

# Making it happen



**SPECIAL NEEDS TRUSTS  
A GUIDE FOR PARENTS**



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# Introduction

This booklet describes a type of legal arrangement that a family may make for a son or daughter with a disability that provides extra financial support for the child throughout his lifetime while ensuring that the child does not lose eligibility for SSI and Medi-Cal. This arrangement is called a “Special Needs Trust.”

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# What is a trust?

A trust is a legal arrangement under which one person (called the trustee) holds financial resources or other property for the benefit of another person (called the beneficiary). The trustee makes decisions about how the resources in the trust are used and how they are managed. Under this type of arrangement, your child would benefit from the trust, but it would not be under his control.

## WHAT'S SPECIAL ABOUT A SPECIAL NEEDS

**TRUST?** A Special Needs Trust (SNT) is a legal arrangement set up for a person with a disability who receives support such as SSI and Medi-Cal. It may be set up by the person's parents, grandparents, guardian/conservator or a court of law. The trustee is responsible for managing the assets of the SNT and for using the funds according to the terms of the trust and the rules established by the government. The trust is overseen by the courts.

The trust can hold financial assets and property, such as a home. It can be used for the purchase of "extras" that the person could not afford to have if he relied only on SSI. In this way, it can improve

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the person's quality of life. Because of the way the law governing Special Needs Trusts is written, the resources in this type of trust do not count as the beneficiary's personal assets. This is very important, as we explain below.

## **HOW COULD MY CHILD WITH A DISABILITY BENEFIT FROM A SPECIAL NEEDS TRUST?**

The special needs trust could provide your child with extras, while protecting his eligibility for public benefits.

Supplemental Security Income (SSI) is a “needs-based” program intended to provide a person with only the absolute necessities, such as food and shelter. Because it is needs-based, there are strict limits on how much income and other resources a person may possess and still be eligible to receive the benefit. For example, an individual receiving SSI may not have more than \$2,000 in resources.

If a person with a disability inherits money or property, it may disqualify him from SSI. If this happens, the person also loses his eligibility for

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Medi-Cal that is linked to SSI. Other benefits, such as housing subsidies provided through the “Section 8” program and In-Home Supportive Services (IHSS) are also based on financial need and may be put at risk if the individual receives an inheritance.

Fortunately, the federal government created the Special Needs Trust as a way for families to provide “extras” for their son or daughter with a disability without risking the loss of his public benefits.<sup>1</sup>

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### **WHAT MAY THE TRUST PURCHASE?** While SSI is intended

to provide basic necessities, the Special Needs Trust is intended to provide for things that are not covered by a public benefit or insurance program. These “special needs” may include the following:

- Educational or vocational expenses
- Entertainment or recreation
- Clothing and grooming expenses
- Transportation
- Advocacy or legal services
- Household expenses
- Medical, dental or therapy services
- Pre-need funeral and burial insurance

<sup>1</sup> This document describes the Third Party Special Needs Trust. There is a second type of Special Needs Trust, called “Self-Settled,” which we mention briefly in a later section.

Types of things that are often purchased by these trusts include vacations, camp or other social-recreational opportunities, computers, televisions and clothing.

As we discussed above, food and shelter are basic necessities rather than special needs. If the trust pays for these things, the beneficiary's monthly SSI may be reduced, but he would not lose it all. The amount may vary from year to year, but currently the person's SSI would not be reduced to less than \$245 per month.

## **MAY THE BENEFICIARY RECEIVE MONEY**

### **DIRECTLY FROM THE TRUST?**

When something is purchased for the beneficiary of a Special Needs Trust, the trust is actually the purchaser. The funds for a purchase are not given to the beneficiary. The trust may make small cash payments to the beneficiary, but they should generally not exceed \$20 per month. Cash payments over this amount would be counted as income for the beneficiary and would result in a dollar-for-dollar reduction in monthly SSI – a one dollar reduc-

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tion for every dollar paid to the beneficiary by the trust. If the cash amount is equal to or greater than the person's SSI benefit, he would lose not only his SSI but also his eligibility for Medi-Cal.

### **WHAT ARE THE MAIN BENEFITS OF A SPECIAL NEEDS TRUST?**

There are three major benefits of this type of trust:

1. The person is able to keep his government benefits.
2. The assets in the trust are protected.
3. After the person's death, the trust is not required to repay Medi-Cal for services provided to the beneficiary. (See the discussion of "Self-Settled Special Needs Trust" below.) The remaining assets of the trust may be distributed to another person or persons.

### **HOW ARE SPECIAL NEEDS TRUSTS FUNDED?**

Special Needs Trusts are often funded by personal wealth or legal settlements, such as from a personal injury or malpractice lawsuit. If neither of these is available to the family, they may purchase life

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insurance which would be paid into the trust, for example, when a parent dies. The decision to purchase insurance for this purpose is a personal one for the family. The regional center does not promote this course of action, particularly if paying premiums on a policy would create a financial hardship for the family.

**COULD WE PLACE RESOURCES IN OUR CHILD'S NAME NOW AND HAVE THEM PLACED IN A THIRD PARTY SPECIAL NEEDS TRUST AFTER WE DIE?**

Assets cannot be placed in this type of trust if they are already owned by your child. A different type of trust called a “Self-Settled Special Needs Trust” can be established with assets already owned by the individual, but this type of trust has some different provisions from the Third Party Trust. One significant difference is that it includes a payback provision. That is, the trust must repay the government the amount that Medi-Cal spent on the beneficiary during his lifetime.

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**WHAT IS THE ROLE OF THE TRUSTEE?** The role of the trustee is a critical one and the decision about who should play that role is one of the most important decisions the family will make. Even though the trustee is required to use the trust's resources according to the terms of the trust and the law, he has some discretion in the decisions he makes.

In addition to spending the trust's funds in ways consistent with the terms of the trust and the law, the trustee is responsible for keeping accurate records and accounting for assets and expenditures. He also has a primary responsibility of loyalty to the beneficiary. This means that he should understand the beneficiary's needs and the available services to ensure that the beneficiary is receiving the services that he needs and that the services are appropriate.

The trustee should understand the requirements of public benefit programs as well as the legal requirements of the trust, including tax implications. He should also ensure that investments made with assets of the trust are sound and that

the assets are preserved for their intended purpose. A trustee who does not understand any of these things should consult with a lawyer, accountant or other professional expert who can advise him.

The trustee may be a trusted relative or family friend, an institution such as a bank or a professional fiduciary licensed by the State of California. The trust contains a provision permitting payment of reasonable compensation to the trustee.

## **IF I DECIDE I WANT TO CREATE A TRUST, WHAT SHOULD I DO?**

A Special Needs Trust is a complex legal arrangement. Mistakes made when the trust is created or implemented can have serious implications for the beneficiary. A family wishing to establish this type of trust should consult an attorney with experience in estate planning and trust administration. If you do not know an attorney with this experience, you may talk to your HRC Counselor who can refer you to an attorney who has worked with other regional center families. You may also contact your local bar association for referral to an attorney who specializes in Special Needs Trusts.

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