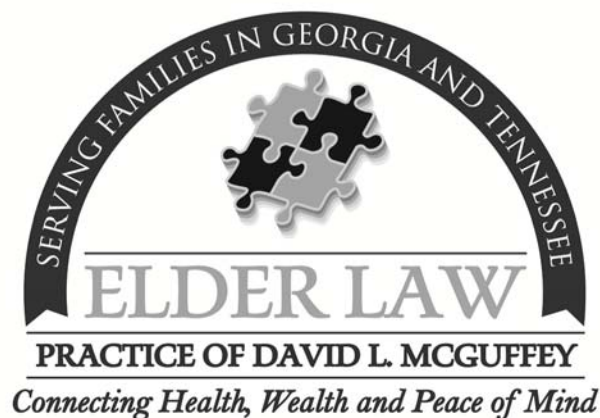


# Special Needs Planning Guide

2015



## Elder Law Practice of David L. McGuffey, LLC

### Dalton Office

400 N. Selvidge Street  
Dalton, Georgia 30722-2023  
(706) 428-0888

### Cartersville Office

1124 N. Tennessee Street, Suite 103  
Cartersville, Georgia 30120  
(800) 241-8755

## **Why should you plan?**

A plan is a goal oriented road map. It helps you arrive at your intended destination. The “destination” when planning for a special needs child is a happy, quality life. Not just any life, but a life filled with quality. Your child should have a life that is as normal as possible. It should include includes friendships, relationships, a job and a safe environment. It should include purpose and appropriate health care. This guide is intended to assist you in developing a plan for your child (or loved one) so those goals become reality.

**Know this:** planning for your special needs child is not something you should put off; **do not procrastinate**. Also, it’s not something you do once and then “it’s done.” Your child’s circumstances will change over time; the plan must change with your child. Planning is an on-going, lifelong process as you respond to your child’s goals, wants, needs and dreams.

Planning begins with a vision of what “the good life” looks like for your child. After you have that vision, then consider those resources necessary to implement your plan. We suggest annual plan updates or adjustments to make sure the plan still works. Approach planning like you would steer a boat, keeping s steady hand on the rudder and adjusting course when necessary. Anytime there is a major change in your child’s life or support structure, the plan should be re-evaluated.

Don’t be afraid to build a team. Planning is challenging and can be hard work. There are many resources out there and many professionals who can help you. Consider including family, friends, financial experts, therapists, educators, counsels and, of course, an attorney who specializes in special needs law. But most of all, include the person who is the object of the plan. **Make sure your child’s voice is heard.**

## **Other Parents**

Have you ever heard someone say “you’ll understand if you walk a mile in my shoes?” Other parents of special needs children understand what you’re going through because they’ve been where you are. That’s why it’s important to connect, through support groups, community groups or online forums. If you search google or Facebook and insert your child’s diagnosis along with the words “group” or “support group,” you are almost guaranteed to find help.

Imagine this scenario: it’s 9:00 a.m. and your child’s IEP is scheduled for 3:00 p.m. this afternoon. Something in the plan proposed by the school system doesn’t make sense. You know in your gut that it won’t work. Who can you call to get advice? While there might be an advocacy group out there to help you, another parent might have the answer. And, what makes it better, other parents have “skin in the game” because they have a special needs child too. That makes it much more likely they will take your last minute call.

If you don’t know where to start, ask your pediatrician, a local children’s hospital, or special education teachers about family support groups. As stated above, you can also find groups on the internet. A quick google search pulled up this directory: Parent Support Groups for Children with Disabilities or Special Needs, at <http://www.childrendisabilities.info/parenting/groups-childrendisabilities.html>. If you don’t find a group that meets your needs, start your own.

Another great resource is Parent to Parent of Georgia. You can reach P2P at 800-229-2038, or find them on the internet at <http://p2pga.org/>.

## Basic Information

*(Use additional sheets if you have more than one special needs child)*

Child's Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Social Security # \_\_\_\_\_

### Living Arrangement:

My child is living:  At home  In a group setting  In a facility

Address: \_\_\_\_\_

\_\_\_\_\_

Telephone No. \_\_\_\_\_

Fax No. \_\_\_\_\_

E-mail: \_\_\_\_\_

Contact person: \_\_\_\_\_

Is this expected to change? \_\_\_\_\_

### Decision-making:

- My child is a minor
- My child is an adult and can make his or her own decisions
- My child is an adult, but cannot make decisions

### Disability: (check all that apply):

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|---|--|
| <input type="checkbox"/> Asperger Syndrome                | <input type="checkbox"/> Fragile X Syndrome            |
| <input type="checkbox"/> Attention Deficit Disorder (ADD) | <input type="checkbox"/> Mental Illness                |
| <input type="checkbox"/> Autism                           | <input type="checkbox"/> Mental Retardation            |
| <input type="checkbox"/> Bi-Polar Disorder                | <input type="checkbox"/> Obsessive Compulsive Disorder |
| <input type="checkbox"/> Blindness                        | <input type="checkbox"/> Paraplegia/paresthesia        |

*Special Needs Planning Guide*

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|--|---|
| <input type="checkbox"/> Borderline Personality Disorder | <input type="checkbox"/> Quadriplegia             |
| <input type="checkbox"/> Brain Injury                    | <input type="checkbox"/> Rett Syndrome            |
| <input type="checkbox"/> Cerebral Palsy                  | <input type="checkbox"/> Schizoaffective Disorder |
| <input type="checkbox"/> Deafness                        | <input type="checkbox"/> Schizophrenia            |
| <input type="checkbox"/> Depression                      | <input type="checkbox"/> Spina BiFida             |
| <input type="checkbox"/> Developmentally Delayed         | <input type="checkbox"/> Tourette's Syndrome      |
| <input type="checkbox"/> Dissociative Disorder           | <input type="checkbox"/> Traumatic Brain Injury   |
| <input type="checkbox"/> Down Syndrome                   | <input type="checkbox"/> Epilepsy                 |
| <input type="checkbox"/> Other: _____                    |   |

My child's prognosis is: \_\_\_\_\_

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Needs:

My child needs the following right now: \_\_\_\_\_

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In the future, my child will need: \_\_\_\_\_

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## **Planning During Your Lifetime**

Planning to take care of your child during your lifetime (and truly any plan) should be person-centered.<sup>1</sup> It should begin with a needs assessment. Every good plan has four parts: assessment, actually planning, implementation of the plan, and re-assessment. It's a never ending cycle that continues to evolve over time.

The assessment begins by considering your child's ability and limitations. Where are the strengths and where are the weaknesses? What supports are needed to compensate for weaknesses?

Consider, for example, your child's social life. Who are his or her friends and companions? What life skills will your child need assistance with as he or she interacts socially? What assistance will your child need to "fit in?" Is it something as simple as having the right shoes, or will it be something more complicated like taking lessons, or still more complicated like therapy?

Make a list of your child's strengths and weaknesses:

**Strengths:**

**Weaknesses:**

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For each weakness, brainstorm about what support your child needs.

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<sup>1</sup> A short but helpful paper is Person-Centered Planning: A Tool for Transition, available at: <http://roadmap.p2pga.org/images/stories/NCSET - Person Centered Planning.pdf>.

## **Contingency Planning – A Letter of Intent**

No one else knows your child or loved one as well as you do. They couldn't possibly because they don't have your shared experiences. They don't know your child's history, experiences, habits, and wishes. They didn't share your struggles. That's why it's critical that you share your story in something referred to as a letter of intent.

If you were unable to care for your child or loved one, then someone would have to step in and pick up the pieces. Your child would become dependent on others who do not possess your insight into his or her well-being. Providing those caregivers with background knowledge and information will minimize the disruption and disorientation that will occur when you die or when you are to care for your child.

Although a letter of intent can guide how your estate plan is implemented, it is not a formal legal document. You can prepare it yourself on notebook paper or on your computer. The goal is to memorialize your knowledge of your child's needs so others can, as best they can, step into your shoes. It should be a road map for a new caregiver as they look after your child. It should include enough information and insight so caregivers don't have to waste time "re-inventing the wheel" dealing with problems you previously solved.

Your letter can begin just like any other letter. Address it to the persons you nominated as your child's guardian, conservator or trustee. Because things happen, you should probably include a reference to the person's title since a successor might be appointed. Your letter should cover everything you think is important. The following points are things you should consider, but there may be others as well.

Family History and Values: History and values tell us where you come from and provides context. They tell us what's important and what gives life purpose. Information about where you were born, raised and married might be helpful, not just as a historical note, but because it might be necessary to track down records at some point. Include anecdotes about yourself and your family if you think they would either be interesting to your child, or instructive to his or her caregivers. Identify anyone who is significant to your child, especially those who should be involved in his or her life. Also mention those persons who should not be involved and

provide reasons (in case your child's caregiver has to justify keeping them away). Describe your religious heritage if it is a meaningful of family values. Identify any clergy or other important leaders who should be a part of your child's life.

**A Day in the Life:** It is important to provide a broad overview of where your child is now, and what your hopes are for his or her future. It is equally important to put some "meat on the bone" and provide detail about your child's daily routines. Every child is different. Each has different abilities and limitations. Include a list of your child's daily routines, favorite activities, and events or tasks he loves or hates. Which activities build self-esteem and which activities frustrate your child.

**Personal preferences:** Provide specific detail about foods your child likes, activities that make him or her happy. Provide similar details about things he or she doesn't like or, if you want to steer your child away from specific concerns, provide detail about those concerns. Mention social activities your child enjoys, i.e., sports, dances, museums or movies. Include favorite vacation spots and travelling companions. Does your child enjoy camp?

**Health and Health Care:** Describe in detail your child's disability (and abilities), medical history and allergies, as well as current doctors, therapists and hospitals. Describe how often your child attends medical and therapy appointments, and their purpose. What are your child's therapy goals? If your child is on any medications, what are the current medications? Are there future concerns, such as future surgeries? If your child has health insurance, who is the provider, what is the policy number and the phone number for questions?

**Education:** Where does your child attend school? What are his or her educational experiences? What your desires for your child's future education, including regular and special classes, specific schools, related services, mainstreaming, extracurricular activities and recreation? Do you want your child's educational plan to place emphasis on vocational training, academics or other matters? Are there specific programs or teachers you prefer? Is there a specific college you prefer? Do you have a college savings plan?

**Public Benefits:** Does your child receive public benefits? If so, then list which ones, including Medicaid, Medicare, SSI/SSDI, Supplemental



Nutrition Assistance Program (food stamps), and housing assistance. Provide the caseworker's contact information, identification numbers for your child's case(s), the recertification process for each benefit, including important dates and other reporting requirements. If you have had problems with any of the caseworkers, detail those problems so the person coming behind you can try to minimize them.

**Employment:** For most people, having a job provides someone with purpose. With that in mind, if your child can work, employment attempts should be supported. Provide details concerning the types of work and work environments your child seems to enjoy; i.e., open employment with supervision, a sheltered workshop or an activity center. If there are specific companies you believe your child would be interested in, or if there are companies in your community that might employ your child, list them.

**"Home" and Surroundings:** What does "home" look like for your child? We are not talking about the floor plan. What is the environment like? Who should your child live with? Who are his or her friends? Are there any people who might take advantage of your child? After you are gone, do you want the home maintained, or will your child live with someone else? Will your child be moving to another neighborhood or another State? Should a group home be considered? Should your child have a roommate? Should your child have pets?

**General matters:** If there is anything else that is important to you or your child, write it down. For example, if your child has behavioral issues, then what sets your child off and what calms him or her? If there is a special date with significance for your family, what is it? If there are family traditions or rituals, what are they? Have you given thought to your child's prospects for marriage? What should final arrangements be like (burial or cremation)?

Preparing a letter of intent like this can be difficult. First, it can be a lot of work if you include significant detail. It can evoke feelings of anxiety. It forces you to consider what your child's life would be like without you. We urge you not to view it that way. Instead, view it as a contingency plan and take a deep breath. It's worst case scenario planning. If something happens to you, you will know that the person picking up the pieces has the information they need to meet your child's needs.





**Education:** \_\_\_\_\_  
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**Public Benefits:** \_\_\_\_\_  
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## **Building a Team**

The phrase “it takes a village” has significant meaning when planning for your special needs child. Earlier in this guide, we asked you to identify your child’s weaknesses. Those are the areas where your child will need assistance. The planning team might include parents, advisors, educators, psychologists, life skills coaches, job coaches, care managers and others. There may also be areas where you need assistance building a plan. The following are just a few of the team members you should consider.

**Your Child:** Do not forget to include your child in the planning process. A people-centered plan always includes the person for whom you are planning. After all, it’s their life. Inclusion promotes dignity.

**Your Child’s friends:** Including those who will be part of your child’s social network, to the extent they are capable of participating, will breathe life into the plan. It will give the plan hands and feet. Plans don’t implement themselves.

**A Financial Planner:** You may not have the expertise, the time or the desire to actively plan and manage certain financial aspects of your life. You might need help getting started. A financial planner can provide an objective, third-party perspective on what are often emotional, difficult decisions. Financial planners are professionals who make sure you stay focused and follow through with your financial plans. You can find out more about financial planners through the Financial Planning Association (<http://www.plannersearch.org>) or the CFP Board ([www.cfp.net](http://www.cfp.net)).

**Accountant:** An accountant can assist in the development of a tax strategy that stretches family dollars by minimizing taxes. An article by Regina Levy, CPA titled “Tax Strategies for Parents of Kids with Special Needs” discusses many of these strategies.<sup>2</sup> Accountants can also assist with money management, paying bills and other matters.

**The Replacements:** Consider how you will place team members in the future. Will you have to hire non-family members after a death? Do you have life insurance on key members of the team?

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<sup>2</sup> <https://www.tacanow.org/family-resources/tax-strategies-for-parents-of-kids-with-special-needs/>

## **Budgeting and Finances**

The old saying is that money makes the world go around. In this context, planning for your child, money is what enables him or her to access the goods and services you want for your child. Simply put, money is a tool.

Wise financial planning can go a long way toward enabling your child's success. In order to make a good financial plan, you must give careful consideration to both current and future needs of your loved one and available resources to meet those needs.

If your child's needs are great, or if his or her prospects for gainful employment are limited, then budgeting is critical. A budget is not a prison that limits your child. It is a spending plan designed to make sure money last as long as it need to last.

Start with the resources available today and those you expect to set aside in the future. (*See discussion of public benefits eligibility*). Then discuss how those resources should be used.

What resources does your child have now?:

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What resources do you expect to set aside in the future and whether they will be set aside during your lifetime or after your death?:

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## **Budgeting and Finances Budget Worksheet 1**

This Worksheet is designed to determine your child's share of family expenses. Only include family necessities. Do not include items that are purchased specifically for one individual.

<b>Family expenses</b>	<b>Monthly Estimate</b>	<b>Cost per person</b>
<b>Monthly housing expenses</b> Mortgage Rent Maintenance Insurance	\$	\$
<b>Utilities</b> Heat Electric Phone Cable TV	\$	\$
<b>Vehicle expense</b> Car payment Insurance Maintenance Gas	\$	\$
<b>Groceries</b>	\$	\$
<b>Other:</b>	\$	\$
<b>Other:</b>	\$	\$
<b>Other:</b>	\$	\$
<b>Subtotal</b>	\$	\$



## **Budgeting and Finances Budget Worksheet 2**

This worksheet is intended to identify your special needs child's individual expenses:

<b>Child only expenses</b>	<b>Monthly estimate</b>
Clothing expense	\$
Personal items	\$
<b>Educational expenses</b> School fees Books Activities Other	\$
Other expenses	\$
<b>Special needs expenses</b>	<b>Monthly Estimate</b>
Transportation Needs	\$
<b>Medical expenses not covered</b> Medications Therapy Medical Equipment	\$
<b>Special Education</b> Computer Adaptive equipment Tutors	\$
Cost of missing work	\$
Respite care	\$
<b>Activities</b> Sports Social Arts	\$
Other expenses	\$
<b>Subtotal</b>	<b>\$</b>

## **Budgeting and Finances**

### **Total Expenses**

Subtotal from Worksheet 1	\$
Subtotal from Worksheet 2	\$
Total costs per month	\$

The budgeting worksheets included in this planning guide are designed to get you thinking. There may be other expenses you need to include. Some items listed above might not apply to you. Also, budgets change over time so it should be updated as transitions occur. Consider your budget today, but also consider how the budget will be different if your child “graduates” to another residential setting, or if you aren’t in the picture. Use additional pages as necessary. Also, don’t limit your budget to necessities. Budget for those things your child wants, like a PS4.

### **Future Considerations**

Your child’s growth and development will bring new challenges. Another factor to consider as you plan your budget is saving for the future. The following list includes examples of future expenses your child might incur.

- Transition planning
- Vocational training
- College
- Occupational therapy
- Counselling
- Financial planning
- Pets
- Entertainment
- Emergency situations

## **Employment**

Georgia's Vocational Rehabilitation Program (VR) provides services to persons with disabilities as they prepare for gainful employment. Information about the VR program is available at [http://www.dol.state.ga.us/js/job\\_seekers\\_w\\_disabilities.htm](http://www.dol.state.ga.us/js/job_seekers_w_disabilities.htm).

### **Disability.gov**

Includes extensive information regarding people with disabilities, and links to numerous web sites offering resources, services, and technical assistance.

<https://www.disability.gov/>

### **Disability Resources Monthly Regional Resources Directory**

A comprehensive well-organized information resource for people with disabilities.

<http://www.disabilityresources.org/>

### **Benefits.gov**

This is a confidential tool designed to help people find government benefit programs for which they may be eligible.

<http://www.benefits.gov/>

### **Georgia Council on Developmental Disabilities**

Access information about this planning council which is charged with improving public policies that affect people with developmental disabilities and their families.

<http://www.gcdd.org/>

### **ABILITYJobs for Job Seekers**

Post a résumé on this site that provides a place where people with disabilities can seek employment.

<http://abilityjobs.com/>

### **Job Accommodation Network (JAN)**

Link to comprehensive information about employing and retaining workers with disabilities, including resources for job accommodations.

<http://askjan.org/>

### **National Organization on Disability**

Access current disability-related news as well as a wide range of resources and information about increasing the participation of people with disabilities in all aspects of life.

<http://www.nod.org/>

### **Southeast ADA Center**

Learn about this regional center and its resources including, services to promote awareness about the ADA, accessible information technology, and the rights and abilities of people with disabilities.

<http://www.adasoutheast.org/>

### **Office of Disability Employment Policy (ODEP)**

Link to the U.S. Department of Labor office which helps increase employment opportunities for people with disabilities through education, training, assistive technology, and awareness programs.

<http://www.dol.gov/odep/index.htm>

### **The Work Site**

This Social Security Administration (SSA) web site facilitates the employment of beneficiaries with disabilities through partnerships and program innovation.

<http://www.ssa.gov/work/>

## **Education**

This planning guide cannot cover all there is to consider in asserting your child's educational rights. There are, however, many good guides you should review. The best resource available for parents is Wrights Law: <http://www.wrightslaw.com/>. Another good resource is the special education page at Navigate Life Texas <https://www.navigatelifetexas.org/en/education-schools>.

Laws that impact students with disabilities include:

- Section 504 of the Rehabilitation Act
- Individuals with Disabilities Education Act (IDEA)
- No Child Left Behind (NCLB)
- Elementary and Secondary Education Act (ESEA)
- Quality Basic Education (QBE)
- Americans with Disabilities Act (ADA)

IDEA requires that procedures be in place to address the following:

- FAPE: Free Appropriate Public Education for children who are eligible
- Provided at no cost to parents
- Educational benefit with opportunity to learn

IDEA requires that procedures be in place to address the following:

- LRE: Least Restrictive Environment. Students are removed from general education only when services cannot be provided in the general education setting with supports.

Parent Involvement:

- Parents are involved in all aspects of special education
- Parents are part of every team that makes decisions about the student

Students are entitled to an Individualized Education Plan (IEP)

- Annual plan, must be reviewed at least one time per year
- Progress reporting on annual goals
- State IEP Form with minimum requirements
- IEPs look different from system to system

## **Public Benefits**

The purpose for securing public benefits is to *stretch* family dollars. Most families have a limited pool of resources. With that in mind, when you shift expenses to a public benefits program you are protecting family dollars that can be used to fund your child's quality of life. Remember, most special needs children will not have significant earnings so protecting dollars is critical.

Entitlement for most public benefits begins with a determination that the individual is disabled.

“Disability” for an adult is defined as the inability to engage in any “substantial gainful activity” (SGA) due to any medically determinable physical or mental impairment, or combination of impairments, that has lasted or can be expected to last for a continuous period of at least 12 months, or result in death.

“Disability” for a minor is defined as a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months.

### Social Security Disability Benefits:

To qualify for SSDI a person must meet Social Security's definition of “disabled.” If he or she is working then it cannot be “substantial work” – known as Substantial Gainful Employment. This year, someone who earns more than \$1090 per month (in 2015) is gainfully employed and cannot get SSDI. You must also have worked a sufficient number of quarters and paid into the system unless the applicant is an eligible disabled child. A child with a disability who has never paid into the system may be eligible for SSDI based on his parent's work record provided the disability began before the age of 22 and the parent is dead, disabled or retired. An eligible child is a Childhood Disability Beneficiary (CDB). The amount of the monthly check is roughly 50 percent of the parent's monthly cash payment at retirement, and 75 percent at death.

**Supplement Security Income:**

Those who meet Social Security's definition of disabled and are financially needy may qualify for SSI. Financial need is based on both assets and monthly income. To qualify, the individual must own no more than \$2,000 in countable assets. Certain assets such as a home, car, prepaid funeral, burial plot, furniture or personal property are considered "exempt." In other words, they are not counted toward eligibility. To qualify for SSI, the disabled individual's monthly income must not exceed the qualifying amount (\$733 in 2015). A qualified individual receives SSI to supplement the monthly income. Receiving direct or "in kind" income (such as cash gifts or free room and board from relatives) can reduce the amount of the monthly benefit.

Children under the age of 18 may be eligible for SSI if they meet Social Security's definition of "disability for children", but many, do not qualify because the parents' income is too high. This is because prior to age 18, a parent's income is "deemed" available to the child. After the age of 18, there is no more deeming so eligibility is based on the child's own income and resources.

**Medicare:**

After being qualified for SSDI for 24 months, a disabled individual qualifies for Medicare. This is the same medical insurance benefits available to retired people. Premiums for the insurance are deducted from the Social Security check. Part A pays for in-patient care in a hospital, skilled nursing facility or hospice. Part B pays for out-patient care such as doctor visits and other medical services and supplies. Part D pays for prescription drug coverage. Medicare generally pays for 80% of the Medicare approved amount of the bill.

Most retired individuals purchase supplemental policies to cover Medicare co-pays and deductibles. You should consult an independent insurance agent, or the State Health Insurance

Assistance Program (SHIP) to see what options are available for younger disabled individuals.<sup>3</sup>

Medicaid:

Medicaid is available to pay the medical bills of disabled individuals with a financial need. In Georgia, Medicaid mirrors the SSI resource requirements, so Medicaid recipients can have no more than \$2,000 in countable resources. The monthly income requirements are the same. Some people who have more income than Medicaid and SSI limits can qualify for Medicaid by “spending down” a portion of their income each month on medical bills or by a direct payment into the system. This “spend down” will offset their income enough to qualify them for Medicaid benefits.

It is important to distinguish entitlement benefits, which are provided because the worker has paid into the Social Security system from welfare benefits, which are based on a financial need. A person may receive SSDI and Medicare regardless of how much he owns or what other income he may have. A person receiving SSI or Medicaid may lose those benefits if he receives a financial windfall such as an inheritance or settlement of a lawsuit or if his income increases above the qualifying level.

Medicaid is divided into classes of assistance. Each class of assistance is designed to help a specific group of individuals with specific needs. The eligibility criteria for these COAs varies. Some of the more important COAs are as follows:

Community Care Services Program (CCSP)<sup>4</sup>

CCSP provides home and community-based services to people who have a functional impairment or who have a disability. The program helps people remain in their own home, the home of a caregiver, or in other community settings as long as possible.

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<sup>3</sup>

[http://www.mygeorgiacares.org/OutreachandEducation/StateHealthInsuranceAssistanceProgram\(SHIP\).aspx](http://www.mygeorgiacares.org/OutreachandEducation/StateHealthInsuranceAssistanceProgram(SHIP).aspx)

<sup>4</sup> <https://aging.dhs.georgia.gov/community-care-services-program>

**Independent Care Waiver Services Program (ICWP)<sup>5</sup>**

The ICWP is a home and community based waiver intended to help adult Medicaid recipients with physical disabilities live in their own homes or in the community instead of a hospital or nursing facility. ICWP services may also be available for persons with traumatic brain injuries (TBI). This program is generally available for recipients between the ages of 21 and 64.

**NOW and COMP Waivers<sup>6</sup>**

The New Options Waiver (NOW) and the Comprehensive Supports Waiver Program (COMP) are intended to provide home and community-based services for people with intellectual disabilities or developmental disabilities. A diagnosis of developmental disability includes intellectual disability or other related developmental conditions such as cerebral palsy, epilepsy, autism or neurological problems that require a level of care provided in an ICF/ID.

**Georgia Pediatric Program Waiver (GAPP)<sup>7</sup>**

The GAPP Waiver program may provide services in medical daycare settings to medically fragile children with multiple system diagnoses who meet an institutional level of care. Children receive services in their homes, communities, and in ‘medical’ day care settings rather than placing children in a nursing facility or hospital.

**Katie Beckett (Deeming) Medicaid Program<sup>8</sup>**

This is not a waiver services program, but a category of eligibility for Medicaid assistance. For that reason, it is sometimes referred to as the “Deeming Waiver.”

The Katie Beckett Medicaid Program (KB) permits Georgia to ignore family income for certain children with disabilities. It allows Medicaid benefits to be provided to children 18 years of age or less

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[https://dch.georgia.gov/sites/dch.georgia.gov/files/imported/vgn/images/portal/cit\\_1210/49/47/75995826IndependentCareWaiverProgram\\_FY12.pdf](https://dch.georgia.gov/sites/dch.georgia.gov/files/imported/vgn/images/portal/cit_1210/49/47/75995826IndependentCareWaiverProgram_FY12.pdf)

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[https://dch.georgia.gov/sites/dch.georgia.gov/files/imported/vgn/images/portal/cit\\_1210/49/43/92560099NOW\\_COMP\\_FY12.pdf](https://dch.georgia.gov/sites/dch.georgia.gov/files/imported/vgn/images/portal/cit_1210/49/43/92560099NOW_COMP_FY12.pdf)

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[http://dch.georgia.gov/sites/dch.georgia.gov/files/GAPP\\_FY14\\_Final.pdf](http://dch.georgia.gov/sites/dch.georgia.gov/files/GAPP_FY14_Final.pdf)

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<https://dch.georgia.gov/tefrakatie-beckett>



who qualify as “disabled individuals” under the Social Security Act and who live at home rather than in an institution. These children must meet specific criteria to be covered. Qualification for Katie Beckett Medicaid should not be based on medical diagnosis but rather based on the institutional level of care the child requires.

Money Follows the Person (MFP)<sup>9</sup>

MFP is a grant designed to help individuals who are in nursing facilities and ICF/IDs to return to their homes and communities. Through partnerships with the Department of Human Services, the Department of Behavioral Health and Developmental Disabilities, the Department of Community Affairs, and other state and local agencies and organizations, the Georgia Department of Community Health (DCH) seeks to transition individuals from institutional settings to the community.

Service Options Using Resources in a Community Environment (SOURCE)<sup>10</sup>

SOURCE is a primary-care case management program serving elderly and disabled individuals. It is intended to improve the health of people with chronic health conditions. SOURCE links primary medical care with support services through case managers who work with the individuals and their primary-care provider (PCP).

Other benefits that might be available include housing assistance and food stamps.

Housing Choice Voucher Program: The Housing Choice Voucher Program is part of Georgia's comprehensive housing program administered by the Georgia Department of Community Affairs (DCA). This is a tenant-based assistance program that assists low income individuals and families rent safe, decent, and sanitary dwelling units in the private rental market. The program was created by the Housing and Community Development Act of 1974 and is funded by the United States Department of Housing and Urban Development (HUD). The goals of the Housing Choice Voucher Program (HCV) are to:

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<sup>9</sup> <https://dch.georgia.gov/georgia-money-follows-person-ga-mfp>

<sup>10</sup> <https://dch.georgia.gov/service-options-using-resources-community-environment-source>

## *Special Needs Planning Guide*

1. Provide improved living conditions for low income persons while maintaining their rent payments at an affordable level;
2. Promote freedom of housing choice and integrate lower income and minority persons into mainstream society;
3. Provide decent, safe, and sanitary housing for eligible participants; and
4. Provide an incentive to private property owners to rent to lower income persons by offering timely subsidy payments.

**Food Stamps:** The Georgia Supplemental Nutrition Assistance Program (SNAP), also known as the Food Stamp Program is a federally funded program that provides monthly benefits to low-income households to help pay for the cost of food. A household may be one person living alone, a family, or several unrelated individuals living together who routinely purchase and prepare meals together. Anyone may apply for food stamp benefits. The program helps households that have limited income and resources

Special needs attorneys like those at the Elder Law Practice of David L. McGuffey assist families in securing public benefits they are entitled to receive.

## **Decision-Making**

Is your child capable of making his or her own decisions? If so, what supports and assistance will help your child make better decisions? For example, would he or she benefit from the advice of a financial planner or another professional? If your child is old enough, should he or she execute a power of attorney, health care advance directive and/or a HIPAA release? These documents would empower others to assist your child even though your child would be the ultimate decision-maker.

Questions to consider include:

1. What are your child's abilities and inabilities?
2. What rights can your child handle responsibly? Should your child have the right to marry? Vote? Drive?
3. What does your child want and will your child accept help? Some adults refuse to sign powers of attorney but that doesn't mean they don't need help. If your child refuses help, will they get hurt? What are the risks, and are they serious risks or just things you'd prefer to avoid?
4. Is your child vulnerable to the influence of people who might take advantage of or abuse your child?
5. How paternalistic should you be in protecting them?
6. Do you need to stay involved in your child's life and, if so, have you established the right relationships to do that without a guardianship?
7. If you do apply for full or limited guardianship, the court might use words like "incapacitated" to describe your child. What if your child hears those words? How will it affect him or her?
8. Would someone else likely apply for guardianship if you don't?
9. Who will be the guardian or hold a power of attorney?

If your child is not capable of making his or her own decisions, then a guardianship and/or conservatorship may be necessary.<sup>11</sup> This should be done by the time he or she is 18, with planning beginning a few months prior to his or her birthday.<sup>12</sup>

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<sup>11</sup> <https://www.gaprobate.org/guardianship.php>

<sup>12</sup> A guardianship petition can be filed as early as six months prior to your child's 18<sup>th</sup> birthday. O.C.G.A. § 29-2-20(b).

In Georgia, a guardian is the person who makes personal decisions (e.g., where you live, medical decisions, etc.) for someone who lacks legal capacity. A conservator is the person who makes financial decisions for a person who lacks legal capacity.

During your lifetime: When an individual turns 18, the law presumes he or she has capacity. For a parent who is caring for a special needs child, this means you are no longer presumed to speak for your child. Health care providers might not work with you any longer. It might be necessary to file a Petition for Guardianship.

After your death: If one parent of a child is dead, generally the other parent will have custody of a minor child. If both parents are deceased and one of them named a guardian in his or her Will, then the court usually appoints the person nominated in the Will. The same applies to appointing someone to manage money.

Your lawyer can help you sort these out these details and can prepare and file the appropriate documents.

Guardianship Handbooks are available from the Council of Probate Judges of Georgia at [https://www.gaprobate.org/guardian\\_handbook.php](https://www.gaprobate.org/guardian_handbook.php)

## **Establishing a Special Needs Trust**

Special needs trusts are tools families use to protect disabled individuals. They are written so the beneficiary can enjoy the use of property that is held in the trust for his or her benefit, while at the same time allowing the beneficiary to receive essential needs-based government benefits. They can be formed for anyone who is under the age of 65 and is disabled. Assets placed inside the trust do not count toward eligibility for means-tested benefits such as SSI and Medicaid. They can be structured in several different ways.

### Self-settled versus Third Party:

Initially, there are two ways to structure special needs trusts and deciding which is appropriate depends on who owns the assets going into the trust. If your child (or the person with special needs) owns the trust, then it is a self-settled trust. If someone else owns the assets going in the trust, then the better choice is a third party trust.

The two broad categories described above can be further divided between individual (family or advisor operated) special needs trusts, and pooled (charity operated). An attorney can draft an individual self-settled or third party trust and name any person you believe should be named (other than the beneficiary) as the trustee. The trustee is the person responsible for administering the trust. A pooled trust, on the other hand, is an existing trust that you “join” by completing a joinder agreement.

Trusts are complicated legal instruments. There are rules regarding who can establish and trust and there are many rules regarding how these trusts must be structured. If they are prepared improperly, you may be worse off with the trust than you were without it. This is illustrated by a recent court case, *Draper v. Colvin*, where a special needs trust was established improperly and the trust beneficiary was denied benefits.<sup>13</sup> You should hire an attorney who understands public benefits laws to prepare your child’s special needs trust.

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<sup>13</sup> <http://law.justia.com/cases/federal/appellate-courts/ca8/13-2757/13-2757-2015-03-03.html>

## **Funding a Special Needs Trust**

If you are (or a family member is) leaving assets for your child, it is important to leave them to the Trust rather than to your child. The reason why this is important is because vesting occurs the moment an individual has a right to take money or property. Once assets vest in an individual, the rules change regarding how they are treated when seeking eligibility for public benefits.

When considering how much to put in the trust, go back to your budget and think about your child's life expectancy. Chances the right amount is what the budget shows he or she will need for the rest of their life. If you need assistance making the calculation, MetLife has a special needs calculator on its website: <http://www.metlifeiseasier.com/specialneedscalculator>.

Term life insurance payable to the trust is probably the most inexpensive way to provide for a child. It is usually affordable for young parents. You can purchase \$250,000 (or more) and list your child's special needs trust as the beneficiary.

Retirement benefits like 401(k)s and IRAs are tricky. The beneficiary of an inherited retirement account must generally begin taking distributions in the year following the employee's death. Those distributions will be deemed income unless they are paid to a properly structured trust. Even if you have a special needs trust, it may or may not be drafted to comply with the IRS rules. You should speak with your lawyer about this issue if you plan to leave retirement accounts for your special needs child.

Other assets may be left to a special needs trust, but keep in mind that if they are creating expenses, the assets might need to be liquidated. An asset that costs your child money to maintain probably doesn't do him or her any good.

Sample terms in Will if a trust was previously established: I leave  
[describe gift] to the Trustee of a special needs trust for [child's  
name], established on [Date].

## **Administering the Special Needs Trust**

The Trustee you chose will administer the Trust, so make certain you chose the right person. Ask a special needs lawyer if you need advice on this. Also, the letter of intent you prepared will guide your trustee in knowing your priorities while administering the trust.

A first party special needs trust must be administered for the “sole benefit” of the beneficiary. Distributions that are not for the beneficiary’s “sole benefit” will trigger an SSI and a Medicaid transfer penalty. The result will be a loss of benefits.

Distributing more than \$20 cash a month directly to beneficiary – unearned income reduces SSI (dollar for dollar).

Distributions which are deemed in-kind support and maintenance (ISM) will reduce benefits up to the presumed maximum value (PMV), which is one-third of the benefit rate plus \$20. Payments for food or shelter are ISM and will cause a reduction in benefits. The only ten “food and shelter” items are:

1. Food
2. Mortgage (including property ins. required by lender)
3. Real property taxes (less any tax rebate/credit)
4. Rent
5. Heating fuel
6. Gas
7. Electricity
8. Water
9. Sewer
10. Garbage removal

If you have questions concerning a distribution, you should contact an Elder Law Attorney (or special needs law attorney) before you make the distribution.

For further reading, the Special Needs Alliance publishes a free trustee guide that is available at <http://www.specialneedsalliance.org/free-trustee-handbook/>.



## Able Act Accounts

The ABLE Act creates a new Section 529A (within the Tax Code) establishing Qualified ABLE Programs. The ABLE Program accounts are intended to be easy to open and available in any state, although each state must take action to make the accounts available to its residents. Assets in an ABLE account and distributions from the account for qualifying expenses would be disregarded or receive special treatment when determining the beneficiary's eligibility for most federal means-tested benefits.

An eligible individual may have **one** ABLE account, which must be established in the state in which he resides (or in a state that provides ABLE account services for his home state).

- Any person, such as a family member, friend, or the person with a disability, may contribute to an ABLE account for an eligible beneficiary.
- An ABLE account may not receive annual **cumulative** contributions exceeding the annual gift-tax exemption (**\$14,000** in 2015).
- Eligibility – An eligible individual is a person (1) who is entitled to benefits on the basis of disability or blindness under the Supplemental Security Income (SSI) program or under the Social Security disability, retirement, and survivors program OR (2) who submits certification that meets the criteria for a disability certification (to be defined in future regulations). An eligible individual's disability must have occurred before the age 26.
- Designated Beneficiary – The eligible individual who established the ABLE account and who is the owner of the account is the “designated beneficiary.”
- Qualified disability expenses are any expenses made for the benefit of the designated beneficiary and related to his/her disability, including: education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative



services, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and other expenses, which are approved by the Secretary of the Treasury under regulations.

ABLE accounts have limited value when parents are doing lifetime planning for their children because cumulative annual contributions are limited, and only the first \$100,000 is exempt when seeking eligibility for Supplemental Security Income. Also, amounts remaining in the account after the beneficiary's death are subject to a Medicaid pay-back claim, so they may not be available for other family members.

## **Your Own Estate Plan**

As you consider your child's needs, do not neglect your own. Who will make decisions for you if you are incapacitated? Do you have an advance directive for health care? Who will make financial decisions for you? Do you have a power of attorney? Do you have long-term care insurance?

Have you executed a Will? Does your Will include a special needs trust for your child? One mistake parents commonly make is disinheriting their special needs child. Don't do that. Life is full of uncertainties. What if you leave money to someone else (not in a trust) believing they will take care of your child? That puts your special needs child at-risk if the person holding the money dies, goes bankrupt, gets divorced or gets sued. What if they spend the money? Once money is gone, it's usually difficult (or impossible) to get it back. A special needs trust is a much better solution.

### **Checklist:**

- Make certain that your wills and trusts are properly executed.
- Review your documents and assets with a qualified financial planner and special needs attorney.
- Coordinate the ownership of assets and beneficiary designations of your retirement plans, life insurance policies, disability insurance, long-term care insurance and annuities with your estate plan.
- Communicate to your other children, or future caretakers, of your plans and their role that you wish them to carry on. This is not a time to leave surprises.
- Make certain that you do not leave a "financial burden" to siblings or future caretakers—an equally distributed estate may not be a fair distribution to all.
- If life insurance is needed to provide for the supplemental needs of your child, make sure that it is properly in place (i.e., ownership and beneficiary designations are coordinated) and premiums are adequately funded.
- Review and update your letter of intent.

An estate plan is one of the tools available to plan for your child's future. Hire an attorney to help you get it right. The Elder Law Practice of David L. McGuffey offers a variety of services to meet your needs and fit your budget.

## **Resources**

### **The Elder Law Practice of David L. McGuffey**

We are a full service law firm, focusing our practice on the needs of elders and individuals with special needs. Our main office is in Dalton, Georgia and our satellite office is in Cartersville, but we serve special needs families throughout Georgia and Tennessee. If you want to know more about our practice, visit our website at [www.mcguffey.net](http://www.mcguffey.net) or call (706) 428-0888.

H. Wright, **The Complete Guide to Creating a Special Needs Life Plan** (paperback, available at amazon.com)

### **Annie E. Casey Foundation**

The Annie E. Casey Foundation is a private charitable organization “dedicated to helping build better futures for disadvantaged children in the United States.” The Foundation’s website has a Knowledge Center that includes publications and other resources that have been developed by Casey or one of their grantees. There are several publications and videos, including *The Money Trap* and *I Know Where I’m Going (But Will My Cash Keep Up?)*: Parts I & II, that include valuable information and activities that introduce and reinforce financial education topics. For more information, visit <http://www.aecf.org/>

### **Babies Can’t Wait**

Babies Can't Wait (BCW) is Georgia's statewide interagency service delivery system for infants and toddlers with developmental delays or disabilities and their families. BCW is established by Part C of the Individuals with Disabilities Education Act (IDEA) which guarantees all eligible children, regardless of their disability, access to services that will enhance their development. <https://www.bcw-bibs.com/>

### **KnowledgeCenter**

*Budgets Are Sexy: Where Financial Nerds Are Cool* “Budgets Are Sexy is a personal finance blog that won’t put you to sleep.—Benjamin Franklin.” The blogger, J. Money, started writing five years ago (when he was in his 20s) and has fun covering such topics as budgeting, good giveaways, a life list, recommended things to spend money on, and other great financial resources. To read and contribute to the blog, visit <http://www.budgetsaresexy.com>.

### **Consumer Financial Protection Bureau**

The Consumer Financial Protection Bureau (CFPB) is a new federal agency that is responsible for regulating consumer protection with regard to financial products and services. CFPB is concerned about such areas as credit discrimination, pay day lending, making sure people understand their right to see credit reports, debit and ATM overdraft coverage, and gift card terms and conditions.

For more information, visit their website,  
<http://www.consumerfinance.gov>.

### **Georgia Advocacy Office**

A private non-profit corporation. Its mission is to work with and for oppressed and vulnerable individuals in Georgia who are labeled as disabled or mentally ill to secure their protection and advocacy. GAO's work is mandated by Congress, and GAO has been designated by Georgia as the agency to implement Protection and Advocacy within the state.

<http://thegao.org/>

### **JumpStart Coalition for Personal Financial Literacy**

The JumpStart Coalition for Personal Financial Literacy is a coalition of organizations that share an interest in advancing financial literacy among students. JumpStart's online clearinghouse has a very comprehensive collection of financial education resources, including booklets and pamphlets on specific topics, activities, on-line games, and teacher lesson plans. For more information, visit <http://jumpstart.org>.

### **Money Smart—a Financial Education Program**

Created by the Federal Deposit Insurance Corporation (FDIC), Money Smart is a comprehensive financial education curriculum that teaches the basics of handling money and finances, including how to budget, save money, and how to avoid making "wrong" decisions that may result in years of financial pain. The curriculum is available free of charge. For additional information, call toll-free 877-275-3342 or go on-line to

<http://www.fdic.gov/consumers/consumer/moneysmart/index.html>.

### **Muscular Dystrophy Association**

<http://www.mda.org/>

### **MyMoney**

MyMoney.gov is the U.S. government's website dedicated to financial education. Resources are available to learn about budgeting, credit building, financial planning, understanding privacy issues, saving and investing. There are links to other government programs that offer financial educational programs, such as Consumer Financial Protection Bureau and the Federal Trade Commission. For more information, visit [www.mymoney.gov](http://www.mymoney.gov) or call 1-888-MyMoney (696-6639).

### **National Foundation for Credit Counseling**

As the nation's largest financial counseling organization, NFCC provides information about of the non-profit credit counseling agencies. For more information, go to <http://www.nfcc.org>.

### **Navigate Life Texas**

This is a unique website that includes a roadmap for planning the future with your special needs loved one. Although the services described are in Texas, the ideas discussed there apply special needs families located everywhere. <https://www.navigatelifetexas.org>

### **Parent to Parent of Georgia**

Parent to Parent of Georgia offers a variety of services to Georgia families impacted by disabilities or special healthcare needs. <http://p2pga.org/>. P2P's website includes a roadmap to success, located at <http://roadmap.p2pga.org/>.

### **Protected Tomorrows**

A financial planning firm that enhances the lives of people with special needs through a comprehensive life planning process. It creates Future Care Plans™, which address the needs of the individual with developmental disabilities, mental illness, physical disabilities, or cognitive and neurological diseases. <http://protectedtomorrows.com/>

### **Special Needs Alliance**

A national, non-profit organization committed to helping individuals with disabilities, their families and the professionals who serve them. <http://www.specialneedsalliance.org/>

**Tax Assistance**

(VITA) program. For more information, visit their website [www.pathwayspa.org](http://www.pathwayspa.org) or call 610-543-5022.

**Practical Money Skills for Life**

To help people learn about the essentials of personal finance, Visa has partnered with consumer advocates, educators and financial institutions to develop the Practical Money Skills programs. You can access free educational resources, including personal finance articles, lesson plans, and games (including the popular Financial Football and Soccer games) from their website, [www.practicalmoneyskills.com](http://www.practicalmoneyskills.com).

**Special Needs Rendezvous**

This is a Facebook page administered by the Elder Law Practice that serves as a clearing house for news, tips, resources, events and other information for the special needs community.

<https://www.facebook.com/georgiaspecialneedslaw?ref=hl>

**State and Local Government websites**

<http://www.statelocalgov.net/>

**The Arc**

<http://www.thearc.org/>

**United Cerebral Palsy**

<http://ucp.org/>

**U.S. Department of Health & Human Services**

<http://www.hhs.gov/>

**FREE 30 MINUTE INITIAL CONSULTATION  
(\$200 Value – Free with this Coupon)**

**Meet with David L. McGuffey to discuss special needs planning, guardianships, Wills, powers of attorney, advance directives, special needs trusts and more.**

**Call (706) 428-0888 Today to set up your appointment**

## Meet David L. McGuffey



David L. McGuffey is in private practice with the Elder Law Practice of David L. McGuffey, LLC, located in Dalton, Georgia and in Cartersville. David limits his practice to Elder Law and Special Needs Law. That means he helps individuals who are elders or who have special needs, as well as their caregivers. Much of David's practice is devoted to helping individuals with chronic health conditions find, get and pay for good long-term care. David is certified as an Elder Law Attorney by the National Elder Law Foundation. David is AV rated by Martindale-Hubbell. In 2012, David was invited to join NAELA's Council of Advanced Practitioners, an invitation-only group of the leading Elder Law Attorneys in the

United States. David was selected as a "Georgia Super Lawyer" in the field of Elder Law for 2013, 2014, 2015.

David attended Georgia State University (B.A., 1987; J.D., 1993). He is a member of the National Academy of Elder Law Attorneys and various local bar associations. He is a past Chair of the State Bar of Georgia's Elder Law Section and the Tennessee Bar Association's Elder Law Section. David served as Chair of one of the American Association for Justice's national litigation groups from 2006-2007, taking approximately 40 cases to a jury and has argued non-jury cases. David holds memberships in other groups associated with elder advocacy. David is a member of the Board of Directors of the National Academy of Elder Law Attorneys. He serves on various committees for special interest groups working for Elders and Individuals with special needs. He is a former member of the Board of Directors of the National Elder Law Foundation, Board of Directors of the National Consumer Voice for Quality Long-Term Care, the Board of Governors for the Georgia Chapter of the Alzheimer's Association, and the Northwest Georgia Health Care Partnership. He has served as an advisory committee member for various health care organizations.