



ACT

The Arc Community Trust of Pennsylvania

Preparing for the Future Ensuring Your Child's Future



No one else knows your child as well as you do, and no one ever could. You are a walking encyclopedia of your child's history, experiences, habits, and wishes. If your child has special needs, the family's history adds a helpful chapter to your child's book, one detailing your child's unique medical, behavioral and educational requirements.

What would happen if you suddenly became unable to provide your child with the needed supports? Without you, your child would become dependent on other caregivers who simply do not possess all of your personal knowledge and insight. However, there are steps you can take now to

minimize the natural disruption and disorientation that will occur upon your death or if you become unable to care for your child during your lifetime.

First and foremost, you should appoint a legal guardian for any child who is not expected to be able manage personal, financial or medical decisions without assistance. Second, you could prepare a letter of intent to help loved ones and your child manage a difficult transition when you no longer are the primary caregiver. A letter of intent is an important planning tool for parents of children with special needs (including adult children), and also may be useful when planning for minor children who are not expected to face special challenges.

LIFE PLAN GETTING STARTED

Are you ready to get started? ACT has prepared a fillable workbook for you and your family. Simply go to ACT's website and download the workbook and get started. You can begin and continue to add information at your own speed.

www.ArcTrust.org/resources/links-and-resources

Importance of a Life Plan

Although a letter of intent is one of the most important estate planning documents a parent can prepare, it is not a formal legal document that must be created by an attorney. The goal of a Life Plan is to memorialize your knowledge of your child's needs so that you may guide future caregivers, guardians, agents and trustees in providing the best possible care to your child. Simply put, a thoughtful Life Plan ensures that those who come after you need not waste precious time figuring out the best way to manage and care for your child.

Use this workbook as a guidepost to help you organize the important information you will need to draft your Child's Life Plan. Once you complete the workbook, seek legal counsel from an experienced special needs planning attorney to assist you with drafting the legal letter. While with your attorney, have them prepare estate planning documents, including a Will that appoints a guardian for your child, a Power of Attorney to carry on, to the extent possible, what you have been doing for your child, and a Special Needs Trust in which you appoint a qualified trustee such as ACT.

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HOW AN ABLE ACCOUNT CAN HELP

After speaking with families and attorneys, it's apparent that there is still confusion about when to establish an SNT and when to start an ABLE account. The main point is that these two vehicles work towards the same purpose of maximizing future benefits for the individual with a disability. In many situations families will want to avail themselves of both tools to enhance the quality of life of their loved one with special needs.

COMPARE OPTIONS

Review the comparison chart on ACT's website under the "Links and Resources" section. Your Trust Administrator can discuss possible options.

In order to avoid paying back the State for Medicaid benefits, a third party SNT can be used to harbor long term assets. **Short term savings can be kept in an ABLE account to provide a**

flexibility in how funds are used for the individual. ABLE accounts can be replenished with contributions coming from the individual's work earnings, family members and even from the SNT. Since funds can move from an SNT to an ABLE account penalty free, contributions to the ABLE account can be a means of providing penalty free withdrawals from the SNT.

For example, when using a SNT for room and board individuals receiving Public benefits face penalties for withdrawals made. This penalty can amount up to 1/3rd of the individual's SSI payment. At the current maximum of \$735 dollars, that reduction translates to \$245 a month! Since ABLE accounts don't have such a penalty, a simple strategy for SNT withdrawals is for the trust to contribute to the ABLE account first and then have the ABLE account make the regular room and board type payment on behalf of the individual. Such a strategy shows the complimentary nature of the two accounts.

An ABLE account is not an ideal vehicle to manage significant third party funds due to the likelihood of a Medicaid payback claim upon the death of the beneficiary. For most individuals with disabilities, **an ABLE account is most helpful as a secondary tool to help secure their financial futures.** SNTs retain assets at the death of the individual, while ABLE accounts have more flexible withdrawal rules, but the assets most likely will go to Medicaid at the end of the individual's life.

Both SNTs and ABLE accounts should be strongly considered by families as key savings and planning tools for individuals with

disabilities. One tool need not be considered over the other. Contact your Trust Administrator to discuss how you may utilize an ABLE account.

SNT VACATION DISTRIBUTIONS

Summer is upon us and many families who are planning their vacations have questions as to which travel-related expenses can be covered by their child's SNT. You may simply want to take your child with special needs on vacation but many families may want to visit their child with special needs, or experience a medical emergency that may require travel to care for the loved one.

Each trust document and family situation is unique, and trustees use their discretion to carry out the intent of the trust as best they can. However, not every distribution that a trust company might otherwise support is allowable by The Social Security Administration ("SSA"), or by PA's Department of Human Services ("DHS"), or other agencies that govern housing and other benefits.

At one time, SSA maintained a rule that said that payments made from first party trusts must be for the "sole benefit" of the beneficiary. The rules that govern SSA now say that SSA will not attack trustee payments that are made for the "primary benefit" of the beneficiary, such as a payment to enable a family member to be present where that presence is necessary for the "safety or medical well-being of the individual". The expenses for other individuals accompanying them on the trip would not be reimbursed. In other words, parent(s) travel expenses could be reimbursed, **but not those for the siblings of the child with special needs.**

Of course, SSA rule changes do not necessarily change the terms of a trust, or the rules of DHS. But this change does provide greater flexibility for some trusts. **To find out whether a trust can reimburse a family**

member for specific travel expenses, contact the Trust Administrator to discuss the planned trip, and the kind of receipts and requests that will need to be submitted, in advance of the trip.

DISTRIBUTION

Contact your TA when planning your travel, so that we may be of assistance, mitigating conflicts or challenges prior to your trip.

www.arctrust.org/trust-distributions