

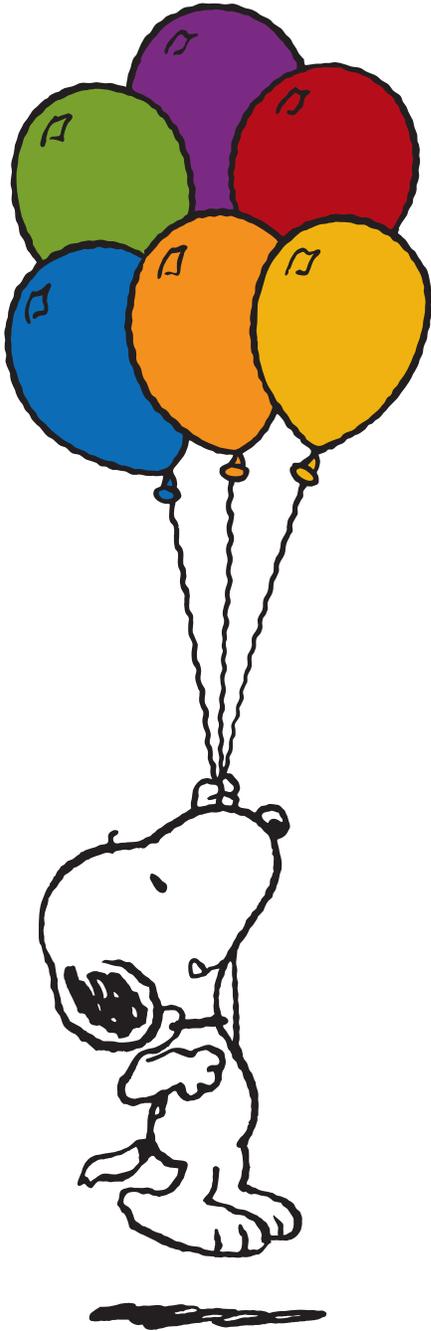
# Planning for Your Child or Other Dependent with Special Needs

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MetLife Consumer Education Center

**Caring for a person with special needs takes special planning.** Particular needs will always be present, and you must consider and prepare for them. Taking steps now can help secure your child’s well-being, today and tomorrow. Areas you should consider include your child’s legal, financial, medical and educational needs.

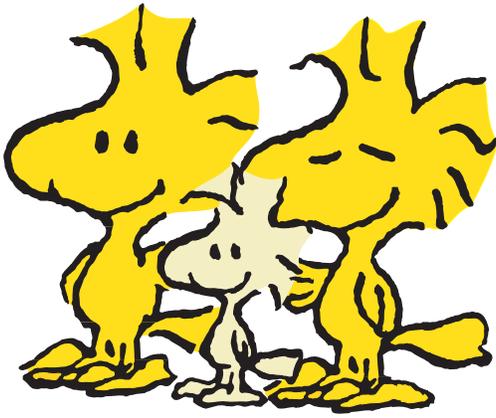
These same concerns exist if you are the caretaker or guardian of an adult with special needs.

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## Planning for the Future

Addressing legal issues is a crucial step in planning for the future. Creating and planning your estate is vital to meeting your child's lifetime needs. These issues fall into three main categories: wills, guardianships and special needs trusts.

### Last Will and Testament

A will declares how you want your estate to be distributed and allows you to select a guardian for your child when you die. It may be especially important to prevent asset distributions directly to a child with special needs. If parents die without a will, generally state law will distribute assets to the children. **Assets in excess of \$2,000 distributed to a person with a disability may jeopardize government benefits, adversely affecting the quality of life for a person with special needs.**

### Guardianships and Conservatorships\*

A guardianship or conservatorship is a legal mechanism that grants a designated adult legal power to make decisions for another person, one who is considered unable to make decisions himself or herself. In the case of a minor child, generally guardianship or conservatorship will terminate when the child turns 18 or, in some states, upon marriage if the child marries before age 18.

There are also different types of guardianship or conservatorship, each of which grants the guardian or conservator different powers. A "natural guardian" generally refers to a parent. In most cases, a natural guardian has custodial rights but only limited rights to control the assets of a child. "Guardianship of the person" is similar to custody. A "guardian ad litem" is often appointed only for the limited purposes of litigation. "Guardian of the estate" or "guardian of the property" or "conservator" usually refers to someone appointed to manage assets of and make financial decisions for the person deemed incapable. When your child turns 18, he or she may need a guardian or conservator to manage some aspects of his or her life.

\* Use of terms such as guardian or conservator and their meanings vary according to state. You should seek the advice of your own legal counsel to determine whether these kinds of mechanisms are available in your state and applicable to your own circumstances.

## General Conservatorship or Guardianship of the Person and Estate

This type of conservatorship or guardianship typically provides full decision-making powers — with respect to finances, medical decisions, living arrangements, etc.—for a person deemed to be unable to make decisions or perform necessary tasks on his or her own.

## Limited Conservatorship or Guardianship

Powers of a conservator or guardian can often be limited to reflect the needs of the individual who is incapacitated or disabled, and laws in a number of states specifically provide for the appointment of a limited conservator or guardian for certain individuals with developmental disabilities.\*\* These types of arrangements are often used in special needs cases. A limited conservator or limited guardian is appropriate for individuals whose conditions impair their ability to care for themselves or their property, but not to the extent that a general conservatorship or full guardianship is required. For example, California law provides that a limited conservator may be appointed only:

- For adults who have a developmental disability.
- When a court finds that the conservatee lacks the capacity to perform some, but not all, of the tasks necessary for personal needs or to manage financial resources.

A limited conservatorship or limited guardianship encourages maximum self-reliance and independence for the adult with developmental disabilities by giving the conservator or guardian power only over those activities that the individual is unable to handle.

## Alternatives to Guardianship and Conservatorship

Depending on personal circumstances, avenues other than guardianship and conservatorship relationships may exist that can help an individual feel more independent and minimize legal involvement. For example, if your child only needs assistance managing his money, he may be eligible for help through the Supplemental Security Income program (SSI) offered by the Federal government. If appropriate, an SSI Representative Payee can be designated to receive and disburse SSI money on behalf of your child, a function that might otherwise be performed by a court-appointed guardian. The Representative Payee must make an annual accounting to the Social Security Administration on how funds are spent.

Another option is Durable Power of Attorney, whereby the individual who has a disability allows certain decisions, such as medical, property, or living situation, to be made by another person, on his behalf, with-

\*\* Developmental disabilities generally are severe, chronic disabilities attributable to mental and/or physical impairment which manifest before age 22 and are likely to continue indefinitely. They result in substantial limitations in three or more areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, as well as the continuous need for individually planned and coordinated services.

out court intervention. A Special Needs Trust can also be effectively used by a trustee to manage the finances and personal effects of a person who has a disability, rather than a court-appointed general guardianship or conservatorship.



## Letter of Intent

A letter of intent is another important document parents should have. Although not legally binding, this document provides direction for the person or persons who will care for your child or other dependent with special needs. The letter should detail medical history, daily care needs, housing and services, as well as your specific wishes and expectations as they relate to your child's future. It is a working document for the future caregiver to follow.

One of the best ways to get started developing this letter is to think of a day in the life of your child. What are his or her habits? What are his or her routines? What makes him or her upset?

Share the letter of intent with the person(s) who will be caring for your child. Discuss it. If you aren't comfortable that they share your views or that they are willing to respect them, you may want to reconsider your choice. A letter of intent is often the most important part of the plan.

## Special Needs Trusts

Many well-intentioned parents don't realize that an inheritance may cause many problems for their child. Under current federal law, any inheritance of more than \$2,000 disqualifies individuals with disabilities from most federal needs based assistance. Benefits from state public assistance programs may also be affected.

A special needs trust, however, offers a means of protecting your child's eligibility for these benefits, while addressing the ongoing care and needs of your child or other dependent with special needs.

## Trusts, in General

Very generally, a trust is a legal entity which permits one person, the donor, to give something to a second person, the trustee, with qualifications that it must be used for the benefit of someone else, the beneficiary.

Assets are owned by the trust. The trustee is usually given the power to manage those assets (e.g., to sell assets, to invest trust funds). In addition, in the case of a special needs trust, the trustee has the discretion to use trust assets for the benefit of the child with special needs. Trusts are governed by state laws and should only be drafted by an attorney who is familiar with this area of law. In addition to legal fees, there may be costs associated with transferring assets to, and administration of, a trust.

## Advantage

The primary advantage a special needs trust offers over a direct gift or inheritance is that, if arranged properly, the assets in the trust do not actually belong to the beneficiary. In this way, the trust can provide benefits to an individual but not cause the individual who has a disability to be disqualified from government programs.

A special needs trust holds title to property for the benefit of a child or adult who has a disability. The special needs trust can be used to provide for the needs of a person with a disability and to supplement benefits received from various governmental assistance programs.

Special needs trusts typically provide for:

- eyeglasses
- annual independent check-ups
- transportation (including vehicle purchase)
- equipment
- training programs
- maintenance
- education
- insurance (including payment of premiums)
- rehabilitation

Special needs trusts also may allow a trustee to give the beneficiary money for:

- various forms of entertainment (e.g., movies)
- electronic equipment
- trips and vacations
- computer equipment
- athletic training and competitions
- companion services/home health aide
- other items to enhance self-esteem
- higher quality of medical or dental care that is otherwise provided by any local, state or federal agency or any private insurance policy (where it is clearly supplemental)

A trust can hold cash, stocks, personal property, and real property. It can own and/or be the beneficiary of life insurance. Special needs

trusts also can be used to protect personal injury settlements or judgments from jeopardizing government benefit eligibility. Most importantly, special needs trusts can help parents coordinate their estate plans and provide peace of mind, knowing their child will be provided for.



## Planning for Financial Needs

### Savings

You want the best for your child's/dependent's lifetime care, but sometimes sufficient financial resources to meet those needs may not be available. The death of one or both parents or other caretaker can easily disrupt the continuation of your child's financial safety net.

Figuring out what your dependent is likely to need is tricky. Ask yourself: What type of life do you envision for the individual with special needs? How much money will he/she need for quality lifetime care?

Start answering the question by estimating your child's current monthly expenses (whether the costs are paid by you, private insurance, etc.). Annualize these costs. Then, assuming a modest interest rate, determine the lump sum amount you will need to produce that much income on an annual basis without depleting principal. Of course, this does not take inflation or other factors into consideration.

If you are just beginning to accumulate assets to fund a special needs trust, there are a variety of funding options. Discuss these options and which ones might be best for you with an insurance agent, financial planner or other financial professional who specializes in special needs trusts.

A special needs trust can contain personal property, such as artwork. Keep in mind, these assets may not be readily converted into cash. A value of a home also is susceptible to market fluctuation. Moreover, you may want the family home to stay in the family and not have to be sold to provide necessary care.

### Investments

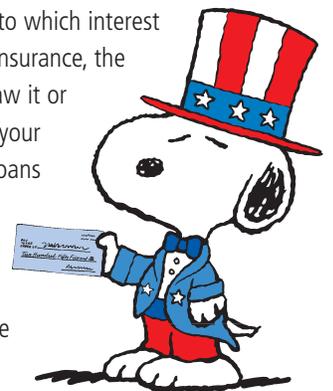
Investments, like mutual funds and stock, are another funding option. These types of options provide an opportunity for growth, however, they do not generally provide a guaranteed amount of income due to market fluctuation and other factors. Retirement plans may offer another option. You may be able to name the trust as beneficiary for any death benefit provided by the plan.

### Life Insurance

Many special needs trusts are funded, at least in part, with some type of life insurance. Life insurance provides an alternative that can create an asset. Insurance proceeds are generally paid free of income tax and, as long as the estate is not named as beneficiary, usually outside of probate. It also can be free of federal estate tax when properly structured, and it allows you to provide the cash needed to provide for your child with special needs, while keeping the rest of your estate intact for your other family members.

Here are descriptions of the basic types of life insurance.

- **Term life insurance** offers protection that insures your family for a specified period of time—usually anywhere from one to 20 years. A term policy pays a benefit if you die during the period covered by the policy. If you stop paying premiums, the insurance stops. These policies do not build a cash value.
- **Whole life insurance** or permanent insurance provides protection, as well as a cash value. Additionally, many companies pay policyholders an annual dividend. Dividends provide both flexibility and increased value to your life insurance policy. They can add more coverage to your overall insurance benefits and can build a sizable cash value. They are not, however, guaranteed. Of course, life insurance should not be purchased solely for accumulation. Its primary purpose is protection.
- **Universal life insurance** is flexible. These policies are interest-sensitive and permit the owner to adjust the death benefit and/or premium payments, within limits, to fit the individual's situation. Your premiums are credited to an accumulation fund, from which costs are deducted and to which interest is then credited. As with whole life insurance, the cash value is yours. You may withdraw it or borrow against it at any time. Read your policy carefully to understand how loans and withdrawals affect the death benefit.
- **Variable life insurance** is for those who want to tie the cash value of their life insurance policy to the



performance of the financial markets. You decide among several investment options how your net premiums are to be invested. While monies invested in the investment options have potential for growth, such funds are subject to market risks including the loss of principal. In other words, some may make or lose money depending upon the performance of the market and the investment options you select.

- **Survivorship life insurance** is a joint insurance policy taken out on the lives of two people that provides death benefits on the second death when the money is needed the most. Since the policy premium pays one death benefit, the premium can be substantially less than separate stand-alone policies. There are many types of survivorship life insurance policies. Check with your attorney and insurance agent to determine the policy that will best meet your needs.

Your individual needs and the needs of your child will help determine which type of insurance is best for you. Insurance policies often contain limitations, exclusions, reductions of benefits and terms for keeping them in force. Be sure to ask for full details regarding the policy and its costs.

The potential long-term care for the caregiver should be taken into consideration and planned for. There are steps that can be taken now in the event that a caregiver can no longer care for his or her dependent. Many people think of "long-term care" as something for older people; however an accident or illness can strike at any age. It is especially important for caregivers to prepare for their own care while arranging for the continued care of their dependents.

## Finding Financial Aid

Raising a child is expensive. Raising a child with disabilities is even more expensive. The unique supplies, equipment, treatments and procedures a child needs can strain even families with significant personal assets. Fortunately, financial relief may be available. State and federal government programs, community resources, Social Security benefits, private foundations, medical insurance and special education resources provide aid. Consult city, county, state and federal agencies for help in answering financial aid questions.

Generally, government benefits are paid to a disabled *dependent* child, based on family income. But once a child turns 18, these benefits are awarded based on the child's own assets and income (even if the child is still living at home with the parents).

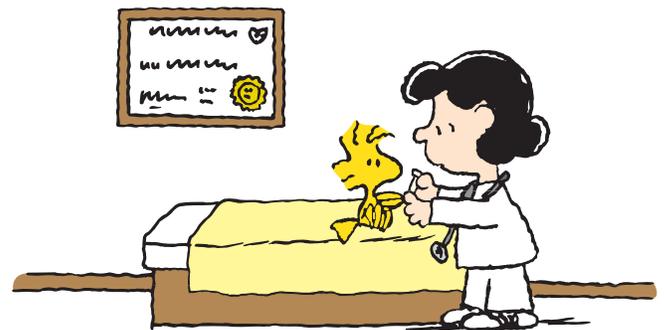
The most important public benefit programs are Medicaid and Supplemental Security Income (SSI).

- **Medicaid** is a state-administered, federally reimbursed program that pays for needed medical care for eligible persons. An

applicant's medical diagnosis, finances and age are used in determining eligibility. To apply for benefits, contact your local Medicaid office or the state health department.

- **SSI** is a federal program that provides income from the federal government to certain individuals with disabilities. Cash benefits are paid each month, up to the "Federal Benefit Rate." To apply for SSI, contact your local Social Security Administration office.

Eligibility for both of these programs is based on need, as well as disability. A person is not qualified to receive SSI if he or she has "countable resources" in excess of \$2,000 or "countable income" in excess of the Federal Benefit Rate. Keep in mind that gifts or inheritance are "countable resources" and may reduce payments received or cause the child to lose SSI benefits for an extended period of time. Also, assets in a special needs trust may be claimed by Medicaid upon the death of the beneficiary if Medicaid paid benefits while the trust was in effect. Medicaid laws and the laws pertaining to special needs trusts vary from state to state. Contact your local Social Security Administration office for additional information.



## Planning for Medical Needs

Specialized medical treatment may be needed for individuals with special needs, sometimes beginning in a neo-natal intensive care unit. Other times the need for such treatments arise much later as you or your pediatrician begin to notice developments that give rise to questions.

You need to take precautions to ensure that you make the most of your medical insurance coverage. Otherwise, you could be left holding the bill—or a large part of it.

Obtaining medical insurance authorization for specialized services and products, such as therapy or medical equipment, can be complicated. The following are tips to better manage your medical insurance and get much needed benefits paid:



- **Read your policy!** If you have any questions about coverage, call your insurer and ask them to clarify exactly what is covered, under what conditions and at what rate. For example, traditional therapy services often do not take into account the specific needs of infants and children requiring therapeutic intervention. There also may be limits on therapy services.
- **Create a one-page summary of your policy provisions as well as one for limitations and exclusions.** This summary can be given to the treating physician or therapist who will either be writing a report or speaking to an insurance company representative on your child's behalf.
- **Check the list of participating providers if you are part of a Preferred Provider Plan or Health Maintenance Organization (HMO).** You may be limited to using only providers within the network. Make sure there are professionals qualified to serve children and/or adults with special needs. You may have the option of using out-of-network providers, but be required to pay more out of pocket. The out-of-network option may be useful if your child requires non-participating medical specialists such as pediatric therapists or neurosurgeons.
- **Speak with the same case manager or claims supervisor, if possible.** When you call your insurance company, ask for the name and phone number of the representative and try to speak with that person every time. He or she may become familiar with the needs of your child and you will not have to repeat your child's story.
- **Request a case manager be assigned to you if your child has ongoing medical or therapy services.** Working with the same people can provide continuity of services.
- **Include a photograph of your child when you submit a claim or begin your relationship with a case manager.** Photos can personalize a case file, which might earn "special treatment" when trying to resolve problems that might arise.
- **Obtain prior authorization for therapy, prescriptions or equipment from your insurer.** Call your case manager and ask if there is any procedure regarding prior authorization. Your insurer may require a letter of medical necessity, or the written prescription from your primary care physician.
- **Stay on top of your child's case.** Document everything, from phone calls to faxes, and include dates. Send all correspondence by certified mail so you have a return receipt for documents you send. Call the insurer if you don't get a timely acknowledgment of your correspondence. Keep copies of everything.

- **Obtain a claim denial in writing.** It should include the specific reason for denial. Insurance companies are legally obligated to provide this. Question denials, and if you believe the claim is valid, appeal the denial and resubmit the claim.

Making the most of your medical insurance can be time-consuming and sometimes exasperating. However, being the parent of a child with special needs also means being his or her advocate. By being organized and proactive, you can give your child the best possible quality of life.

## Planning for Educational Needs

As a special needs parent, you can take steps to make sure your child gets the best education possible. To do so requires becoming an active advocate and participant in your child's educational plan. The first step is knowing the special education laws and what they provide.

### Early Intervention

Early intervention provides support for infants and young children who have disabilities or developmental delays. Early intervention services include, but are not limited to, identification and screening, occupational therapy, speech pathology, and physiotherapy. These services are provided for the purpose of lessening the effects of the conditions and enhancing the child's development. Early intervention can have significant impact the child and the family by reducing the number of special services needed, reducing stress and frustration, and possibly making the child indistinguishable from mainstream classmates.

### Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA), which amended the Education For All Handicapped Children Act, requires that children with disabilities receive:

1. Free appropriate public education (for children ages 3–21).
2. Education as close to home as possible with children who do not have disabilities.

3. Supplemental services (such as speech therapy or a classroom aide) to complete their education.
4. An assessment to determine the child's needs.

In order to assure that your child gets the best possible education, this law includes two protections: Individualized Education Program and Due Process.

### Individualized Education Program (IEP)

An IEP is a written statement about your child's abilities and impairments required under the IDEA. It's developed by you, school district personnel and educational professionals who have evaluated your child's abilities. In some cases, the school nurse or primary health care provider should be included. The IEP must be revised at least annually for all children with disabilities.

### Transition from School to Adult Life

Transition planning is crucial to a child's/dependent's success after high school. Local non-profit organization(s) can assist in helping you obtain additional information required for these services.

### Due Process

Due Process generally requires that no changes are made in a child's IEP without certain procedural protections. The scope of this is not absolute but due process provides a mechanism for resolution of disagreements.

Before entering an IEP meeting, parents should understand what their overall rights and responsibilities are:

You have the right to information about your child and the child's educational program. You have the responsibility to seek and maintain this information.

You have the right to review your child's records. You have the responsibility to ask questions when you do not understand terms in reports.



You have the right to be full partners in your child's educational program. You have the responsibility to become and remain active members of the team.

You have the right to make suggestions or recommendations about your child's program or services. You have the responsibility to do so.

You have the right to a vision for your child's future. You have the responsibility to help your child achieve it.

### Who Can Help

Planning for your child is a daunting task. To do it right, you might be wise to turn to experts for help.

An attorney who specializes in estate planning for families with a child with special needs can help you establish a special needs trust. Insurance agents, financial planners, and other financial professionals who specialize in needs planning, guidance counselors and parents of other children with special needs also are good resources. In addition, there are countless organizations that offer different types of assistance. A sampling is shown on the final pages of this booklet. Information on others can be found on the Internet or at the library.

It is important that you take the time today to provide for your child's tomorrow. You want to make sure that the ongoing care and needs of your child will be addressed no matter when you die.

## For More Information

### Organizations & Information

#### MetDESK®

##### MetLife's Division of Estate Planning for Special Kids

[www.metlife.com/desk](http://www.metlife.com/desk) 1-877-MetDESK/877-638-3375

MetDESK is committed to helping families through the maze of legal and financial complexities that surround planning for the future of children and other dependents with special needs. Working with a qualified legal advisor, your MetDESK Specialist can help you secure lifetime care and quality of life for your child or other dependent with special needs. Your Specialist will help you build financial freedom and peace of mind for you and your loved ones.

##### The Americans with Disabilities Act (ADA)

[www.disabilityinfo.gov](http://www.disabilityinfo.gov)

The ADA of 1990 is a civil rights law created to assure equal opportunity for people with disabilities in all aspects of American life.

##### The Arc of the United States

[www.thearc.org](http://www.thearc.org) 800/433-5255

The Arc works to advance federal public policy in the interest of protecting and enhancing the vital programs and services for people with intellectual and developmental disabilities and their families.

##### Autism Society of America (ASA)

[www.autism-society.org](http://www.autism-society.org) 800/3AUTISM (800-328-8476)

ASA increases public awareness about the day-to-day issues faced by people on the Autism spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research, and advocacy.

##### Genetic Alliance, Inc.

[www.geneticalliance.org](http://www.geneticalliance.org) 800/336-GENE

Genetic Alliance, Inc. is a non-profit organization dedicated to helping individuals who have genetic disorders and their families.

##### Huntington's Disease Society of America (HDSA)

[www.hdsa.org](http://www.hdsa.org) 800/345-HDSA (4372)

HDSA is a national non-profit voluntary health agency dedicated to finding a cure for Huntington's Disease.

##### National Council on Disability (NCD)

[www.ncd.gov](http://www.ncd.gov) 202/272-2004

The NCD is an independent federal agency making recommendations to the President and Congress on issues affecting some 54 million Americans with disabilities.

##### National Down Syndrome Congress (NDSC)

[www.ndscenter.org](http://www.ndscenter.org) 800/232-NDSC (6372)

The mission of NDSC is to provide information, advocacy, and support concerning all aspects of life for individuals with Down Syndrome.

##### National Down Syndrome Society (NDSS)

[www.ndss.org](http://www.ndss.org) 800/221-4602

NDSS envisions a world in which all people with Down Syndrome have the opportunity to realize their life aspirations.

##### National Dissemination Center for Children with Disabilities

[www.nichcy.org](http://www.nichcy.org) 800/695-0285

This national information and referral center provides information on disabilities and disability-related issues for families, educators, and other professionals.

##### National Organization for Rare Disorders (NORD)

[www.rarediseases.org](http://www.rarediseases.org) 800/999-6673

Federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them.

##### TASH

[www.tash.org](http://www.tash.org) 202/263-5600

TASH is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm.

##### The Tuberous Sclerosis Alliance (TS Alliance)

[www.tsalliance.org](http://www.tsalliance.org) 800/225-6872

The TS Alliance is the only national voluntary health organization for the genetic disorder known as tuberous sclerosis complex (TSC).

##### United Cerebral Palsy (UCP)

[www.ucp.org](http://www.ucp.org) 800/872-5827

UCP's mission is to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network.



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**1-800-METLIFE**

Or contact your local MetLife representative.

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