RYAN & ASSOCIATES

Planning for a Child with Special Needs

A practical guide for building a secure, supported future

FAMILY PLANNING GUIDE

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BEGIN WITH THE FUTURE

Planning protects more than money

Families often begin with one difficult question: “What will happen when I am no longer able to provide care?” A coordinated plan turns that concern into clear assignments, documents, funding, and next steps.

1. Understand	Abilities, support needs, health, education, housing, relationships, and the individual's own preferences.
2. Document	A will, letter of intent, powers of attorney or supported-decision documents, health directives, and benefit records.
3. Protect	Special needs trust and ABLE-account decisions designed to avoid unintended harm to means-tested benefits.
4. Fund	Savings, investments, retirement assets, life insurance, public benefits, and other resources coordinated with the legal plan.
5. Review	Update the plan as needs, laws, programs, caregivers, trustees, and family circumstances change.

Use a team

Special-needs planning often involves an attorney experienced in disability and estate planning, a benefits specialist, medical and education professionals, a tax professional, and an insurance or financial professional. Each role is different.

LEGAL FOUNDATION

Documents that carry the plan forward

Legal planning should preserve eligibility, identify decision-makers, and describe how assets and care responsibilities will be managed. State law controls many details.

Will	Directs estate administration and can nominate a guardian for a minor. Avoid leaving assets directly to a beneficiary when doing so could disrupt means-tested benefits.
Guardian or conservator	May be considered when an adult cannot make some or all decisions. Limited arrangements and less restrictive alternatives should also be discussed with counsel.
Special needs trust	Can hold and manage assets for supplemental needs while helping preserve access to qualifying benefits when properly drafted and administered.
Power of attorney	Allows an adult who has legal capacity to authorize another person to handle specified financial or legal matters.
Health-care documents	May include a health-care power, advance directive, HIPAA authorization, and supported decision-making documents where available.
Beneficiary designations	Retirement plans, insurance, annuities, payable-on-death accounts, and other transfers must align with the trust and estate plan.

Important

Do not rely on generic forms or beneficiary language. Have an attorney who regularly works with special-needs families coordinate the documents and ownership structure.

SPECIAL NEEDS TRUST

Protecting benefits while improving quality of life

A properly structured trust may hold resources for a person with a disability without placing those assets directly in the individual's name. Trust type, source of funds, payback rules, and distributions matter.

Planning point	Questions to resolve
Trust type	Is this a third-party trust funded by family assets, or a first-party trust funded with the beneficiary's own assets?
Trustee	Who can manage investments, records, taxes, distributions, vendors, and benefit coordination over many years?
Distribution standard	Which supplemental needs may the trustee pay, and how can payments affect SSI, Medicaid, housing, or other benefits?
Funding	Which assets, accounts, gifts, inheritances, and insurance benefits will flow to the trust?
Successors	Who serves if the original trustee, guardian, care manager, or advocate cannot continue?
Family communication	Do grandparents and other relatives know not to leave assets directly to the beneficiary without professional review?

Trust resources may potentially support items such as education, transportation, equipment, therapies, companions, recreation, insurance premiums, and other quality-of-life needs, subject to the trust document and benefit rules.

ABLE ACCOUNTS

A flexible tool for qualified disability expenses

An ABLE account is a tax-advantaged account owned by an eligible individual with a disability. It can complement, but does not replace, a special needs trust.

Eligibility update	Beginning in 2026, the disability or blindness must have begun before age 46, replacing the former before-age-26 rule.
Tax treatment	Contributions use after-tax dollars. Earnings and withdrawals for qualified disability expenses are generally federal income-tax free.
Qualified expenses	May include education, housing, transportation, employment support, assistive technology, health, legal fees, financial management, and other qualifying disability-related expenses.
Benefit interaction	ABLE balances and distributions receive special treatment for federal means-tested benefits. SSI treatment changes when an account exceeds $100,000.
Contribution rules	Annual and additional working-beneficiary limits can change. Confirm the current limit with the plan or a tax professional.
Estate recovery	After the beneficiary dies, state Medicaid recovery rules may apply to remaining funds, depending on applicable law and expenses.

Trust or ABLE account?

They serve different purposes. An ABLE account can provide practical spending flexibility, while a special needs trust may manage larger family resources and long-term distributions. Professional coordination is essential.

HEALTH AND PUBLIC BENEFITS

Build a benefits file before a crisis

Medical coverage, therapies, equipment, prescriptions, case management, and public-benefit eligibility should be documented in one organized record.

- Confirm specialists, facilities, therapies, equipment, prescriptions, prior-authorization rules, and appeal rights under private coverage.
- Ask whether an insurer or medical group can assign a case manager familiar with the individual's diagnoses and ongoing needs.
- Review dependent-coverage rules before age 26 and ask whether coverage can continue for an adult disabled dependent under the specific plan.
- At age 18, review SSI and Medicaid eligibility using the individual's own income and resources, subject to program rules.
- Maintain copies of benefit awards, denials, renewals, notices, identification numbers, medical summaries, and representative-payee information.
- Coordinate trust and ABLE distributions with a qualified benefits specialist before paying housing, food, or cash directly.

Avoid outdated assumptions

Program eligibility and interaction rules are detailed and may change. Confirm current SSI, Medicaid, Medicare, waiver, housing, and state-program rules before transferring assets or changing how expenses are paid.

A concise medical summary should include

Diagnosis and functional needs	Current clinicians and pharmacies
Medications and allergies	Therapies and equipment
Emergency and communication needs	Insurance and authorization contacts

EDUCATION AND TRANSITION

Plan for today and adulthood

IDEA supports eligible children through early intervention and special education. Transition planning should begin well before the student exits the public-school system.

Birth through age 2	IDEA Part C supports early-intervention services for eligible infants and toddlers and their families.
Ages 3 through 21	IDEA Part B makes a free appropriate public education available to eligible children and youth, subject to federal and state rules.
IEP	The individualized education program describes current performance, goals, services, supports, placement, and progress measurement.
Parent participation	Parents have rights to records, meetings, evaluations, notice, mediation, complaints, and due process under IDEA.
Transition	The plan may address further education, employment, independent living, transportation, benefits, health care, and community participation.
After school	Identify adult-service systems, vocational supports, college accommodations, regional resources, and waiting lists years before graduation.

FUNDING THE PLAN

Match resources to future needs

A legal plan without funding may not meet the family's goals. Estimate the gap, identify which resources arrive during life and at death, and make ownership and beneficiary designations consistent.

Savings and investments	Flexible resources for near-term or long-term needs; ownership and beneficiary designations affect benefit planning.
Retirement accounts	Require coordinated beneficiary and distribution planning. Naming an individual or trust can have different tax and benefit consequences.
Life insurance	Can create a known death benefit to help fund a properly drafted trust when a parent or caregiver dies.
Family gifts and inheritances	Relatives should coordinate gifts and estate plans so assets do not pass directly to the beneficiary unintentionally.
Public benefits	May provide income, health coverage, housing, employment, or support services, but should not be assumed to cover every need.
ABLE account	Can support eligible disability expenses with flexible access, within applicable eligibility and contribution rules.

Estimate the gap

Project essential support, housing, health, transportation, advocacy, recreation, equipment, and care-coordination costs. Then subtract dependable income and public benefits to identify the amount the family may need to fund.

LETTER OF INTENT

Write down what only your family knows

A letter of intent is usually not legally binding, but it can become the practical operating manual for future caregivers, trustees, guardians, advocates, and family members.

Profile	Name, preferred name, birth information, communication style, strengths, preferences, routines, and important relationships
Medical	Diagnoses, medications, allergies, clinicians, therapies, equipment, emergency instructions, and record location
Daily life	Bathing, dressing, eating, money management, transportation, behavior supports, sensory needs, and safety
Home and community	Preferred living setting, roommates, neighborhood, faith community, recreation, employment, and transportation
Education and work	Programs completed, skills, accommodations, goals, workplace supports, and important contacts
Financial and legal	Benefits, insurance, trust, ABLE account, trustee, guardian, agents, advisors, and key documents
Care preferences	What creates comfort or distress, successful routines, food preferences, celebrations, and quality-of-life priorities

Keep it current

Review the letter at least annually and after major health, education, housing, employment, caregiver, or legal changes. Tell the planning team where the current version is stored.

FAMILY WORKSHEET 1

The individual and daily life

Use these prompts to prepare for conversations with your legal, benefits, education, medical, insurance, and financial professionals.

Name and date of birth

Primary diagnoses or disabilities

Strengths, interests, preferences, and important relationships

Communication style and decision-making abilities

Daily-living capabilities and support needs

Medical needs, medications, therapies, equipment, and emergency instructions

Current living arrangement and preferred future arrangement

FAMILY WORKSHEET 2

Benefits, legal documents, and resources

Record what exists today and identify missing information or documents.

Topic	Current status / follow-up
SSI, SSDI, Medicaid, Medicare, waiver, housing, or other benefits	
Will, trust, guardian or conservator, power of attorney, health documents	
Trustee, successor trustee, guardian, agents, advocates, and care coordinator	
ABLE account and assets held in the individual's name	
Life insurance, retirement accounts, investments, property, and beneficiary designations	
Education, vocational, employment, and transition services	
Monthly income and projected expenses	

Questions and next actions

Which professional or agency needs to be contacted first?

What must be completed in the next 30, 90, and 365 days?

YOUR NEXT STEP

Build the team, then coordinate the plan

The most valuable first meeting is often a discovery conversation: what exists, what is missing, which risks matter most, and which professional should act next.

- Gather current benefit notices, insurance statements, account statements, estate documents, school records, and medical summaries.
- List every person and organization involved in care, education, benefits, housing, employment, legal work, and finances.
- Schedule a review with an attorney experienced in special-needs planning before changing ownership or beneficiaries.
- Confirm current benefit and ABLE rules with qualified specialists.
- Create or update the letter of intent and tell successors where it is stored.
- Review the plan annually and whenever life changes.

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Current reference points: Social Security Administration ABLE guidance (2026); U.S. Department of Education IDEA resources; Medicaid.gov special-needs trust guidance. Source guide provided by the client and updated for the 2026 ABLE eligibility expansion.

Disclosure: This guide is educational and does not provide legal, tax, investment, benefits, medical, or individualized insurance advice. Laws and program rules vary by state and change over time. Consult qualified attorneys, tax professionals, benefits specialists, medical and education professionals, and appropriately licensed insurance or financial professionals before acting.