Planning for Adulthood

A GUIDE FOR FAMILIES & CARETAKERS OF CHILDREN

with Congenital Myotonic Dystrophy

Myotonic Dystrophy
FOUNDATION

Thank You

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Myotonic Dystrophy FOUNDATION

Planning for Adulthood:

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Table of Contents

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For families of children living with congenital myotonic dystrophy (CDM), the transition into adulthood can feel overwhelming. New legal, medical, and financial responsibilities begin at age 18, and planning ahead can make the process smoother.

This resource is designed to support parents and caregivers of young adults affected by CDM in the United States (US) prepare for the transition to legal adulthood. The resource will cover information on legal decision-making, education transitions, healthcare transitions, planning for benefits, and financial security. Every family's situation is different, and laws and benefits vary by state. This guide provides an overview of key areas to explore with qualified professionals, such as attorneys and benefits specialists, as you plan for your child's future.

NOTE

Throughout this guide the word "support" or "supports" signifies the people and resources that help an individual and their family manage healthcare, education, legal matters, finances, and daily life, while staying safe and as independent as possible.

While this resource was created for families of individuals living with CDM, some of the information may also be helpful for families of individuals with juvenile-onset myotonic dystrophy. Many of the considerations discussed here can apply across childhood and young adulthood. Families should consider their individual circumstances and consult professionals to determine what options are most appropriate for their situation.

Legal Decision-Making

In most US states, when your child turns 18, you no longer have legal authority to make decisions on their behalf. It is important to begin the process of sorting out legal decision making before your child turns 18. Meeting with an attorney before their 18th birthday to discuss options that best meet your needs is a crucial first step.

To best support your child's safety and independence you may consider several options, such as 1) **guardianship and/or conservatorship**, 2) **power of attorney**, or 3) **supported decision-making**. Children living with CDM have a wide range of cognitive function abilities; certain legal options may not be suitable for some families. This guide aims to provide a wide range of information to support families in a variety of different situations. The right choice for your family depends on your family's unique situation, so it may help to talk with an attorney or legal representative. Be sure to start the process at least 6-12 months before your child becomes a legal adult to give yourself plenty of time to navigate logistics like court hearings and gathering paperwork.

This guide includes short overviews of each option. These are meant to provide general information and should not be considered legal advice.

Guardianship and/or Conservatorship

In the United States (US) guardianships and/or conservatorships are legal arrangements that allow a court to give someone the authority to make decisions for another person who cannot safely make certain decisions on their own. This may include decisions about healthcare, living arrangements, or money. Each state uses terms a little differently to describe these legal arrangements. Some states only use the term guardianship, other states only use the term **conservatorship**, and some states use both terms interchangeably. A **guardian** is usually responsible for personal and health-related decisions, such as where someone lives or the medical care they receive. A **conservator** is generally responsible for financial matters, such as managing money or property. In some cases, one person may serve as both guardian and conservator.

The term "ward" typically refers to the person under guardianship, and "conservatee" typically refers to the person under conservatorship, though this can vary from state to state.

Two different types of guardianship exist:

1. **Temporary guardianship**: used in more emergency-related, short-term situations. For example, if a parent of a minor child has passed away, or a decision about moving someone to a nursing home needs to be made.
2. **Permanent guardianship**: used in long-term situations such as when a person has a severe developmental disability or long-term mental illness. If circumstances will not change within 90 days, it typically makes more sense to seek permanent guardianship. Note: Despite its name, permanent guardianship is only in place as long as it's needed.

Whether you petition for **temporary guardianship** or **permanent guardianship**, the court will evaluate your situation and determine whether *full* guardianship or *limited* guardianship is most appropriate.

It is important to understand the difference between the terms guardianship of “person” and guardianship of “estate.” Guardianship of “person” means the guardian makes decisions about the ward’s well-being (like healthcare, education, and housing decisions)[1]. Guardianship of “estate” means the guardian manages the ward’s assets and financial affairs (like paying bills, filling taxes, and investing funds)[2].

Full guardianship (also sometimes called *plenary* guardianship): the guardian has guardianship of both the “person” and “estate”.

Limited guardianship: the guardian assists the ward with specific areas of decision-making determined by the court, but it still allows for the ward to keep a level of autonomy (ability to make some of their own decisions). *Limited* guardianship is usually used when someone is unable to manage certain parts of their life (like healthcare decisions) but can still handle other responsibilities independently (like housing decisions). With limited guardianship, the ward can make choices about some areas of life, but the guardian makes decisions about others.

Power of Attorney

Power of attorney is a legal document that allows an appointed person (or “agent”) to act on behalf of an individual when the individual requests it (i.e., give their consent) or are incapacitated (physically or mentally unable to manage affairs)[3]. Power of attorney must be established before a person becomes incapacitated. There are two main types of power of attorney: 1) **healthcare**, which allows the agent to make medical decisions when the individual requests or is incapacitated, and 2) **financial** which allows the agent to assist with money management when the individual requests or is incapacitated. You can have both healthcare and financial power of attorney, with the same person or different people appointed to make decisions for each. Power of attorney allows your child to retain their rights unless they request your help and give their consent or become incapacitated.

GUARDIANSHIP VS. POWER OF ATTORNEY

It may help to think of the difference between guardianship and power of attorney like your child riding a bike.

With **guardianship**, you’re on the bike with your child, steering together and keeping them safe as you go.

With **power of attorney**, you’re running alongside the bike. You can only step in to help when your child asks for it (they give consent), or if they can’t keep riding on their own anymore (when they become incapacitated).

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[1] “Guardian of the Person.” Legal Information Institute, January 2022. ***www.law.cornell.edu/wex/guardian_of_the_person***

[2] “Guardian of the Estate.” Legal Information Institute, January 2022. ***www.law.cornell.edu/wex/guardian_of_the_estate***

[3] “What Is a Power of Attorney (Poa)?” Consumer Financial Protection Bureau, January 29, 2024. ***www.consumerfinance.gov/ask-cfpb/what-is-a-power-of-attorney-poa-en-1149/.***

Supported Decision-Making

When an individual chooses supporters (such as family members or friends) to help them with decision making, this is called supported decision-making[4]. Supporters do not make decisions for the person, and no court approval is needed. Unlike guardianship or power of attorney, supported decision-making does not give anyone legal authority to act for another person. It can be a good option for someone who wants help but is not ready for guardianship or power of attorney. Someone can have supported decision-making in place and later add guardianship or power of attorney if additional support becomes necessary. In these cases, the guardian may choose to continue using supported decision-making for certain types of choices or may take a more direct role in making decisions. Likewise, a person under guardianship who wishes to have more say in their choices could request their guardian try supported decision-making as a way to begin shifting how decisions are made. Guardianship, however, ultimately overrides supported decision-making.

NOTE

Supported decision-making is included in this guide with the aim of providing the most comprehensive information about the options possible. Many families with children living with CDM find that supported decision-making is not suitable or sufficient for their situation.

✓ LEGAL DECISION-MAKING CHECKLIST

SCAN TO VISIT the Special Needs Alliance website

- ▶ Find a lawyer licensed in your state who specializes in estate planning. *The Special Needs Alliance* is a resource that helps individuals with disabilities, and their families, connect with nearby attorneys who specialize in disability law.

SCAN TO VISIT the Council of Parent Attorneys and Advocates website

- ▶ You may want to interview your attorney before hiring them to make sure you're comfortable with them and feel confident in their abilities. The Council of Parent Attorneys and Advocates provides *information about choosing an attorney* that may be helpful.
- ▶ Work with your attorney to decide whether guardianship, power of attorney, and/or supported decision-making would be most appropriate for your child.

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[4] "Supportive Decision Making." American Bar Association, November 21, 2023. ***www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/supported-decision-making/.***

Education Transitions

As your child approaches adulthood, planning for changes in their education and daily structure is an important step. The type of support your child utilizes may change significantly as they leave the K–12 system. Thinking ahead about possible pathways after high school may help families prepare for what comes next and avoid gaps in services.

During the school years, many students living with CDM receive services under the **Individuals with Disabilities Education Act** (**IDEA**). IDEA provides students with a **Free Appropriate Public Education** (**FAPE**) and legally requires a **Least Restrictive Environment (LRE)** which means a child who gets special education should learn alongside general education peers as much as possible. IDEA also provides other supports through an **Individualized Education Program** (**IEP**) or 504 plan. Beginning at age 16 (or earlier in some states), the IEP must include a transition plan focused on preparing the student for adulthood.

NOTE

In most states, you can access advocates to help you navigate the education system. You can learn more through organizations like *The Arc* or the *Learning Disabilities Association of America (LDA)*, which have local chapters with resources.

SCAN TO VISIT

The Arc's website

SCAN TO VISIT

the Learning Disabilities Assoc. of America website

Families should work closely with their IEP team to anticipate coming changes, such as shifts in therapy needs, communication support, or physical accessibility. It can also be helpful to invite outside providers (such as physical therapists, speech-language pathologists, or specialists familiar with CDM) to contribute insight during transition planning meetings.

IDEA also provides the option for your child to continue to receive instruction, transition services and community experiences, including vocational rehabilitation and training, through the age of 21, unless your state laws specify younger. Some states extend this beyond age 22. Each pathway will look different, and preparing early may help ensure a smoother shift into adulthood.

SCAN TO VISIT MDF's IDEA guide

MDF's *Going to School with Myotonic Dystrophy: A Guide to Understanding Special Education and IDEA* offers a more detailed overview of these protections and how they work in the United States.

While IDEA plays an important role during the school years, these protections typically end when a student graduates or ages out of the system (often at age 21 or 22, depending on the state). What comes next depends on your child's abilities, health needs, and educational pathway. Families generally choose one of two pathways:

1. Transitioning to Higher Education or Training

In some cases, a young adult living with CDM may earn a high school diploma and pursue college, vocational training, or another postsecondary program.

- In the United States, colleges and training programs are governed by the **Americans with Disabilities Act (ADA)** and **Section 504 of the Rehabilitation Act of 1973**, not IDEA. Support is provided as accommodations, not services, and must be requested by the student. Accommodations may include extended test time, flexible attendance, note-taking support, or accessible housing.
- Vocational rehabilitation programs are run by individual states and can help your child prepare for and maintain a job. They may receive an individualized rehabilitation program, counseling and guidance, training, job placement, and services to support job retention. Many applicants are referred by schools, hospitals, welfare agencies, and other organizations, but your child may apply directly for service as well[5].
- The **Office of Special Education and Rehabilitative Services (OSERS)** supports educational and vocational programs for young adults with disabilities.

2. Transitioning to Adult Services and Day Programs

For some young adults living with CDM, college is not the right fit. It may make more sense to pursue more direct support and services in adulthood. Options may include:

- Adult day programs or community-based programs.
- Supported employment or volunteer opportunities.
- Life skills or transition programs.
- Home- and community-based services through Medicaid or state disability agencies.

SCAN TO VISIT the OSERS guide on coordinating transition services

The Office of Special Education and Rehabilitative Services (OSERS) has published a guide about *coordinating transition services* that may be useful as you work to find the best option for you and your child. Because these services can be difficult to access once school-based supports end, early planning is especially important.

SCAN TO VISIT OSERS guide on post secondary education and employment

OSERS guide on *Post Secondary Education and Employment for Students and Youth with Disabilities* may be helpful as you navigate the transition process.

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[5] "People with disabilities: Vocational rehabilitation" Career One Stop. Accessed January 2026., January 29, 2024. *www.careeronestop.org/ResourcesFor/WorkersWithDisabilities/vocational-rehabilitation.aspx.*

EDUCATION TRANSITIONS CHECKLIST

- Review your child’s IEP and transition plan before leaving high school.
- Discuss post-high school goals with your child, school team, and healthcare providers.
- Explore postsecondary options, such as college, vocational training, or supported programs.
- Learn how accommodations work under ADA and Section 504 if pursuing higher education.
- Contact vocational rehabilitation and adult disability service agencies and begin applications for adult services before your child ages out of IDEA.

INTERNATIONAL RESOURCES FOR SCHOOL TRANSITIONS

Australia

www.raisingchildren.net.au/disability/disability-rights-the-law/rights/education-rights-disability

Canada

www.aidecanada.ca/resources/learn/help-with-transitions/transition-to-adulthood-services-continuing-to-foster-self-determination-choices-and-self-advocacy

Europe

www.esn-eu.org/sites/default/files/publications/Vulnerable_Youth_in_Transition%2C_Practice_Examples.pdf

United Kingdom

www.ndti.org.uk/programme/preparing-for-adulthood/

Healthcare Transitions

Transitioning from pediatric to adult healthcare can be a challenging part of entering adulthood for individuals with CDM and their families. Beginning healthcare transition planning in adolescence (around age 16) allows families, providers, and youth to work together to build skills, identify goals, and prepare all necessary medical information well ahead of the actual transfer to adult clinicians.

Many hospitals and clinics have strict age cutoffs and will not continue providing pediatric care once someone reaches adulthood. However, some larger or university-based medical centers may allow medically complex individuals to continue with established pediatric specialists into their early 20s, which is often beneficial for your child. Policies differ between institutions, and these exceptions are not always publicized, so it can be helpful to ask your pediatric providers directly whether extended care is possible.

UNDERSTANDING HIPAA

When your child turns 18, your rights as their parent or guardian change, especially when it comes to medical decisions and access to health information. Under the **Health Insurance Portability and Accountability Act** (**HIPAA**), healthcare providers or guardian/s cannot share an adult patient's protected health information without that patient's permission, even if the patient has significant medical needs or disabilities. To continue participating in your child's care after they turn 18, you will need their explicit consent. If they have capacity, your child can sign a HIPAA release form, allowing healthcare teams to share medical information with you and permitting you to speak directly with their clinicians. If your child is unable to sign such a document, or will need ongoing support in making medical decisions, families may also want to explore options such as a supported decision-making arrangement or guardianship (see Legal Decision-Making section for more information).

Healthcare transitions work best when they are treated as a gradual process rather than a single event. A high-quality transition process includes developing a formal **transition plan** (sometimes called **plan of care**) that is updated regularly and kept in the child's medical chart. This plan should outline your child's health history, current needs, transition goals, and the roles of all involved caregivers and clinicians. Health care providers should also complete transition readiness assessments to help identify skills and knowledge your child is building and where additional support is needed.

SCAN TO VISIT MDF's Find A Doctor Map

Families may need to identify adult neurologists, pulmonologists, cardiologists, GI specialists, sleep specialists, and other clinicians knowledgeable about myotonic dystrophy. Because adult providers with DM-specific experience can be difficult to find, planning ahead is essential. Your child's pediatric health care provider may be able to refer families to adult care. Additionally, MDF's ***Find a Doctor Map*** may be a helpful starting point for locating clinicians in your region who are recommended by DM community members.

When it is time for a transfer of care, your pediatric team should complete a **comprehensive transfer package**. This often includes:

- A **transfer letter** from your health care provider.
- A copy of a **final readiness assessment**.
- A **plan of care**.
- An **updated medical summary and emergency care plan**.
- Any **guardianship or health proxy** (a legal document that appoints a trusted person to make medical decisions on your behalf if you become unable to communicate or make decisions yourself) **documents**.
- **Information about myotonic dystrophy** (such as MDF's DM Clinical Care Recommendations for *Children Living with CDM* and *adults with DM1*).

NOTE

You may want to apply for a government ID for your child in case you need to travel for care or other reasons. In the United States you can apply for a passport for your child at any age. The age at which your child can obtain other forms of identification varies by state.

You may also want to request a **portable medical summary** for your records as well as copies of other therapy reports. Providing this information ensures the new adult provider receives a complete and accurate picture of your child's healthcare needs, DM-specific considerations, and support requirements.

NOTE

Provider willingness to participate in the transition process will vary across health systems. You may encounter resistance from your child's healthcare team and need to more actively advocate for the best care for your child.

With early preparation, communication, and the right supports in place, transitioning to adult healthcare can be smoother, and tailored to your child's needs.

HEALTHCARE TRANSITIONS CHECKLIST

- Starting around age 16, work with your healthcare team and your child to develop a transition plan that is continually updated.
- Ask your pediatric specialists whether they allow patients with complex medical needs to stay beyond age 18 and, if so, for how long.
- Begin identifying adult providers early, ideally 1–2 years before transition. Use the MDF Find a Doctor Map to locate clinicians recommended by DM community members. Schedule introductory appointments with adult providers before leaving pediatric care when possible.
- Request copies of medical records, care plans, and therapy summaries to help your new adult providers understand your child's history.
- Obtain a HIPAA release form your healthcare provider when your child turns 18.

Planning for Benefits

In the United States, as your child approaches adulthood, it is important to understand what public benefits may be available to support their needs. Public benefits are government-funded programs that provide financial, medical, or social assistance to individuals and families in need of support in order to help meet basic living expenses and improve well-being. **Public benefits** may be able to help with healthcare and daily living expenses, but each program has its own rules and requirements. Some programs are based on disability and work history, while others depend on financial need and have strict income and asset limits. Because of this, it is important to plan carefully. Knowing how these programs work and how to protect your child's eligibility will help ensure long-term security and support.

PUBLIC BENEFITS AT A GLANCE	
Paid Benefits (Income Support)	
Social Security Disability Insurance (SSDI) provides cash benefits to replace some of the income you can no longer earn due to disability. You must have sufficient work history (or have a parent with sufficient work history for minors) and meet disability criteria to be entitled to these benefits.	**Supplemental Security Income** (SSI) provides cash benefits to assist people who are poor, elderly, blind, and/or disabled who have limited means. You do not need to have a work history to qualify, but you must have little or no income and resources. For children under the age of 18, benefits are based off their parent(s)' income and resources.
Healthcare (Health Insurance)	
Medicare is a US federal health insurance program for people aged 65+ and those with certain disabilities. Someone living with DM doesn't automatically qualify for Medicare. They must receive Social Security Disability Insurance (SSDI) benefits for 24 months to be eligible, and then, generally, they will be automatically enrolled[6].	**Medicaid** is a joint US federal and state program that helps cover medical costs for people with limited income and resources[7]. In many states, children who get SSI qualify automatically for Medicaid. Medicaid waiver programs help people who need a higher level of support receive home and community-based services (HCBS), like healthcare and daily living assistance. In some states, waivers allow kids to receive Medicaid regardless of parents' income. Each state has its own rules about who qualifies. You can contact your state's Medicaid office to find out if you qualify. *Note: You can have both Medicaid and Medicare at the same time. This is known as "Dual Eligibility".*

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[6] "Medicare Coverage for People with Disabilities." Center for Medicare Advocacy. Accessed October 2025. ***medicareadvocacy.org/medicare-info/medicare-coverage-for-people-with-disabilities/#is%20available***

[7] "What's the Difference between Medicare and Medicaid?" Department of Health and Human Services, December 8, 2022. ***www.hhs.gov/answers/medicare-and-medicaid/what-is-the-difference-between-medicare-medicaid/index.html.***

LOOKING FOR INFORMATION ABOUT APPLYING FOR SOCIAL SECURITY DISABILITY BENEFITS?

Check out MDF's *Social Security Toolkit* or *past conference session* about Social Security administration benefits.

SCAN TO ACCESS

MDF's Social Security Toolkit

SCAN TO VIEW

the past conference session

A child (under age 18) may be able to get Social Security benefits if their parent is retired or disabled and entitled to social security benefits OR has died after working and paying Social Security taxes. To qualify, the child must be single and:

- under age 18, or
- 18 to 19 and still in high school, or
- 18 or older with a disability that started before age 22.

Once your child turns 18, they can apply for benefits. **Applying at this stage is very important because it shows Social Security that their disability began before age 22**. Your child will need a bank account in their own name to receive SSI benefits as an adult. If your child is not able to apply or handle their own money, you can apply to be their "representative payee." This means you would receive and manage their benefits for them.

SCAN TO VISIT Medicaid's contact website

Your young adult living with CDM may benefit from Home and Community-Based Service (HCBS) Waivers which are state-run Medicaid programs that help individuals receive care in their homes and communities. This care may include case management, therapies, day programs, adult day care, in-home assistance with activities of daily life, home modifications for accessibility and safety, and more[8]. To learn more about this service and apply, you can reach out to your local Medicaid office by using the *"Contact Your State Medicaid Agency"* tool on this official Medicaid.gov website.

Some benefit programs have strict income and asset limits which vary by state, so it is important to understand what benefits your child may be receiving and plan carefully. For example, if your child has Supplemental Security Income (SSI) or is on Medicaid and you leave an inheritance directly to them, it could mean they exceed the asset limit in your state and would lose their SSI and/or Medicaid coverage (*Note*: Social Security Disability Insurance (SSDI) and Medicare are not income and resource dependent). The next section on financial security will discuss potential inheritance options that protect your child's benefits.

As of 2017, CDM is on the Social Security Administration (SSA)'s **Compassionate Allowance List** (CAL). The Compassionate Allowances initiative helps the SSA quickly identify conditions that always meet Social Security disability standards. This is not a separate program from SSDI or SSI but instead moves applicants with a condition on the Compassionate Allowance List to the front of the line for a disability decision. When you apply for benefits for your child, be sure to include the name "congenital myotonic dystrophy" where it asks for your CAL allegation/condition so your application can be fast tracked.

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[8] "Home & Community-Based Services 1915(c)"." Medicaid.gov. Accessed January 2026. ***www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c.***

PLANNING FOR BENEFITS CHECKLIST

- Review eligibility for Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). You can work with a social security disability attorney, utilize resources on the Social Security Administration's website ***SSI***, ***SSDI***, and/or utilize the ***Patient Advocate Foundation***, a non-profit with dedicated case managers that can help you access benefits. Remember that CDM receives priority review as it is on the Compassionate Allowance List.
- Understand income and asset limits for SSI. Generally, countable assets (such as cash, bank accounts, stocks, and land) must be less than $2,000 at the time of application[9]. Once you've been approved, the Social Security Administration will review your eligibility every 1 to 6 years, or when you report a change that affects eligibility (such as marriage)[10]. If your child has both Medicare and Medicaid (dual eligibility) income and asset limits may be higher[11].
- Work with your child when they turn 18 to apply for benefits. This is important to establish a disability record before age 22.
  - If your child cannot apply for or manage their benefits on their own, you will need to apply to be appointed as your child's representative payee before starting the benefits application process.
  - Be sure to list congenital myotonic dystrophy as the Compassionate Allowance List allegation on your application.
- Avoid unintentionally disqualifying your child from benefits by leaving assets directly in their name (see "Financial Security" section for more information).

BENEFIT RESOURCES

SCAN TO VIEW

the SSA's SSI website

SCAN TO VIEW

the SSA's SSDI website

SCAN TO VIEW

the Patient Advocate Foundation's website

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[9] "SSI Spotlight on Resources." Social Security Administration. 2025. ***www.ssa.gov/ssi/spotlights/spot-resources.htm***

[10] "Redeterminations." Social Security Administration. Accessed October 2025. ***www.ssa.gov/ssi/text-redets-ussi.htm#:~:text=We%20redetermine%20eligibility%20and%20benefit,%2C%20resources%2C%20and%20living%20arrangements.***

[11] "Beneficiaries Dually Eligible for Medicare & Medicaid." Centers for Medicare & Medicaid Services. June 2024. ***www.ssa.gov/ssi/text-redets-ussi.htm#:~:text=We%20redetermine%20eligibility%20and%20benefit,%2C%20resources%2C%20and%20living%20arrangements.***

Financial Security

It is important to plan for your child's long-term financial security. Careful planning helps protect their access to public benefits while ensuring they have the resources they need throughout adulthood. This section explains the key tools families often use, including **wills, trusts (including Special Needs Trusts), and ABLE accounts.**

Will

Making a will can give you peace of mind and help prevent disagreements in your family by clearly stating what should happen to your money, property, and belongings after you pass away. A **will** is a legal document where a person (the "testator") explains who will receive their things and who will take care of any dependents (like children) after they die[12]. In most US states, a valid will must be written down, signed by the testator, notarized (officially verified by a licensed notary to confirm identity and prevent fraud), and witnessed by two people. The will should name someone as the "**executor**," who is the person responsible for making sure the instructions in the will are carried out[13]. The will usually goes through a court process called "**probate**." This process checks that the will is valid, pays any debts and taxes, and then distributes what's left to the people named in the will. There are two common types of wills:

1. **Standalone Will**: States how all property and assets should be given out.
2. **Pour-Over Will**: States that any remaining assets should be moved into a trust[14].

Trust

A **trust** is a legal arrangement where a person or financial institution (called the "**trustee**") manages money or property for someone else (the "**beneficiary**"). A **Special Needs Trust (SNT)** is a type of trust that helps support a person with disabilities without putting their government benefits at risk. With a SNT, benefits like SSI or Medicaid are not affected because the beneficiary does not directly own the money or property in the SNT. The trustee of a SNT can use the trust to pay for extra needs of the beneficiary that benefits don't cover. This can include things like respite care, transportation, home care, or dental and medical costs not paid for by Medicaid or Medicare[15]. There are two types of SNTs: **First Party SNT** and **Third Party SNT**. The differences between these types of trusts are outlined in the chart on the following page.

Achieving a Better Life Experience (ABLE) Account

An **Achieving a Better Life Experience (ABLE) Account** is a type of savings and investment account that allows individuals with disabilities and their loved ones to save and invest money which can then be used for disability-related expenses[16]. Similar to a SNT, money saved in an ABLE account doesn't affect eligibility for public benefits. ABLE accounts are, however, only available to individuals with onset of a disability before age 46 (as of January 2026). Additionally, ABLE accounts do have annual contribution limits (which vary by state), and Federal law states that after the beneficiary's death, once any remaining disability-related expenses are paid, Medicaid can take money from the ABLE account to repay itself for services it provided[17].

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[12] "Will." Legal Information Institute, July 2024. ***www.law.cornell.edu/wex/will***

[13] "Probate." Legal Information Institute, September 2025. ***www.law.cornell.edu/wex/probate***

[14] "Pour Over Will." Legal Information Institute, July 2020. ***www.law.cornell.edu/wex/pour-over_will***

[15] "Your Special Needs Trust ('SNT') Defined." Special Needs Alliance, May 6, 2024. ***www.specialneedsalliance.org/the-voice/your-special-needs-trust-snt-defined-2/.***

[16] "Able Accounts - Tax Benefit for People with Disabilities." Internal Revenue Service. Accessed September 16, 2025. ***www.irs.gov/government-entities/federal-state-local-governments/able-accounts-tax-benefit-for-people-with-disabilities***

[17] "Able Account vs Special Needs Trusts." Special Needs Trusts and Estate Plans, April 17, 2022. ***www.specialneedstrustsonline.com/2022/04/17/able-account-vs-special-needs-trusts/***

TWO TYPES OF SPECIAL NEEDS TRUSTS (SNT)

	First Party SNT	**Third Party SNT**
Who funds it?	The person with a disability (e.g., from an inheritance or lawsuit settlement)	Someone else, like a parent, grandparent, or other family member
Ownership of assets	Belong to the beneficiary before being placed in the trust	Belong to someone other than the beneficiary
Medicaid payback	Yes. If the beneficiary dies or the trust is terminated, leftover money must be used to reimburse Medicaid	No. Medicaid does not have to be paid back. The individual creating the trust decides how leftover money is used if the beneficiary dies
Who decides what happens to leftover funds?	Medicaid rules apply (after payback, any remaining funds may follow other instructions)	The person who set up the trust decides where the remaining money goes
Purpose	Protects benefits while using the beneficiary's own money	Protects benefits while using other people's money to support the beneficiary

LETTERS OF INTENT

A **Letter of Intent** is a non-legally binding document that conveys your wishes, values, and practical instructions about the care of your child. It's not a replacement for legal documents (like wills or trusts), but it does address day-to-day concerns and personal preferences. A Letter of Intent can include details about:

- Your child's daily routines.
- Medical and educational needs.
- Religious or cultural practices you want upheld.

A Letter of Intent can provide specific guidance and reassurance that your priorities and values are made clear[18].

FINANCIAL SECURITY CHECKLIST

- Meet with an estate planning and elder law attorney to help you create your will and discuss financial planning options for you and your family.
- Establish a will – make sure to address the inheritance of your child living with CDM so that receiving funds doesn't impact their benefit eligibility.
    - One way to protect inheritance funds for a child on public benefits is to create a SNT and ensure any inheritance goes into the trust as opposed to directly to your child. Talk to your lawyer to see if establishing a SNT and/or ABLE account would be a good fit for you and your child.
- Review life insurance or other financial planning tools with your attorney.

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[18] "What is a Letter of Intent?" Clarity Legal Group, February 6, 2025, ***www.claritylegalgroup.com/what-is-a-letter-of-intent-why-every-parent-needs-one/***

Overall Age-Based Checklist

16

Age 16: Develop a healthcare transition plan that is updated throughout your child's teenage years. Ask your pediatric provider about extended care to determine at what age your child's care will transition to adult care.

Age 16 (or earlier in some states): Work with your IEP team to create a transition plan focused on your child's educational transition into adulthood.

17

Age 17: Begin the process of exploring legal decision-making options.

18

Age 18: Your child can apply for Social Security benefits (when your child is under age 18, SSI benefits are based off of parent(s)' income and resources). Applying at this stage is very important because it shows Social Security that their disability began before age 22.

Age 18: Obtain a HIPAA release form that allows healthcare teams to share your child's medical information with you.

21

Age 21 (or earlier/later in some states): Your child ages out of IDEA support.

SCAN TO LEARN about MDF's CDM Caregivers Support Group

Your young adult affected by CDM's transition to adulthood can feel daunting, but you do not have to navigate it alone. Talking with other parents who have already navigated these processes and starting the process early can help you feel supported and less overwhelmed. MDF's ***Caregivers of Children with CDM Support Group*** is a great place to connect with other families, ask questions, and learn from their experiences.

While every family's journey is different, planning ahead helps create a foundation of security, independence, and care for your child. With the right support and resources, you can move into this new chapter with hope and confidence for your child's future.

The mission of the Myotonic Dystrophy Foundation is Community, Care, and a Cure.

We support and connect the myotonic dystrophy **community**.
We provide resources and advocate for **care**.
We accelerate research toward treatments and a **cure**.

Myotonic Dystrophy
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