



TRANSITIONS

Legal Issues for Parents and Caregivers of
Special Needs Children Transitioning to Adulthood

January 2013



Dedicated to the teachers, assistants and
therapists on the “Green Hall”

Oak Pointe Elementary School
School District Five of Lexington & Richland Counties
Irmo, South Carolina
Cassy Paschal, Principal

DISCLAIMER

The contributing authors have covered a wide variety of issues concerning parents of transitioning children with disabilities. However, this handbook does not take the place of advice and counsel from a competent attorney where a legal problem or issue exists. Readers should always consult with the appropriate professional(s) before making decisions regarding the various legal, financial and other issues addressed herein.

South Carolina Bar 2012 Transitions Task Force
Co-Chairs:

Franchelle C. Millender
Attorney at Law
Millender Elder Law LLC
Columbia, SC

Amy Landers May
Attorney at Law
The Landers May Firm
Columbia, SC

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INTRODUCTION

You have experienced it, so you understand your role as the parent of a child with disabilities. When your child becomes an adult, the demands remain the same, but the rules change. It is a time of transition. Every person who attains the age of eighteen is presumed to be a competent adult with the capacity needed to make decisions regarding his or her own health and well-being and to manage his or her own funds. However, that is not always the case. Many persons with disabilities are able to make their own decisions. Some need limited assistance, while others require complete care and supervision with all aspects of daily living. Each person has rights and their own unique abilities; these rights and abilities must be given first priority in all questions about future planning.

Depending on the type of disability, its extent, and your **TRANSITIONING CHILD's** functional limitations, your child may be capable of handling some or all of the rights and responsibilities of an adult. Each person is different, and therefore each situation, and each solution, will be different. In the following chapters we will focus on the concept of least restrictive alternatives. These solutions are designed to give your transitioning child as many rights and responsibilities as he or she may be able to handle, given specific functional limitations, while establishing any legal authority needed to effectively and efficiently make decisions in the care of your transitioning child.

To be an advocate you as a parent must be informed. This handbook contains basic information that you will need, and it includes a resource section directing you to general and legal resources to obtain additional information and assistance. In addition to the resources described, South Carolina has many other governmental and private agencies and organizations that provide services for transitioning children. You are encouraged to seek out support and assistance from those agencies, organizations, and partnerships.

We have attached a glossary of those words or phrases that are printed in bold letters to help define terms that may be unfamiliar, together with a list of resources that may be helpful when seeking additional information.

ALTERNATIVES TO GUARDIANSHIPS AND CONSERVATORSHIPS

DURABLE POWER OF ATTORNEY

Many people with disabilities are able to make their own decisions and live their entire lives in the community with the support of friends and family and without the need of a guardian or conservator. It may be possible that your transitioning child has sufficient capacity once he or she turns eighteen (18) years of age, to sign a legal document called a **DURABLE POWER OF ATTORNEY FOR FINANCIAL MATTERS (DPA)**. This document allows the transitioning child, if legally competent, (Principal) to select an Agent who can act on the Principal's behalf and assist with financial matters, without removing the Principal's right to act on his or her own behalf.

The transitioning child may also give the Agent authority to exercise educational rights on behalf of the transitioning child by executing a Durable Power of Attorney. Under the Individuals with Disabilities Education Improvement Act (IDEA), educational rights automatically transfer to the child at age eighteen and parents may no longer participate in making educational decisions without the transitioning child's permission. A child with disabilities is entitled to special education services until graduation from high school or until he or she turns 21, whichever comes first. If the transitioning child is not able to make his or her own educational decisions and is unable to sign a power of attorney, it may be necessary to have a guardian appointed to exercise or assist with the exercise of the educational rights of the child.

A DPA is usually effective from the date of signing until the person who signed the document, the Principal, either revokes it or passes away. Even if the Principal becomes incapacitated, the Agent may continue to act on the Principal's behalf. It is best to record the DPA in the county in which the Principal lives and in any county in which the Principal owns real property. A DPA will result in both the transitioning child and you, as his or her Agent, having simultaneous control over his or her financial and legal affairs. If the child is making poor choices,

you may need to pursue the appointment of a conservator.

HEALTH CARE POWER OF ATTORNEY

Additionally, transitioning children may have capacity to sign a **HEALTH CARE POWER OF ATTORNEY** naming the person they choose to make health care decisions for them, in the event there is a time in the future when they are unable to make decisions for themselves. The authority to make decisions is, by law, **ONLY** effective during periods of time when your child is unable to make his or her own health care decisions; however, a validly executed HCPA gives you as Agent the ability to access medical records or other protected health information of the Principal at any time. To the extent your transitioning child is able to express choices or preferences regarding health care, those should always be considered in making decisions.

REPRESENTATIVE PAYEE

For a person who does not have significant assets, but needs assistance with managing his or her money, a **REPRESENTATIVE PAYEE** for Social Security or Supplemental Security Income benefits may be all that is necessary. If the only income your transitioning child receives is Social Security or Supplemental Security Income, and your child has no other assets needing management, other legal authority, such as a conservatorship, may not be necessary.

ADULT HEALTH CARE CONSENT ACT

If your transitioning child is severely disabled and cannot make decisions regarding care and treatment, you may be able to rely upon South Carolina's **ADULT HEALTH CARE CONSENT ACT** (AHCCA) to make health care decisions on your child's behalf, if two physicians certify that your child is unable to give **INFORMED CONSENT**. This law sets out a priority list of persons who may act on behalf of the individual, such as spouse, parent, adult child, adult sibling, etc. Some health care providers may not recognize the authority granted by the Adult Health Care Consent Act, and they may argue that the Health Insurance Portability and Accountability Act (HIPAA) prevents them from

complying with the AHCCA. The Health Insurance Portability and Accountability Act is a federal health care privacy law commonly known as HIPAA, and some health care providers limit access to medical and health information because of the restrictions of HIPAA.

If these tools do not adequately address the issues you are facing, then other legal solutions, such as a guardianship, conservatorship or other protective order of the court, may be necessary.

GUARDIANSHIPS AND CONSERVATORSHIPS

You have probably heard from someone that you may need a **GUARDIANSHIP**, a **CONSERVATORSHIP**, or both over your transitioning child. This may in fact be the case; however, before pursuing these avenues, you should look carefully at the available alternatives discussed previously.

GUARDIAN OR CONSERVATOR OR BOTH?

The processes for appointment of a Guardian and appointment of a Conservator for your transitioning child are very similar; however, the rights and responsibilities accompanying each appointment are different. A Guardian is appointed to handle the personal, custodial and health care decisions for your transitioning child, while a Conservator is appointed to manage his or her assets and income. If a transitioning child is only receiving Supplemental Security Income or Social Security benefits, or the child's assets are being held in a special needs trust, then the appointment of a Conservator may not be necessary. A careful analysis of any funds or property owned by or anticipated to be received by the transitioning child should be discussed with an attorney, as a Special Needs Trust may be preferable to a conservatorship to ensure the transitioning child retains needs-based government benefits.

LEGAL PROCESS FOR APPOINTMENT

The South Carolina Probate Courts have the authority to appoint and monitor guardians of incapacitated adults with disabilities. The appointment of a guardian is initiated by the filing of a Summons and Petition with the probate court in the county of your transitioning child's residence. By statute, the court must appoint an attorney who also has the duties of a **GUARDIAN AD LITEM** to protect your transitioning child's interest and represent him or her throughout the court proceedings. Your child's rights include, but are not limited to, notice of the proceedings, opportunity to present evidence and to cross-examine opposing witnesses, and opportunity to be present during proceedings. The petition is considered at a hearing before the Probate Judge.

There is no jury, and the proceedings are generally informal. The person filing the petition (the Petitioner) is usually a parent, custodian, or relative, but may be any person with an interest in the welfare of the transitioning child (often called the proposed **WARD**). At the hearing, evidence that the transitioning child needs a guardian must be presented to the judge. Evidence of incapacity usually comes from qualified professionals by way of a Visitor's report and Examiners' reports filed with Court prior to the hearing, the report of the Guardian *ad Litem*, and testimony taken at the hearing. The judge may also speak with your transitioning child, if he or she is present at the hearing, to allow the transitioning child an opportunity to express concerns or preferences.

If the Court finds it is in your child's best interest to have a Guardian, the judge will usually appoint the person nominated in the petition as Guardian. If someone objects to the appointment, the Court must determine whom to appoint. The Court is required to consider persons in the following priority: the person nominated to serve as guardian by the incapacitated person, an agent named by the incapacitated person in a durable power of attorney with health care provisions, the spouse, an adult child, a parent, a person selected by the parent, or another relative, unless the person with priority is disqualified or the court finds there is good cause to believe someone else would better serve the transitioning child's interests.

If the judge finds that the transitioning child is incapacitated and that the proposed guardian is qualified to serve, the Guardian-Ward relationship will be legally established. If the judge decides that the Ward can make some decisions for himself or herself, the court is required to limit the authority of the Guardian and create a limited guardianship. South Carolina law requires that the Court should exercise its authority "to encourage the development of maximum self-reliance and independence of the incapacitated person and make appointive and other orders only to the extent necessitated by the incapacitated person's mental and adaptive limitations or other conditions warranting the procedure." In each case no more restrictions than are necessary should be imposed on the Ward and, likewise, no greater responsibility than is necessary should be imposed on the Guardian.

GUARDIAN DUTIES

The Guardian must, by law, act in the best interest of the Ward. The Guardian must file a report with the Court at least annually, or more frequently as the court requires. The Guardian must keep the Court informed of the transitioning child's status, health and general well-being. The Guardian may be removed by the Court for breach of duties to the Ward. The Guardian may also be removed upon his or her own petition to the Court for release from the appointment, once an acceptable replacement guardian, called a successor guardian, is found. If the guardianship is limited and the Ward is capable of making certain independent decisions, the Guardian should try not to interfere with the transitioning child's opportunity to choose a personal course of action. Guardianship, when used properly, may be a real benefit to your transitioning child.

ESTATE PLANNING FOR PARENTS OF A DISABLED CHILD

When you have a child with special needs, it is important to have your own financial affairs in order. Every competent adult should have a **WILL**, a **DURABLE POWER OF ATTORNEY FOR FINANCIAL MATTERS**, and a **HEALTH CARE POWER OF ATTORNEY**. This is especially important when you are the parent of a child with disabilities. In planning your estate, you should assess the needs that your child will have when you are no longer there to provide for that child.

- Where will the child reside?
- If the child is not competent, who will make his or her decisions?
- Who will provide care?
- Who will handle financial matters?
- If the child is receiving needs-based government benefits, such as SSI or Medicaid, how can you provide for that child without disqualifying the child from receiving these benefits?

If you die without a will, you may forfeit the right to choose who will make decisions for your child. You may also put the child's needs-based benefits in jeopardy if the child inherits assets directly from you. Through careful planning and execution of a will, you can direct who will be in charge of decisions for your child. You can name a guardian for your child in your will and thereby avoid the more costly court process. You can set up a trust for the child so as to provide financially for the child. You can name a **TRUSTEE** to manage money and other property for your child's benefit. You can include provisions in the trust which protect the funds from being counted in calculating financial limits for needs-based benefits, such as Supplemental Security Income and Medicaid. This is commonly referred to as a **THIRD PARTY SPECIAL NEEDS TRUST** (or **SUPPLEMENTAL NEEDS TRUST**). The term "third party" means that the funds going into the trust belong to someone other than the person with disabilities. Third party trusts are governed by different rules than first party trusts, which are discussed in the next section, and can include a great deal of flexibility and discretion in providing for your child. A Third Party Special Needs Trust

can be created in your will or as a separate document.

If your child might receive an inheritance from other family members, it may be advisable to set up a Third Party Special Needs Trust separate from your will. In your will, you can then direct that funds which you wish to provide for your child go into this trust. Grandparents, aunts and uncles can also make contributions to the same trust. Additionally, this type of trust can be the beneficiary of a life insurance policy or retirement benefits for the benefit of your child.

Special Needs (Supplemental Needs) Trusts are technical documents, and it is strongly recommended that you seek the counsel of an elder law or estate planning attorney who is familiar with special needs issues.

In your estate plan, be mindful that your will controls only the disposition of probate assets. Non-probate assets, such as a joint bank account, a life insurance policy with a named beneficiary, or a retirement plan with a designated beneficiary, pass to the person designated. If you name your disabled child as the beneficiary, those funds will pass directly to the child and may cause a loss of benefits and may require the appointment of a Conservator.

In addition to the legal documents you create to protect your child, you may also wish to create a **LETTER OF INTENT**. This is a more informal document where you can discuss your child's needs and wants, along with your wishes for addressing those needs and wants. Additionally, it is advisable for parents to maintain a personal file on their disabled child containing directions for the care of the person with a disability in the event of the parent's accident, illness or death, copies of any and all health insurance documentation, birth certificates, social security information, school records, and lists of the care providers in the community that help you care for your child. Have this file accessible for anyone who may have to assume the role of caregiver to your child and update it frequently.

FIRST PARTY SPECIAL NEEDS TRUSTS AND POOLED TRUSTS

If your child receives assets outright by inheritance or a settlement, he or she may lose vital needs-based government benefits, such as Supplemental Security Income and/or Medicaid. Fortunately, Congress has made provisions in the law that allows a person to protect these funds for future use without giving up benefits. As soon as you find out that your child will be receiving funds, it is essential to examine the options available. Federal law allows the funds to be placed in a **FIRST PARTY SPECIAL NEEDS TRUST** or in a **POOLED TRUST**.

A **FIRST PARTY SPECIAL NEEDS TRUST** is a trust created by a parent, grandparent, legal guardian or a court. The trust is funded with the child's own assets for the child's benefit. The beneficiary of the trust must be disabled and must be under age sixty-five (65) at the time the trust is created and funded. The trust must contain a provision that, at the death of the beneficiary, any sums remaining in the trust are used first to repay Medicaid for amounts paid on behalf of the beneficiary. While a parent may create this trust, the parent does not usually have the legal authority to place the funds belonging to the beneficiary into the trust. If the disabled person is a competent adult, he or she may fund the trust by agreeing to place his or her money in that trust. If the beneficiary has appointed an agent under a durable power of attorney for financial matters, the agent may be able to direct funds to the trust. In all other circumstances, it is necessary to petition the probate court for a **PROTECTIVE ORDER** authorizing the funding of the trust.

As with Third Party Special Needs Trusts, it is important to consult with an attorney who is knowledgeable about special needs issues.

In some circumstances, a **POOLED TRUST** may be the best option for protecting funds of a disabled person who is receiving, or would otherwise qualify for, needs-based government benefits. A pooled trust is established and managed by a non-profit organization for the benefit of disabled persons. Each disabled beneficiary has a separate subaccount within the pooled trust. A subaccount is created by the execution of a

joinder agreement by a Sponsor. The Sponsor may be a parent, grandparent, legal guardian or a court. Unlike a first party special needs trust, the disabled individual, if a competent adult, may be the Sponsor and sign the joinder agreement. As with first party special needs trusts, someone with authority over the assets must fund the subaccount. This could be the disabled individual, if a competent adult, or an agent under a durable power of attorney executed by the beneficiary while he or she was competent to act. If the disabled person is not competent, does not have an agent under a durable power of attorney, or is a minor, a protective order from the probate court will be necessary to fund the subaccount in the Pooled Trust.

CONCLUSION

As a parent of a Transitioning Child, you want to do everything possible to protect that child, but you also want your child to have as much autonomy as possible. This is a difficult balance to maintain. Because access to many services is through needs-based government benefits, most parents need to keep the requirements for these benefits in mind when planning for their child's future. It is suggested that you share and discuss this handbook with your relatives in anticipation of the day an accident, illness or death might leave them to assume the advocacy role for the loved one with a disability. Similarly, it is important to re-evaluate your child's abilities and to revise and update your plan to assure the best quality of life for your child as he or she ages.

GLOSSARY OF TERMS

ADULT HEALTH CARE CONSENT ACT: In South Carolina, the Adult Health Care Consent Act (S.C. Code Section 44-66-10 et seq.) spells out a process in which two physicians perform independent evaluations of an adult and certify whether the person is able to consent to his/her health care. If the person is unable to consent, then the statute sets out a priority of persons to make health care decisions for the person.

CONSERVATORSHIP: An action commenced in the Probate Court alleging that a person is incapacitated and requesting the appointment of a conservator. If the Probate Court finds that a person is incapacitated and needs assistance in handling his or her financial affairs, the court appoints a conservator to protect and manage the assets and income of the incapacitated person.

DURABLE POWER OF ATTORNEY FOR FINANCIAL MATTERS (DPA): A power of attorney allows you (the principal) to name an agent or attorney-in-fact and give that agent the authority to carry out those acts which the principal authorizes on his/her behalf, with the exception of executing a last will and testament. If the power of attorney is durable (contains specific statutory language), incapacity will not terminate the powers of the agent.

FIRST PARTY SPECIAL NEEDS TRUST (42 USC 1396p(d)(4)(A)): A first-party trust is designed to benefit an individual with special needs who is receiving or may qualify to receive needs-based public benefits. A first-party special needs trust allows assets belonging to the disabled person to be set aside for “supplemental” expenses not covered by Supplemental Security Income (SSI) or other funding sources. The following requirements must be met:

- The trust must be established by a parent, grandparent, legal guardian or the court.
- The trust must be “irrevocable”.
- The beneficiary’s assets must be used to fund the trust.
- The beneficiary must be under age 65 at the time the trust is established and funded.

- At the beneficiary's death, the state Medicaid agency must be reimbursed from any funds remaining in the trust.

GUARDIAN AD LITEM: A person appointed by a court to represent the best interest of a person who is or is alleged to be incapacitated in a pending court action.

GUARDIANSHIP: An action commenced in the Probate Court alleging that a person is incapacitated and requesting the appointment of a guardian. If the court finds that the person is incapacitated and needs assistance in making health care and other personal decisions, the court appoints a guardian. The guardian may have full or limited duties and responsibilities based on the court's findings.

HEALTH CARE POWER OF ATTORNEY (HCPA): A Health Care Power of Attorney allows you to designate a person (an "Agent") who will have the authority to make health care decisions on your behalf if you are unconscious, mentally incompetent, or otherwise unable to make such decisions. In South Carolina a person may also express his or her wishes regarding whether to receive life sustaining procedures and artificial nutrition and hydration.

INFORMED CONSENT: Informed consent often refers to the ability of a patient to consent or withhold consent to a medical procedure after the patient has been made aware of the risks and consequences. Under the South Carolina Adult Health Care Consent Act, a person is unable to give informed consent if the person is unable to appreciate the nature and implications of the patient's condition and proposed health care, to make a reasoned decision concerning the proposed health care, or to communicate that decision in an unambiguous manner. This definition does not include minors, and this chapter does not affect the delivery of health care to minors unless they are married or have been determined by a court to be emancipated. A patient's inability to consent must be certified by two licensed physicians, each of whom has examined the patient. However, in an emergency the patient's inability to consent may be certified by a health care professional responsible for the care of the patient if the health care professional states in writing in the patient's record that the delay oc-

casioned by obtaining certification from two licensed physicians would be detrimental to the patient's health.

LETTER OF INTENT: An informal document which is intended to assist future caregivers by describing aspects of your child's life that no one else may be aware of. This information can range from favorite foods to prescribed medications to the specific care and services you want your child to receive, so that caregivers can provide for your child in the best way possible.

POOLED TRUST (42 USC 1396p(d)(4)(C)): A trust created and managed by a non-profit association for the benefit of persons with disabilities. This type of trust must meet the following conditions:

- The trust is established and managed by a non-profit association.
- A separate account is maintained for each beneficiary of the trust, but, for purposes of investment and management of funds, the trust pools these accounts.
- Accounts in the trust are established solely for the benefit of individuals who are disabled, by the parent, grandparent, or legal guardian of such individuals, or by the disabled individual, if competent to do so, or by a court.
- To the extent that amounts remaining in the beneficiary's account upon the death of the beneficiary are not retained by the trust, the trust pays to the State, from such remaining amounts in the account, an amount equal to the total amount of medical assistance paid on behalf of the beneficiary during the beneficiary's lifetime.

PROTECTIVE ORDER (SC CODE §62-5-101): An order issued by the Probate Court for protection of the assets of a minor or incapacitated adult. This may include a conservatorship.

REPRESENTATIVE PAYEE: A person who acts as the recipient of Social Security Disability, Supplemental Security Income, or Social Security Retirement benefits for persons who are not fully capable of managing their own benefits. The appointment is made by the Social Security Administration.

TESTAMENTARY GUARDIAN: A person nominated as guardian of

a minor or disabled person over the age of 18 by the disabled person's parents or by the disabled person's spouse in a will.

THIRD PARTY SPECIAL NEEDS TRUST: A trust designed to benefit an individual with special needs who is receiving or may qualify to receive needs-based public benefits. A third party special (supplemental) needs trust is created and funded by someone other than the disabled beneficiary.

TRANSITIONING CHILD: A person with disabilities or special needs who is attaining the age of majority, eighteen (18), and consequently is transitioning into adulthood under special circumstances and requiring special attention.

TRUSTEE: A person or corporation named to hold and manage the assets of a trust for the beneficiaries of the trust.

WARD: An adult who has been determined by the Probate Court to be incapacitated and for whom a guardian has been appointed.

WILL: A legal declaration of a person's wishes regarding the disposition of his or her property or estate after death. In South Carolina, a will must be in writing signed by the testator in the presence of two witnesses. It should also be notarized.

GENERAL RESOURCES FOR TRANSITIONING CHILDREN AND THEIR PARENTS

Autism Society

www.autism-society.org

Autism Speaks

www.autismspeaks.org

Disability.gov

www.disability.gov

Family Connections of South Carolina

www.familyconnections.sc.org

My Child Without Limits

www.mychildwithoutlimits.com

National Alliance for the Mentally Ill

www.namisc.org

National Guardianship Association

www.guardianship.org

Protection and Advocacy of Persons with Disabilities

www.pandasc.org

PRO-Parents

<http://proparents.org>

Sibling Support Project

www.siblingsupport.org

Social Security Administration

www.ssa.gov

S.C. Autism Society

<http://scautism.org>

S.C. Department of Disabilities and Special Needs

www.ddsn.sc.gov

S.C. Department of Education

<http://ed.sc.gov/>

S.C. Department of Health and Environmental Control

www.scdhec.gov/health/mch/cshcn

S.C. Department of Health and Human Services

www.scdhhs.gov

S.C. Department of Mental Health

www.state.sc.us/dmh

The ARC

www.thearc.org

LEGAL RESOURCES FOR TRANSITIONING CHILDREN AND THEIR PARENTS

Academy of Special Needs Attorneys

www.specialneedsplanners.com

National Academy of Elder Law Attorneys

www.naela.org

South Carolina Lawyer Referral Service

www.scbar.org/PublicServices/FindaLawyer

South Carolina Law Help

www.lawhelp.org/SC

South Carolina Legal Services

www.sclegal.org

Special Needs.com

www.specialneeds.com/categories/legal

Special Needs Alliance

www.specialneedsalliance.com

Special Needs Answers

www.specialneedsanswers.org

South Carolina Probate Court Forms

www.judicial.state.sc.us/forms

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950 Taylor Street • Columbia, SC 29201
803.799.6653 Phone • 803.799.4118 Fax
www.scbare.org

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