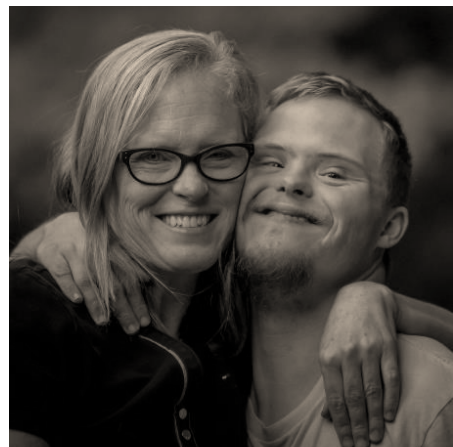




Planning for Your Child Special Needs Letter of Intent Workbook

**Inform future caregivers
of your intentions for the
care of your child**



Strategies & Solutions

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 his unique medical, behavioral and educational requirements.

What would happen if you suddenly became unable to provide your child with the necessary supports he needs? 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.

Importance of Letter of Intent

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 letter of intent is to memorialize your knowledge of your child's needs so that you may guide future caregivers, guardians and trustees in providing the best possible care to your child. Simply put, a thoughtful letter of intent 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 a letter of intent. Once you complete the workbook, seek legal counsel from an experienced special needs planning attorney to assist you with drafting the letter. The letter should be periodically updated. It should also be shared with appropriate people, such as your child's designated guardian.

“To the world you may be
one person, but to one person
you may be the world.”

– Heather Cortez, poet

General Information

Full Legal Name _____ Nickname _____

Social Security Number _____ Date of Birth (mo/day/year) ____/____/____ Gender _____

Address _____

Home Phone _____ Work Phone _____ Cell Phone _____

Email _____

Birth Information

Date of Birth (mo/day/yr) ____/____/____ City _____ State _____

Weight _____ Length _____

Obstetrician (name and location) _____

Delivery Hospital _____

Relevant Information About the Delivery _____

Parent's Information

Full Legal Name _____

Social Security Number _____ Living? ☐ Yes ☐ No

Address _____

Home Phone _____ Work Phone _____ Cell Phone _____

Email _____

Date of Birth (mo/day/yr) ____/____/____ City _____ State _____ Blood Type _____

Marital Status _____ Name of Spouse _____

Parent's Sibling Name/City/Phone _____

Parent's Sibling Name/City/Phone _____

Parent's Sibling Name/City/Phone _____

Parent's Information

Full Legal Name _____

Social Security Number _____ Living? ☐ Yes ☐ No

Address _____

Home Phone _____ Work Phone _____ Cell Phone _____

Email _____

Date of Birth (mo/day/yr) ____/____/____ City _____ State ____ Blood Type ____

Marital Status _____ Name of Spouse _____

Parent's Sibling Name/City/Phone _____

Parent's Sibling Name/City/Phone _____

Parent's Sibling Name/City/Phone _____

Siblings

Name _____ Age _____ Gender _____

Address _____

Home Phone _____ Work Phone _____ Cell Phone _____

Email _____

Name _____ Age _____ Gender _____

Address _____

Home Phone _____ Work Phone _____ Cell Phone _____

Email _____

Name _____ Age _____ Gender _____

Address _____

Home Phone _____ Work Phone _____ Cell Phone _____

Email _____

Other Relatives and Friends

Name _____ Relationship _____

Address _____

Phone _____ Email Address _____

Name _____ Relationship _____

Address _____

Phone _____ Email Address _____

Name _____ Relationship _____

Address _____

Phone _____ Email Address _____

Medical History and Care

Diagnoses _____

Intellectual Functioning Level _____

(typical, mild disab., moderate disab., severe disab., profound disab., undetermined, etc.)

Speech Functioning Level _____

(typical, mildly impeded, severely impeded, requires speech device, etc.)

Mobility Functioning Level _____

(walks unassisted, cane, crutches, scooter, wheelchair, etc.)

Visual Functioning Level _____

(typical, corrective glasses, contact lenses, requires Braille, legally blind, etc.)

Hearing Functioning Level _____

(typical, mild loss, mod. loss, hearing aid(s), use sign lang., cochlear implants, etc.)

Blood Type/Conditions _____

Immunizations/Date (e.g. Smallpox/2010) _____

Physicians

Name/Specialty _____

Address/Phone _____

Findings/Treatment _____

Name/Specialty _____

Address/Phone _____

Findings/Treatment _____

Name/Specialty _____

Address/Phone _____

Findings/Treatment _____

Name/Specialty _____

Address/Phone _____

Findings/Treatment _____

Dentist/Orthodontist _____

Therapists/Phone/Duration (e.g. Dr. Carol Choi speech/513.700.2144/5 yrs) _____

=====

Diagnostic/Genetic Testing Results _____

Allergies/Physician _____

Surgical Procedures/Date/Location (e.g. Tonsils, 2009, Lansing Gen'l Hosp.) _____

Other Hospitalizations or Inpatient Treatment/Date/Location (e.g. asthma attack, 2007, Christ Hosp. Cincinnati) _____

Orthopedic Conditions _____

Cardiac Conditions _____

Devices to Assist with Daily Living (e.g. shower chair, hand splints, etc.) _____

Prescription Medication(s)/Reason/Dosage _____

Over The Counter Medication(s)/Reason/Dosage _____

Dietary Considerations (food allergies, no sugar, nut allergy, choking hazards, favorite foods, etc.) _____

Incontinence Supplies _____

Birth Control _____

Philosophy on New Treatments or Therapies _____

Government Benefits & Service Programs

Benefit/Program _____

Name of Provider _____ Start Date _____

Benefit Amount/Frequency _____ Still Receiving Benefits? ☐

Benefit/Program _____

Name of Provider _____ Start Date _____

Benefit Amount/Frequency _____ Still Receiving Benefits? ☐

Benefit/Program _____

Name of Provider _____ Start Date _____

Benefit Amount/Frequency _____ Still Receiving Benefits? ☐

Benefit/Program _____

Name of Provider _____ Start Date _____

Benefit Amount/Frequency _____ Still Receiving Benefits? ☐

Living Arrangements

Include any required accommodations or restrictions such as shared room, group home, neighborhood setting, etc.

Past _____

Present _____

Future (1st choice) _____

(2nd choice) _____

Personal Finances (skill level, spending habits, allowance, etc.) _____

Education

Previous Schools/Years _____

Current Schools or Programs _____

Vocational Training Programs/Years _____

Integration experiences _____

Employment

Previous Employment/Work Programs _____

Current Employment/Work Programs _____

Employment Assistance Required (e.g. restricted lifting, wheelchair access, etc.) _____

Personality and Habits

Self Esteem _____

Sleep Habits _____

Unique Personality Traits _____

Adaptability to Change _____

Interaction with Animals _____

Is Upset By _____

Shows Anger By _____

Is Afraid of _____

Feels Better When _____

Other Unique Behaviors _____

Recreation & Fitness

Previous Programs/Activities _____

Current Programs/Activities _____

Fitness Level and Skills (e.g. can swim, dance, play basketball, etc.) _____

Vacations _____

Favorite TV/Movies _____

Favorite Music _____

Favorite Books _____

Other Favorite Activities (e.g. museum, zoo visits, pizza parlor, etc.) _____

Spirituality & Values

Religion _____ Preferred Clergy _____

House of Worship Attended _____

Type of Participation in Church Activities _____

What Values (religious or otherwise) Should be Emphasized and Reinforced? _____

Volunteering/Community Involvement _____

Legal Guardians

Current Guardian(s) _____

Address _____

Phone _____ Email Address _____

Successor Guardian(s) _____

Address _____

Phone _____ Email Address _____

Special Needs Trust

Trust Name/Date of Trust _____

Trustee Name/Address _____

Trustee Phone/Email _____

Successor Trustee/Phone/Email _____

Power of Attorney – Finances

Appointed to receive and administer Social Security and government benefits, etc. Name _____ Phone _____

Address _____ Email Address _____

Date Power was Granted (mo/day/yr) ____/____/____ Is Power Durable? ☐

Power of Attorney – Medical

Name _____ Phone _____

Address _____ Email Address _____

Date Power Was Granted (mo/day/yr) ____/____/____ Is Power Durable? ☐

Location of Important Information

Will _____

Trust _____

Insurance Policies

Life _____

Health _____

Accident _____

Homeowners _____

Auto _____

Birth Certificate _____

Marriage Certificate _____

Adoption Papers _____

Military Discharge _____

Tax Records and Returns _____

Bank Accounts/Acct Number (e.g. U.S. Bank/23-987)

Checking_____

Savings_____

Credit Cards/Acct Number _____

Titles

Autos_____ Land_____

Safe Deposit Box_____ Safe Deposit Box Key _____

Other (e.g. power of attorney, Social Security records, etc.) _____

Contacts

Attorney_____Address _____

City _____ State ____ ZIP _____ Current Phone (____) _____

Accountant_____Address _____

City _____ State ____ ZIP _____ Current Phone (____) _____

Insurance Agent_____Address _____

City _____ State ____ ZIP _____ Current Phone (____) _____

Investment Advisor_____ ☐ Check here if investment advisor is also insurance agent

Address _____

City _____ State ____ ZIP _____ Current Phone (____) _____

Bank_____Address _____

City _____ State ____ ZIP _____ Current Phone (____) _____

Bank_____Address _____

City _____ State ____ ZIP _____ Current Phone (____) _____

Final Arrangements

Funeral/Burial Arrangements Have Been Made ☐ Burial ☐ Cremation ☐

Funeral Home Name/Phone _____

Cemetery _____

Casket Preference _____

Headstone Preference _____

Epitaph _____

Pastor Preference _____

Pall Bearers _____

Music (specific songs/hymns and/or musicians) _____

Flowers _____

Other Requests (favorite scripture, memorial ideas) _____

Obituary (In summary, what should it say and where would should it be published?) _____



The Arc Community Trust of Pennsylvania

Arc Community Trust of Pennsylvania
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(F) 610-265-4688

Client's Personal Income / Budget Sheet

Beneficiary: _____ Requested Amt: _____

Trust Account # _____

Please complete **PART A** of the budget sheet with your personal monthly income and housing expenses.

Also please complete **Part B** for monthly estimated **OTHER** expenses

(Part A) Personal Income

SSI / Amount: \$ _____ Food Stamps/ Amt. \$ _____

SSDI / Amount: \$ _____ Other Income Amt. \$ _____

Part (A) Monthly Expenses paid from SSI and/or SSDI Actual

Rent		
Mortgage		
Gas Utility		
Water Utility		
Electric Utility		
Trash Service		
Sewer		
RE Taxes		
Food		
Other _____		

Part (B) Total Other Expenses / For Credit Card Use

Clothing		
Personal Items		
Household Items		
Cable		
Hair Salon		
Bus/trolleys		
Parking		
Taxis		
Vacation		
Other _____		
Other _____		
Other _____		
Total Other Expenses		

Signature: _____

Date: _____

Do Not Write Below This Line

TA Approval: _____

Approved Limit: _____

Special Instructions: _____

Conclusion

Concluding Remarks _____

Completed by _____ Date _____

The Arc Community Trust of Pennsylvania (ACT) has an extensive history in administering First Party, Third Party and Pooled Special Needs Trusts. Since 2001 when ACT was established, our trust administrators have endeavored to enhance the lives of beneficiaries while protecting their governmental benefits.

In effort to enhance the life and provide greater peace of mind to the beneficiary, their families and others responsible for their welfare, The Arc Community Trust of Pennsylvania's mission is; **to serve as trustee for a variety of special needs trusts with integrity and in a manner that exceeds best-practice fiduciary standards, protecting public benefits and financial assets for the beneficiary.**

The ACT staff, leadership and board of directors look forward to working with you!

Self-Funded Special Needs Trust

Self-Settled Special Needs Trusts come in two varieties, **non-Pooled** and **Pooled**. A non-Pooled Special Needs Trust (also known as a Payback Trust) is established for one Trust beneficiary, and the Trustee can be anyone who is qualified to act as Trustee. This is the kind of Trust most people refer to when they use the term Special Needs Trust. A Payback Trust is individually drafted by legal counsel and will be received and reviewed by the government and at the demise of the beneficiary all remaining funds are paid back to the government for services received.

Requirements for a Payback Trust

- ◆ It is for the benefit of an individual with disabilities under 65 years of age.
- ◆ The beneficiary is disabled as defined in 42 USC 1382 c(a)(3).
- ◆ The trust is established by a parent, grandparent, legal guardian or court.
- ◆ At the beneficiary's death, any residual funds are first used to pay back the State or Commonwealth for any Medical Assistance benefits received by the Beneficiary.

Third Party Funded Special Needs Trust

The Third Party Funded Trust is a trust which is created and funded by someone other than the individual with a disability, such as a parent, grandparent, or another loved one. The Third Party Funded Trust is a very effective option that requires advanced planning. This type of trust gives the trustee almost total discretion to spend or not spend on the beneficiary's needs, except that the trustee is always directed not to distribute assets in any way that reduces the beneficiary's government benefits.

Basic differences between this trust and a self-funded trust:

- ◆ The Third Party Funded Trust permit the Settlor, the individual establishing the trust, to direct all residual funds at the time of the beneficiary's death without any pay back to the government.
- ◆ The Third Party Funded Trust permits, perhaps even encourages, more than one concurrent beneficiary. The Third Party Funded Trust can use a family member or corporate fiduciary to serve as the trustee. Each trust is established and maintained individually and must be approved individually by the government.

Pooled Trust

Pooled trusts are a more affordable option to establish and maintain, prolonging the individuals assets. A pooled trust is a trust established and administered by a non-profit organization. A separate account is established for each beneficiary of the trust, but for the purposes of investment and management of funds, the trust pools these accounts. For Pooled Trusts (also known as (d)(4)(C) Trusts), each sub-account is established by the person with a disability, a parent, grandparent, guardian, or a court, and the Trust is funded with the assets of the person with a disability. The Pooled Trust provides that, upon the death of the disabled beneficiary, if there are funds remaining in the beneficiary's sub-account, they are retained by the charity in effort to support

Notes about a Pooled Trust:

- ◆ This trust can be self-created and self-funded.
- ◆ Because there is no "look-back" period on a Pooled Trust, any funds received by the individual, or to which the individual is already entitled, can be deposited into a Pooled Trust and will no longer render the individual ineligible.
- ◆ A Pooled Trust is established using a Social Security Administration pre-approved form and does not require separate court approval. **These trusts are a more affordable option to establish and maintain, prolonging the assets.**

Education Special Needs Trust

In addition to administering pooled and non-pooled special needs trusts, ACT administers educational special needs trusts. Educational trusts are trusts which typically arise out of the settlement of disputes between parents and school districts over whether the school district has provided adequate "free appropriate public education" for a student with disabilities, or whether the school district has properly followed an Individualized Education Plan.

ACT's administration of an educational trust is guided by two documents: the settlement agreement between the parents and the school district and a trust agreement between ACT and either the parents or the school district, depending on who is settling the trust. The settlement agreement, which comes first, is negotiated by lawyers for the parents and the school district. The trust agreement is then drafted by the lawyer for either the parents or the school district.



The Arc Community Trust of Pennsylvania

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