

*2025 National Conference on Special Needs Planning
and Special Needs Trusts*

Sex, Drugs, and Rock & Roll

Atypical Beneficiary Distribution Requests

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“Cause it’s always been a matter of trust!” Billy Joel, “Matter of Trust,” *The Bridge* (1986)

Introduction

Trustees have a daunting task when considering discretionary distributions from a trust. Most requests are fairly standard and follow a somewhat predictable pattern. However, just as quickly as the fiduciary feels that they have seen it all, they receive a request that puts them in uncharted waters, often outside of their comfort zone. When we couple discretionary distribution requests with ever-changing trust laws and public benefits regulations, a fiduciary can quickly become perplexed. Rash decisions, inaction, or action contrary to current case law can subject the fiduciary and their beneficiary (as well as the financial assets of both parties) to enhanced scrutiny and potential litigation.

Even exemplary trustees and their counsel may have to deny certain discretionary distribution requests. But there are often alternatives to outright denial or petitioning a court for instruction. Our overall mission as fiduciaries should be to come up with solutions that make the most financial sense for our beneficiaries¹ while promoting independence and empowering them to lead fulfilling lives.

¹ Throughout this paper, the authors use the terms “beneficiary” or “beneficiaries.” For brevity, the authors have chosen not to add “protected person,” “ward,” or “principal” where “beneficiary” or “beneficiaries” is used. Please be advised that the case law and statutory authority pertaining to a request by a beneficiary, protected person, ward, or principal may differ slightly or greatly depending on the fiduciary relationship of Trustee/Beneficiary, Conservator/Protected Person, Guardian/Ward, and Principal/Agent.

A trustee or fiduciary is charged with many responsibilities and tasks, but above all else, a fiduciary has the duty of loyalty to the beneficiary. This duty is especially relevant in the administration and drafting of Special Needs Trusts (SNT), also known as Disability Trusts or Supplemental Needs Trusts.

SNT trustees are fortunate to advocate for one of the most underserved but most deserving populations in the country. SNT trustees can make a truly significant and tangible difference in their beneficiaries' lives. But the ever-changing public benefits landscape, audit requirements from state and federal agencies, new tax regulations, and liability risk can be complex and overwhelming. That's in addition to serving a diverse clientele that requires and deserves a hands-on approach.

In this paper, the authors aim to share lessons we've learned in our duty as drafters, planners and fiduciaries. This paper will address how and from whom discretionary distribution requests are made, sole benefit impact, discretionary distribution language drafting and implications, beneficiary expectation setting, distribution funding mechanisms and beneficiary-specific lifetime budgetary planning.

I. "I woke up in a SoHo doorway, a policeman knew my name." The Who, "Who Are You" (*title track*), (1978)

Framework Development

Using a framework for the evaluation of discretionary distributions maintains consistency and fairness to the beneficiary and facilitates/enables recordkeeping in the event of discovery. Never

forget that the primary duties of any fiduciary are loyalty and impartiality. Such a framework, however, does not necessarily mean that similar requests from different beneficiaries, or even from the same beneficiary at different times, will result in the same outcome. Each beneficiary and their unique circumstances must be evaluated.

For each beneficiary request, one of the first steps is determining its appropriateness for the individual. It is helpful if the fiduciary knows the beneficiary and their circumstances well. However, should the fiduciary not be able to personally evaluate the needs of the individual, a case/care manager, trust protector/advisor, investment advisor or CPA may be asked to do so. Often, a fiduciary may rely on recommendations from a beneficiary's family member or close friend. Both fiduciaries and drafting attorneys must take extra care to maintain the confidentiality of the beneficiary's protected information and to avoid inadvertently violating attorney-client privilege. However, there may be times when it is in the beneficiary's best interests to waive attorney-client privilege so that the fiduciary can better meet the beneficiary's needs. In these cases, the fiduciary and attorney should fully advise the beneficiary on the implications of waiving attorney-client privilege and potentially ask them to sign a written waiver.

A fiduciary should document all facets of the discretionary distribution request and decision-making process; the who, what, why and when. One of the most telling pieces of information in any situation is who made the request. For example, if a new "player" suddenly enters the life of the beneficiary, this could be one of the first signs of exploitation or undue influence. As we know, most fiduciaries are employed to prevent the exploitation of a vulnerable population, such as the aging, people with disabilities or incapacitated persons. Note that most fiduciaries are mandatory reporters of potential elder abuse (a term which includes abuse of people with disabilities).

The *what and why* are equally important factors in the decision making process. Consider this example from one of our practices:

A trust beneficiary called his trustee and requested a sex reassignment surgery. Rather than simply deny the request, the trustee began to ask questions. He learned that the beneficiary wanted to become a female because he wanted to live on the main floor of his home. The trustee was surprised to hear this because the beneficiary had always lived on the main floor of his trust-owned home. The trustee probed further and learned that the beneficiary had recently taken in two female roommates, who had told him he had to live in the basement because only women could live on the main floor. The beneficiary's proposed solution was to have a sex reassignment surgery. The trustee evicted the female roommates, and the beneficiary was again allowed to live on the main floor of his home.

Accordingly, it is always a good idea to ask more questions when a trustee receives a request that seems out of the ordinary because there may be circumstances under the surface that need to be discovered. So take the time to ask about the *what* and the *why* behind the request in order to learn more.

When the request is made or how frequently it is made is another important factor. Time is one of the best tools for a fiduciary or attorney advising a fiduciary. Following an initial conversation regarding a request, a beneficiary may often change their mind or rescind the request. Sometimes there are beneficiaries who, due to the nature of their disability or incapacity, make requests so

frequently that the fiduciary learns to only follow up on the requests that are repeatedly made. This isn't the best practice for either the fiduciary or the beneficiary. In either of these scenarios: the beneficiary who changes their mind frequently or the beneficiary who knows no boundaries, it is important for the fiduciary to develop beneficiary-specific strategies for handling these requests. In the former situation, the fiduciary will need to know that a follow-up is necessary before following through with the disbursement. In the latter scenario, the fiduciary needs to set firm boundaries around communication. There is not a one size fits all approach to these situations.

Lastly, beyond the who, what, why and when is to ensure that there is proper documentation. An opinion from a professional working with the beneficiary can be a valuable resource. But, a letter of opinion from an attorney does not have to be the only source of protection or solution that a fiduciary may seek. A medical professional, for instance, has a different relationship with the beneficiary and can provide insight into the person's needs. Furthermore, an approval or denial in writing from a professional can go a long way in justifying any expenditure and is highly recommended to properly document the fiduciary's file. And as a side note, if appropriate, the beneficiary might sign a Health Insurance Portability and Accountability Act (HIPAA) release to give a fiduciary access to their applicable medical records to help keep the fiduciary better informed about the beneficiary's medical needs that underlie the requests for disbursements..

II. “Got to be good looking ‘cause he’s so hard to see.” The Beatles, “Come Together,”

Abbey Road, 1969

Expectation Setting

Building a working relationship between the SNT trustee, the drafting or advising attorney, and the beneficiary is critical to establishing a manageable and efficient fiduciary practice.

Cooperative relationships between the trustee and beneficiary also significantly reduce the trustee's risk of litigation. It's important to remember that many SNTs are funded from personal injury or medical malpractice judgments or settlements; therefore, the SNT beneficiary is no stranger to an attorney's office.

At the same time, the SNT attorney and trustee should never lose sight of their importance; the population they serve desperately needs the oversight and attention of a diligent fiduciary and counsel.

Managing beneficiary expectations from the outset of the fiduciary-attorney relationship pays huge dividends throughout the relationship's lifetime. The adage "you never get a second chance at a first impression" certainly applies to how the team should conduct initial meetings and discussions with the beneficiary. Managing risk from the beginning can be accomplished by setting achievable expectations and short-term and long-term goals for the trust.

One should never assume that the beneficiary (or any other non-fiduciary) automatically knows all of the issues surrounding public benefits and SNT administration. Trust administration can seem mysterious to a beneficiary not engaged with its overall processes. That's why developing a common understanding of the issues is invaluable. For example, explaining the vagaries of common trust terms and how different agencies use public benefits language can immediately put the beneficiary and the trustee on the same side of the table.

Another way to foster mutual understanding with a beneficiary is to refer to common "enemies".

By the time an SNT usually funds, the beneficiary is likely frustrated with the red tape of local

public benefits agencies. A sensible trustee can use these shared experiences to their advantage when having to deny certain discretionary distribution requests or in other challenging aspects of the SNT's administration.

It's also important to address beneficiaries' emotional concerns, given the inevitable apprehension that will develop in the beginning stages of any trust's administration. It is very trying for a beneficiary who has been in total control of their assets to turn over day-to-day money management to a third party. The beneficiary's "hot button" items may be anything from investment management to public benefits retention, trust law, or tax regulations. A prudent trustee will manage these beneficiary concerns throughout the trust's administration and relate similar experiences they've had with other beneficiaries. However, this is only possible if they have taken the time to discover and discuss the source of the beneficiary's distress.

In initial meetings, the trustee should strive to engage the beneficiary in all aspects of the trust's administration. Typically, if the beneficiary feels like a part of the overall process, the inevitable bumps and hurdles throughout the SNT's lifetime are easily cleared together. An initial intake meeting should focus on the beneficiary's benefits, disability and lifetime estate planning, as well as their goals for the trust, and personal hobbies and passions - all of which should be recorded for future use.

The trustee should also focus on the beneficiary's short-term goals for the trust, such as the inevitable request for the purchase of a house and/or vehicle, while establishing a monthly and annual budget. The trustee can use this budget as the basis for a trust longevity projection. Seeing depletion rates in hard-and-fast numbers often makes a big impact on how the beneficiary thinks about their budget.

At the beginning of the relationship, the trustee should also focus on the beneficiary's long-term goals - what the authors call "optimal outcomes." As planners, we should learn about beneficiaries' ultimate goals for their trusts, whether it's to provide for their lifetime, start a business, provide for college expenses, pay for annual vacations or leave a legacy or inheritance for their desired remainder persons (as applicable after considering Medicaid recovery).

Having these conversations with the beneficiary and, more importantly, recording them for future use, can help manage the beneficiary's disappointment if a discretionary distribution is denied. For example, the conversation between beneficiary and trustee will be more congenial when they can say, "I'm sorry, but your SNT cannot afford to purchase you a Ferrari and then send you to college in five years, which you stated was one of your goals for your trust."

Bringing these discussions back to common ground is essential in managing a beneficiary's expectations.

In general, change in a beneficiary's lifestyle will always be difficult, especially for the population served by SNT planners. The trustee will almost inevitably face situations wherein the beneficiary's parents facilitated or paid for every one of the beneficiary's requests for funds (or at least, that is what the beneficiary would have the trustee believe). In cases where the beneficiary's parents acted as payment facilitator and also as settlor of the trust and are now deceased, it is not uncommon for the beneficiary to protest having a trust at all, saying things like "Mom and Dad are just trying to control me from beyond the grave." In most of these cases, there are usually very good reasons for the trust's existence: public benefits qualification, inheritance/remainder person concerns or beneficiary spendthrift issues.

That said, the trustee can use this situation to their advantage in managing the beneficiary's expectations by explaining that the trustee is bound by the four corners of the trust document and that the settlor is no longer available to discuss discretionary distribution provisions.

III. “Circumstance has forced my hand, to be a cut-priced person in a low-budget land.”

The Kinks, “Low Budget,” *title track*, (1979)

Budgeting

An SNT beneficiary will never achieve their goals or have their trust last as long as possible without appropriate planning. Both long-term and short-term budgeting are crucial to any beneficiary's investment strategy. The advising attorney and trustee will have to work across multiple disciplines, such as social work, psychology, and fiduciary representation, to fully complete the beneficiary's plan. Considerations should include the goals and needs of the beneficiary, their unique family dynamics, whether the beneficiary has diminished capacity or special needs, and the special circumstances of their lives. Of course, the trustee should also factor in public benefits the beneficiary may be receiving, is entitled to or may be eligible for in the future.

The superb trustee and attorney should also educate and advocate for their beneficiaries. To do so, they may require the services of other professionals: case managers, public benefits planners, agents under power of attorney, conservators and/or guardians, and investment managers. It is important to remember that certain professionals involved in the beneficiary's planning procedure may not be entitled to confidential beneficiary information. Although there is a good

faith effort to approach these issues in a cooperative manner, trustees and attorneys should recognize potential confidentiality and evidentiary issues.

A thorough assessment of a beneficiary's situation should occur before a plan is finalized. In addition to a standard annualized budget for a beneficiary, the following factors should be addressed:

- Beneficiary disability and its specific costs and planning factors
- Life expectancy
- Lifestyle/hobbies
- Age
- Employment (current and future)
- Cost of living
- Tax situation (current and future)
- Beneficiary education
- Beneficiary investment knowledge or experience
- Beneficiary risk tolerance
- Life Care Plan ("LCP")
- Waiver program eligibility
- Community Support Programs eligibility (e.g., HUD, SNAP, etc.)
- Potential future funding opportunities (family lifelong planning [testamentary] or inheritance;
additional settlements or awards)

Often overlooked in planning for beneficiary needs is a review of the beneficiary's current resources. Drafting attorneys should take into account all facets of the beneficiary's financial situation before a trust vehicle is finalized. For example, if a structured settlement annuity is part of the trust's funding (both initial and ongoing), it should be factored into the beneficiary's spending plan. Or if a beneficiary has legacy 529 Plans, a conversion to an ABLE account may be most appropriate (see ABLE Financial Planning Act). When funding a beneficiary's SNT share in testamentary situations, the trustee may discover substantially appreciated legacy assets from a third party. In this case, a consultation with a tax professional or investment advisor may be warranted in order to capture any step-up in tax cost basis opportunities or develop a prudent liquidation or rebalancing strategy that will not be overly onerous to the beneficiary.

Ideally, the planner and trustee should also budget for professional costs and fees for the beneficiary. Such costs may include trustee fees, investment advisory fees, tax preparation fees (both for the trust and the beneficiary as applicable), case management fees and attorney fees. In the final stages of beneficiary financial planning, the drafting attorney and trustee should do a cost-benefit analysis of all needs and desires of the beneficiary from the trust as well as other sources. For example, the beneficiary may wish to pay privately for in-home caregivers, even though such services may be available to them through a Medicaid waiver program. A prudent trustee will review such expenditures with an eye towards trust longevity, even if the beneficiary is insistent otherwise.

Recent case law suggests it is the SNT trustee's duty to research all avenues of paying for such requests before approval in order to protect the trust's longevity. In *Liranzo v. LI Jewish Education/Research*, No. 28863/1996 (N.Y. Sup. Ct. June 25, 2013), a corporate trustee privately paid for caregivers and other services that may have been available to the beneficiary through

public benefits programs. These payments were made at the request of the minor beneficiary's parent. The trust was quickly depleted, and the trustee sought relief from the court when the trust became uneconomical to retain. The court concluded that the trustee should have sought out all available alternative avenues to pay for such services and directed the trustee to reimburse the trust almost \$176,000. Although there were other factors in *Liranzo*, this case certainly speaks to the affirmative duty of the trustee to protect a trust's longevity as well as seek out all available public benefits for a beneficiary as appropriate. The same cost-benefit analysis should be applied in determining how to pay for beneficiary requests. A prudent planner will properly research the most appropriate avenue (i.e., ownership versus lease) to pay for certain expenses, such as adaptive equipment, accessible vehicles and housing.

IV. "You're still young, that's your fault, there's so much you have to know...."

Cat Stevens, "Father and Son," *Tea for the Tillerman*, (1970)

Trusts for Minors/Sole Benefit

A key element of any SNT being administered for a beneficiary receiving public benefits is the "sole benefit rule." The Social Security Administration (SSA) has traditionally held that all discretionary distributions from an SNT must be for the sole benefit of the beneficiary. Any other parties receiving an incidental or ancillary benefit from such distributions must contribute their pro rata share to any such purchase or distribution. However, trust administration under these guidelines has proven nearly impossible in some situations. For instance, when a trustee prudently purchases a big-screen television for a beneficiary with deteriorating eyesight who lives with their parents, are the parents not supposed to watch television with their child? Or are

they supposed to contribute a hypothetical 34% toward the purchase because they have tracked their household television viewing trends?

Thankfully, the SSA's Program Operations Manual System (POMS) Section SI 01120.201.F.3.a now establishes a new "primary benefit" rule recognizes that others might inherently receive an incidental benefit from trust distributions. Under this revision, the SSA now acknowledges that incidental or ancillary benefit is acceptable if the purchase was made primarily to satisfy the needs of the trust beneficiary. Some examples reviewed in this POMS section illustrate that people other than the beneficiary may reside in a home owned by the trust under certain circumstances.

In another scenario, an automobile that is purchased by the trust (but is titled in the name of a non-beneficiary and driven daily by that person) would not be considered for the primary benefit of the SNT beneficiary, even though the automobile is used to transport the beneficiary twice a month to medical appointments.

A prudent trustee will always exercise an abundance of caution before making a distribution for the support or maintenance of a primary beneficiary's minor children, particularly if the beneficiary's issue is not specifically mentioned in the discretionary distribution provisions by the drafting attorney (SNT or otherwise). The trustee must be careful not to supplant the parental duty of support of a minor child to avoid running afoul of case law or other beneficiaries or remainder beneficiaries, such as Medicaid and/or Social Security. This is especially true when administering a trust for the sole benefit of a minor beneficiary and considering a discretionary distribution that will also benefit the beneficiary's parents.

Typically, a trustee or court will define parental support obligations as providing food, clothing, shelter, basic care and education. Parental obligations end once the child reaches the age of majority. Interestingly, there is case law to the contrary. In *McElrath v. Citizens & Southern National Bank*, 229 Ga. 20, 189 S.E.2d 49 (1972), the court found that the drafter's discretionary distributions provision instructing that the trustee "shall use a sufficient amount of the income to provide for the grandchild's support, maintenance and education ..." was a directive to use the income for the support, maintenance and education of the minor children, regardless of the parental obligation of support.

Restatement (Third) of Trusts (*Restatement of the Law Third, Trusts*, American Law Institute © 2003) ("Restatement Third") comment e(3) states that "the presumption is that the trustee should take into account the parental duty to support the child under state law. If the trustee makes a distribution for the benefit of the child, it is really benefiting the parent. The trustee may exercise discretion to distribute for benefits that fall outside the parental obligations." This example makes it clear that drafters and fiduciaries must always carefully consider discretionary distribution requests vis-a-vis the sole benefit rule.

V. "Send lawyers, guns and money - get me out of this!" Warren Zevon, "Lawyers, Guns and Money," *Excitable Boy*, (1978)

"Hey, Joe. Where you goin' with that gun in your hand?" Jimi Hendrix, "Hey Joe," *Are You Experienced*, (1967)

Firearms:

Firearms may benefit the owner for many reasons. Hunting may be a source of food or a social or familial activity. Many proponents of firearms advocate the importance of possession for personal security and individual liberty. Some beneficiaries may feel physically vulnerable, and thus firearm possession may be of utmost importance to them.

That said, the consideration of a firearm purchase for a person with a mental illness or diminished capacity must be considered thoroughly. The ownership of a firearm by a person with mental illness is illegal under federal law. Pursuant to 18 U.S.C. § 922(d), it is unlawful for any person to sell or otherwise dispose of any firearm or ammunition to any person knowing or having reasonable cause to believe that such person “has been adjudicated as a mental defective or has been committed to any mental institution.” In addition, the vast majority of states have laws regarding possession of firearms by people with mental illness. Many states have enacted “red flag” laws, which permit police or family members to petition a state court to order the temporary removal of firearms from a person who may present a danger to others or themselves. Often, these red flag petitions are tied to the firearms owner’s potential mental illness. Not surprisingly, the definition of mental illness varies from state to state. When defining mental illness, some states disallow possession of firearms for those who have been adjudicated incapacitated, others look at the adjudication of mental illness or court-ordered mental health treatment, and some look at the admittance to a treatment facility for drugs and/or alcohol. Also, a handful of states look at the person being found not guilty of a crime due to reason of insanity.

Any fiduciary contemplating a firearm purchase should be well versed in 18 U.S.C. § 922(d), the federal Firearm Possession Prohibition statute. The fiduciary should also consider “constructive possession” (*U.S. v Booth*, et.al. 111 F.3d 2 [1st Cir. September 1997]) or the beneficiary’s access to firearms, potentially in an unmonitored or unsecured estate asset. When weighing a

beneficiary's distribution request for a firearm, never dismiss the potential danger presented by firearms to people other than the beneficiary. Consider the recent Aurora Theater shooting case (Colorado). Sandy and Lonnie Phillips, the mother and stepfather of victim Jessica Ghawi, sued the companies that supplied James Holmes with ammunition and body armor. The Phillipses claimed that the suppliers sold the goods to Holmes over the internet, without ever seeing his face or addressing his state of mind, thus making them negligent. The suit did not ask for damages, only for an injunction requiring dealers to stop their “negligent and dangerous business practices.” Denver U.S. District Court sided with the dealers and dismissed the case (*Phillips v. Lucky Gunner, LLC*, No. 14-CV-02822-RPM, 2015WL 1499382 (D. Colo. Mar. 27, 2015)). The court also ruled that the dealers are entitled to fees and costs from the Phillipses.

To the best of our knowledge and research, there has not yet been a case brought against a fiduciary for purchasing a firearm for a beneficiary who then committed a crime. However, avoiding potential litigation and ensuring the safety of both the beneficiary and the public must be weighed in any potential firearm purchase.

VI. “But I would not feel so all alone....” Bob Dylan, “Rainy Day Women #12 and #35,” *Blonde on Blonde*, (1966)

Marijuana:

Since the authors are from Colorado, we would be remiss not to review the possibility of discretionary distributions for medicinal marijuana. (Please note that the topic of trust distributions for the use of recreational marijuana will not be covered here.) Even in states that have approved medicinal marijuana, there may still be consequences to the beneficiary for

using marijuana, which need to be carefully considered by the trustee when deciding whether to approve such expenditures. For example, should a beneficiary use marijuana while on probation or parole, it could be grounds for re-arrest. As such, a prudent trustee must consider/examine all aspects of a beneficiary's life before making a distribution for medicinal marijuana. As discussed previously, a trustee has the duty of loyalty and impartiality to their beneficiary. The trustee's own values as they relate to marijuana must be set aside when a beneficiary makes a request for its purchase.

Many sources cite the following benefits of marijuana:

- Treatment of glaucoma
- Reversal of the carcinogenic effects of tobacco and improvement of lung health
- Epileptic seizure control
- Decreased symptoms of a severe seizure disorder called Dravet syndrome
- Potential cancer abatement
- Decreased anxiety
- Reduced progression of Alzheimer's disease
- Easement of multiple sclerosis pain
- Easement of pain, severity and recurrence of muscle spasms
- Lessened side effects and increased effectiveness of hepatitis C treatment
- Treatment of inflammatory bowel diseases
- Relief from arthritis discomfort
- Boosted metabolism
- Improvement in the symptoms of lupus, an autoimmune disorder
- Increased creativity

The inherent clash between state and federal laws regarding marijuana is particularly difficult for trustees to navigate, especially if a beneficiary receives public benefits. For example, public housing authorities (the program traditionally known as HUD or Section 8) follow federal regulations and do not allow marijuana use, regardless of laws in individual states. The same applies to recipients of SNAP Benefits (food stamps). Also, given that some states have passed laws authorizing drug testing for public assistance recipients, fiduciaries must be aware how easily beneficiaries could lose eligibility for government benefits due to marijuana use.

In addition, a trustee might approve discretionary distributions for marijuana and then discover later they have unintentionally caused the beneficiary to be terminated from their place of employment. In 2015, Colorado's Supreme Court ruled that medicinal marijuana user Brandon Coats, who was fired by Dish Network after testing positive for marijuana use, had no recourse for losing his job. While Dish Network agreed that Mr. Coats wasn't "high" on the job, they explained they acted in accordance with their company-wide zero-tolerance drug policy (*Coats v. Dish Network, LLC*, 350 P. 3d 849 (Colo. 2015)).

Similar rulings have been decided in California, Montana and Washington. It is not unimaginable that if Mr. Coats had a trust, the trustee who had issued a discretionary distribution for his medicinal marijuana could potentially be liable for his lost wages and/or medical benefits.

VII. "Roam if you want to, Roam around the world." The B-52's, "Roam," *Cosmic Thing*, (1989)

Elective Surgery, Supplemental Medical Care, Medical or Dental Care outside of the U.S.

Elective surgery, supplemental medical care or medical/dental care outside of the U.S. must be carefully evaluated by the trustee. If a fiduciary is considering such a request, it is important to seek a Medicare and/or Medicaid (as applicable) denial before making the decision to approve or deny a request. Also, the fiduciary should certainly obtain a medical opinion letter advocating for the surgery or medical care in order to properly document their files and defend against future potential litigation. Evaluating medical providers outside of the US could be much more difficult for the fiduciary considering differing regulations and requirements. Potential considerations should be recommendation from a primary physician, references from the provider, insurance coverage, online reviews, etc. and then if everything checks out, proceeding with extreme caution.

Gender Affirming Care

Gender affirming care can have significant benefits for those who receive them. In fact, disallowing a treatment/surgery to someone with gender dysphoria may cause depression, low self-esteem and difficulty forming social relationships. The trustee's concern must be balanced with ensuring the well-being of the beneficiary along with examining the long-term impact any choice may have. In a situation with gender affirming care the trustee may be asked to assist financially with social or medical transitioning. Socially transitioning is the process of the person adopting the name, pronouns and gender expression (like clothing, hairstyle etc) that match their identity. It is important that the trustee be supportive in this process, including understanding that gender specific clothing is not a sole benefit issue. This can be a major organizational shift if there has been a strong policy on purchasing gender conforming clothing to prove sole benefit. A recent study published in the journal *Pediatrics* followed 317 socially transitioned children as

their authentic gender for more than year and found that almost 95% continued to identify as transgender five years later. Doctors interviewed for an ABC news story regarding the study agreed with the findings with one saying that he is “always surprised by anecdotal reports that transgender youth frequently retransition because it’s not what he’s seen on a large scale in his medical practice”.² Medical transitioning is when there is medical involvement like hormone treatment, gender affirming surgery etc. It would be wise for the trustee to obtain a medical opinion letter advocating for the treatment in order to properly document their files. This includes understanding the potential of co-existing psychiatric disorders and treatment that may be needed. The National Library of Medicine documents a peer reviewed study regarding the surgery and the mental health concerns.³

If a trustee is considering a request for any type of gender affirming medical care, it is important to seek a Medicare and/or Medicaid (as applicable) denial before making the decision to approve or deny a request. Section 1557 of the Affordable Care Act prohibits discrimination based on sex, but states have recently moved to implement restrictions on gender affirming health care, especially for youth. As of May 2023 at least 18 states have passed laws or policies that restrict gender affirming care for people under the age of legal majority and at least 14 others are considering or have introduced bills. While opponents of such legislation see this as an infringement on the rights of families to make their own health decisions, supporters believe that

²Abcnews.go.com (2023, August 15) Most Children who have socially transitioned still identify as transgender years later:Study <https://abcnews.go.com/Health/children-socially-transitioned-identify-transgender-years-study/story?id=84450021>

³ Ncbi.nlm.nih.gov (2023, September 18) /Transexual attractions and sexual reassignment surger: Risks and potential risks
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4771004/#:~:text=In%20a%202015%2C%20Boston%20study,leth al%20intent%2C%20and%20both%20inpatient>

people should wait until they are legal adults to make these decisions. It is clear this is a divisive issue.

This leads us to the question of if a trustee should consider the impact it may have on their business. The recent “Bud Light Effect” has shown that anti-transgender beliefs can have significant impact on one’s business. Although a trustee will not necessarily be advertising their support of the transgender community as Bud Light did with Dylan Mulvaney, a transgender activist, the beneficiary getting the support from their trust may. A disclosure by the beneficiary on social media that their trust helped them in their care can have potential backlash from those that do not agree with gender affirming care. The solution may be simple, to reply as you would with anyone who makes a negative statement regarding your organization online. That may mean staying silent or having a prepared statement. This should be considered proactively and then reviewed in real time as an incident develops.

VIII. “Blackbird singing in the dead of night...” The Beatles, “Blackbird,” *The White Album*, (1968)

Animals

Animals, especially those serving as pets, are very important to many people and the people we serve with disabilities are no different. In fact, the people we serve may have even greater need for animals that are characterized as a service or emotional support animal. As with any disbursement request, one must consider the budget and other factors outlined in the framework discussed earlier, bearing in mind that people sometimes become emotionally tied to their animals in a way that makes it difficult to make rational decisions about their care. A trustee

must evaluate all of the factors that are relevant before making a decision about the animal and the expenses surrounding it.

IX. “This is the end, my only friend, the end.” The Doors, “The End,” *Live at The Matrix*, (1967)

Conclusion

A beneficiary who is engaged is always more likely to refer the trustee’s and attorney’s services to friends and family. The engaged beneficiary is also more willing to work through issues collaboratively with their trustee and counsel.

Conversely, the disgruntled or unengaged beneficiary is more likely to speak poorly about the trustee and attorney in the community (falsely or otherwise) and “game the system” in regard to their public benefits. Additionally, the unengaged beneficiary will frequently lead with litigation, inevitably contacting a different attorney for trustee dispute resolution. No one wins in this situation; it simply drives up costs to the trust, which is ultimately to the beneficiary’s financial detriment.

The work done by an SNT attorney and trustee [OR ...done by SNT attorneys and trustees] is significant and honorable. It is absolutely vital to the community of people with disabilities and essential for the advancement of their rights and the enhancement of their quality of life. As practitioners in this arena, we are able to make tangible differences in our clients’ lives. We are extremely proud and humbled to be counted among the ranks of elder law attorneys and trustees.

Resources and Acknowledgements

Sex, Drugs, and Rock & Roll. Atypical Beneficiary Requests, CBA-CLE (2015 Elder Law Retreat). Megan Brand, Marco Chayet, Peter Wall.

Hartley Goldstone, Navigating The Trustscape TM

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