

# Wills, Guardianship & Special Needs Trusts

*What military families need to know*



***STOMP***

*Specialized Training Of Military Parents*

***WORKING TOGETHER FOR MILITARY FAMILIES OF  
INDIVIDUALS WITH DISABILITIES***

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## STOMP -A Project of Washington PAVE

### Wills, Trusts, and Guardianship



#### **Planning for the future**

In 2000, there were 4.3 million U.S. residents with developmental disabilities, including those with cerebral palsy, autism, neurological disorders and mental retardation, according to a 2002 study by the Coleman Institute for Cognitive Disabilities in Boulder, CO. With improved medical care, nutrition and exercise, this is the first generation of children with significant disabilities, including developmental disabilities, to reach adulthood. Which means for the first time, physicians, educators and other experts have had to encourage parents to prepare for the future.

"Unfortunately, if nothing is in place, their children are subject to what someone else may decide after their death," says Sharon Davis, director of family services for the Arc of the United States in Silver Springs, Md.

When parents rely on their other children to take over care, they don't consider that, through the years, unexpected things may occur to alter their plans. Additionally, the designated children may face challenges to being the caregiver, such as a divorce, an automobile accident, illness, or a spouse who is not willing to share that responsibility. Parents, themselves, may face situations in which they become debilitated and are unable to make a determination about the supports or services the child with disabilities may need. Without specific written instructions and designation of a guardian, the courts will be forced to determine who and how the individual may need to be served.

Parents ages 30 to 40 should set up trusts or guardianships to protect savings, earmarked for the care of their child with a significant disability, said Marty Ford, the director of legal advocacy for The Arc. Younger parents may also want to consider beginning the process. This can be particularly important for a military member who may be placed at any time into harms way. Imagine if you will, the potential negative impact to SSI, Medicaid, or other finance based support that would occur if the military member were to die unexpectedly and there were no protections in place. Additionally, if the military member and the other parent of the child are

divorced, the funds could go directly to the child and the potential for long-term negative impact could be significant.

When a family doesn't plan ahead and place any funds they want set aside for the care of the person with disabilities, situations such as divorce or accidents can quickly deplete or totally absorb those undesignated funds. "If there's a divorce, all savings must be divided equally between spouses, as stated in the decree," Ford says. "Or if there's an automobile accident and a person is being sued, the money can be claimed to pay a settlement."

As the population ages, more and more people are faced with complicated financial decisions. "Elderly people are unaware of the challenges they face if they're not prepared", says Chris Privett, Communications Director for The Arc.

Experts suggest that parents consider the following, in order to protect the future of their child with a developmental disability:

Know your child's future earning capacity.

1. Determine if your child will need Medicaid or long-term care.
2. Will family members provide assistance after you're gone? If so, they should serve as trustees, holding money in their control. This money will not be available to creditors.
3. If there is family support, set up a letter of intent, explaining their roles.
4. Hire an attorney or estate planner who understands the Medicaid or SSI laws; this person will assist in writing a special needs trust for your child.

But there's more to planning your child's future.

Knowing that your child is safe and connected to the community is also a growing concern. "The surviving child needs to avoid being isolated, and he needs to be able to participate in community activities," says Drew Dixon, community director of intervention services for the Arc of Dallas.

Dixon urges parents to contact their local developmental disability authority when their child reaches age 14. Then, a service coordinator will show the family what options are available in the form of housing or group homes. "Make arrangements as soon as possible," says Dixon, "because some group homes have a waiting list of nine years."

To insure the needs of the person with disabilities are addressed, guardianship at the age of majority and special needs trusts are an essential part of the planning process that needs to occur. Additionally, the family needs to have current wills. These will help to provide a stable basis for planning, and assist in decisions that will be made once you, as the parent, are gone. As Mr. Bill Dussault, (Esq. noted

disability rights attorney) has stated, "Will and guardianship are like life insurance, you hope you never need them, but they are really difficult to get the day after you do."

For the first time, many people with developmental disabilities are enjoying a typical life expectancy. Many will survive their parents and siblings. For this reason, it is necessary for families to prepare a plan for the care and supervision of their loved one after they are gone, or are no longer able. This involves consideration of your child's plans for the future, living and working arrangements, the kind of life you hope for them when you are no longer around, and arranging the necessary financial situation to support this life. Planning should begin immediately. Regardless of whether the person with a disability is 4 months or 40 years old, planning is necessary, the sooner the better, but better late than never.

## **Understanding Guardianship**

### **Why do we need to think about guardianship? As our child's parents, aren't we already their legal guardian?**

When your child reaches the age of majority (their 18<sup>th</sup> birthday in most States) he/she becomes an adult under the law, regardless of their disabilities. You must take affirmative action in order to become your child's legal guardian. This is not legally required of parents of children with disabilities; however, if you do nothing, your child will be considered an adult under the law. If this happens, the individual can enter into contracts, be held accountable for expenses; be denied medical services that are not of an emergent basis, based on their inability to be determined competent to approve such services, as well as many other things.

Individuals with disabilities and their families must take the time to consider guardianship and the potential ramifications of not appointing a guardian. If they decide legal guardianship (sometimes referred to as applying to become the persons' conservator) is appropriate, the potential guardian needs to apply, and must go to court to be appointed.

In the event you, as a family, decide that guardianship is needed, you must recognize that, if the individual who is disabled moves to another State, the guardianship application will have to be done again in the new State. This is because there is no reciprocal process between States in regards to guardianship. The process can be fairly quick, or somewhat lengthy, depending on the requirements within each State. As laws vary between States, families should consult legal counsel specializing in guardianship.

### **What does guardianship involve?**

Guardianship is the legal power to care for another person, and manage his or her affairs. A guardian helps protect someone from harm or neglect, and may help make decisions about his or her money, health and property. When a guardian is appointed, the court decides the level of guardianship required for each individual, based on his/her ability to handle personal decisions about money, property and similar matters.

A person's parents, or another interested person, may file a petition for guardianship in Probate Court. The court makes all decisions about guardianships, with the help of knowledgeable individuals and the documentation that is provided in support of the petition. In many States a family can acquire a petition package that includes all necessary forms and procedures. This can be obtained from the court, or from advocacy organization such as The Arc.

The court usually looks at evaluations from a psychologist or psychiatrist, and from a doctor. A person's own doctor or psychiatrist can perform these. Various public agencies, such as a school district or a mental health agency, can also provide these evaluations. Additionally, the Court will appoint a Guardian-ad-litem to protect the rights of the individual for whom the petition has been made. This person is required to interview the individual, the perspective guardian, and to make specific recommendations to the court.

If the court finds that a person is unable to make some decisions for themselves, regarding their person, money, or their property, it may appoint a partial guardian, who has responsibility for making those decisions in that specific area. If the court finds that an individual requires total assistance with all daily living, and also requires assistance with all decisions, it may appoint a plenary or full guardian. In order to create the least restrictive situation possible, partial guardianship is always the preferred form.

### **Who can become a guardian?**

A guardian may be a family member, a friend, an unrelated person who has received specialized training, as well as a bank or a public or private nonprofit corporation. Many parents choose to become their child's guardian and also assign a guardian for the future, when they may no longer be around or able to continue as guardian. Often this person is a sibling of the individual with a disability.

Once appointed, the guardian has a fiduciary obligation to the ward. This means he or she must act primarily for the benefit of the person with a disability, or ward. Furthermore, if he is appointed guardian of the estate, he must not invest the money in something that is risky or otherwise careless.

In determining what is in the best interests of the ward, the guardian should always consider the reasonable preference of the person. The guardian should take great care to avoid the appearance of self-dealing in handling the affairs of his ward. In

many States the guardian must file annual reports to the court on the estate or person with a disability.

There are several areas of decision making over which there may be restriction on the power of a guardian. These include, but are not limited to, placement in a facility, extraordinary medical treatment and fundamental and/or constitutional rights. These are complex and confusing areas of law. Talk to a knowledgeable attorney or advocate if you have questions.

### **Types of Guardianship**

There are several types of guardianship, including plenary or full guardianship, partial guardianship, guardianship of the person, guardianship of the estate and temporary or stand-by guardianship.

- A Guardian of the Person helps you make decisions about your personal affairs such as medical, health, housing, education and employment.
- A Guardian of the Estate helps you make decisions about your money and property.
- A Partial Guardian helps you with only some decisions. For example, you may only want help with decisions about money. You may not need help deciding where to work, where to live or with whom to live.
- Plenary/Full Guardian helps you with all decisions.
- Temporary Guardian in case of an emergency, temporary guardianship can be granted.

### **Changing Guardian**

A person has the right to change their guardian's duties, or change guardian, under certain circumstances. The court should verbally tell individuals and families about this right. The court should also give a written statement, explaining how to ask for a change in guardianship.

The individual for whom guardianship has been acquired, the guardian or any other interested person, may petition the court for a change in guardianship. To do this a letter must be written, or a request must be made to the court by phone. The court may then appoint someone to help prepare the petition. A hearing will be held to talk about the requested changes in guardianship. If an attorney is needed, the court will provide one.

Sometimes disagreements between the Ward and the Guardian can occur. There may also be situations where the individual disagrees with the need for a guardian. In such situations you can ask for a mediator to help you work out your

disagreements, or you may make a request for someone to conduct an evaluation of the person's abilities.

It is important to know what the evaluators, as well as what other interested people, will say about the person's capabilities. Family, friends and school, job or workshop and home staff, may all have different ideas about the individual's abilities. A knowledgeable attorney, or advocate, can help petition the court for a change in guardianship, but in most States ONLY an attorney can represent a person who is not representing him or herself.

### **Alternatives to Guardianship**

As well as considering guardianship at the varying levels, individuals with disabilities and their families should also consider the alternatives. Guardianship should only be used when necessary or when someone is in danger of being harmed or neglected and whenever possible or reasonable, the least restrictive choice is preferable. Some alternatives to consider are:

- Representative payee
- Protective order
- Advocacy

**Representative payee:** Helps a person manage their money. A representative payee is appointed if the SSA determines a person is unable to handle payments. A representative payee will not be appointed just because you or someone else asks for one. There must be proof that such an appointment is needed. The SSA will consider information such as court decisions, input from doctors and other important factors. The appointment of a representative payee does not mean a person is legally incompetent; it simply means some assistance is needed with paying bills and handling money.

The goal is to appoint someone who will best serve the interests of the person with a disability. That person could be a parent, guardian, friend, spouse or another relative. A person can also choose an organization; the trustee of their special needs trust, or a volunteer from a local advocacy organization.

If an individual with a disability and/or their family is unable to find someone to act as representative payee, the Social Security Administration will help you find one. Call the SSA at (800) 772-1213 or (800) 325-0778 (TTD) for more information.

**Protective order:** This alternative to guardianship works well when court intervention is needed for a one-time unusual situation. For example, you were hurt in an accident and are receiving a payment from an insurance company. The company may want you to have a guardian to receive the payment and sign the release of liability. A protective order can be used for the same purposes without

the need for a guardian. You can ask the court for a protective order, or someone else can ask on your behalf. If the court issues a protective order for a particular situation, it does not mean that you are legally incapacitated. It simply means you need protection regarding a particular situation. A knowledgeable attorney or advocate can help you petition the court for a protective order.

**Advocates:** Advocates can give a person advice and support on how to best handle their personal affairs. Volunteers such as family members and friends, as well as professionals from local advocacy organizations, can be advocates. Advocates can be very important in helping protect a person's safety and well being, by providing them with up-to-date information on rules, procedures, housing and benefits to help them live more independently in their community. Advocates can also go with a person to meetings and make telephone calls to help gather information. They can talk to other professionals such as social workers, caseworker from Social Security or job coaches. They can also contact agencies or organizations on behalf of the individual that may be able to offer assistance.

### **Issues Surrounding Wills and Guardianship for military families**

It is extremely important that all parents of children with disabilities and special needs consider what will happen in the event of their death, or when that young person turns the age of majority; it is even more critical for the military family.

Here are a few questions you need to ask:

- What happens if we are overseas or away from our family and something happens to my spouse and myself – How will we insure that our children are cared for, and that our wishes are met?
- What about benefits?
- If we acquire guardianship for our adult family member, and then PCS to a new duty station, will we have to start all over again?
- What about when I retire – If I take out survivor benefits, can I assign them in my will so that they don't negatively impact on my child's services?

These questions are critical, and must be answered. Planning must include how you will address each of these questions. So let's take them one at a time and discuss some of the issues military families face with regards to them.

**What happens if we are overseas or away from our family and something happens to my spouse and myself – How will we insure that our children are cared for and that our wishes are met?**

Your will expresses your wishes in the event of your death. You need to plan accordingly. If you are away from family, and you have designated specific individuals to care for your child, you will need to insure that they are aware of your desire and are willing to take on that responsibility. In your will or in a letter of intent, you may wish to include language that stipulates that funds from your life insurance or other assets, can be used to assure that your child(ren) are transported to that individual, or that the individual's travel expenses, to acquire your children, will be covered. This is particularly important if you have one person (or couple) caring for your children, and another person or entity having oversight of your assets.

The more detail you include in your will, the better.

### **What about benefits?**

Your family member will be eligible for all of the regular benefits (i.e. commissary, exchange, medical) that they were eligible prior to your death, at least until the age of twenty-one. If however, the child is significantly disabled, the guardian you have appointed can fill out the appropriate paperwork, so that your family member can continue to benefit from the privileges they have been receiving, for the remainder of their life.

In your will or letter of intent you may wish to include information about this right, so that the guardian can follow those instructions. There are forms that you can acquire to help with this. Contact the JAG or ID section for these.

### **If we acquire guardianship for our adult family member, and then PCS to a new duty station, will we have to start all over again?**

One of the major challenges for military families is the frequent relocating that the job can require. If you have a significantly disabled family member who turns age of majority, it is important that you apply for guardianship (conservatorship) to protect your adult child. This legal process is specific to the State in which the person, for whom the guardianship is acquired, is living. If you PCS, and your adult child will travel and reside with you at the new duty station within the United States, you will need to acquire guardianship from within that State. If you go overseas with the adult child, the current guardianship should suffice in any military setting while you are overseas, as the host nations do not have a system similar to the United States'.

If the adult child remains in the State where guardianship was taken out, then you need not make changes to the guardianship. Even if you are living somewhere else, as long as the person, for whom the guardianship was acquired, remains in the State from where the approval for guardianship took place, then the guardianship remains valid for the duration of the time established by the State for that guardianship.

## **What about when I retire – If I take out survivor benefits, can I assign them in my will so that they don't negatively impact on my child's services?**

You can assign insurance to a "Special Needs Trust" which the individual with a disability does not have direct access to, but for which the funds are being used; however, you cannot direct survivor benefits to such a trust. The funds must go directly to the individual. This has caused some significant problems for survivors who have been, or are receiving, Supplemental Security Income (SSI), as the survivor benefit exceeds the allowable unearned income. By exceeding this allowable amount, the individual loses the right to SSI, which in many States is the key to the door for access to adult services. Without that eligibility, they can be denied many of the other supports needed for them to continue to work and live in their community.

This is an issue that STOMP is greatly concerned about because of the impact on families. Military members need to be aware of the current situation before making such decisions. The only way to correct this current inequity is for Congress to pass language that will allow the Survivor Benefits to be placed in a special needs trust.



## **The Special Needs Trust**

### **What is a Special Needs Trust?**

This document enables family and friends to leave assets to provide for the person with a disability. When properly drafted, the funding assets are not considered to belong to the person, but they are placed in the trust to provide for their supplemental needs. When applying for any government benefits and programs (which are often necessary for children and adults with disabilities), this is important, because any assets that they have may be counted against them, and consequently cause them to become ineligible for programs. These programs can range from SSI eligibility and/or Medicaid, to residential placements. In other words, the ramifications of a person inheriting money or assets, without the use of a special needs trust, can have as huge an effect on their life, as having to move them from a home they know and love because of this inheritance.

After the initial disqualification for services, what subsequently happens is that government programs eat up the funds until a person has no assets anymore, at

which time they will once again qualify for the government programs. It is important for families to understand that government programs were designed to cover basic living needs. A trust provides a way for a person to access some of the comforts and recreation we all thrive on, that is not considered necessary in such programs. The creation of a Special Needs Trust will avoid the termination of benefits, and protect an individual's right to some of the things you would ensure they have if you were still around.

**As a military family with limited income and assets, is it really necessary for us to create a Special Needs Trust?**

Yes. Even if your family has very limited income and savings, you may be worth a great deal more after your death. Consider the value of all your assets, your vehicle(s), your belongings, your home, furniture etc. that may be sold after your death. Also consider your life insurance and that of your spouse and any other children. If your child with a disability is the sole beneficiary, he or she could inherit a fortune from your military life insurance alone. Many non-military spouses have a 401K or other retirement plan, which family may inherit after their death.

All this considered, it is perhaps *more* important to ensure that there is a Special Needs Trust in place when a person will only inherit a modest amount. It is because the person has limited assets that it is crucial to provide them with the best protection possible.

**Is there any risk in leaving assets to other family members designated to provide for the person with a disability?**

Yes, even though you trust others to use your assets to provide for your loved one, problems can arise that they will have no control over. If assets are left to another person, outside of a Special Needs Trust, those assets legally belong to them. The assets are exposed to loss due to lawsuits, creditors, divorce and the death of the holder of the funds. When the individual is named Trustee of the Special Needs Trust, you will be avoiding any situations in their life that could have a negative impact on the availability of those funds, and provide protection for the person with a disability.

**What is the best way to leave information for the person's care when you are no longer able or here to provide it?**

A detailed document known as the "Letter of Intent" is used. This letter is not a legal document; however, it includes details about the person's day-to-day care needs, abilities, diet, activities, rights, medical care, etc. It is recommended that you provide a videotape containing instructions for those who need assistance with typical activities of daily living, such as bathing, dressing and food preparation.

**What are the key issues to address in planning for the future?**

Lifestyle addresses the day-to-day care of the person. Legal includes wills, trusts, guardianship and trustees. Financial needs include creating a budget and providing funds to support it. Government benefits include Social Security, Medicare, Medicaid and military pensions.

### **Who can I choose to serve as a guardian and/or trustee?**

Anyone who you feel you can trust to fulfill your wishes and provide the best care and attention for your loved one. A good way to protect the interest of the individual is to assign one person as the guardian, and another as the trustee. This way each person has another individual to answer to in regards to the decisions they make, with or on behalf of the person in question. This provides an extra protective measure for their well-being.

### **If I do all of this, will I still need to consider a will?**

Yes, you will need to still develop a Last Will and Testament, to specify how your estate will be dispersed. A regular military will is probably not going to be sufficient, as you will need to identify the Special Needs Trust as a part of your Will. Additionally, if the language is not correct, it can have negative consequences in how those assets are divided.

The key to insuring this works for you and your family member is to connect with a knowledgeable attorney or advocate. There are organizations specifically designed to provide such support and information. A first step would be to contact either the National Arc, or a local Arc office for information on attorneys or other individuals within your area who have this specialized knowledge. This will enable you to make the best decisions possible.

***This information is provided to help military families have a better understanding of the need for an appropriate will, and for consideration of guardianship, when their family members turn the age of majority. It is not meant to take the place of competent legal council. When considering such critical issues, it is always important to talk with individuals who have expertise in special needs trusts, the development of a will when there is a family member with disabilities, and in how to acquire appropriate guardianship when a person is in need of such support.***

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