

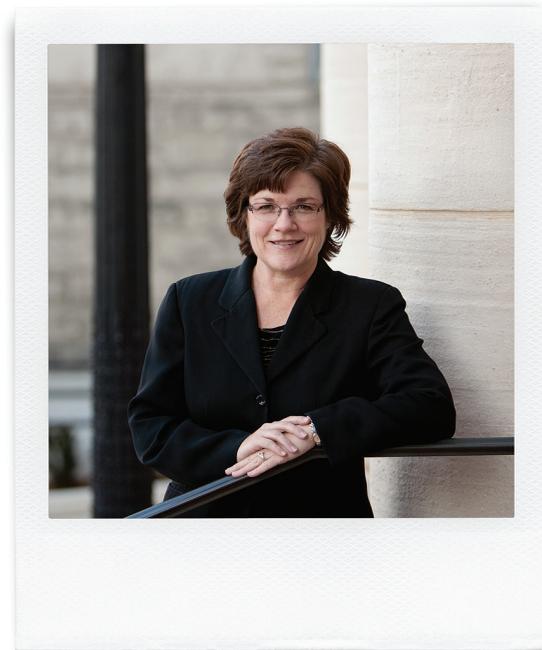
Medical Directive: The Utah Advance Healthcare Directive names the people you want to act on your behalf when you are unable to communicate your desires for medical treatment.

Revocable Trust: Some parents will want to choose a revocable trust along with a will that pours over the parents' assets into the trust upon death. This choice allows a family to avoid probate with the accompanying delay, court costs, and attorney fees. When a revocable trust is coupled with a "stand alone" special needs, the caretaker of the disabled child will have instant access to funds rather than waiting for an often lengthy and expensive court process. Additionally, with the stand alone special needs trust, other families members such as grandparents can contribute to the child's special needs trust either through their own estate planning or with life-time gifts.

Letter of Intent: Along with securing appropriate legal documents, parents should also consider drafting a letter of intent. Although not a legal document, this letter provides future caregivers and guardians with a clear understanding of the child's physicians, health and medical concerns, specific care strategies that parents have learned and developed over the years, the child's personality traits and preferences, dietary requirements, financial and legal information, and the parents' vision and hopes for their child's future.



Lisa Thornton first and foremost is "mom" to her daughter Kate who happens to have Prader-Willi syndrome. Lisa has served as the president of the Utah Prader-Willi Syndrome Association for the last several years and also sits on several boards of organizations devoted to helping people with disabilities. She is also an attorney who has donated thousands of hours to help Utah families and the special children they love.



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Providing Special Needs Trusts, Estate Planning, Guardianships, and Assistance with Social Security and Medicaid



Lisa understands the joy and challenges of life with a special needs child. Her daughter Kate was born with Prader-Willi syndrome.

**HELPING UTAH FAMILIES
PROTECT THE ONES THEY LOVE**

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Legal Protection for Your Family

When a baby with special needs is born, parents are initially consumed with the medical needs of their child and coming to grips with the fact that their baby likely won't have the kind of life they expected. Soon a routine of doctor visits, therapy, and worry settles in as "normal."



Nagging fears soon arise about who will care for their child if and when the parents cannot. Somewhere along this journey, hopefully sooner rather than later, parents of a child with disabilities will get legal documents in place to protect themselves and their child. Generally, a **special needs trust** should be established for the child with disabilities. By age 18 it is often necessary for a family to secure **guardianship** over a disabled individual and the parents should also apply for **Social Security Income** and **Medicaid** for their child. It is also recommended that each parent have a will that names a guardian for their minor children, a **power of attorney**, and a **medical directive**. Parents may also want to consider a **revocable trust** as part of their estate planning.

PROTECTION FOR YOUR CHILD

Special Needs Trust: Through special needs trusts parents can leave money for the benefit of their disabled child without disqualifying the child from government benefits. These funds are intended to supplement and not replace those benefits and can be used to purchase items that Medicaid will not such as a home, wheelchairs, vacations, hair care, dental care, recreational and cultural experiences, and a personal attendant.

When parents die, close and trusted families members can act as trustees, or the ones who follow the parents' instructions as to how the money can be spent. Usually, funds should not be given directly to the child because the child may not be able to manage the money carefully and because the funds would disqualify the child from SSI, DSPD, and Medicaid benefits. Similarly, parents should not give the money to a sibling of the disabled child with the understanding that the sibling will then take care of the disabled child. Among other problems, the sibling could spend the money; a future spouse of the sibling could resent the situation, especially if the money disqualifies them from receiving certain benefits of their own children, such as student loans; and divorce or other life events may transfer the funds to another and thwart the parents' wish that the money be used for the disabled child.

Guardianship: Once a child with disabilities reaches 18 years, the law considers him an adult and parents are no longer able to make decisions for him. He is presumed competent unless a court determines otherwise. This has many implications for parents. For instance, medical insurance companies and physicians often will no longer speak with parents regarding the health issues of their child. If the child runs away, many law enforcement agencies view the disabled child as an "adult" and will not search for the disabled individual as readily.



Parents should secure guardianship as close to the child's 18th birthday as possible. Utah requires that parents hire an attorney to represent their child in the proceedings. The parents can represent themselves or have an attorney, different from their child's attorney, represent them.

Social Security Income: When a disabled child turns 18, parents should apply for Social Security Income (SSI). Often SSI will be denied on the first try, but parents should appeal the denial because the success rate of these appeals is very high and often back payments are awarded. Even if parents can afford to care for their child at age 18 and beyond, it is a good idea to receive this benefit and use other offsetting funds to help fund the child's special needs trust.

Medicaid: Medicaid provides long-term medical care for adults and children with disabilities. When your child receives SSI, he will automatically receive medical insurance through Medicaid. This will often be the only insurance for which your child can qualify after the age of about 26, depending on the rules of the parents' private insurance.

PROTECTION FOR PARENTS

Will: A will is a basic legal document that allows you to direct to whom your property will be distributed. The executor is named in your will and is the person that will administer your wishes upon your death. The will is the tool by which you leave assets to your children, grandchildren, charities, or other heirs. If you die without a will, you die intestate. State law will then determine how your assets will be distributed. Under state law, if you die without a will, your child with disabilities will likely receive assets of more than \$2,000 and would become ineligible for government benefits such as SSI, Medicaid, and DSPD. A will also allows you to name a guardian for your minor children.

Power of Attorney: A power of attorney names those to act for you, often a spouse or adult child, while you are still living if you become disabled or incapacitated and cannot make decision on your own regarding your financial matters.