

A PLANNING GUIDE FOR PARENTS OF CHILDREN WHO HAVE SPECIAL NEEDS

Below are action items to take when you have a child, of any age, who has special needs.

Personal Information

Keep all of your records and your child's personal information (name, nicknames, date and place of birth, phone numbers, Medicare number, Medicaid number, addresses, etc.) in an accessible place. You should also keep a separate folder with copies of birth certificates, adoption papers, military service records, passports, deeds, health insurance cards, insurance policies, stock certificates, marriage and death certificates of parents, Social Security cards, automobile titles, divorce decrees, usernames, and passwords.

Emergency Contacts

Create a document listing emergency contacts for you and your child. Include contact information for your spouse, partner, significant other, children, siblings, and parents. For your child, you should have the name and all of contact information of the person(s) you want to care for your child in case of an emergency.

Medical Providers and History

This list should include the names and contact information of primary care providers and specialists, medications, allergies, significant family history, insurance companies and policy numbers, health insurance, medical equipment providers, therapists, independent service coordination agency, care managers and any Medicaid or Medicare information. If you have prepaid your or your child's funeral or burial, keep this information here as well. If your child is still in school, include information about his or her school, individual education plan, and staff at the school who work with your child.

Financial Information

Create a document for financial information. This includes the gross and net amount of each source of annual income (employment, social security, supplemental security income, etc.) and current value of assets such as home, car, stock, trusts, etc., the death benefit (if any), and all beneficiary designations associated with the asset. Also include policy numbers and contact information, the names of any of your financial advisors, a copy of your most recent tax return, information on property taxes or rental lease and a section on recurring bills, including whether the bill is paid on-line or by an automated payment. If you have a safe-deposit box, where is the key? For your child, you should include all information concerning his or her representative payee accounts and special needs trust accounts. Copies of statements should be kept in a safe place or scanned and stored securely online.

Legal Information and Documents

Do you have a power of attorney for health care, power of attorney for property/finances? A will? A living trust? Have you created a special needs trust for your child? If yes, where are these documents? Do you have any contract or loans? Make sure to keep the documents up-to-date and have the current contact information for your attorney, executors, agents, trustees, beneficiaries, etc.

If you don't have legal documents, meet with an attorney who concentrates in assisting people who have special needs. This is a specialized area of law and not all attorneys have the understanding, experience, nor compassion to assist you. Not only can an attorney draft the necessary documents for expressing how you want your property, finances, health care, and care of your children handled following your death and/or incapacity, but your attorney can also help you set up financial strategies, such as trusts, to ensure that your child with a disability can continue to maintain a quality life when you are gone. The attorney should also be familiar with Medicare, Medicaid, Social

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Appointments are also available in Arlington Heights,
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conferencing or telephone.



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Security, and Supplemental Security Income (SSI) and the unique challenges that a disability brings to the estate planning process. This attorney can also assist to determine what arrangements should be made for you or your child at death.

Public Benefits

Investigate what public programs your loved one qualifies for and / or is entitled to.

Social Security: A Federal insurance program that provides benefits to people who are retired, unemployed, or have a disability. There are three main types: Social Security Retirement Income (SS), Social Security Disability Income (SSDI), and Supplemental Security Income (SSI)

Medicare: A national health insurance program that is primarily for people aged 65 and older but also for some younger people who have a disability status as determined by the Social Security Administration, and people with end stage renal disease and ALS.

Medicaid: A program supported with Federal and State Funds that helps with health care costs, facility based, and personal care services. In Illinois, the "Medicaid Agency" is the Illinois Department of Healthcare and Family Services. For determination of eligibility, Illinois Department of Human Services is the coordinating agency.

Medicaid Waivers: state-run programs that use federal and state funds to pay for services for people with certain health conditions. They permit states to use flexibility to design publicly financed health care systems outside of certain federal Medicaid statutory and regulatory requirements. Each state has different Waivers with different eligibility requirements or services. Illinois has nine (9) Home and Community-Based Service (HCBS) waivers. Each waiver is designed for individuals with similar needs and offers a different set of services.

SNAP (Supplemental Nutrition Assistance Program): a federal program that provides food-purchasing assistance that is coordinated the Illinois Department of Human Services

PUNS List (for people who have a developmental disability)

Work with your local Independent Services Coordination Agency (ISC) to be included on the PUNS list. It is for anyone who may need help from the government to pay for services now, or in the future.

To locate your ISC, <https://www.dhs.state.il.us/page.aspx?module=12&officetype=&county> or <https://www.dhs.state.il.us/page.aspx?item=41131>, <https://www.illinoislifespan.org/about-us/>

Guardianship

If you are the guardian of your child, make sure you identify the people to succeed you if you are no longer able to serve. If you do not have a guardianship for your child but believe it may be needed after your death, you should discuss this with your attorney and obtain advice on the steps to take to be sure your child will be protected. Your planning should include identifying possible guardians and making sure those individuals understand the steps they will need to take to have the court appoint them for that role.

Review and Update your Plan.

Remember that planning for the future is a process, not a one-time task. As circumstances change for you and your child, you will need to revisit your plan annually.

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This information is not to be considered legal advice. The attorneys at Dutton Casey & Mesoloras concentrate in elder law, special needs planning, estate planning, guardianship, and probate matters and are here to assist you and / or someone you care about. Appointments are available in Arlington Heights, Chicago, Naperville, Skokie, and via phone or video conference.

Resources:

Academy of Special Needs Planners – www.specialneedsanswers.com

National Elder Law Foundation – www.nelf.org

National Academy of Elder Law Attorneys – www.naela.org

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