

From Supplemental to Essential: When the Special Needs Trust Becomes the Safety Net

Tara Anne Pleat, Esq., CELA

I. Introduction

For decades, the basic premise of special needs trust planning has been reflected in the name of the trust itself. A supplemental needs trust is intended to supplement, rather than supplant, publicly funded benefits and services available to an individual with a disability. Public benefits provide the foundation. Private trust assets add to that foundation by paying for the things that government programs do not provide.

That remains an important legal construct. Increasingly, however, it is an incomplete description of the world in which these trusts are being administered.

Families planning for loved ones with disabilities are confronting a service-delivery system that is under significant strain. Home- and community-based services may be authorized but unavailable. Residential programs may exist but have no openings. Approved direct-support hours may go unfilled because an agency cannot recruit or retain workers. Care coordination may technically be part of a Medicaid-funded service package but be spread among professionals carrying workloads that do not permit individualized oversight. Families may spend years on waiting lists for waiver services while parents and siblings continue to provide the care that the public system is expected eventually to assume.

This is not merely a question of government spending. It is a question of capacity.

Care requires people. People must be available, trained, supported and paid; and ideally not exhausted. A legislature can authorize a program. An agency can approve a service. A court can recognize a right. None of those actions, standing alone, creates an available caregiver at two o'clock in the morning on a Saturday.

That distinction has become increasingly important for special needs planners.

In 2025, forty-one states maintained waiting or interest lists for Medicaid home- and community-based services, and more than 600,000 individuals appeared on those lists.ⁱ The figures are imperfect because states use different methodologies and many do not determine full program eligibility before placing an individual on a list. They nevertheless illustrate a basic problem: legal entitlement and practical access are not the same thing. In 2025, individuals on these lists waited an average of thirty-two months for services, while individuals with intellectual and developmental disabilities waited an average of thirty-seven months.ⁱⁱ

The workforce statistics tell the same story from another direction. In its 2025 survey of 469 organizations providing community-based services to people with intellectual and

developmental disabilities, ANCOR reported that 88 percent experienced moderate or severe staffing shortages. Sixty-two percent turned away new referrals because they did not have sufficient staff, 29 percent discontinued programs or services, and more than half operated in communities where few or no alternative providers offered comparable services.ⁱⁱⁱ The Medicaid and CHIP Payment and Access Commission has likewise identified persistent workforce shortages as a significant obstacle to the delivery of home- and community-based services, noting annual turnover rates among HCBS workers of approximately 40 to 60 percent.^{iv}

For families, those numbers translate into something far more personal. A service that cannot be staffed is not a service. An approved residential program without an available bed is not housing. An authorization for forty hours of support that can be staffed for only twenty-five hours is not forty hours of support.

The traditional planning model assumes that the public system provides a floor and the special needs trust builds upon it. In some communities and for some beneficiaries, that floor is increasingly unstable.

The consequence is that the trust may no longer be asked simply to purchase the traditional “extras.” It may be required to pay for private caregivers, care management, housing, transportation, advocacy, technology, therapy, household assistance and other supports that are essential to the beneficiary's ability to remain safe and engaged in the community.

The supplemental needs trust may therefore become something considerably more important.

It may become the beneficiary's financial safety net.

Recognizing that reality is not an argument against Medicaid. It is not an argument against public benefits, community integration, increased funding, or advocacy. Medicaid is foundational to the long-term support system for individuals with disabilities in the United States, and preserving access to it will remain central to special needs planning.

But we cannot responsibly plan for a system we wish existed rather than the system families actually encounter.

The planning objective cannot simply be preservation of benefits. The objective is to construct the most stable and sustainable life possible for the beneficiary by coordinating all available resources: public benefits, private funds, family and community supports, technology and professional assistance.

Public benefits are an essential part of that plan.

They are not the plan itself.

II. The Widening Gap Between Expectation and Capacity

The challenge facing long-term-care and disability systems is sometimes described as a funding problem. Funding unquestionably matters, but that description is incomplete.

It is also a capacity problem.

The United States is attempting to deliver increasingly individualized, labor-intensive care in home and community settings at precisely the same time that demand for those services is increasing and the workforce available to provide them remains inadequate.

That tension did not emerge overnight. Over the last several decades, disability policy has appropriately moved away from large institutional models and toward community integration, autonomy and person-centered services. The Supreme Court's decision in *Olmstead v. L.C.* recognized that unjustified segregation of individuals with disabilities constitutes discrimination under Title II of the Americans with Disabilities Act and reinforced the expectation that individuals should receive services in the most integrated setting appropriate to their needs.^v

That principle changed lives but it also requires infrastructure.

Community living does not eliminate the need for assistance. It changes where and how that assistance must be delivered. Instead of concentrating workers and services within an institution, a community-based system may require staff to reach individuals in homes, apartments, workplaces and day programs across a broad geographic area. It requires transportation, supervision, case management, housing, medical coordination and reliable direct-support professionals.

Person-centered care is also inherently labor intensive. The more individualized the system becomes, the more difficult it becomes to achieve economies of scale.

At the same time, more people need care.

Individuals with significant disabilities are living longer. The general population is aging. Families are smaller and more geographically dispersed. The cohort of working-age individuals available both as paid workers and as unpaid family caregivers is under increasing pressure.

Family caregiving itself has grown dramatically. AARP and the National Alliance for Caregiving estimated in 2025 that approximately 63 million Americans (roughly one in four adults) were providing ongoing care to an adult or child with a complex medical condition or disability. That represented an increase of approximately 20 million caregivers over the preceding decade.^{vi^6}

Those numbers should concern special needs planners because the formal and informal care systems are interconnected.

When formal services are unavailable, families fill the gap. When families can no longer fill the gap, formal services are asked to do more. When neither has sufficient capacity, the individual with the disability bears the consequence. This is why conversations about long-term planning cannot begin and end with eligibility. Eligibility is a legal determination, service delivery is a human one.

A beneficiary may be eligible for a Medicaid waiver and nevertheless lack an available provider. A beneficiary may qualify for residential services and remain at home with aging parents because no appropriate placement exists. A beneficiary may have a case manager but little meaningful contact because the case manager is responsible for too many individuals. A plan of care may authorize services that cannot be fully staffed.

The difference between what appears on paper and what happens in someone's home can be substantial.

For the special needs planner, three distinct questions therefore matter: whether the beneficiary is eligible for a particular support, whether that support is actually available and whether the available support is adequate.

The difference among eligibility, availability and adequacy should become part of the planning vocabulary.

It is possible to be eligible for something that is unavailable.

It is equally possible for something to be available but inadequate.

Until those distinctions are understood, the financial plan rests on an assumption rather than an assessment.

III. The Family Has Always Been Part of the Infrastructure

The strain on the formal service-delivery system exposes something else that special needs planners have always known but have not always quantified.

Families are part of the care infrastructure.

Parents of individuals with significant disabilities routinely perform an extraordinary range of functions without compensation and often without identifying what they do as "services." They coordinate medical appointments, supervise staff, manage benefits, communicate with providers, arrange transportation, purchase clothing and household items, monitor medications, maintain social connections, respond to crises and provide the historical and personal knowledge that allows everyone else to understand the beneficiary.

Those activities become so embedded in family life that they disappear from the financial plan.

A family may accurately report that its adult child receives Medicaid-funded residential or community services. That tells the planner very little about what happens when the transportation van does not arrive, a new staff person does not understand the beneficiary's communication style, the pharmacy cannot obtain a refill, or a benefits notice appears in the mail.

Who resolves those problems?

Often, it is a parent.

The importance of that contribution is difficult to overstate because it combines labor with judgment.

A paid caregiver can perform a task. A parent may know why the task matters, whether it has been performed properly and what to do when something changes.

The parent may also be the person who recognizes that the beneficiary is unusually quiet, that an apparently minor behavioral change usually precedes illness, that a particular staff member is a poor match, or that the beneficiary is agreeing to something simply because the beneficiary does not want to disappoint another person.

That knowledge is not replaced automatically when the parent dies. This is one of the places where the traditional family life cycle and the experience of a family that includes an individual with significant disabilities diverge.

In a more traditional family cycle, parents provide increasingly less support as children move toward independence. Later, the relationship may reverse as adult children assist aging parents.

When a child has significant lifelong support needs, parental responsibility may remain intense for decades. The parents themselves age, but the support obligation does not necessarily decline. Eventually, the family faces a transition that is less like handing responsibility to a successor and more like attempting to replace an entire operating system.

Families often assume that a sibling will “take care of” the person with the disability and as most planners know that phrase needs to be unpacked.

Does it mean the sibling will serve as trustee? Attend medical appointments? Monitor residential staff? Manage Medicaid recertifications? Respond to emergencies? Spend weekends providing respite? Provide transportation? Invite the sibling with the disability home for holidays? Find a replacement caregiver when the agency cannot staff a shift? Move the beneficiary into the sibling's home?

Those are profoundly different commitments, and do parents *really* want that for their typical children.

The sibling may be loving and willing while nevertheless being unable to replicate what a parent has done. The sibling may live several states away. The sibling may have children, employment, a spouse, aging parents or personal health limitations. The sibling may be capable of advocacy but uncomfortable managing money. The sibling may be an excellent trustee but unable to provide direct care.

Good planning should not depend on vague expectations of family sacrifice.

The appropriate question is not simply who will replace the parent. It is which functions the parent currently performs, which of those functions can be transferred to other family members, which can be provided through public programs and which will have to be purchased privately.

Once the question is framed that way, the importance of private financial resources becomes obvious.

IV. When “Supplemental” Starts Paying for Essential Support

Historically, planners often described special needs trust distributions by giving examples of enhancements to public benefits: travel, entertainment, computers, furniture, additional therapy, recreation, education or other expenditures that improved quality of life without replacing basic governmental support.

Those expenditures remain important. Quality of life is not trivial simply because a need is not medical.

But the distinction between supplemental and essential spending has become increasingly difficult to maintain in practice.

Consider housing.

If the beneficiary cannot obtain a suitable publicly funded residential placement, a trust may need to purchase, rent or help maintain housing. If an aging parent dies and the beneficiary has lived in the family home for decades, the trust may be called upon to stabilize that arrangement while a long-term plan is developed. The trust may need to fund modifications, property management, household assistance or a companion arrangement. ***Housing is not an extra.***

Consider direct care.

If Medicaid has authorized services but no worker is available, a trust with sufficient resources may need to pay privately for assistance that the public system theoretically covers. ***That care is not an extra.***

Consider care management.

A beneficiary may technically receive Medicaid-funded case management, but a professional trustee located hundreds of miles away may need an independent person to visit the beneficiary, communicate with providers and identify unmet needs. The private care manager may become the trustee's reliable source of information about what is actually happening on the ground.

That is not an extra either.

Nor are transportation, benefits advocacy, emergency staffing, household support or the technology necessary to communicate and live safely.

This does not mean a trustee should automatically replace every unavailable public service with private dollars. Few trusts could sustain that approach over a beneficiary's lifetime. What it does mean is that we should stop assuming that private trust expenditures necessarily represent luxury or enhancement while public programs cover necessity.

In an unstable service environment, the same expenditure may move back and forth across that line. A privately paid aide may be supplemental while Medicaid services are fully staffed and essential when they are not. A private care manager may be helpful when public coordination is working well and indispensable when it is not. A housing expenditure may initially enhance independence and later become necessary to prevent homelessness or institutionalization.

The legal name of the trust has not changed but the work the trust is doing has.

V. Funding the Life That Will Actually Exist

Once that reality is acknowledged, the financial planning conversation has to change as well.

Families commonly ask how much should be left to a special needs trust. The question cannot be answered by using a universal target.

A \$1 million trust may provide substantial security for one beneficiary and be plainly insufficient for another. The result depends upon the beneficiary's age, life expectancy, health, level of disability, housing, geography, public benefits, family support, investment performance and the amount of privately funded care that will be necessary.

The most important variable may be the one that does not appear on the family's current budget: unpaid family labor.

If a parent provides thirty hours each week of supervision, transportation, coordination and personal assistance, the beneficiary's current support needs are not inexpensive simply because no check is written for those thirty hours.

The cost has been absorbed by the family. When the parent is gone, some portion of that cost likely will become financial.

That reality should inform life insurance planning, retirement-account beneficiary designations, estate equalization discussions and decisions about how much of a parent's estate should pass to the child with the disability rather than to other beneficiaries. It should also inform expectations about siblings.

Leaving assets equally among children and informally asking one child to use part of an inheritance to help a sibling with a disability is generally a poor substitute for intentional planning. It creates no reliable funding source, no fiduciary structure and no assurance that the money will remain available when the beneficiary needs it.

Even where a trust has already been established, planners should periodically revisit the funding assumptions. The question is not simply what the trust is worth. The better question is *what the trust will be expected to purchase over the beneficiary's lifetime*.

That analysis should account for housing, private care, transportation, technology, medical and therapeutic needs, professional administration, benefits advocacy and the potential cost of replacing the coordination currently supplied, typically for free, by family.

It should also acknowledge uncertainty.

No planner can predict the Medicaid system thirty years from now. Nor can the planner reliably predict the beneficiary's support needs at age sixty based solely upon needs at age thirty. Accordingly, financial projections should not assume that every currently authorized public service will remain available, fully staffed and adequate indefinitely. Financial projections should also incorporate the long-term care needs of the caregiver.

That does not require projecting the collapse of the public system, it requires a margin for reality.

VI. The Trustee's Job Changes When the Trust Becomes the Backstop

The pressures affecting families also change trust administration.

A special needs trustee is not a guardian merely by virtue of serving as trustee. A trustee is not ordinarily the beneficiary's health-care agent, service coordinator, residential provider or direct caregiver. Careless drafting should not turn the trustee into all those things.

At the same time, a trustee responsible for exercising broad distribution discretion cannot do that job intelligently without understanding the beneficiary's circumstances.

A trustee cannot administer a special needs trust solely from account statements.

The legal issue is familiar. Discretion requires judgment, and judgment requires information. General fiduciary principles require trustees to act in good faith, in accordance with the terms and purposes of the trust, and based on information appropriate to the decision being made.^{vii}

The practical issue is harder: how does the trustee obtain that information?

A competent adult beneficiary may be able to communicate directly with the trustee, identify needs and request distributions. Another beneficiary may have difficulty communicating or may not appreciate it when a service is inadequate. Family may provide reliable information, but family may be unavailable, exhausted, conflicted or geographically distant. Medicaid-funded staff may be helpful, but staffing instability may make reliance on those individuals difficult.

The problem can be illustrated by something as simple as a winter coat. The trustee may have unquestioned authority to buy the beneficiary a winter coat. The transaction will have no meaningful effect on benefits and may plainly serve the purposes of the trust. But if nobody tells the trustee that the beneficiary needs a coat, the scope of the trustee's distribution authority is irrelevant. That is the administrative challenge presented by a beneficiary who cannot independently advocate. It is also why private care management and advocacy can become essential trust expenditures.

A care manager can visit the beneficiary, speak with staff, understand the service plan, identify unmet needs and provide the trustee with information necessary to exercise discretion. The care manager does not become the trustee. Nor should the trustee simply delegate discretionary judgment to the care manager.

The care manager supplies information. The trustee uses it.

This distinction becomes especially important for professional and corporate trustees. Those fiduciaries may offer continuity, investment infrastructure, accounting, tax administration and institutional experience. They may nevertheless be located hundreds of miles from the beneficiary and have limited firsthand knowledge of the disability-service environment in which the beneficiary lives.

Conversely, a family trustee may know the beneficiary intimately but lack experience with public benefits, investments, fiduciary accounting or long-term budgeting.

Neither structure is inherently defective, but both require a way to fill the gaps.

A well-administered special needs trust should therefore have a reliable process for learning about the beneficiary's life. Depending upon the circumstances, that may involve regular communication with the beneficiary, family, a guardian or agent, residential providers, care managers, benefits specialists or other trusted professionals.

The objective is not to create bureaucracy. It is to avoid administering the trust in the dark.

VII. Eligibility, Availability and Adequacy as a Fiduciary Framework

The same distinction that should guide planning can help trustees make distribution decisions.

The traditional distribution inquiry often focuses heavily on whether a public benefit will pay for a particular good or service and whether a trust distribution will impair eligibility. Those questions remain necessary, but they are no longer (and never really were) sufficient.

Suppose a beneficiary needs a particular service and Medicaid will theoretically fund it. The trustee should first determine whether the beneficiary is eligible for the service. If the answer is no, the trust may be the only realistic source of funding. If the beneficiary is eligible, the next question is whether the service is actually available. Is there a provider? Is there an opening? Can the authorized hours be staffed? Can services begin in a reasonable period of time? If the answer is yes, the trustee must still consider *adequacy*.

Does the service meet the beneficiary's needs? Is staffing sufficiently reliable? Does the program allow the beneficiary to remain safely in the current setting? Is the service available at the intensity necessary to accomplish its intended purpose?

Only after answering those questions can the trustee intelligently assess whether private trust funds should be used. This is not an invitation for trustees to substitute their preferences for public policy or to purchase a more expensive private service simply because it is available. The trust has a finite life. Every dollar spent today is unavailable tomorrow.

For many beneficiaries, effective use of public benefits is the only way to make private resources last throughout life. But conserving trust assets is also not a neutral decision.

A trustee who declines to spend trust funds while a beneficiary loses stable housing has made a discretionary decision.

A trustee who waits indefinitely for a provider to become available while a parent in her eighties continues to provide care has made a discretionary decision.

A trustee who preserves a modest cash benefit while refusing an expenditure that would materially improve the beneficiary's safety or independence has made a discretionary decision.

The decision may be justified. But it should be recognized as a decision and supported by a reasonable process.

This point has appeared before in special needs trust administration. In *Matter of JP Morgan Chase Bank, N.A. (Marie H.)*, a New York Surrogate's Court criticized administration of a substantial discretionary trust where the fiduciaries had protected and invested the assets but had failed for a significant period to become sufficiently knowledgeable about the beneficiary's actual circumstances and needs. Once appropriate care-management assistance was brought into the administration, trust funds began to be used in the manner contemplated for the beneficiary.^{viii}

The broader lesson is not uniquely New York.

A trustee cannot reasonably exercise discretion about needs the trustee has made no meaningful effort to understand.

VIII. When Preservation of Benefits Produces the Wrong Result

Special needs planning appropriately places significant emphasis on preservation of benefits. That emphasis can become distorted when preservation itself becomes the measure of success. The purpose of a special needs trust is not to achieve the highest possible SSI payment. Nor is it to preserve the largest possible trust remainder. The purpose is to serve the beneficiary within the parameters established by the governing instrument and applicable law.

Sometimes those goals will align perfectly with benefits preservation and sometimes they will not. Housing is the easiest example.

A trust distribution for shelter may affect an SSI recipient's monthly cash benefit. The trustee therefore needs to understand the consequences before making the expenditure. But if trust-funded housing provides the beneficiary with a safe and stable living arrangement that is otherwise unavailable, the fact that SSI may be reduced does not necessarily make the distribution a poor decision.

The trustee should compare the value of the benefit lost with the value of the housing obtained. That is a very different analysis from simply asking whether SSI will be affected.

The Social Security Administration's own changes to the in-kind support and maintenance rules illustrate the danger of allowing benefit mechanics to dominate long-term trust design. Effective September 30, 2024, SSA stopped including food in the calculation of in-kind support and maintenance and expanded a rental-subsidy

exception nationwide.^{ix} Planning assumptions that governed trust administration for decades changed through administrative action.

A trust for a young beneficiary may operate for half a century.

Today's benefits manual cannot sensibly become tomorrow's immutable statement of settlor intent.

The same principle applies beyond SSI.

Assume a Medicaid waiver authorizes personal-care services, but the provider has been unable to staff the authorized hours for several months. If the trust has sufficient resources, paying privately for part of that care may be entirely appropriate.

The fact that Medicaid theoretically covers the service does not put a caregiver in the home.

Similarly, an available public service may be so limited that it does not accomplish the beneficiary's actual objective. A transportation benefit that cannot reliably get the beneficiary to employment may have little practical value. A care-management program that processes required paperwork but cannot provide individualized advocacy may need to be supplemented with private support.

None of this suggests that trustees should abandon efforts to obtain appropriate public services. To the contrary, trust funds may appropriately be used for legal representation, benefits consultation and advocacy precisely because publicly funded benefits remain so important.

The distinction is that benefits preservation should be a strategy employed for the beneficiary.

IX. Scarcity Exists Inside the Trust Too

Public resources are not the only scarce resources. Many special needs trusts are modest.

A trust holding several hundred thousand dollars for a beneficiary in early adulthood cannot possibly replace a lifetime of Medicaid-funded care. Even a multimillion-dollar trust can be depleted rapidly if it is required to provide intensive private staffing over decades.

Recognizing the limitations of the public system therefore should not produce unrealistic expectations of private money.

The trust cannot become a substitute Medicaid program.

It can, however, be used strategically.

That requires trustees to distinguish expenditures that merely duplicate reliable existing services from expenditures that address meaningful unmet needs. It requires consideration of whether spending now may avoid a substantially larger problem later. It requires attention to the beneficiary's life expectancy, foreseeable transitions, housing and the likelihood that family supports will diminish.

It also requires the trustee to recognize that quality of life is part of the analysis. An excessively conservative trust can fail in a different way from an excessively generous one.

If a beneficiary lives for decades with little meaningful use of trust assets because the trustee is focused almost exclusively on preservation of principal, the administration may technically conserve the fund while failing to fulfill the settlor's purpose.

This is particularly striking in a first-party trust subject to Medicaid reimbursement at the beneficiary's death. Preserving substantial assets that could have been used appropriately for the beneficiary during life may ultimately benefit the reimbursement claimant rather than the beneficiary for whom the trust was established.

That does not mean a first-party trust should be intentionally exhausted. It means preservation is not the only relevant value. The same issue arises in third-party trusts with remainder beneficiaries.

Parents often provide that assets remaining at the death of the beneficiary with a disability will pass to siblings, descendants or charities. That is ordinary and appropriate planning. But a remainder interest should not silently become a competing lifetime objective unless the settlor intended it to be one.

A family trustee who is also a remainder beneficiary may feel pressure to conserve assets. A corporate trustee may simply default to conservative spending because the trust is silent about priorities. Where the settlor intends the beneficiary's lifetime welfare to be paramount (which will almost always be the case), that intent should be clear.

The trustee should not administer an SNT designed for a lifetime beneficiary as though the preservation of an inheritance for the next generation were an equal purpose.

X. The Trust Cannot Replace a Support System by Itself

There is a temptation in estate planning to believe that if we have drafted a sufficiently comprehensive trust and funded it adequately, we have solved the problem.

We have not.

Money is a tool, someone still must know what to do with it. My law partner will often say money does not equal quality of life, money + advocacy equals quality of life.

The most successful long-term plans therefore tend to surround the beneficiary with a network rather than relying on a single heroic successor. That network may include a trustee, family members, a care manager, a benefits specialist, an attorney, a financial professional, a guardian or agent where appropriate, service providers and other people who know the beneficiary personally. Financial administration and human-services administration are different competencies.

The professional trustee who manages assets and exercises distribution discretion may need someone locally who understands the beneficiary's daily life. The family member with intimate knowledge of the beneficiary may need a professional fiduciary to manage money. The care manager may understand services but should not necessarily control trust distributions. The benefits specialist may know Medicaid and SSI but not the beneficiary. The plan should permit those roles to work together and it should also preserve institutional memory.

It should also preserve institutional memory.

A trust instrument tells the trustee what the trustee is legally authorized to do. It does not explain what the beneficiary's morning routine looks like, which physician the beneficiary trusts, which foods the beneficiary refuses, how the beneficiary expresses discomfort, what activities provide joy, who the beneficiary's friends are or what a parent has learned through forty years of trial and error.

Those things belong in a life plan, letter of intent or similar companion document. The most useful question a planner can ask a parent may be remarkably simple:

What are you doing for this person now that somebody else will need to know how to do when you are gone?

The answer frequently reveals the real planning problem.

XI. Testing the Plan Before Crisis

Families should also be encouraged, where possible, to test portions of the support system before the primary caregiver is gone.

Parents who have advocated for a child for decades may find it difficult to step aside even temporarily. They know the system. They know the beneficiary. They can often perform a task more quickly and effectively than a new provider.

But waiting until a parent's death or incapacity to determine whether the successor system works creates unnecessary risk. A gradual transition can reveal strengths and weaknesses while the parent is still available to intervene.

A sibling can begin attending care-planning meetings.

A care manager can take responsibility for selected coordination functions.

A Medicaid-funded provider can be asked to assume a task historically performed by the family.

A future trustee can learn about the beneficiary's services and meet the people involved.

The family can see whether transportation works without parental backup.

If the system succeeds, confidence grows.

If it fails, failure is valuable information.

The family learns that the written plan depends upon support that may not actually exist. Private funding can be reassessed. Roles can be changed. Additional professionals can be brought in. Expectations can be adjusted. It is far better to discover those vulnerabilities while the people who know the beneficiary best are still available to respond.

XII. Limited Drafting Implications

The detailed drafting of modern third-party special needs trusts warrants its own discussion, and it is addressed elsewhere in these Stetson materials. The central drafting lesson for present purposes is narrower.

If the trust ultimately serves as the financial backstop when public services cannot meet the beneficiary's needs, the governing instrument should not prevent the trustee from responding to that reality.

A trust that commands preservation of public benefits regardless of circumstance may produce exactly the wrong result when the beneficiary needs housing, care or another essential support that cannot otherwise be obtained. Similarly, the trustee should have authority to obtain the information necessary to exercise discretion. If that requires employing a private care manager, benefits specialist, advocate or other professional, the instrument should permit it.

A third-party trust should also make clear, where consistent with the settlor's intent, that the beneficiary's lifetime interests take priority over preservation of assets for remainder beneficiaries.

One formulation may provide:

The Trustee shall consider the availability and value of governmental and private benefits, services and resources available to the Beneficiary but shall not be required to withhold an otherwise appropriate distribution solely because the distribution may reduce, suspend or eliminate a benefit. The Trustee may make such a distribution when the Trustee reasonably determines that the expenditure better serves the Beneficiary's health, safety, welfare, independence, dignity or quality of life.

A related provision may address service scarcity directly:

In determining whether to make a distribution for a good or service that may be available through a governmental or private program, the Trustee may consider not only the Beneficiary's legal eligibility for the program, but also the actual availability, reliability, timeliness and adequacy of the good or service and the reasonably foreseeable consequences to the Beneficiary if the Trustee declines to supplement or replace it with privately funded support.

The trustee should also be empowered to obtain assistance:

The Trustee may employ and compensate a care manager, social worker, public-benefits specialist, housing advocate, attorney or other professional to assess the Beneficiary's circumstances, identify unmet needs, evaluate available services, facilitate communication and make recommendations to the Trustee. Any such adviser shall serve in an advisory capacity unless separately appointed to a fiduciary office, and the Trustee shall retain responsibility for the exercise of discretionary authority.

Finally, where consistent with the settlor's wishes:

During the Beneficiary's lifetime, the Settlor's primary concern is the Beneficiary. The Trustee shall not withhold an otherwise appropriate distribution merely to preserve trust property for a remainder beneficiary, and no remainder beneficiary may object to a distribution properly made for the Beneficiary because the distribution reduces property that may ultimately pass in remainder.

These are not intended as a complete set of model provisions but to illustrate the point.

If the surrounding service system is uncertain, the governing instrument should create flexibility rather than impose assumptions about how care will be delivered decades into the future.

XIII. Conclusion

The special needs trust remains one of the most important planning tools available to families of individuals with disabilities, but the environment in which it operates has changed. Publicly funded systems are being asked to provide increasingly

individualized, labor-intensive services to a growing population at the same time the workforce required to deliver those services is under extraordinary pressure. Meanwhile, the unpaid family caregivers who have historically filled countless gaps are aging, financially strained, and finite. The result is a widening divide between what the system promises and what families can reliably obtain. Sometimes that gap is caused by inadequate funding. Sometimes it is workforce shortages, bureaucracy, geography, housing scarcity, or provider capacity. Sometimes the system simply fails. Whatever the cause, planners have to confront the reality in front of them. Eligibility for Medicaid-funded services does not guarantee that an appropriate provider will be available when needed. Financial projections that assign no economic value to decades of unpaid parental support are incomplete. Trustees cannot assume that a theoretically available public benefit is actually delivering an adequate service. Families cannot assume that a sibling, agency, or professional fiduciary will somehow absorb every function the parents currently perform. Identifying these limits is not an argument against Medicaid, stronger public systems, or continued advocacy. It is what responsible planning requires.

Families planning today cannot wait for the system of tomorrow. They have to build from the resources that actually exist, and for many beneficiaries that will require Medicaid-funded services, Social Security benefits, family and community involvement, technology, professional care management, advocacy, and private funds working together. The special needs trust sits at the center of that private planning. Its historic role was to preserve eligibility while providing supplemental benefits. Its practical role is now much broader. It may pay for the care manager who sees a problem before it becomes a crisis, the private support needed when an authorized shift goes unfilled, the housing the public system cannot provide, the advocate who challenges an inappropriate reduction in services, or the transportation and technology necessary to sustain community life. These are not merely enhancements. They may be what keeps the plan functioning. The challenge for special needs planners is not to abandon the concept of supplementation, but to recognize that the line between supplemental and essential support has moved. Public benefits should be preserved when preservation serves the beneficiary. Private resources should be protected so they remain available over the beneficiary's lifetime. But neither preservation of benefits nor preservation of principal should ever displace the central purpose of the planning: the person. In an increasingly fragile service-delivery environment, the supplemental needs trust may be the resource that makes the rest of the plan possible. It may be the safety net beneath the safety net.

Appendix A

Questions for Counsel and Families: Testing the Assumptions Behind the Plan

A useful special needs planning discussion should move beyond identifying benefits and naming fiduciaries. Counsel should understand what the beneficiary's daily life actually requires and how much of that life is presently being sustained by family.

The family should be asked to describe an ordinary week. Who provides transportation? Who arranges medical care? Who communicates with service providers? Who handles benefits paperwork? Who monitors whether authorized services are actually delivered? Who manages emergencies? Who knows the beneficiary's routines, preferences, communication style and warning signs?

The discussion should then turn to transition. If the principal caregiver could no longer perform those functions tomorrow, who would assume each one? Is that person aware of the expectation? Is the person willing and realistically able to do it? If no family member can perform the role, does an appropriate professional or agency exist, and what would that service cost?

Public benefits should be examined at the same level of detail. What services is the beneficiary legally eligible to receive? Which of those services is the beneficiary actually receiving? Are authorized hours fully staffed? Are there waiting lists for additional services? Is the current housing sustainable? Are available providers adequate and reliable? How much unpaid family intervention is currently necessary to make publicly funded services work?

The financial plan should then be tested against those answers. What expenses will arise when unpaid family assistance is no longer available? Does the projected trust funding assume that existing governmental services will continue unchanged? Has the financial plan accounted for private care management, housing, transportation, advocacy and emergency support? If the public service system becomes less reliable, how much additional private expenditure could the trust sustain?

Finally, the family should consider whether the transition can be tested while the current caregivers are still able to participate. Can a successor attend planning meetings now? Can a care manager assume selected responsibilities? Can an agency take over a task the parent currently performs? Can the future trustee become familiar with the beneficiary before a crisis forces an immediate transition?

The object is not to predict every future problem. It is to identify which parts of the current plan depend upon assumptions that have never been tested.

Appendix B

Questions for Trustees: Eligibility, Availability and Adequacy

When a beneficiary needs a significant good or service that may be available through a public program, the trustee should first identify the relevant benefit and determine the beneficiary's legal eligibility. That is only the beginning.

The trustee should then determine whether the service is actually available. Is there an appropriate provider? Can the provider begin services within a reasonable period? Can authorized hours be staffed? Is an appropriate residential placement actually open? Does the transportation benefit function in the beneficiary's community?

If a service is available, the trustee should evaluate adequacy. Does it meet the beneficiary's actual needs? Is it reliable? Is the amount of service sufficient? Does it promote the beneficiary's safety, independence and community participation, or is it merely the closest available option?

The trustee should next consider the proposed private expenditure. What will the expenditure accomplish? What governmental benefit, if any, may be reduced? What is the economic value of the benefit that may be affected? Is there a less expensive private alternative? Is the expenditure likely to prevent a larger future cost or a more restrictive placement?

Finally, the trustee should consider the consequences of declining the expenditure. What happens to the beneficiary if no private money is spent? Does the beneficiary remain safe? Does a family member continue filling the gap without compensation? Is housing jeopardized? Does the beneficiary lose employment, community participation or meaningful social connection? Does the unmet need create a foreseeable crisis?

The proper fiduciary analysis is not simply whether a government program theoretically pays for the same category of service. The question is whether the trustee, after considering the beneficiary's circumstances, available public and private resources and the long-term sustainability of the trust, has made an informed decision about what course best advances the purposes of the trust.

ⁱ Alice Burns, Abby Wolk & Molly O'Malley Watts, *A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2025*, KFF (Nov. 20, 2025). KFF cautions that states differ significantly in their screening and reporting methodologies, so waiting-list data should not be treated as a uniform measure of unmet need.

ⁱⁱ Id. KFF reported an average 2025 waiting period of thirty-two months among responding states, with an average of thirty-seven months for individuals with intellectual and developmental disabilities.

ⁱⁱⁱ ANCOR, *The State of America's Direct Support Workforce Crisis 2025* (2025). The survey included 469 community-based providers operating in forty-eight states and the District of Columbia. Eighty-eight percent reported moderate or severe staffing shortages; 62 percent had turned away referrals for lack of staff; 29 percent had discontinued programs or services; and 56 percent operated in areas with few or no alternative providers offering comparable services.

^{iv} Medicaid & CHIP Payment & Access Comm'n, *Report to Congress on Medicaid and CHIP* (Mar. 2026), ch. 1, discussing Medicaid payment policies supporting the HCBS workforce and noting annual HCBS-worker turnover of approximately 40 to 60 percent.

^v *Olmstead v. L.C.*, 527 U.S. 581, 597–603 (1999).

^{vi} AARP & National Alliance for Caregiving, *Caregiving in the U.S. 2025* (July 2025). The study estimates that approximately 63 million Americans provide ongoing care to an adult or child with a complex medical condition or disability, an increase of approximately 20 million from 2015.

^{vii} See Restatement (Third) of Trusts §§ 50, 76, 77 (Am. L. Inst. 2003); Uniform Trust Code §§ 801–804, 814. The precise duties and scope of review applicable to discretionary trustees vary under governing state law.

^{viii} *Matter of JP Morgan Chase Bank, N.A. (Marie H.)*, 38 Misc. 3d 363, 376–80, 956 N.Y.S.2d 856 (Sur. Ct. N.Y. Cnty. 2012). The case has long been useful in illustrating the affirmative need for a trustee administering a discretionary trust for a beneficiary with significant disabilities to obtain sufficient information about the beneficiary and available services to make informed distribution decisions. The administrative principle is also reflected in special needs trust literature emphasizing communication, investigation, consideration and documentation in the exercise of trustee discretion, including an article submitted by Edward Wilcenski & Tara Anne Pleat (me 😊) being presented at this Stetson conference.

^{ix} Social Security Administration, *Helpful SSI Changes Reducing Customer Burden Take Effect* (Sept. 30, 2024); Social Security Administration, *SSI Spotlight on Living Arrangements Regulatory Changes*, 2026 ed. Effective September 30, 2024, SSA stopped counting food in its in-kind support and maintenance calculation, expanded the rental-subsidy exception nationwide and revised the public-assistance-household rules.