You can get these items at <http://www.irs.gov> or call the IRS at 1-800-829-3676.

Child Welfare Services

1. Getting services for children with mental retardation/development disabilities

Authority: Some federal laws apply, but state laws are more important for child welfare services.

Service

Child welfare offices offer family support services when families are suspected of abusing or neglecting their children. If the children have disabilities, the State Mental Retardation/Developmental Disability agency can provide services. Read more about family support programs in **Part One: Children and Youth Through Age 21**.

Your state may also have special services for infants born with very significant disabilities. Most states have respite care for families and they may also have other services.

Eligibility

Families who need help keeping their family together may qualify. There are no income rules for family support programs. You may qualify for other social services that do have income rules if the state uses Federal Title XX funds to provide them. See "Programs to Help Families Meet Other Basic Needs" in **Part One: Children and Youth Through Age 21**.

For more information

Call your state Mental Retardation/Developmental Disabilities (MR/DD) agency or the DD Council. To find your state MR/DD office, click on "State Member Agencies" at <http://www.nasdds.org/index/shtml>. To find the DD Council, see **Part Four: Where Can Families Get Help?**

In [name your state], contact the department of [name agency that runs the welfare or social services programs]. Ask for the local county office that can help you.

2. Finding another home for children with mental retardation/developmental disabilities

Authority: State laws are different.

Service

Sometimes families face a very serious crisis. Examples include a parent abusing a child or the family losing its home. These kinds of situations may make you feel that you need to give up custody of your child for a short time. The state or county child welfare office will help you avoid doing this. They may be able to provide special services because your child has mental retardation or related developmental disabilities. Before giving up custody, you must ask if you can get respite care or family support services.

The child welfare office may agree with you and think that it is better for your child to live elsewhere for a while. If so, they will find your child a foster home. Once the child welfare office decides that you are ready to have your child return home, they can provide you with some special services. These will vary by state.

Eligibility

Any family can ask for this help. The state child welfare office will decide if your situation requires that your child live elsewhere for a while.

If your child goes into foster care, it is very important that you stay in touch by calling or visiting. You must be able to show the child welfare office that you want to know how your child is doing while living in foster care.

For more information

The state or county welfare or social service office may be able to help you. These offices may be part of the department of human or social services.

In [name your state], contact the department of [name appropriate agency]. Ask what local county office can help you.

In [name your state], the child welfare agency is called [give name]. They have [a toll-free number or county offices] that you can call for help.

3. Adopting children with mental retardation/developmental disabilities

Authority: Social Security Act, Title IV-E (Title 4-E)

Benefit

Parents who adopt “special needs” children qualify for cash assistance. States define “special needs”, but it always includes children with disabilities.



You can get a one-time payment for the adoption costs. You may get up to \$2,000, but each state decides what it will pay. You also get money every month to help care for your child until he or she is age 18. You may get the monthly cash until your child is age 21 depending on how significant the disability is.

Eligibility

Parents of any income may qualify if you adopt children who have “special needs.” You must meet with the state child welfare agency to decide how much cash you need to take care of your child’s special needs. The amount you get may change in the future if you and the agency agree to something different.

For more information

The National Adoption Information Clearinghouse can help you if you want to adopt or have adopted a child who has special needs. Go to <http://www.calib.com/naic> and click first on “Parents” and then on “Introduction to Adoption.” There you will find a section called “Adopting a Child with Special Needs.”

You can learn about adoption subsidies in all the states through the National Adoption Assistance Training Resource and Information Network at (800) 470-6665. You can also check <http://www.nacac.org/adoption subsidy.html> to find the Adoption Subsidy Administrator in your state.

4. Tax credit for special needs adoptions

Authority: Internal Revenue Code Sections 23 and 137

Benefit

Families who adopt “special needs” children may qualify for a special tax credit of up to \$10,160 in 2003. The credit is part of the federal income tax program. Families do not receive any direct cash payment under this tax credit. You can only get it if you adopt a U.S. child who has special needs.

Eligibility

You are eligible if you adopt a child with special needs who was born in the U.S. To qualify, you must file IRS Form 8839 with your Form 1040 or 1040A. If you are married, you must file a joint tax return to qualify for the credit.

For more information

Read the IRS Publication 968, Tax Benefits for Adoption. You can get it and Form 8839 at <http://www.irs.gov> or by calling the IRS at 1-800-829-3676.

5. Preventing child abuse and neglect

Authority: Some federal laws apply, but state laws are more important and they are different state-to-state.

Service

All states have child protective systems to help prevent child abuse and neglect. They get federal grants to improve both public and private child protective service systems.

Eligibility

There are no eligibility requirements. The state and local child protective programs help children of all incomes who are under age 18.

For more information

If you suspect that a child you know who has mental retardation or developmental disabilities is being abused or neglected, contact the local child protective service agency. This agency may be part of the county human or social services department.



Many states have a toll free child abuse hotline. To get the number in your state, call the Child Help's National Child Abuse Hotline at 1-800-4-A-CHILD (800-422-4453) or TDD, 1-800-2 A CHILD.

You can also call the state Protection & Advocacy (P&A) agency. To find this group, see **Part Four: Where Can Families Get Help?**

[In (state), the child protective service agency is the (agency name). The state toll-free number to report child abuse is (give telephone number)]



Part Two: Age Specific Services

Services for Infants & Very Young Children

1. Early Intervention

Authority: Individuals with Disabilities Education Act Amendments of 1997 (IDEA), Part C, Early Intervention Services for Infants and Toddlers with Disabilities

Service

States receive funds to organize and provide early intervention services for infants and toddlers with disabilities and their families. Different agencies will give you services. For example, you may be able to get help from childcare programs, child development specialists, social workers, nurses or different kinds of therapists. These may include physical, occupational or speech therapists. Some services are provided in your home. Others are available at both regular child care centers as well as special centers and programs.

Eligibility

All children with certain mental retardation and related developmental disabilities are eligible from birth until they reach age 3. Some states charge fees based on your ability to pay for services. Children “at risk” of a developmental delay may also get services.

To apply

Each state has one agency that coordinates early intervention services. It is often in the education department, but may also be in the health department. You can find your state early intervention coordinator at <http://www.nectas.unc.edu/contact/txtptccoord.asp>.

You can also call your local school district and ask for the early intervention coordinator.

2. Pre-School Children

Authority: Individuals with Disabilities Education Act Amendments of 1997 (IDEA), Part B, Section 619

Service

States get funds to provide a “free and appropriate public education” (FAPE) and related services to every child with a disability ages 3-5.



The law requires that FAPE be in the “least restrictive setting.” This means that schools must make every effort to place your child in regular pre-school activities with children who do not have disabilities.

Eligibility

Children who have certain disabilities are eligible from ages 3-5. States may also serve 2 year olds with disabilities who will turn 3 during the school year. Children qualify if they have mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments or specific learning disabilities.

State and local education agencies may also serve children ages 3-9 who have developmental delays. States define the group of children who have developmental delays that they will serve.

To apply

Contact your State Director of Special Education. For a list of all the state directors, go to http://www.nasdse.org/state_directors_of_special_educa.htm. You can also call your local school district and ask for special education director.

3. Early Head Start/Head Start

Authority: Head Start Act, as amended

Service

Early Head Start and Head Start programs provide education, health and social services to children from families with low-incomes before they start school. Public and private non-profit agencies run Head Start programs in almost every county of the United States.

Children who attend Head Start get a number of educational activities. They also get free medical and dental care and healthy meals and snacks. Children and families with special needs get mental health and other services. Your family may also get social services to meet your own needs.

Eligibility

Children from birth-age 5 may qualify if their families are low-income. Some children also come from higher income families. Local Head Start programs across the country decide who they will serve based on the needs of families in their communities. There are waiting lists because local programs often do not have enough money to serve all eligible children.



At least 10 percent of all children enrolled in each Head Start program must have disabilities. Some programs serve even more children with disabilities. The children with disabilities who apply for Head Start do not have to meet the income rules although most of them do.

Early Head Start programs serve children from birth through age 3. Head Start serves children 3 or 4 years old until they enter school.

To apply

You can use the Internet to find a Head Start program near you. Go to <http://www2.acf.dhhs.gov/programs/hsb/grantees/search/search.asp>. If you find a program in your area, call them to ask if your grandson qualifies and how to enroll him.

4. Child care

Authority: Child Care and Development Block Grant Act of 1990, as amended

Service

States get funds to help pay for childcare for low-income families.

Eligibility

There are financial and other rules that vary among states. Federal law requires states to first serve “very low-income families” and “children with special needs.” Each state can define what families are in these groups.

The law covers children under age 13, but your state may cover children up to age 19 if they have disabilities and your family qualifies.

States must spend most of these funds to help families who are on welfare or are moving from welfare to work. States may charge families for childcare using a sliding fee based on income.

For more information

The federal government funds Child Care Aware to help parents find information on child care resources in their community. Go to <http://www.childcareaware.org> to use its “Child Care Connector” for your own zip code. You can also call Child Care Aware at 1-800-424-2246.

Call your county’s office for children’s services and ask about childcare in your area.

[In (state), call (name of office that houses child care services).]



School Age Children

1. Public education

Authority: Individuals with Disabilities Education Act Amendments of 1997 (IDEA), Part B

Service

States get federal funds to provide appropriate education and related services to children with disabilities. Local school districts get this money to provide a “free and appropriate public education” (FAPE) and related services. All children with disabilities from age 5- 21 qualify. See the previous section, “Services for Infants & Very Young Children,” to read about services for children under age 5.

The law requires that schools use the “least restrictive setting.” This means that schools must make every effort to teach your child in regular classrooms with students who do not have disabilities.

Each eligible student must have an “individualized education program” (IEP) every year. The IEP describes what classroom and other services your child needs to participate in the regular curriculum for his or her grade. By law, parents must help write their child’s IEP. Parents also help decide the setting where their children will receive their education.

Eligibility

Public special education programs must be provided at no cost to parents. Under the law, children must have certain specific disabilities to qualify for special education. These disabilities include: mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments or specific learning disabilities.

State and local education agencies may also serve children ages 3-9 who have developmental delays. States can define the group of children who have developmental delays that they will serve.

Some children with disabilities do not qualify for special education, but may get special accommodations in their classrooms or other school activities under the Section 504 anti-discrimination laws of the Rehabilitation Act.



To apply

If you think your child needs special education or any special services to participate in school, you must ask the school to evaluate your child. Also ask about assistive technology that may help your child in the classroom or other school activities.

You can call or write your child's teacher, the principal of your child's school or the Director of Special Education in your school district. If the school thinks that your child has a disability, they will do an evaluation for free. The school may also offer to do an evaluation if a teacher thinks your child needs special education.

If you have trouble getting help from your local school district, call either the Parent Training Information (PTI) Center or the Protection & Advocacy (P&A) agency in your state. To find these groups, see **Part Four: Where Can Families Get Help?**

You can also call the state director of special education. You will find a list at http://www.nasdse.org/state_directors_of_special_educa.htm.

2. Special Accommodations (Section 504 plans)

Authority: Rehabilitation Act of 1973, Section 504

Benefit

Section 504 is a civil rights law that prohibits discrimination on the basis of disability. It protects the rights of individuals with disabilities in all programs and activities that get federal funds, including schools. Under Section 504, students can get the accommodations and services they need to be with other students who do not have disabilities in their classroom and school activities. The U.S. Department of Education enforces Section 504 through its Office for Civil Rights (OCR).

Section 504 also protects children with disabilities against discrimination in day care, hospitals, nursing homes, mental health centers and other human service programs that receive federal funds. See the section "Protection against discrimination because of disability" in **Part Three: Civil Rights Protections**.



Eligibility

All children with mental retardation should receive IDEA special education services through an IEP. Some children with related developmental disabilities may not qualify for IDEA services. They may qualify to receive services under Section 504. Under the Section 504 law, “disability” means a physical or mental impairment that substantially limits one or more of the individual’s major life activities. Section 504 also protects all students who qualify for IDEA.

If your child does not qualify for IDEA, ask about getting a “504 plan.” A 504 plan describes what accommodations and services the school will provide to allow your child to learn and play with other students who do not have disabilities. A 504 plan may include assistive technology that will help your child participate in all classroom and other school activities.

To apply

All school districts are required to have a 504 coordinator. Call your local school district and ask to have your child evaluated for a 504 plan.



Adolescents Making Transition to Adult Life

1. Plan for Achieving Self-Support (PASS)

Authority: Social Security Act, Title IX (Title 19), Section 1612 (b) and 1613 (a)

Benefit

PASS is a special program to let individuals with disabilities who receive SSI set aside earnings. A PASS is helpful because that money would normally count when SSA decides how much SSI your child can get each month.

Your child must use his or her PASS money to pay for something that will help him or her work. For example, your child may want to save money to buy equipment to start a business or to buy a wheelchair or computer to attend a training program.

Eligibility

This program is very complicated and may not be useful for everyone.

A PASS specialist at SSA must approve your child's written PASS. The PASS must have very specific details about how the individual will use the money. Your child must describe a realistic work goal and describe the necessary steps to reach the goal within a timeframe. The PASS must indicate how much money your child will save to reach the work goal.

To apply

Call 1-800-772-1213 and ask the SSA operator for a toll-free number for the PASS specialist in your region. Also, you can go to www.sssa.gov/work/workincentives.htm.

You can get copies of the PASS form (SSA-545-BK) at this Web site, from a local SSA office or from the regional PASS specialist.

2. Vocational services

Authority: Rehabilitation Act Amendments of 1998; Individuals with Disabilities Education Act Amendments of 1997 (IDEA), Part B

Service

States are required to help individuals with disabilities get a job or get to work. Each state has a vocational rehabilitation (VR) agency that provides services or funds local agencies to help. Services vary among states, especially for adolescents and young adults. The state VR agency may help assess your child's needs and provide advice about jobs or vocational training.

The federal special education law has rules for transition services for children who have an "individualized educational program" (IEP) The IEP is described earlier in the "School Age Children" section of **Part Two**. Starting at age 14, schools must begin planning transition services for these children. If your child is close to age 14 or older, you should talk with his or her IEP team about transition services. Be sure to ask that someone from the state VR agency attend IEP meetings. This is very important to help plan your child's transition services to prepare him or her for a job.

Later, the state VR agency is required to help young people develop an "Individualized Plan for Employment" (IPE). Your goal is to help coordinate your child's school transition plan and the VR plan.

All states have some "supported employment" services for people with the most significant disabilities. Some vocational rehabilitation agencies also provide medical and related services to help make it easier for the person with the disability to be trained and get a job. In many states, the Mental Retardation/Developmental Disabilities (MR/DD) agency provides most of the employment services for people with disabilities.

Eligibility

People with mental retardation and related developmental disabilities may be eligible for vocational rehabilitation or supported employment services. The rules vary among states. Often these services are limited to adults who have the most significant disabilities. You should ask for help from your VR agency when doing transition planning for your child's IEP.

To apply

Each state has a rehabilitation agency. It may be in your state department of education or labor or it may be a separate agency.

In [name your state], the vocational rehabilitation agency is part of the department of [give name].

To find your state MR/DD agency, click on "State Member Agencies" at <http://www.nasdds.org/index.shtml>.



Part Three: Civil Rights Protections

1. Resolving conflicts between schools and parents of children with disabilities

Authority: Individuals with Disabilities Education Act Amendments of 1997 (IDEA), Part B, Section 615

Benefit

The federal special education law has rules that protect the rights of students with disabilities when decisions are made about their educational services. Schools must give parents a copy of these rules that are called “procedural safeguards.” The procedural safeguards have four parts: (1) prior notice, (2) impartial due process hearing, (3) mediation and (4) attorneys’ fees.

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

States must make mediation available if parents want to use it instead of having a hearing. Parents often find that a mediator can help them and the school district reach an acceptable agreement. Some parents still believe that they must get a lawyer and go to court to get the educational services that they want for their child with a disability. If parents sue and win, the judge may pay for their attorneys’ fees.

Eligibility

States are required by law to have certain procedural safeguards. They must have a mediation system for parents and schools to use if they choose to do so. When there are lawsuits against school districts, the individual courts decide whether parents can get attorneys’ fees. The fees are only awarded if the parents win.

For more information

To read more about parent’s rights under IDEA, go to <http://www.thearc.org/faqs/qa-idea-rights.html>. You will also find information, in English and Spanish, from the Family & Advocates Partnership for Education at <http://fape.org>.

You can call the state Protection & Advocacy (P&A) agency or your state Parent Training and Information (PTI) Center. To find these groups, see **Part Four: Where Can Families Get Help?**



2. Protection against discrimination because of disability

(a) Section 504

Authority: Rehabilitation Act of 1973, Section 504

Benefit

Section 504 is a civil rights law that prohibits discrimination on the basis of disability. It protects the rights of individuals with disabilities in programs and activities that get federal funds. Section 504 also protects children with disabilities against discrimination in schools, day care, hospitals, nursing homes, mental health centers and other human service programs that receive federal funds.

The U.S. Department of Education enforces Section 504 through its Office for Civil Rights (OCR). This office investigates complaints about discrimination in special education. The U.S. Department of Health and Human Services also has an Office for Civil Rights (OCR) that handles complaints for health and human services programs.

Eligibility

If you think a school or any program that gets federal funds has discriminated against your child or another student you know because of their disability, you can file a complaint. Under Section 504 “disability” means a physical or mental impairment that substantially limits one or more of the individual’s major life activities. Section 504 covers children who qualify for IDEA.

For more information

For complaints about schools: read how to file a complaint at www.ed.gov/offices/OCR/complaintprocess.html. You can also call the Washington, D.C. Office for Civil Rights at 1-800-421-3481 (TDD: 877-521-2172) or send e-mail to OCR@ed.gov.

For complaints about health and human service programs: go to www.hhs.gov/ocr. You can also call the Washington, D.C. Office for Civil Rights at 1-800-368-1019 (TDD: 1-800-537-7697 or send e-mail to OCRMAIL@hhs.gov.



(b) Americans with Disabilities Act (ADA)

Authority: Americans with Disabilities Act (ADA)

Benefit

The ADA is the most far-reaching federal civil-rights law protecting people with disabilities. It affects the rights of people with disabilities to have access to many activities and services.

The law covers employment discrimination; programs provided by state and local governments; telecommunications; and places of “public accommodation.” Examples of “public accommodation” include businesses, transportation and non-profit service providers. The ADA requires access both to the actual locations and to the programs offered by the agencies and businesses that it covers. It applies to agencies or businesses whether or not they receive federal funds.

Eligibility

The ADA protects individuals who have a disability. You are covered if you have a significant physical or mental impairment. This impairment must “substantially limit” one or more of your major life activities.

The ADA also covers you if you have a history of a condition that affects your major activities or if people think you have such a condition.

For more information

Call the ADA Information Line at 1-800-514-0301 or 1-800-514-0383 (TDD).

Go to <http://www.usdoj.gov> and click on “Disabilities.” You can read about how to file a complaint and it links you to the U.S. Department of Justice’s ADA Home Page.

The federal Department of Education funds Disability and Business Technical Assistance Centers (called “DBTACs”) around the country. These Centers provide technical assistance, training and resource referrals about the ADA. It mostly helps employers, but anyone can call them for information. To find the regional center in your area, call 1-800-949-4232 (voice or TTY) or go to www.adata.org.

Also call your state Protection & Advocacy (P&A) agency and ask if your state or local community has other anti-discrimination laws. To find this group, see **Part Four: Where Can Families Get Help?** Your local Office of Human Rights or the State Attorney General’s Office will also know about state or local laws that can help you.



Part Four: Where Can Families Get Help?

The groups listed below provide information or services to people with mental retardation and related developmental disabilities and their families. In this Guide:

- We use the term “mental retardation” for children who have an IQ below 70-75. Their daily living skills are significantly limited and they have the condition before age 18.
- We use the term “developmental disability” for children who have a mental or physical disability that appears before age 22 that will probably continue indefinitely. Their daily living skills are significantly limited. They will need services for a long time or for their entire life.

Remember that some states define “mental retardation” and “developmental disabilities” differently. Be sure to check the state definitions because they can affect what services your family and child can get.

1. The Arc

Service

The Arc is the national organization of and for people with mental retardation and related developmental disabilities and their families. It works to promote and improve benefits, supports and services for children and adults with mental retardation and related disabilities so that they can live with their families and in the community. There are volunteers across the county and staff in Washington, D.C. who work hard to help ensure that families have access to the benefits, supports and services described in this Resource Guide.

The Arc has about 1,000 state and local chapters across the U.S and about 140,000 members.

For more information

Go to <http://www.thearc.org> and click on the "Locations" button. This will give you the contact for your nearest chapter and a link to its website.

Chapters offer different supports and services, but they all provide basic information or will refer you to other agencies. They can also suggest ways for you to get involved to help improve the lives of children and adults with mental retardation and their families.

2. State Developmental Disabilities Council

Authority: Developmental Disabilities Assistance and Bill of Rights Act of 2000, Title I



Service

Federal funds are provided to each state for an organization that plans and coordinates services for adults and children with developmental disabilities. Many Councils use these funds as grants to non-profit organizations that provide supports for families. Others use funds to train people with disabilities and family members to be their own advocates through a program called Partners in Policymaking.

Eligibility

There are no financial rules. The Councils all provide basic information to help adults and children who have developmental disabilities.

For more information

Go to <http://www.acf.dhhs.gov/programs/add> to find your state Developmental Disabilities Council.

You can also go to <http://www.naddc.org> for information. Click on "DD Councils" and it will link you to your state Council and its Executive Director.

Go to www.partnersinpolicymaking.org to find your state contact if you would like to get more training as a parent advocate.

3. Protection & Advocacy Agency (P&A)

Authority: Developmental Disabilities Assistance and Bill of Rights Act of 2000, Title I and other federal laws for adults and children with all types of disabilities

Service

Each state gets federal funds for an organization that provides legal and other advocacy services to adults and children with disabilities. The P&A also investigates conditions in facilities and programs that take care of people with disabilities. Many P&A agencies provide help to families so they can get education and other services for their children with disabilities.

Eligibility

Each state P&A decides what services it will provide. Community representatives and P&A staff members make these decisions together.



For more information

Go to <http://www.protectionandadvocacy.com> for a state-by-state list of these groups and their Web sites if they have one.

4. University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCE) (formerly University Affiliated Program or UAP)

Authority: Developmental Disabilities Assistance and Bill of Rights Act of 2000, Title I

Service

The Centers offer different services for children, adults and families in each state. They train people at universities and medical centers to serve adults and children with developmental disabilities and their families. Some Centers also provide advocacy training for parents and family members.

Eligibility

There are no financial rules. The UCEs serve adults and children who have developmental disabilities and their families. They offer different services, but they all provide basic information or can refer you to other agencies.

For more information

Go to <http://www.acf.dhhs.gov/programs/add> to find your state UCE.

You can also find a list of all UCEs (and their Web sites if they have one) at <http://www.aucd.org>

5. Parent Training Information (PTI) Center

Authority: Individuals with Disabilities Education Act Amendments of 1997 (IDEA), Part D

Service

Federal funds are provided for at least one parent organization in each state to help parents learn more about the needs of your children with disabilities. The Centers can help you talk with professionals about what your child needs. They can also help you learn how to participate in planning processes for your child's education. The Centers have a lot of information about programs, services and resources in your state.



Eligibility

There are no financial rules. PTIs provide information to parents of infants, toddlers, school-aged children and young adults with disabilities and the professionals who work with them.

For more information

Go to <http://www.ed.gov/Programs/bastmp/SPTIC.htm> to find your nearest PTI.

Another list (and Web sites if they have one) is at <http://www.taalliance.org/PTIs.htm>.

6. National Information Center for Children and Youth with Disabilities (NICHCY)

Service

The National Information Center for Children and Youth with Disabilities is often just called “NICHCY”. It is a national information and referral center about disabilities for families and professionals. Its special focus is children and youth from birth to age 22.

For more information

NICHCY has information specialists who can answer specific questions from parents. Call 1-800-695-0285 or e-mail nichcy@aed.org.

Go to www.nichcy.org to find their “State Resource Sheets.” The state groups and agencies that are listed can often refer you to local groups that may be able help you.

7. National Center for Family Support

Service

The National Center for Family Support provides training and technical assistance on family support to 42 project sites. The U.S. Administration on Developmental Disabilities funds the Center and these sites.

For more information

Go to <http://www.familysupport-hsri.org> and click on “Site Projects” to find information about your state.



8. The Beach Center on Families and Disability

Service

The Beach Center is a research and training center that conducts research, offers training and technical assistance, and provides information on family issues when there is a child with a disability in the family. Through its Web site, The Beach Center can provide information about child services and legal rights in early intervention and special education programs. They also have information about parent support and research on families and disability.

For more information

Go to <http://www.beachcenter.org> and click on “Family.”