



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

## Planning for the Future for your loved one with CdLS

*By Beth Dixon, District Court Judge and Former CdLS Foundation Board Member.*

In general terms, estate planning is the process of developing a plan for the effective management, enjoyment, and distribution of your property at the least possible cost to your survivors. For most people, this is accomplished through a simple will and a few other standard legal documents. For families that include an individual with disabilities, however, traditional estate planning tools are ineffective.

Families of individuals with CdLS should think in terms of “future planning” rather than simply estate planning. Future Planning is more encompassing and includes the goal of establishing a lifetime personal support system for your child with CdLS as well as providing financial security. A conventional estate plan will rarely meet the needs of an individual with disabilities and may even prove to be detrimental by causing a loss of federal and state assistance, residential services, or health care benefits. The following hypothetical examples show possible consequences of utilizing traditional estate planning methods:

*Mrs. H’s will provides that her estate be divided equally between her three children. At the time of her death, her estate contained \$240,000.00. Mrs. H’s youngest daughter has CdLS and has lived in a Medicaid funded group home for the last three years. Her \$80,000.00 inheritance is immediately attached by the federal government to pay for her past cost of care, which is more than \$5000.00 per month. The daughter receives nothing from her mother’s estate.*

*Grandmother T wants to do something special for her grandson Jack, who has CdLS. At the time of her death, Jack’s parents are surprised to learn that Grandmother T has left Jack a specific bequest of \$15,000.00 in her will. Although Jack lives at home, he receives health insurance coverage under the Medicaid program that pays for his many therapies and doctor visits. Jack is now ineligible for Medicaid until all his funds above \$2000.00 are spent.*

*Aunt Susan does not have any children and wants her nephew Sam, who has CdLS, to be her sole beneficiary. Sam has constant medical needs and is a recipient of Supplemental Security Income (SSI) and Medicaid. Aunt Susan knows that Sam is not capable of handling money, so she sets up a trust with \$50,000.00. The trust document provides that the funds are for Sam’s “care and maintenance.” Ruling that this language creates a support trust, the court allows the state to cease SSI and Medicaid payments on behalf of Sam until the entire trust fund is spent. The funds are depleted within a year to pay for Sam’s medical needs.*

Thankfully, there are specialized future planning methods to help families avoid unintended pitfalls such as these examples. A good plan will allow an heir with disabilities to preserve government benefit eligibility, provide for supplemental needs, and allow for a successful



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transition in caretakers. Wills, trusts, guardianship plans, letters of intent, and communication amongst family members are all essential elements of good future planning.

## **WILLS**

A will is the cornerstone of every future plan. No matter how large or small your estate, everybody needs a will. If you die without a will (intestacy), the laws of the state in which you live will determine how your estate is divided. These intestacy laws are very rigid and usually include some share for all surviving children. They make no provisions for special circumstances such as disability or incompetency. Failing to make a will can sabotage your good intentions in planning for your child's future. There is no one-size-fits-all solution for the best way to pass financial resources and assets to a child with CdLS, but families should know what options are available and decide upon the best plan for their family.

### **Exclusion/Disinheritance**

Since assets of \$2000.00 or more will disqualify an otherwise eligible individual from many government health and support benefits, it is generally not advisable to leave a direct bequest to an individual with CdLS. A way to insure that a person with CdLS is not disqualified from their current or future government assistance benefits is to specifically disinherit, or exclude, that child from your will. This is usually a very painful decision for parents and may lead to feelings of guilt about not treating all heirs equally. Exclusion can be a very good plan, however, especially for families with limited financial resources. It may be the best plan that you can make for your loved one with CdLS. A simple sentence in the will such as "I specifically make no provisions for my daughter Emily, who has CdLS, except to leave her my love and affection knowing Emily will be cared for otherwise" will suffice.

### **Direct Bequest**

As previously stated, it is generally not advisable to make a direct bequest to an individual with CdLS. Besides the benefit ineligibility, there are other hazards to a direct bequest. Who will manage the funds? Will there be enough money in your estate to fund the gift? Will unscrupulous people try to take advantage of your disabled loved one? What happens when the money runs out? If the beneficiary of the bequest lives in a Medicaid-funded care facility, the inheritance can be immediately attached by the government to pay for past and future cost of care. Making a direct testamentary gift to a person with CdLS may be emotionally satisfying, but should be done only with extreme caution and full understanding of the risks and consequences.

### **Morally Obligated Gift**

A morally obligated gift is money left to an individual, asking that individual to use the funds for the benefit of the child with CdLS. This type of bequest may indeed provide funds for the CdLS person and will not interfere with benefit eligibility. The obligation to provide for the person with CdLS is not legally enforceable, however, and since the funds actually belong to the beneficiary, they can be lost if the beneficiary has financial difficulties, or suffers a bankruptcy or divorce. Often, too, a morally obligated gift can create conflict and

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resentment if the beneficiary perceives the obligation as overly burdensome or requiring them to spend their own money to care for the person who is disabled once the gift is expended. If considering a morally obligated bequest, always discuss this arrangement with family members and the perspective obligor and get their consent prior to including this option in your future planning.

## TRUSTS

Another option for financial planning is to establish a trust to benefit the individual with CdLS. A trust can be very flexible and provide a wide range of benefits. Although there are administrative costs associated with the maintenance of trusts, it is still a very practical option for most families. There are two forms of trusts – “testamentary” trusts, which are established through the will of a benefactor and do not come into being until after the death of the benefactor, and “intervivos” or living trusts, which are set up and funded during the lifetime of the benefactor and can survive after their death. Two different types of trusts can benefit individuals with CdLS. The first is a support trust, and the second is a supplemental needs trust.

### Support Trust

This type of trust authorizes the trust funds to be utilized for any need, including basic support and maintenance, of the beneficiary. It can be designed to meet very specific needs and can be highly individualized. A support trust, however, will likely disqualify an individual from government benefits. It is therefore only advisable if the trust is large enough to generate substantial income to cover all needs, including medical expenses, of the person with CdLS for their entire lifetime.

### Supplemental Needs Trust

This type of trust came into existence pursuant to federal law in 1993. A supplemental needs trust (SNT) is currently one of the best tools available to insure that an inheritance actually reaches a person with CdLS. A SNT is not a support trust – it is specifically designed to supplement, not supplant, government benefits. Funds in a SNT can be used to purchase goods and services to positively enhance the beneficiary’s life, but cannot be used for basic needs like food, clothing, and shelter. An SNT also cannot provide for direct payments of any kind, such as allowances or income, to the beneficiary. SNT funds can be used to provide vacations, computers, companions and other extras to enhance the quality of life of your loved one with CdLS. A properly written SNT does not disqualify the beneficiary from government benefits, however, because the assets in the trust are not owned by the person with CdLS and aren’t used for their support or maintenance.

If the future plan for your loved one with CdLS includes a supplemental needs trust, consider setting this trust up as an “intervivos” (during a parent’s lifetime) trust, even if it is not going to be fully funded until after the death of the primary benefactors. With the trust established, family and friends can make contributions to the trust at any time. Also, having a SNT in existence creates a beneficiary (i.e., “The Jane Doe Supplemental Needs Trust”) for

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grandparents and others to designate in their wills or other estate planning documents. A SNT can also be set up as a testamentary trust, but there will be a lag time between the beneficiary's death and the operation of the SNT due to probate requirements.

## **Other Financial Pitfalls**

When contemplating financial future planning, do not overlook life insurance, pension plans, IRAs, annuities, and 401(K) plans. Inadvertently including your child with CdLS as a beneficiary or owner of one of these accounts or financial products can also undermine your plan and put government benefits in jeopardy. A supplemental needs trust rather than the person with CdLS may be the more appropriate beneficiary. While it is usually difficult to discuss financial matters with friends and relatives, it is an essential part of future planning for your child with CdLS. Talk about your plan with your family – let them know how to leave money to your child. It is your responsibility to spread the word so that your child's benefits are not put at risk.

## **GUARDIANSHIP**

A guardian is a person appointed by the court to be responsible for a person judged incompetent to make his or her own care and financial decisions. Parents are automatically guardians of their minor children. When a person turns 18, however, regardless of level of disability, a parent is no longer that person's guardian until appointed so by the court. It can come as a shock for parents or other care providers to be turned away by a medical office because that parent can no longer legally consent to non-emergency treatment for their child with CdLS. Anticipating and preparing for a child reaching the age of majority is an important part of future planning.

Seeking guardianship is usually not a complicated process and begins at your local courthouse. A hearing, typically informal, will be necessary and the burden is on the person seeking guardianship to show that the ward is not competent to handle his or her affairs. This is usually easily shown through medical testimony or medical documentation. Most states allow guardianship proceedings to begin six months prior to the child's 18th birthday. Check with your local Clerk of Court to learn more about the application process and evidence necessary in your state.

## **LETTER OF INTENT/CARE PLAN**

A unique, and very important, part of future planning for families of individuals with CdLS is the creation of a Letter of Intent. This is a non-legal, non-technical labor of love that is written by parents, family members and/or other care providers. The Letter should describe your child's history, current status, and your hopes and dreams for his or her care upon and after your death. When possible, also include input from the person with CdLS. By compiling this information about your loved one, you are giving future care providers the knowledge and insight needed to provide the best possible care for your child. They will have an accessible record of your child's likes, dislikes, skills, weaknesses, and behavior management techniques to help make the transition between care givers as smooth as possible.

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The Letter of Intent is often simply addressed “To Whom It May Concern”. It may be in letter form or put into a notebook or binder for easy reference. It should include a list of persons to be contacted in the event of your death or incapacity, such as your priest or pastor, other children or family members, your attorney or a case manager. In the Letter you should discuss all aspects of your family member’s life. Pass on your knowledge of things that have pleased your family member with CdLS, and of things that have been failures. Discuss your child’s history and your future desires in the following areas: family history; successor guardianship plans; housing/residential care; educational needs; employment history; medical care and management; behavior management; social environmental; and religious environment. You may have many other topics not listed here that are an important part of your child’s daily life. There is no limit to the amount of information that you can pass on through the Letter.

This document, unlike a traditional letter, remains a work-in-progress. It should be added to at least annually, and each time there is a significant change in your family member’s life. It is important to keep the Letter current. It is important, too, that family members know about the Letter of Intent and where to find it when needed. A nice habit to develop is to update your Letter of Intent on your child’s birthday as a special gift to that special someone with CdLS.

*We thank Judge Dixon for providing this comprehensive article. Her specific knowledge of the judicial process as well as her experiences as a mom of a child with CdLS are immeasurable gifts to the Foundation and our families.*