When Your Child Becomes an Adult: Practical Solutions to Potential Problems

When a child who has special needs becomes a legal adult (18 years old in most states), a parent is no longer recognized as a person who can make decisions for that child. If your child is two to three years or less from this significant birthday, this is the time to evaluate your situation.

What changes? What’s at risk?

“Depending on your child’s level of self-care and decision-making abilities, leaving your child to make his or her own decisions could be troublesome to strategies you may have put in place over the years,” says Karen Starowski¹, a Special Care Planner who’s earned the Chartered Special Needs Consultant designation² and who’s associated with MassMutual Arizona³ in Scottsdale, Arizona, a general agency of Massachusetts Mutual Life Insurance Company (MassMutual). Here are some things that could be affected.

- **Health care** – Because of medical privacy laws, parents no longer have the legal right to medical records and can no longer make decisions for a child who’s reached the age of majority. Neither will you be made aware that your child is a patient of a doctor or medical facility or get answers to questions you ask of your child’s medical providers, unless your child has authorized it.

- **Education** – Rights to educational records transfer to the student once the student is a legal adult. Your child can sign a waiver allowing you to have access to information, but only when you request it (for example, grades won’t automatically be mailed to you).

Also remember that if your child is receiving an Individual Education Plan (IEP) in high school, the plan includes services to transition him or her into adulthood (educational, employment, residential, etc.) and qualifies your child for special accommodations in public college (application process, testing, etc.).

- **Social security benefits** – When a child receiving benefits becomes an adult, different rules apply in determining whether or not the person is disabled and in calculating the benefit amount. You and your child should consider how this might affect your child’s adult lifestyle. If your child hadn’t previously qualified for benefits because your household income was too high, he or she may be eligible as an adult.

Remember, too, that losing social security benefits also risks Medicare/Medicaid coverage and eligibility for other programs and services (utility discounts, residential waivers, food stamps) offered by local, regional, and national organizations and governments.

- **Employment** – Your child may decide to work. If he or she’s also receiving social security benefits, employment earnings may put those benefits at risk. Social security limits how much a person can earn and still qualify for benefits. If your child loses benefits, then stops working and needs governmental assistance again, the reapplication process is arduous. Waiting for approval could take months, and if an appeal is necessary, years. (www.ssa.gov/appeals/DataSets/01_NetStat_Report.html)

Meanwhile, how does your child meet financial needs?

- **Family** – How will decisions your child makes regarding health, education, employment, affect your family finances, relationships, goals, peace of mind, and family dynamics?

**Considerations**

Evaluate your child’s ability to make decisions. Have discussions about issues that may arise and how decisions made about one thing, such as going to work, might affect another thing, such as affecting eligibility for government benefits. You may decide your child needs help only with medical-related
decisions or shouldn’t make any decisions at all. There are a variety of options to choose from, giving parents a range of decision-making authority – from specific to complete. The particular options available to you depends on your child’s understanding and capacity to enter into legal contracts.

- **Letter of intent** – “This is not a legal document but an important one that’s continually updated with information about the social, medical, educational, and family life of a person with special needs,” explains Starbowski. “It’s primarily used to provide detailed information for a person who may need to step in to care for a person with special needs. However, it could also be useful to your child when he or she begins independent adulthood.” For example, the document will list all medical caregivers and their contact information, medications (types, doses, and how/where to get refills), and contact info for friends and family – information your child would have to compile anyway. It’s a helpful start.

- **Review of the family’s financial strategy** – Include your child in a discussion of decisions you’ve made over the years to ensure the best financial well-being for the whole family. (If you haven’t yet created a financial strategy, this is a good time to do so.) Help your child understand how decisions he or she makes may affect the whole family, and how some decisions may have long-term effects. “A child may want to live on one’s own, and may be able to support that concept now, but will health issues prevent that five or ten years from now?” questions Starbowski. “Consider how that might affect family finances, but also think about the personal and emotional benefits and disadvantages any decision might have. What options or compromises might help your child and the family get what you all need? How might a well thought-out financial strategy help you meet those needs?"

- **Guardianships** – Petitioning the court to name yourself or another trusted person (or persons) as guardian for your child provides the guardian with full or limited decision-making authority, depending on the type of guardianship you choose. “A full guardianship gives the guardian the power to make all decisions for the child,” Starbowski explains. “If your child will be unable to make decisions as an adult, this solution can eliminate many problems. For instance, you’ll continue to have the right to all medical information; privacy laws won’t be an issue. And potentially unscrupulous persons your child may meet will not be able to take advantage of your child’s finances.”

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It’s a legal document, so you’ll need to have an attorney’s help. “Be sure to use an attorney who’s experienced in special needs law,” advises Starbowski. “You’ll want a document that serves your family’s needs and won’t contradict other legal or financial strategies you’ve created for your family.”

- **Special needs trust** – There are many types of trusts, each funded in different ways and created for specific purposes. Working together with financial and legal professionals who have experience in serving people with special needs can help you determine which is right for you. A trust can help provide financial support for certain expenses for your child during adulthood and help ensure ongoing eligibility for government benefits received now or in the future.

- **Medical directives** – A variety of documents can give you some control over obtaining information about your child’s medical care and making medical decisions for or with your child. These documents include a standard form health care proxy (grants a person authority to make medical decisions for another person if and when that person becomes incapable), living will (specifies a person’s preferences for treatment under certain circumstances, such as irreversible conditions or life-sustaining measures), and medical power of attorney you create with an attorney (authorizing a person to make medical decisions for another, which is more specific than a standard for health care proxy, such as defining the range and timing of authority).

- **Powers of attorney** – A durable power of attorney gives one person authority over the finances of another person. As with a medical power of attorney, it can specify the range of authority and when the authority is allowed (for example, only during hospitalization).

**Plan ahead**

Kids grow up quickly. Take time now to plan for the day your child will be an adult. Let that birthday be a time for family celebration, knowing you’ve examined the potential problems, the solutions, and your options. Put the right strategy in place for your child – and your family.

1. www.financialguide.com/Karen-Starbowski
2. A Special Care Planner, a title used by MassMutual financial professionals, is someone who has received advanced training and information in estate and tax planning concepts, special needs trusts, government programs, and the emotional dynamics of working with people with disabilities and other special needs and their families. The certificate program was offered by The American College in Bryn Mawr, PA, exclusively for MassMutual financial professionals. Additionally, a designation of Chartered Special Needs Consultant (ChSNC), which evolved from the certificate program, is now offered through the American College for financial professionals. MassMutual financial professionals who have completed the certificate program, or received the ChSNC designation, can use the Special Care Planner title.
3. www.arizona.massmutual.com/
4. You can request a free Letter of Intent template from any MassMutual Special Care Planner or here: https://www.massmutual.com/individuals/goals/care-for-a-loved-one-with-special-needs (scroll down and click on the “Talk to us” button to request one by email).

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A Special Care Planner through MassMutual’s SpecialCare™ program can assist parents in drafting Letters of Intent and can help make a difference in the quality of life for an individual with special needs, their caregiver and other family members. Through SpecialCare you will learn valuable financial strategies, identify financial strategy solutions, access vital information, and meet certified specialists who will work with you and your professional advisors – your banker, accountant or financial planner, lawyer, social workers and health care providers – to review your financial picture and offer options to fit the needs of each situation. For more details, visit MassMutual’s website at http://www.MassMutual.com/specialcare, or call 1-800-272-2216.

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