

A GUIDE TO CARING FOR SOMEONE WITH A DISABILITY

EMPOWERING FAMILIES - NURTURING FUTURES





CLIENT INFORMATION FORM

Today's Date: _____

Client's First Name: _____

Last Name: _____

Date of Birth: _____

Gender: _____

Diagnosis: _____

Primary Caregiver Information

First Name: _____

Last Name: _____

Email: _____

Cell #: _____

Relationship to Client: _____

Other Responsible Party

First Name: _____

Last Name: _____

Email: _____

Cell #: _____

Relationship to Client: _____

Permission is hereby granted for the above information to be shared between Parenting Special Kids Network and Pathways For Life solely as needed to best serve the Client. This information should be disclosed only to relevant personnel involved in the Client's care and must remain confidential in accordance with applicable privacy policies and regulations.



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WHAT IS PSKNETWORK?

OUR MISSION

Our mission is to create a nurturing and empowering community where parents and caregivers of children with disabilities, of all ages, find support, access to resources, and personalized assistance to ensure their children receive the services they need to thrive.

OUR VISION

We strive to cultivate an environment where every caregiver feels empowered to advocate for their child's unique needs and aspirations, ensuring they receive the necessary services and opportunities to thrive and reach their fullest potential.

ABOUT US

Parenting Special Kids Network was founded by Jeff Thibault, a husband, father of four, and passionate advocate for people raising children with disabilities. Jeff and his wife, Debbie, have firsthand experience navigating life with their daughter, who has an intellectual disability and an anxiety disorder.

With over 35 years of leadership and family ministry experience, Jeff is dedicated to supporting parents and caregivers who may feel overwhelmed, uncertain, or alone in their journey..

Caring for a child with an intellectual or developmental disability comes with unique challenges—but every child has purpose, and no one should walk this road alone. That's why Parenting Special Kids Network exists: to guide, support, and walk alongside families every step of the way.





RESOURCE & SERVICE NEEDS ASSESSMENT

Services	Got it	Need it
AHCCCS	<input type="checkbox"/>	<input type="checkbox"/>
ALTCS	<input type="checkbox"/>	<input type="checkbox"/>
AzEIP	<input type="checkbox"/>	<input type="checkbox"/>
ESA Funds	<input type="checkbox"/>	<input type="checkbox"/>
DDD	<input type="checkbox"/>	<input type="checkbox"/>
SSI or SSDI	<input type="checkbox"/>	<input type="checkbox"/>
Special Needs Trust	<input type="checkbox"/>	<input type="checkbox"/>
Letter of Intent	<input type="checkbox"/>	<input type="checkbox"/>
ABLE Account	<input type="checkbox"/>	<input type="checkbox"/>
DAC	<input type="checkbox"/>	<input type="checkbox"/>
Survivor Benefits	<input type="checkbox"/>	<input type="checkbox"/>
Guardianship or Power of Attorney	<input type="checkbox"/>	<input type="checkbox"/>
Special Needs Attorney	<input type="checkbox"/>	<input type="checkbox"/>
Employment	<input type="checkbox"/>	<input type="checkbox"/>
Transportation	<input type="checkbox"/>	<input type="checkbox"/>
Long Term Housing	<input type="checkbox"/>	<input type="checkbox"/>
Profession Financial Planner	<input type="checkbox"/>	<input type="checkbox"/>
My End-of-Life Plan	<input type="checkbox"/>	<input type="checkbox"/>



QUESTIONS OR CONCERNS?

After reviewing the list on the previous page, what concerns or questions do you have about your child's future?

A large, empty rectangular box with a light blue border, intended for writing notes or concerns. A light blue exclamation mark and question mark (!?) are positioned in the bottom right corner of the box.A large, empty rectangular box with a light blue border, intended for writing notes or concerns. A light blue exclamation mark and question mark (!?) are positioned in the bottom right corner of the box.A large, empty rectangular box with a light blue border, intended for writing notes or concerns. A light blue exclamation mark and question mark (!?) are positioned in the bottom right corner of the box.A large, empty rectangular box with a light blue border, intended for writing notes or concerns. A light blue exclamation mark and question mark (!?) are positioned in the bottom right corner of the box.



ARIZONA SERVICES

AHCCCS

The Arizona Health Care Cost Containment System is the state's Medicaid program, providing healthcare coverage to low-income individuals and people with qualifying disabilities. Learn more at www.azahcccs.gov

DDD

The Division of Developmental Disabilities empowers individuals with qualifying developmental disabilities to lead healthy, self-directed, and meaningful lives. Learn more at www.des.az.gov/ddd

AzEIP

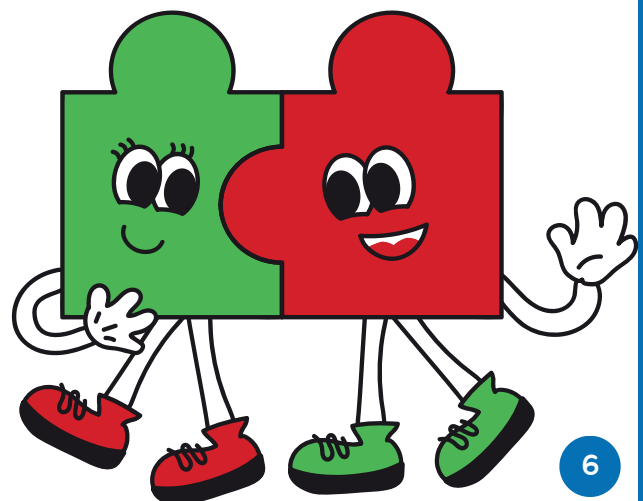
The Arizona Early Intervention Program provides services and support for infants and toddlers (birth to age two) with disabilities or developmental delays and their families. These services help families and caregivers support the child's growth and development. Learn more at www.des.az.gov

ESA

The Empowerment Scholarship Account is a state-funded program in Arizona that allows eligible students to use public education funds for learning options outside the traditional public school system. Learn more at www.azed.gov/esa

ALTCS

The Arizona Long Term Care System provides Medicaid long-term care for individuals who are elderly, physically disabled, or developmentally disabled and require nursing-level care, which can be delivered at home or in community-based settings. Learn more at www.azahcccs.gov/altcs





AZ SERVICES TO DO LIST

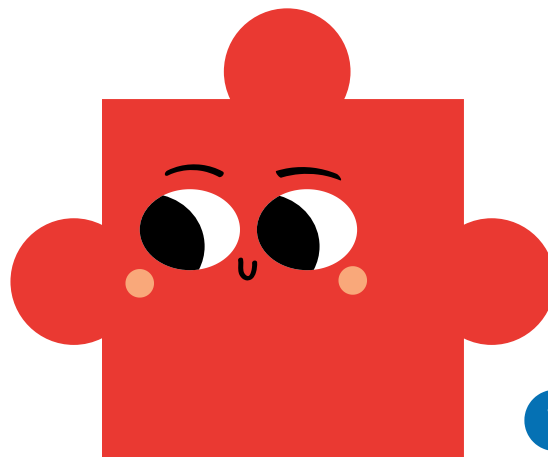
AHCCCS

DDD

AZEIP

ESA

ALTCS





FEDERAL BENEFITS

DAC

Disabled Adult Child benefits provide Social Security payments to adults whose disability began before age 22, based on a parent's Social Security record. This helps adults with lifelong disabilities receive income and health coverage, even if they have never worked.

Learn more at www.ssa.gov/family

SSI

Supplemental Security Income is a federal program that provides monthly cash payments to adults who are 65 or older, or to people who are blind or have a disability, and who have limited income and resources.

Learn more at www.ssa.gov/ssi

SSDI

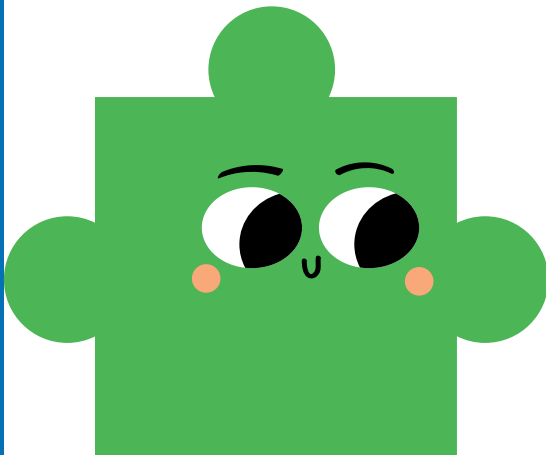
Social Security Disability Insurance is a federal program that provides monthly cash benefits to people who cannot work due to a qualifying disability and who have paid into Social Security through payroll taxes.

Learn more at www.ssa.gov/disability

Survivor Benefits

Social Security Survivor Benefits provide monthly financial support to spouses, dependent children, and dependent parents of a worker who has passed away. The benefit amount depends on the worker's earnings and the survivor's age and relationship to the worker.

Learn more at www.ssa.gov/benefits/survivors





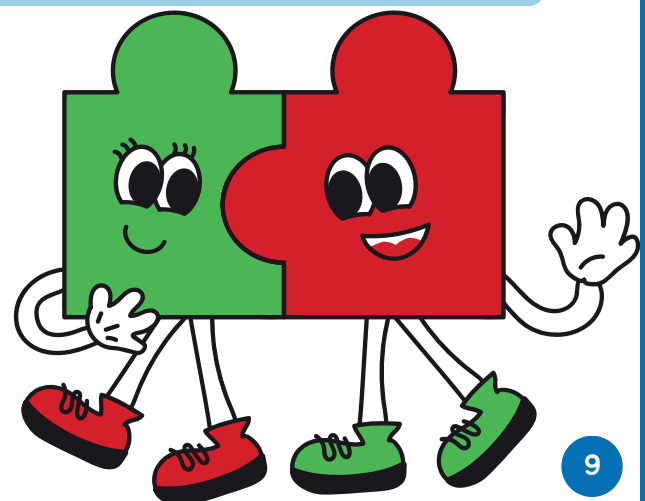
FEDERAL BENEFITS TO DO LIST

DAC

SSI

SSDI

Survivor Benefits

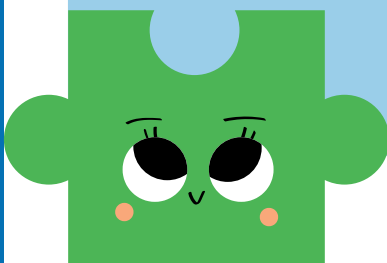




SPECIAL NEEDS TRUST

Special Needs Trusts (SNTs) are legal tools designed to help individuals with disabilities receive financial support while maintaining eligibility for government benefits such as Supplemental Security Income (SSI) and Medicaid. There are two main types of SNTs: First-Party and Third-Party. While both serve similar purposes, they differ in funding, rules, and administration.

1st Party	3rd Party
Subject to Medicaid payback	Not subject to Medicaid payback
Court involvement	Court rarely involved
Subject to financial distribution limits set by the trust, state statute, and federal law.	Minimal restrictions on financial distributions
Subject to disclosure and ongoing requirements to federal and state benefit agencies upon funding and distributions.	Subject to disclosure upon funding
Subject to being audited by agencies	Occasionally audited by agencies
A First-Party Special Needs Trust is useful for a person with a disability who receives government benefits and is about to receive funds, such as from a legal settlement. It safeguards their benefits, but establishing and managing it can be complicated. Consulting with an experienced attorney is critical. Learn more at www.specialneedsalliance.org	A Third-Party Special Needs Trust is an effective way to provide a gift or inheritance to a loved one with disabilities without impacting their benefits. It preserves their support while allowing the trust creator to determine where any remaining funds go after the beneficiary dies. Learn more at www.specialneedsalliance.org





LETTER OF INTENT

What is a Letter of Intent?

A Letter of Intent (LOI) is a non-legal document written by parents or caregivers of a person with special needs. It provides personal guidance and instructions to future caregivers, trustees, or guardians, ensuring continuity of care. While a Special Needs Trust handles finances, an LOI explains how to best care for your loved one.

Why a Letter of Intent Is Important and What to Include

Why is it Important?

- Bridges the gap between legal/financial planning and daily life.
- Captures personal details that legal documents cannot.
- Helps ensure continuity of care when caregivers or trustees change.
- Living document: should be updated regularly.

What to Include in a Letter of Intent

1. Personal & Family History
 - Background, relationships, cultural or religious values.
2. Daily Routines & Preferences
 - Sleep schedule, diet, hobbies, dislikes, communication needs.
3. Medical & Therapy Information
 - Diagnoses, medications, allergies, doctors, therapies.
4. Education & Employment
 - School history, job skills, programs, and supports.
5. Living Arrangements & Social Life
 - Housing preferences, friendships, social/religious involvement.
6. Legal & Financial Notes
 - Location of important documents, contact info for professionals.
7. Future Hopes & Goals
 - Long-term wishes, values, and vision for your loved one's life.



ABLE & 529 ACCOUNTS

ABLE accounts provide a way for individuals with disabilities to save money tax-free without risking eligibility for government benefits like SSI and Medicaid. The funds must be used for qualified disability expenses such as education, housing, and healthcare.

Eligibility is limited to those whose disability began before age 26, (limit jumps to age 46 in 2026), and opening an account is typically simple. These state-sponsored accounts can be opened regardless of your state of residence.

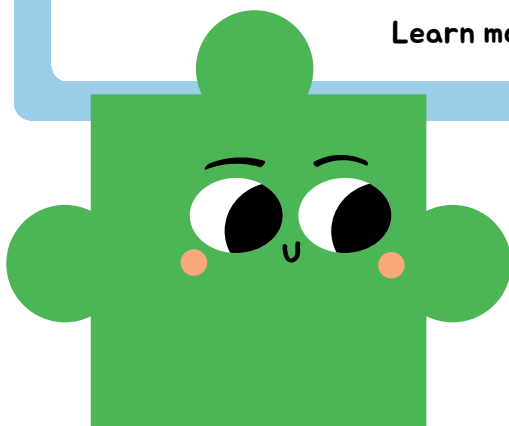
One key advantage is that ABLE account funds are excluded from federal asset tests, though there are limits—such as a \$19,000 annual contribution cap (as of 2025). Those who work can contribute an additional \$16,500. The lifetime cap is \$100,000.

It's important to note the Medicaid payback provision, which may allow states to claim remaining funds upon the beneficiary's death to cover Medicaid costs, depending on state laws.

ABLE accounts can complement Special Needs Trusts and offer a flexible way for loved ones to contribute financially. Families should carefully weigh the benefits and limitations as part of their broader special needs planning strategy.

Funds from a 529 education savings plan can be rolled over into an ABLE account without taxes or penalties, provided the ABLE account belongs to the same beneficiary or an eligible family member. The rollover amount, combined with other contributions, must remain within the ABLE account's annual contribution limit.

Learn more at www.irs.gov/ableaccounts





IS GUARDIANSHIP THE BEST OPTION?

GUARDIANSHIP

- Who Decides? Court-appointed guardian
- Covers: Personal and healthcare decisions (living arrangements, daily care, medical treatment)
- Court Involvement: Yes – requires a court order and oversight
- Independence: Low – most personal rights are transferred to the guardian
- Ends When: The court terminates guardianship or the individual regains capacity

CONSERVATORSHIP

- Who Decides? Court-appointed conservator
- Covers: Financial management (income, property, bills, investments)
- Court Involvement: Yes – requires a court order and oversight
- Independence: Low – the conservator controls financial matters
- Ends When: The court ends the conservatorship or the individual regains capacity

LIMITED GUARDIANSHIP

- Who Decides? Guardian, but with restricted powers
- Covers: Only specific areas such as housing or medical care, as ordered by the court
- Court Involvement: Yes – but scope is narrower than full guardianship
- Independence: Medium – the individual keeps rights not granted to the guardian
- Ends When: The court modifies or ends the guardianship

SUPPORTED DECISION-MAKING

- Who Decides? The individual, with guidance from chosen supporters
- Covers: Any personal, medical, or financial decision where assistance is helpful
- Court Involvement: No – voluntary agreement
- Independence: High – all rights remain with the individual
- Ends When: The individual chooses to end the agreement

POWER OF ATTORNEY (POA)

- Who Decides? An 'agent' chosen by the individual
- Covers: Healthcare (Healthcare POA) or financial matters (Financial POA)
- Court Involvement: No – established through a legal document, not court
- Independence: High – the individual voluntarily delegates authority
- Ends When: Revoked by the individual, or ends if they lose capacity (unless durable POA)



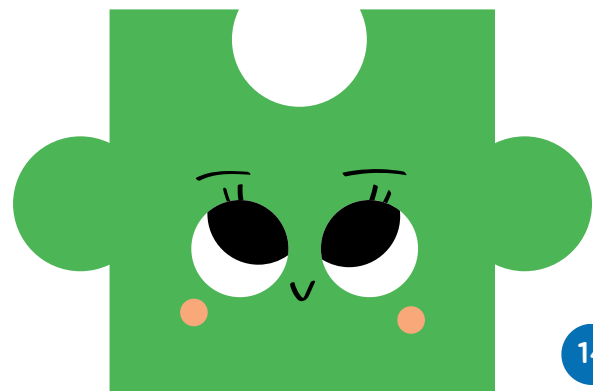
LEGAL TO DO LIST

ABLE Account

Guardianship/POA

Letter of Intent

Special Needs Trust





LONG TERM PLANNING

LEGAL & BENEFITS PLANNING

- Explore Guardianship, Powers of Attorney & Alternatives
- Work with a Special Needs Attorney
- Understand Federal & State Disability Laws
- Keep Organized Records

ESTATE & TRUST PLANNING

- Create or Update a Will and Special Needs Trust
- Review Legal Documents Annually
- Ensure Proper Funding of Trust(s)
- Coordinate with Public Benefits

EDUCATION & TRANSITION PLANNING

- Plan for Education Beyond High School (College, Vocational, Community Programs)
- Review & Update the IEP or 504 Plan
- Explore Empowerment Scholarship Accounts (ESA) & Other Funding Options
- Keep Comprehensive Education Records
- Participate in Community & Online Learning
- Connect with Local Resource Centers & Peer Groups

COMMUNITY & INDEPENDENT LIVING

- Explore Employment & Day Programs
- Plan for Housing & Residential Supports
- Include Succession Planning for Ongoing Care

FINANCIAL PLANNING

- Create Short & Long-Term Budgets
- Evaluate Insurance Policies (life, health, long-term care)
- Consult a Financial Advisor
- Review Plans Annually

SUPPORT NETWORK

- Identify Advocacy & Support Groups
- Engage Family & Friends
- Build a Team of Legal & Financial Professionals
- Connect with Service Providers & Care Coordinators

OTHER NEEDS & GOALS

- Write a Letter of Intent for Caregivers & Trustees
- Complete a Service Needs Assessment (Page 4 of this guide)
- Document Medical, Health, & Support Needs
- Define Family Goals & Long-Term Vision



LONG TERM PLANNING QUESTIONS OR CONCERNS



THANK YOU

Disclaimer

This Guide is intended to provide general information about special needs, available resources, and related topics. The content within is not, and should not be construed as, legal advice. This Guide does not establish a formal relationship between you and Parenting Special Kids Network or any of its representatives. Laws, regulations, and best practices related to planning are subject to change, and the information presented here may not reflect the most current legal developments. Every individual's situation is unique; therefore, you should consult with a qualified estate or special needs attorney for advice tailored to your specific circumstances before making any decisions that may affect your legal rights or obligations.

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Acknowledgments

This guide is the intellectual property of Jeff D. Thibault and has been made available through the Parenting Special Kids Network.

Special thanks to Emily R. Taylor, Attorney PLLC, (www.emilyrtaylor.com), whose work inspired this resource; to Makaela Lehmeier for her creative design contributions; and to Pathways for Life for printing support (www.pathwaysforlife.care).



Pay It Forward

There is no charge for our services, as all operating expenses are covered by donations from generous families and grants from organizations. If you have benefited from our services and would like to help another family, please visit our website to make a 'pay it forward' donation. In addition, PSKN is an Arizona Qualifying Charitable Organization, and donations may qualify for a dollar-for-dollar state tax credit.

PSKNetwork Contact Information



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