IN THE UNITED STATES COURT OF APPEALS
FOR THE THIRD CIRCUIT

No. 11-3439

ZACKERY LEWIS, *et al.,*

Appellees,

vs.

GARY ALEXANDER, in his official capacity
as secretary of Department of Public Welfare
of the Commonwealth of Pennsylvania, *et al.*,

Appellants.

BRIEF OF *AMICI CURIAE* SPECIAL NEEDS ALLIANCE, Inc., NATIONAL ACADEMY OF ELDER LAW ATTORNEYS, Inc., and PENNSYLVANIA ASSOCIATION OF ELDER LAW ATTORNEYS, Inc. IN SUPPORT OF APPELLEES AND FOR AFFIRMANCE

On appeal from the Order of the United States District Court for the Eastern District of Pennsylvania dated August 23, 2011 Entering Summary Judgment for Plaintiffs and Providing Declaratory and Injunctive Relief

Shirley B. Whitenack
Schenck, Price, Smith & King, LLP
220 Park Avenue, PO Box 991
Florham Park, NJ 07932
973-539-1000

Ron M. Landsman
Ron M. Landsman, P.A.
200-A Monroe Street, Suite 110
Rockville, MD 20850
240-403-4300

Marielle F. Hazen
Hazen Elder Law
2000 Linglestown Road, Suite 202
Harrisburg, PA 17110
717-540-4332

Attorneys for Amici curiae

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STATEMENT OF CORPORATE DISCLOSURE - RULE 26.1

Each of the entities whose attorneys are signing this brief are non-profit membership corporations, not publicly traded, and do not have parent entities. The National Academy of Elder Law Attorneys and the Pennsylvania Association of Elder Law Attorneys are related; PAELA is a chapter of NAELA, so that it must meet certain standards and all of its members are also members of NAELA.

STATEMENT OF AUTHORSHIP AND SUPPORT - RULE 29(c)(5)

No counsel to a party authored this brief, contributed money to fund its preparation or submission, and no person other than the amici and their staff, members and counsel contributed money to fund the preparation and submission of this brief.

CONSENT TO FILE - RULE 29(a)

Counsel for Appellants and Appellees both consent to the filing of this brief on December 13, 2011.

IN THE UNITED STATES COURT OF APPEALS
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The Special Needs Alliance, Inc., the National Academy of Elder Law Attorneys, Inc., and Pennsylvania Association of Elder Law Attorneys, Inc., respectfully submit this ***Brief of Amici Curiae*** in support of the Appellees in this matter.

IDENTITY OF AMICI, INTEREST IN THE CASE, AND SOURCE OF AUTHORITY TO FILE

The Special Needs Alliance, Inc. (SNA)

The Special Needs Alliance, Inc. (SNA), is a nation-wide association of attorneys who devote a significant portion of their practices to estate planning for families with a disabled family member, often involving the use of a special needs

trust. On the model of the American College of Trust and Estate Counsel, SNA limits its membership to individuals who have substantial experience and knowledge in trust drafting and management and public benefits, two areas of law not previously related to each other until the development of special needs trusts beginning in the 1990s.

SNA members may represent any of the parties interested in a special needs trust – the beneficiary, settlors, or trustees – as well as serving on the board of directors of pooled trusts, as trustees themselves or as guardians ***ad litem*** for probate or civil division courts called upon to approve the creation of a trust or its funding with the assets of a minor or disabled individual. In these multiple roles, SNA members see the reality of life with a special needs trust and have developed expertise on many of the legal questions presented to trustees and courts involved in managing special needs trusts.

SNA's interest is Federal public benefits law, what Congress requires of State Medicaid agencies in dealing with special needs trusts, and the scope of State regulation of special needs trusts in general and pooled trust specifically.

The Board of Directors of the Special Needs Alliance has authorized the undersigned attorneys to file this Brief on its behalf.

National Academy of Elder Law Attorneys, Inc., and the Pennsylvania Association of Elder Law Attorneys, Inc.

The National Academy of Elder Law Attorneys, Inc., (NAELA) and the Pennsylvania Association of Elder Law Attorneys (PAELA) are professional organizations of attorneys concerned with legal issues affecting the elderly and disabled. NAELA has in the past ten years established sections specifically devoted to special needs trusts and the needs of clients who require them, and programs on SNTs are a regular part of NAELA's semi-annual conferences and institutes.

NAELA's and PAELA's interest, like that of SNA, is Federal public benefits law, what Congress requires of State Medicaid agencies in dealing with special needs trusts, and the scope of State regulation of special needs trusts in general and pooled trust specifically.

The Boards of Directors of the National Academy of Elder Law Attorneys, Inc., and of Pennsylvania Association of Elder Law Attorneys, Inc., authorized the undersigned attorneys to file this Brief on their behalf.

ISSUES PRESENTED

1. In mandating trust accounts "solely for the benefit of [disabled] individuals," did Congress intend to authorize State Medicaid agencies to micro-manage the work of non-profit trustees?

2. Does the cap on retention threaten the success of Congress' plan to encourage the creation of non-profit trust entities caring for an under-served disabled population?

STATEMENT OF THE CASE

Congress has since 1993 formally recognized that many people getting means-tested Medicaid[1] benefits will have other, unmet needs. This fact was long recognized by state courts in allowing the coordination of private wealth and means-tested public benefits.[2] Congress joined that policy movement by making specific provision for using private funds to assist public benefits beneficiaries to meet those needs without loss of public benefits.[3] The problem Congress sought to solve that year was the abusive use of self-settled trusts to obtain Medicaid long term (nursing home) care benefits. Its earlier effort to disable the use of "Medicaid qualifying trusts" had been ineffective,[4] so in re-visiting the problem Congress enacted a much broader prohibition.[5] The very breadth of the new proscription, however, required that

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[1] Section 1901 of the Social Security Act of 1935, as amended, 42 U.S.C. § 1396 ***et seq.***, and formally known as Medical Assistance.

[2] ***See. e.g., Lang v. Commonwealth Dept. Of Public Welfare,*** 528 A.2d 1335 (Pa. 1987). ***See generally,*** Rosenberg, Joseph, "Supplemental Needs Trusts for People with Disabilities: The Development of a Private Trust in the Public Interest," 10 **B.U. PUB.INT. L. J**. 91, 127-130 (2000) (hereinafter Rosenberg, "Supplemental Needs Trusts").

[3] Pooled trusts ante-dated the Federal statute authorizing self-settled pooled trust accounts; ***see*** Rosenberg, "Supplemental Needs Trusts," 10 **B.U. PUB.INT. L. J**. at 109-122.

[4] 42 U.S.C. § 1396a(k), repealed.

[5] Unlike the MQT provision, which only reached the exercise of trustee discretion, the (continued...)

Congress also act to preserve (if not expand) the use of trusts in connection with public benefits. It provided two kinds of trusts to preserve assets for disabled individuals, individual and "pooled" trusts, similar but not identical, both within the rubric of "special" or "supplemental" needs trusts.[6] Individual and pooled trusts are easily compared:

	Individual trust	Pooled trust account
Disabled	Required	Required
Age limit	Under age 65	None

[5](...continued)
new provisions were quite broad. First, they counted as the trust of an applicant a trust where "assets of the individual were used to form all or part of the corpus of the trust" and the trust was created by, ***inter alia***, "[a] person, including any court..., acting at the direction or upon the request of the individual ... ." Second, the corpus of the trust would be considered available for Medicaid purposes "if there are any circumstances under which payment from the trust could be made to or for the benefit of the individual ...." 42 U.S.C. § 1396p(d)(2)(A) & (iv) and (3)(B)(i).

[6]

> The terms *special* and *supplemental*, describing the needs these trusts meet, do not have precise meaning and are, as a practical matter, interchangeable. They do not appear in any organic or authorizing statute, although now they may be used in regulations to identify their subjects or targets. The notion of "supplemental" is that the trust is "to supplement, not supplant," public benefits. The word *special* is probably drawn from special education, which often serves the same public. Although special education refers to specific, enhanced teaching services, an SNT often meets basic needs such as food, shelter, and transportation, while the beneficiary gets special services available through public benefits.

Landsman, Ron, "Special Needs Trusts," in Soled, Jay (ed.), ***The ABA Practical Guide to Estate Planning***, pp. 189-190 (2011)(footnotes omitted). ***See also*** Myskowski, Jan, "Special Needs Trusts in the Era of the Uniform Trust Code," NHBA Bar Journal, Spring 2005 ("The terms 'special ...' and 'supplemental ...' are used interchangeably, along with other similar terms").

Established by	Parent, grandparent, legal guardian or court	Beneficiary, parent, grandparent, legal guardian or court
Payback required	All amounts, on death of beneficiary	"To the extent ... not retained by the trust," all amounts, on death of beneficiary
Operated by	Any trustee	Non-profit association
"Sole benefit"	From funding exception "solely for the benefit of a[disabled] individual"	Accounts are established "solely for the benefit of [disabled] individuals ... ."

The trust provisions are embedded in, and an integral part of, the section of the statute dealing with liens, recoveries and transfers of assets, each element of which is binding on the States:

42 U.S.C. § 1396p(a)(1)(A): "***No*** lien may be imposed against the property of any individual prior to his death on account of medical assistance paid ... on his behalf ... except" (emphasis added) as provided in the following sections.[7]

42 U.S.C. § 1396p(b)(1): "***No*** adjustment or recovery of any medical assistance correctly paid ... may be made, except" (emphasis added) for recovery required in three specified circumstances. Where Congress intended to give States an option, it said so, ***e.g.,*** 42 U.S.C. § 1396p(b)(1)(B)(ii)("at the option of the State," it may recover

[7] ***See Arkansas Department of Health and Human Services v. Ahlborn***, 547 U.S. 268, 164 L.Ed.2d 459, 126 S.Ct. 1752 (2006).

for goods and services in addition to long term care, waiver and related hospital and drugs services).

42 U.S.C. § 1396p(c)(1)(A): "In order to meet the requirements of this subsection..., the State Plan ***must provide***" for a denial of long-term care and related benefits in certain situations, and further requires:

> [a]n individual ***shall not be ineligible*** for medical assistance by reason of [the mandatory anti-transfer rules] to the extent that –
>
> ....
>
> (B) the assets –
>
> ....
>
> (iii) were transferred to ... a trust (including a trust described in subsection (d)(4) of this section) established solely for the benefit of [] the individual's [blind or disabled] child ..., or
>
> (iv) were transferred to a trust (including a trust described in subsection (d)(4) of this section) established solely for the benefit of an individual under 65 years of age who is disabled ... .

42 U.S.C. § 1396p(c)(2) (emphasis added). This provision is of course directed at state Medicaid agencies, which determine eligibility, giving individual beneficiaries the right to utilize, ***inter alia***, pooled special needs trusts (PSNTs) meeting Federal requirements without loss of their benefits. It specifically references 42 U.S.C. § 1396p(d)(4) as identifying the trusts, ***inter alia,*** that people may utilize without losing eligibility.

Presumably reflecting its satisfaction with those arrangements, Congress in 1999 extended the exclusion for income and assets in self-settled payback trusts to the

SSI program, so that SSI beneficiaries, too, could enjoy the benefits of trusts even while collecting income.[8]

Pennsylvania enacted the statute at issue in this case, 62 P.S. § 1414, in July 2005 as part of the public welfare code. It defined a "special needs trust" to include a trust or a pooled trust account of the type referenced in the Federal statute, 42 U.S.C. § 1396p(d)(4)(C), for disabled individuals as defined in the Federal statute, 42 U.S.C. § 1382c(a)(3), containing the person's assets and for the purpose of "establishing or maintaining" Medicaid eligibility, which is of course the purpose of the exclusion of such trusts from the mandatory transfer rules in 42 U.S.C. § 1396p(c)(2). 62 P.S. § 1414(f). It required that such trusts be approved by a court of competent jurisdiction "if required by rules of court" and by the Department of Public Welfare, providing no standard for courts but directing the Department to address conformity with the Medicaid statute, state law including 62 P.S. § 1414, and broadly including "any regulations or statements of policy adopted by the department to implement this section." 62 P.S. § 1414(b)(4). It also imposed the following substantive limitations:

-- The beneficiary has to be under age 65;

-- The beneficiary must "have special needs that will not be met without the trust."

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[8] Foster Care Independence Act, Pub.L. 106-169, § 206, 113 Stat. 1822 (Ded. 14, 1999), ***amending*** 42 U.S.C. § 1382b(e)(5).

-- Distributions from the trust must be for the "sole benefit" of the beneficiary.

-- Distributions "must have a reasonable relationship to the [special][9] needs of the beneficiary," defined as products or services "to increase the beneficiary's quality of life ***and*** [which] are related to the treatment of the beneficiary's disability" (emphasis added).[10]

62 P.S. § 1414(b)(1), (b)(2), (b)(3)(i), (b)3(ii), and (f).

Finally, it also required that pooled trusts, upon the beneficiary's death, "shall provide that no more than fifty percent of the amount remaining in the beneficiary's account may be retained by the trust" without obligation to, ***inter alia***, repay the state. All of these provisions are to be enforced by the power to seek a court order terminating the trust for any violation.

Suit was brought by two pooled trusts and eight individuals who had pooled trust accounts established prior to the effective date of the act; four individuals with post-act accounts were later added.

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Memorandum Opinion, pp. 13-14 (App. (I), p. 59a-60a).

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The list does not include such basics as shelter or clothing, nor reading and other entertainment materials or electronic devices of any kind. It includes education, transportation, travel and dietary needs and supplements only if they are disability-related.

There is no dispute that the Department intends to enforce the act. While the Department contends that it is relevant that it has not decided ***how*** to enforce the remaining provisions, there would appear to be no serious dispute that the Pennsylvania statute plainly prohibits actions that the pooled trusts now commonly engage in, ***e.g.,*** paying for food, clothing or shelter for beneficiaries or for other goods and services that are not related to the individual beneficiary's disability. As such, it sets a legal standard that conscientious trustees violate at the risk of significant financial liability in the future.

SUMMARY OF ARGUMENT

The Department's arguments rest on suggestions or representations about pooled special needs trusts that fail to reflect accurately their scope and operation. To the extent it bears upon the underlying technical legal issues, a close review of the complicated decisions trusts must make, viewed in the specific Federal legislation, shows that Congress was not giving States any special authority in taking over the management of non-profit pooled special needs trusts. Similarly, denial of the right of retention provided by Congress in the federal statute would undercut the special role Congress marked out for non-profit pooled SNTs.

ARGUMENT

The Department in its appeal of the District Court's decision raises justiciability and other jurisprudential issues, ***e.g.,*** whether Plaintiffs are entitled to relief for the wrongs complained of under Section 1983 or the Supremacy Clause, and whether Federal preemption applies. On its face, these arguments do not address the nature or extent of the conflict between the state statute and the Federal law, but in its brief the State either minimizes the conflict (***e.g.,*** Brief of Appellant, pp. 28-30) it disregards the effects to avoid the legal consequences of absolute and direct inconsistency. These factual claims seriously misrepresent the reality of special needs trusts. The State's presumptions or conclusions about how special needs trusts operate and what Congress must have intended, based on somewhat fanciful factual scenarios, are at odds with the reality of the role SNTs play – as Congress intended – in improving the lives of disabled individuals. The legal issues in this case are too important to be resolved based on a skewed understanding, indeed almost a flippant description, of the role of SNTs in American life today – a role that is exactly as Congress intended without State limitations and micro-managing.

The ***amici*** file this brief to provide the Court with a broader view of the role of SNTs and how they operate, so that the Court will have a better factual basis to the extent that these considerations bear upon the technical legal grounds on which the Department relies to evade compliance with Federal law.

1. CONGRESS DID NOT AUTHORIZE STATE MEDICAID AGENCIES TO MICRO-MANAGE THE WORK OF NON-PROFIT TRUSTEES.

Congress chose as its mechanism for coordinating private wealth and public benefits the familiar state law entity of the trust. There is no general Federal law of trusts. The means Congress used can only be properly understood in the context of the law and the legal system within whose ambit Congress was acting.

> [T]o the extent that [Congressional] policies refer to, incorporate, or depend on state law then the court will to that extent apply state law – not because of ***Erie*** [***Erie Railroad Co. v. Tompkins***, 304 U.S. 64 (1938)], but because the statutory policy so requires.

Pritchard v. Smith, 289 F.2d 153, 155 (8th Cir. 1961), ***citing*** I ***Moore's Federal Practice***, § 0.323 (22). In ***Molzof v. United States***, 502 U.S. 301, 307-308 (1992)***,*** the question was what constituted "punitive damages" as used in a Federal statute with reference to state law remedies.

> [W]here Congress borrows terms of art in which are accumulated the legal tradition and meaning of centuries of practice, it presumably knows and adopts the cluster of ideas that were attached to each borrowed work in the body of learning from which it was taken and the meaning its use will convey to the judicial mind unless otherwise instructed. In such case, absence of contrary direction may be taken as satisfaction with widely accepted definitions, not as a departure from them..

502 U.S. at 307-308, citing and quoting ***Morissette v. United States*****,** 342 U.S. 246, 263, 72 S.Ct. 240, 250 (1952). The question is, what was Congress' intent in using this

language? ***See also***, ***Sereboff v. Mid Atlantic Medical Services, LLC***, 547 U.S. 356, 361, 126 S.Ct. 1869, 1873 (2006); ***Ex parte Schreiber,*** 110 U.S. 76 (1884).

In directing that special needs trusts be for the "sole benefit" of the disabled beneficiary,[11] Congress was addressing a fundamental duty of trustees under the law of trusts. A trustee is normally required to take into consideration the interests of both the life beneficiary as well as the remainderman under the duty of impartiality. ***See, generally***, American Law Institute, ***Restatement of the Law - Restatement (Third) of Trusts***, § 79. "[T]he duty [requires] balancing the naturally conflicting concerns of life and remainder beneficiaries," ***id.,*** General Comment (a), in all areas of trustee performance, including, especially relevant here, in making discretionary distributions. ***Id.*** A settlor of a trust may of course establish priority among beneficiaries, and if so the trustee is required to "give effect to the rights and priorities of the various beneficiaries ... as expressed or implied by the terms of the trust." ***Id.,*** Comment b: Meaning of Impartiality.

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[11] The use of "sole benefit," though widely accepted and indeed rather obvious given Congress' fundamental purposes, is not so straightforward in the Federal statute. The exclusion for special needs trusts does not refer to sole benefit for individual trusts, ***see*** 42 U.S.C. § 1396p(d)(4)(A), and the reference in pooled trusts ("[a]ccounts ... are established solely for the benefit of individuals who are disabled") could mean only that the trust can have only disabled beneficiaries, not able-bodied ones. 42 U.S.C. § 1396p(d)(4)(C)(iii). Rather, the phrase appears in the provisions exempting certain transfers from the anti-transfer rules: "to a trust (including a trust described in subsection (d)(4) of this section) established solely for the benefit of" the beneficiary's child or any person under age 65. 42 U.S.C. § 1396p(c)(2)(B)(iii) & (iv).

In requiring "sole benefit" for the disabled beneficiary, Congress was appropriately requiring that to enjoy the benefits of the exclusion from the transfer and availability rules, the trust settlor give the interests of the disabled beneficiary not only priority but exclusivity in trustee decision-making, disregarding the interests of remaindermen. Congress focused on the needs of disabled individuals, preserving their rights to get Medicaid and SSI while enjoying the benefit of valuable assets, and an independent trustee would fail to act in the best interests of the beneficiary at its peril.

There is no gainsaying that in electing to use the state law of trusts as the basis for managing this private wealth/public benefit interface, Congress intended that general state trust law would control.[12] But it is quite something else to say that Congress was inviting the States by special provisions to micro-manage what trustees do as fiduciaries and limit the availability of trusts for many people who could benefit from them. By limiting trusts to those whose "special needs ... will not be met without the trust," and limiting trustees to making expenditures only for services related to the "treatment of the beneficiary's disability," Pennsylvania would undermine the very system Congress sought to put in place.

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[12] ***Cf. Brief of Appellant***, pp. 24-25. As the District Court noted, the statute was not enacted as part of general trust legislation but specifically for the purpose of limiting the availability of Medicaid for individuals using special needs trusts as authorized by Congress. ***Memorandum Opinion*** at 27 (App. (I), p. 73a).

The two provisions are inter-related. The latter limits distributions to goods and services for the treatment of the beneficiary's disability, while the former would attempt to screen out those potential beneficiaries who could ***never*** satisfy that test by a prediction at the outset of a condition that could last 50 years or more. The fundamental problem is that Congress never intended to limit, nor authorized the States to limit, the use of special needs trusts to goods and service for treating the beneficiary's disability. While Congress said little in the legislative history about its purposes, the professionals who work in the area over the past two decades have developed clear notions about the scope of what Congress did.

> A special needs trust is not just about public benefits eligibility for the beneficiary – it is about something more – supplementing what is covered by public benefits so that a beneficiary who has a disability may have a better quality of life.[13]

An SNT might be used for housing, transportation (including if appropriate a vehicle with no adaptive modifications at all), travel and vacation, entertainment and social activities, among other things:[14]

> The stated purpose of most SNTs is to improve the quality of life of the SNT beneficiary to the greatest extent possible. This is usually stated in terms of supplementing services already available through governmental programs. As a result, as long as the SNT trustee is granted appropriate discretion in the

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[13] Zimring, ***Fundamentals of Special Needs Trusts***, § 1.05[1], p. 1-11.

[14] ***Id***., § 6.03, p. 6-5 ***et seq.***, § 6.05[2], p. 6-17, § 6.07[2][a], p. 6-23, 6.07[2][d], p. 6-24

> SNT, there is no reason the SNT cannot provide the SNT beneficiary with the opportunity to experience as wide a range of cultural and recreational activities as she is capable of handling whether they be trips to Disneyland, rock concert tickets, athletic club memberships – virtually anything a person similarly situated to the SNT beneficiary would do or want to do absent the disability.[15]

Another leading treatise on special needs trusts gives these examples of permissible distributions for a trust beneficiary receiving SSI benefits:[16]

- Home purchase ...;
- Home improvements, repairs and maintenance ...;
- Tools to perform home improvements ...;
- School tuition, books, and supplies;
- Health and insurance premiums;
- Entertainment purposes, including books and magazines; trips to movies, plays, museums, and sporting events; audio/video equipment; or hobby supplies;
- Purchase and maintenance of car, or bus passes;
- Household goods and other items of personal property ...;
- Clothing;
- ... cleaning supplies and paper products;
- Telephone expenses;
- Dental care ... and other medical costs not covered by any benefit program;

....[17]

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[15] ***Id.***, § 6.07[2][d], p. 6-24.

[16] The significance of SSI is that distributions are limited compared to other public benefits beneficiaries. Under SSI, payments of shelter or food are "in-kind support and maintenance" (ISM) and counted as income to some extent even if paid directly to service providers. If "counted" as income, they reduce or eliminate the public benefit and so are to be avoided if possible. Begley, Tom, and Canellos, Angela, ***Special Needs Trusts Handbook*****,** § 9.04[B][1], p. 9-35.

[17] Begley and Canellos, § 9.04[B], p. 9-34.

Others who have studied special needs trust have all along understood SNTs to serve the many needs – not narrowly tied to the triggering disability – not met by public benefits. An SNT

> mitigates the inadequacies of government benefit programs for people with disabilities. [It] is designed to enhance the beneficiary's quality of life through the purchase of additional goods and services ... [such as] educational and vocational training, computers and software, ... and recreational activities.[18]
>
> SSI and Medicaid provide the disabled with only the bare necessities needed to maintain their health and support. SNT's can provide the disabled child with the additional materials and services that the parent would have provided during their lifetime. Some "luxuries" SNT's can provide include transportation, travel, vacations, entertainment, reading materials, computer equipment, toiletries, and companionship. ... Although these benefits are often deemed "luxuries," that term is really a misnomer because what may be a luxury to a healthy child is actually a necessity to a disabled child.[19]
>
> Generally, need-based government programs provide only the bare necessities to the disabled person. These programs do not provide all that the child or adult may need and, therefore, the individual planning an estate usually wants to ensure that the property and its income supplement the government benefits. For example, government benefits currently would not pay for travel, entertainment, over-the-counter medications, reading materials or toiletries.[20]

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[18] Rosenberg, ***supra***, at 93-95

[19] Field, Jennifer, "Special Needs Trusts: Providing for Disabled Children Without Sacrificing Public Benefits," 24 Journal of Juvenile Law 79, 81-82, 81 (2003-2004)(footnotes omitted).

[20] Harp, Chadwick A., "Estate Planning for the Disabled Beneficiary," 11 APR Property and Probate 14, 15 (March-April 1997).

Pennsylvania's attempt to micro-manage pooled (and other) special needs trusts by limiting and specifying the items for which they may make distributions runs afoul of Congress' directive to impose that duty on trustees to determine what is in the best interests of the disabled beneficiary, for whose sole benefit the trust or trust account must be established. Simple general rules from Harrisburg, painted with a broad brush as they must be, cannot possibly address the best interests of the beneficiary in the subtlety and complexity that SNT trustees deal with every day.

That complexity can go in a number of different directions. A simple rule would, for example, prohibit payments to family members for providing any good or service for the beneficiary, while allowing payment to third party professional service providers. But such a rule is too broad. A trustee might decide, as the independent trustee did in the ***Hobbs*** case, with probate court approval (a fact in the record not acknowledged by either court[21]), that it was less expensive to use trust funds to pay the mother for providing some of the necessary care. Conversely, the same rule is too narrow. For example, every dollar spent for a beneficiary that relieves the parents or family in some way benefits them and the non-disabled children. It is not just what they themselves do not have to spend money on; it is relief from burdens many of which are unique to seriously disabled children. The non-disabled children benefit

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[21] ***Hobbs v. Zenderman***, 579 F.3d 1171 (10th Cir. 2009), ***aff'g***, 542 F.Supp.2d 1220 (D.N.M. 2008).

fairly directly when a special needs trust pays for an aide to care for their disabled sibling, freeing up their mother to spend more time with them. To say that such payments are thus for the sole benefit of the disabled beneficiary because paid for a good or service for him or her is simply to deny the reality of the intermingling of the health and welfare and interests of family members living together. ***See also*** Zimring, ***Fundamental of Special Needs Trusts***, § 6.04[7], p. 6-16. If the family cannot afford decent housing, does the trustee leave his beneficiary in squalor or deny her the obvious benefit of the presence of family members? These are the kinds of difficult, discriminating decisions that the system established by Congress leaves to fiduciary trustees.

The limit to goods and services treating the beneficiary's specific disability would leave trustees unable to exercise reasonable discretion in providing for their beneficiaries in a wide variety of other ways. For example, depression is far more common among the disabled, generally,[22] and yet unless depression were "***the***

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[22] Studies have shown that symptoms of depression may be 2 to 10 times more common in individuals with disabilities or chronic illnesses, and depression is one of the most common "secondary conditions" associated with disability and chronic illness.

Thompson, Karla, Ph.D., ***Depression and Disability: A Practical Guide***, p. 1 (NC Office on Disability and Health 2002) (accessed on-line at http://www.fpg.unc.edu/~ncodh/pdfs/depression.pdf). ***See, e.g.,*** Maag, John W., and Reid, Robert, "Depression Among Students with Learning Disabilities: Assessing the Risk," 39:1 ***Journal of Learning Disabilities*** 3 (2006).

beneficiary's disability," as opposed to one that arose later as a result of the disability, the trustee would be barred from paying for any good or service to alleviate the beneficiary's suffering.

The Department makes much of the fact that it has never opposed the establishment of an account because the individual does not have special needs[23] nor blocked a specific disbursement, ***Brief of Appellant***, p. 8, 14, and suggests that it would only use the latter to block "luxury items such as Jaguar automobiles, expensive jewelry, and Rolex watches under this provision." ***Id.*** at 14. Rejection of the statute "say[s] that pooled trust beneficiaries can use their accounts to buy fast cars, fur coats, and diamond jewelry – all while the taxpayers are paying their medical bills." ***Id.*** at 29. It is presumably to restrain the ability to buy such luxury items that the Department is concerned to impose these restrictions "to bar millionaires from using SNTs to shelter their money and qualify for Medicaid. ... [Absent these restrictions,] Bill Gates and Warren Buffet could put all their assets into a SNT and qualify for Medicaid if they become disabled." ***Id.*** at 31, 32.[24] In the same breath, the Department acknowledges that it has allowed "millionaires" to establish PSNT accounts. ***Id.*** at 14.

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[23] We assume it means special needs "that will not be met without the trust," as provided in the statute, 62 P.S. 1414(b)(2).

[24] And, of course, putting aside that Messrs. Gates and Buffet would then have to pay far more in Federal estate and gift taxes than they could every conceivably benefit from the Medicaid program.

It is difficult to find a nexus between the regulation and its defense. The claim that the regulation only reaches luxury items and "allows a broad arrange of pooled trust expenditures including payment for virtually anything that will increase the beneficiary's quality of life" (***Brief for Appellant***, p. 28) appears somewhat divorced from reality unless the term "quality of life" has some narrow and peculiar meaning, known only to the Department. ***Cf.***, ***supra,*** fn. 10. It is also divorced from the reality that the vast majority of PSNT beneficiary accounts are too small even to utilize private bank trust services. The large account sought to be established by Plaintiff Lewis, ***see*** p. 27, below, is the exception to, not the rule of, life in the PSNT world.

The existing system of fiduciary trustees subject to probate court jurisdiction is more than adequate to deal with the (short) parade of horribles that the Department suggests. A trustee who made luxury purchases would almost certainly be violating its duties of prudence and due care.[25] The state as ***parens patrie***, ***Gibbs v. Titelman,*** 369 F.Supp. 38 (D.C.Pa., 1973), ***reversed on other grounds***, 502 F.2d 1107 (3rd Cir. 1974), ***cert.den.***, 419 U.S. 1039, could certainly step in if any of the hypothetical ever actually arose.

This is not to say that a state, were it actually to identify problem areas with special needs trusts, could never deal with the problem by legislation rather than case-

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[25] ***Restatement of the Law - Restatement (Third) of Trusts***, § 77, Comment on Subsections (1) and (2): (b).

by-case orphans court litigation. That is plainly a remedy available by reason of Congress' use of trusts as the mechanism for coordinating public wealth and public benefits. But that is not what the legislation at issue here does. Rather, it affirmatively limits the use of SNTs and even denies people access to them notwithstanding that they fall squarely within the protections enacted by Congress.

The Department's arguments come down to two elements. First, whatever the statute says, we would never apply it as written but only to really, really rich people who don't really need Medicaid anyway (and putting aside why they would go to the trouble of getting it). Second, even if flatly contrary to Congress' mandate, the procedural niceties of Section 1983, the Supremacy Clause and justiciability doctrine do not permit the Federal court to protect individuals injured by this law now.

But the Department's assurances are not very assuring to trustees who must make disbursement decisions every day and who face liability risks if – as a result of action taken by Department years later – someone thinks they have a claim because the trustee failed to adhere to Pennsylvania's strict rule as written. The present limits on trustee discretion, however later enforced, are real and present dangers to the effective use of special needs trusts. The issue is not just Department enforcement, as it claims, but establishing a standard of conduct that may result in imposition of liability at any time in the future, and thus constraining the action of trustees today.

2. THE CAP ON RETENTION THREATENS THE SUCCESS OF CONGRESS' PLAN TO ENCOURAGE THE CREATION OF NON-PROFIT TRUST ENTITIES CARING FOR AN UNDER-SERVED DISABLED POPULATION.

Congress provided specifically for non-profit managed pooled special needs trusts, recognizing the reality that it was non-profit charitable groups that were attending to the long-term financial management needs of those suffering permanent mental and physical disability.[26]

> Nonprofit groups perform caregiving functions that were previously the responsibility of parents and, from a historical perspective, were assumed by the extended family and informal support networks. The pooled trust provisions [of OBRA '93] implicitly recognize this and expand the authority of these groups to assume financial management responsibilities for people with disability.[27]

Pooled trusts were developed exactly to meet the needs of those who had long-term needs but insufficient resources to use the commercial bank and trust department services available to the wealthy.

But for Congress' action, the problem would continue to this day. Banks, brokerage firms and trust departments – when they do consider serving as trustee of a trust for a disabled person – still have minimum asset limits from $250,000 to $1,000,000, whether for special needs or not. For example, Mass Mutual, whose trust

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[26] ***See, supra***, Rosenberg, "Supplemental Needs Trusts," 10 **B.U. PUB. INT. L. J**. at 127-130, 132-133.

[27] ***Id.*** at 133.

company will serve as trustee of a special needs trust, has a minimum for SNTs of $350,000.

Moreover, special needs trust services are more difficult to provide than conventional trust work, require a wider range of knowledge and skills, and present unique potential liability problems. To start with, it involves all of the same financial skills – long term investing with regard to tax and other concerns. But it also requires, in addition, knowledge of and attention to the income rules for public benefits like SSI and Medicaid.[28] To the extent that the beneficiary has special medical needs, and the more so when there is psychiatric illness, as is often the case, the beneficiary presents far more demands on the time of trust officers and requires more subtle personal and professional skills. Finally, special needs trust work adds new areas of liability. In addition to all that may be required for conventional trusts, there is the potential liability for the inadvertent loss of Medicaid benefits when expensive health care services are required. The competence required of the attorney drafting a special needs trust applies (with one exception) to the SNT trustee as well:

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[28] The SSI income rules are especially confusing to those familiar with investment income and tax treatment of income because much that is not income for tax purposes is income for SSI purposes, and conversely a lot of taxable income would not count as income under the SSI program. ***See*** Butenhoff, Ann, and Bomster, Judith, "Comparing Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)," ***The Voice Newsletter***, Vol 5, No. 2 (January 2011)(http://specialneedsalliance.com/the-voice/5/2).

> An attorney drafting a SNT for a person with disabilities must be familiar with what public benefits are available to the beneficiary, how the trust may affect eligibility for those public benefits, and what agencies are or will be involved at the federal, state and local level in dealing with those benefits. Further, drafting a SNT requires familiarity with what one usually refers to as traditional estate planning, i.e., trust law, income, estate and gift tax law, and real property taxation. .... On top of this, it is probably necessary to have some knowledge of medical terminology so that one can intelligently read a Life Care Plan in order to properly draft the distribution provisions of the SNT to conform to the beneficiary's needs in the years to come.[29]

In light of the difficulties, Congress' special leave for the creation of pooled special needs trusts is a great success. There are now hundreds of PSNTs around the country, two or more in most states, most relatively small and serving well-defined geographical areas where they can maintain close contact with beneficiaries and know the details of the local public benefit system. Many were generated by non-profit organizations that subsidized them by providing staff, space and other administrative support while the trusts got up and running. Many have now gotten to operational size only because of the non-profit operational support and, to a lesser extent, retention of funds from the accounts of deceased beneficiaries, while serving those who could never qualify for private fiduciary services from banks or trust companies.

Besides being flatly inconsistent with the language of the Federal statute, Pennsylvania's limit would undo the benefits of what Congress has provided by

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[29] ***Zimring, et al.***, ***Fundamentals of Special Needs Trust***, § 2.03[1], p. 2-8. The deleted sentence concerns financial decisions that are only made before funding, ***e.g.***, the use of a tax-favored structured settlement, and so are not the obligation of the trustee.

denying non-profit trusts an important source of revenue for benefits and services that enhance their role in the community and attract new beneficiaries. The Department makes no claim that its position will not irreparably harm the PSNTs in the state, only that it is not barred by Federal law from doing so. But even that argument rests on thin logic. The Federal statute requires state Medicaid programs not to deny eligibility by reason of transfers to trusts meeting the requirements of 42 U.S.C. § 1396p(d)(4)(C). A trust meets that requirement if it repays Medicaid all of the funds (up to the total Medicaid claim) it does not retain from a specific account. That is to say, all that Congress required is payback ***after*** retention, while Pennsylvania – in direct conflict – requires payback ***without regard to*** the trust's desire – or need – for retention after the first 50% retained. To say, as the Department does, that Congress did not grant a ***right*** to retain 100%, ***Brief of Appellant*** , p. 27, misses the point that Congress determined that there would be no ***duty*** to repay: it requires States to exempt transfers to trusts that are not required to repay to the extent the trust retains the funds. It would of course be a different matter entirely if pooled trusts claimed they could distribute retained funds some other way, but that is not the case. The one obligation of which Congress relieved them was the duty to pay the state to the extent they retained funds from a deceased beneficiary's account.[30] Pennsylvania is not entitled, as a recipient of

[30] Similarly, the Department's argument under, ***e.g., Blessing v. Freestone***, 520 U.S. (continued...)

Federal funds for its Medicaid program, to disregard that clear and unequivocal direction from Congress and deny benefits to individuals who want to give funds to pooled trusts that will retain them rather than re-paying Medicaid.[31]

What Pennsylvania seeks to do by this legislation is achieve wholesale what it failed to do retail in ***Lewis v. Magee Women's Hospital***, 67 Pa. D.&C.4th 362 (Pa.Comm.Pl. 2004), 2004 WL 2526187. There, Plaintiff Zackery Lewis sought to place his medical malpractice settlement in a pooled trust, The Family Trust, also a plaintiff in this action, which the Department of Public Welfare opposed because it would deny them any post-mortem recovery. Applying the best interests of the child as the standard, the court rejected DPW's claim, explaining:

> I find that the request of the parents of Zackery Lewis, to place the settlement proceeds in The Family Trust, is consistent with Zackery Lewis' best interests. In determining what type of trust will best serve Zackery Lewis' interests, they favor a mission-based trust with trained professionals over a traditional trust, the trustee of which may be a trust department of a financial institution.

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[30](...continued)
329 (1997), fails to acknowledge that it is the beneficiary's right to use such trusts that is protected. It fails to explain why the post-mortem disposition of one's assets is not a morally and emotionally significant right that has real legal significance. It is not irrelevant to note that there is a whole financial-legal industry devoted to that concern only.

[31]
The authority from the CMS ***State Medicaid Manual*** does not, of course, arise to the level of authority requiring ***Chevron*** deference (***Chevron US.A. v. Natural Resources Defense Council***, 467 U.S. 837 (1984)), which the Department does not bother to address, ***see Brief of Appellant,*** p. 27.

In thwarting the best interests of disabled Medicaid beneficiaries, Pennsylvania would also seriously damage its PSNTs. It is of course entitled to enact unwise policies for itself, if it so chooses, just as a farmer can eat his seed corn if he is so inclined. But it is not free to do so in violation of a contrary directive from Congress with which it has agree to comply as a condition of Federal funding of its Medicaid program.

CONCLUSION

For the foregoing reasons, the decision of the District Court should be affirmed.

Respectfully submitted,

s/Shirley Whitenack
Shirley Whitenack
Schenck, Price, Smith & King, LLP
220 Park Avenue, PO Box 991
Florham Park, NJ 07932
973-539-1000

s/Ron M. Landsman
Ron M. Landsman
Ron M. Landsman, P.A.
200-A Monroe Street, Suite 110
Rockville, MD 20850
240-403-4301

s/Marielle F. Hazen
s/Marielle F. Hazen
Hazen Elder Law
2000 Linglestown Road, Suite 202
Harrisburg, PA 17110
717-540-4332

STATUTORY ADDENDUM

42 U.S.C. § 1396p. Liens, adjustments and recoveries, and transfers of assets

(a) Imposition of lien against property of an individual on account of medical assistance rendered to him under a State plan

(1) No lien may be imposed against the property of any individual prior to his death on account of medical assistance paid or to be paid on his behalf under the State plan, except—

(A) pursuant to the judgment of a court on account of benefits incorrectly paid on behalf of such individual, or (B) in the case of the real property of an individual—

(i) who is an inpatient in a nursing facility, intermediate care facility for the mentally retarded, or other medical institution, if such individual is required, as a condition of receiving services in such institution under the State plan, to spend for costs of medical care all but a minimal amount of his income required for personal needs, and

(ii) with respect to whom the State determines, after notice and opportunity for a hearing (in accordance with procedures established by the State), that he cannot reasonably be expected to be discharged from

the medical institution and to return home, except as provided in paragraph (2).

(2) No lien may be imposed under paragraph (1)(B) on such individual's home if—

(A) the spouse of such individual,

(B) such individual's child who is under age 21, or (with respect to States eligible to participate in the State program established under subchapter XVI of this chapter) is blind or permanently and totally disabled, or (with respect to States which are not eligible to participate in such program) is blind or disabled as defined in section 1382c of this title, or (C) a sibling of such individual (who has an equity interest in such home and who was residing in such individual's home for a period of at least one year immediately before the date of the individual's admission to the medical institution), is lawfully residing in such home.

(3) Any lien imposed with respect to an individual pursuant to paragraph (1)(B) shall dissolve upon that individual's discharge from the medical institution and return home.

(b) Adjustment or recovery of medical assistance correctly paid under a State plan

(1) No adjustment or recovery of any medical assistance correctly paid on behalf of an individual under the State plan may be made, except that the State shall seek adjustment or recovery of any medical assistance correctly paid on behalf of an individual under the State plan in the case of the following individuals:

(A) In the case of an individual described in subsection (a)(1)(B) of this section, the State shall seek adjustment or recovery from the individual's estate or upon sale of the property subject to a lien imposed on account of medical assistance paid on behalf of the individual.

(B) In the case of an individual who was 55 years of age or older when the individual received such medical assistance, the State shall seek adjustment or recovery from the individual's estate, but only for medical assistance
consisting of—

(i) nursing facility services, home and community-based services, and related hospital and prescription drug services, or

(ii) at the option of the State, any items or services under the State plan (but not including medical assistance for medicare cost-sharing or for benefits described in section 1396a(a)(10)(E) of this title).

(C)[Partnership programs - deleted.]

(2) Any adjustment or recovery under paragraph (1) may be made only after the death of the individual's surviving spouse, if any, and only at a time—

(A) when he has no surviving child who is under age 21, or (with respect to States eligible to participate in the State program established under subchapter XVI of this chapter) is blind or permanently and totally disabled, or (with respect to States which are not eligible to participate in such program) is blind or disabled as defined in section 1382c of this title; and

(B) in the case of a lien on an individual's home under subsection (a)(1)(B) of this section, when—

(i) no sibling of the individual (who was residing in the individual's home for a period of at least one year immediately

before the date of the individual's admission to the medical institution), and

(ii) no son or daughter of the individual (who was residing in the individual's home for a period of at least two years immediately before the date of the individual's admission to the medical institution, and who establishes to the satisfaction of the State that he or she provided care to such individual which permitted such individual to reside at home rather than in an institution), is lawfully residing in such home who has lawfully resided in such home on a continuous basis since the date of the individual's admission to the medical institution.

(3)(A) The State agency shall establish procedures (in accordance with standards specified by the Secretary) under which the agency shall waive the application of this subsection (other than paragraph (1)(C)) if such application would work an undue hardship as determined on the basis of criteria established by the Secretary.

(B) The standards specified by the Secretary under subparagraph (A) shall require that the procedures established by the State agency under subparagraph (A) exempt income, resources, and property that are exempt from the application of this subsection as of April 1, 2003, under manual instructions issued to carry out this subsection (as in effect on such date) because of the Federal responsibility for Indian Tribes and Alaska Native Villages. Nothing in this subparagraph shall be construed as preventing the Secretary from providing additional estate recovery exemptions under this subchapter for Indians.

(4) For purposes of this subsection, the term ''estate'', with respect to a deceased individual—

(A) shall include all real and personal property and other assets included within the individual's estate, as defined for purposes of State probate law; and

(B) may include, at the option of the State (and shall include, in the case of an individual to whom paragraph (1)(C)(i) applies), any other real and personal property and other assets in which the individual had any legal title or interest at the time of death (to the extent of such interest), including such assets conveyed to a survivor, heir, or assign of the deceased individual through joint tenancy, tenancy in common, survivorship, life estate, living trust, or other arrangement.

(5)[Annuities - deleted.]

(c) Taking into account certain transfers of assets

(1)(A) In order to meet the requirements of this subsection for purposes of section 1396a(a)(18) of this title, the State plan must provide that if an institutionalized individual or the spouse of such an individual (or, at the option of a State, a noninstitutionalized individual or the spouse of such an individual) disposes of assets for less than fair market value on or after the look-back date specified in subparagraph (B)(i), the individual is ineligible for medical assistance for services described in subparagraph (C)(i) (or, in the case of a noninstitutionalized individual, for the services described in subparagraph (C)(ii)) during the period beginning on the date specified in subparagraph (D) and equal to the number of months specified in subparagraph (E).

(B)(i) The look-back date specified in this subparagraph is a date that is 36 months (or, in the case of payments from a trust or portions of a trust that are treated as assets disposed of by the individual pursuant to paragraph (3)(A)(iii) or (3)(B)(ii) of subsection (d) of this section or in the case of any other disposal of assets made on or after February 8, 2006, 60 months) before the date specified in clause (ii).

(ii) The date specified in this clause, with respect to—

(I) an institutionalized individual is the first date as of which the individual both is an institutionalized individual and has applied for medical assistance under the State plan, or

(II) a noninstitutionalized individual is the date on which the individual applies for medical assistance under the State plan or, if later, the date on which the individual disposes of assets for less than fair market value.

(C)(i) The services described in this subparagraph with respect to an institutionalized individual are the following:

(I) Nursing facility services.

(II) A level of care in any institution equivalent to that of nursing facility services.

(III) Home or community-based services furnished under a waiver granted under subsection (c) or (d) of section 1396n of this title.

(ii) The services described in this subparagraph with respect to a noninstitutionalized individual are services (not including any services described in clause (i)) that are described in paragraph (7), (22), or (24) of section 1396d(a) of this title, and, at the option of a State, other long-term care services for which medical assistance

is otherwise available under the State plan to individuals requiring long-term care.

(D) through (J) - deleted

(2) An individual shall not be ineligible for medical assistance by reason of paragraph (1) to the extent that—

(A) the assets transferred were a home and title to the home was transferred to—

(i) the spouse of such individual;

(ii) a child of such individual who

(I) is under age 21, or (II) (with respect to States eligible to participate in the State program established under subchapter XVI of this chapter) is blind or permanently and totally disabled, or (with respect to States which are not eligible to participate in such program) is blind or disabled as defined in section 1382c of this title;

(iii) a sibling of such individual who has an equity interest in such home and who was residing in such individual's home for a period of at least one year immediately before the date the individual becomes an institutionalized individual; or

(iv) a son or daughter of such individual (other than a child described in clause (ii)) who was residing in such individual's home for a period of at least two years immediately before the date the individual becomes an institutionalized individual, and who (as determined by the State) provided care to such individual which permitted such individual to reside at home rather than in such an institution or facility;

(B) the assets—

(i) were transferred to the individual's spouse or to another for the sole benefit of the individual's spouse, (ii) were transferred from the individual's spouse to another for the sole benefit of the individual's spouse,

(iii) were transferred to, or to a trust (including a trust described in subsection (d)(4) of this section) established solely for the benefit of, the individual's child described in subparagraph (A)(ii)(II), or

(iv) were transferred to a trust (including a trust described in subsection (d)(4) of this section) established solely for the benefit

of an individual under 65 years of age who is disabled (as defined in section 1382c(a)(3) of this title);

(C) a satisfactory showing is made to the State (in accordance with regulations promulgated by the Secretary) that (i) the individual intended to dispose of the assets either at fair market value, or for other valuable consideration, (ii) the assets were transferred exclusively for a purpose other than to qualify for medical assistance, or (iii) all assets transferred for less than fair market value have been returned to the individual; or

(D) the State determines, under procedures established by the State (in accordance with standards specified by the Secretary), that the denial of eligibility would work an undue hardship as determined on the basis of criteria established by the Secretary. The procedures established under subparagraph

(D) shall permit the facility in which the institutionalized individual is residing to file an undue hardship waiver application on behalf of the individual with the consent of the individual or the personal representative of the individual.

While an application for an undue hardship waiver is pending under subparagraph (D) in the case of an individual who is a resident of a nursing facility, if the application meets such criteria as the Secretary specifies, the State may provide for payments for nursing facility services in order to hold the bed for the individual at the facility, but not in excess of payments for 30 days.

(3) For purposes of this subsection, in the case of an asset held by an individual in common with another person or persons in a joint tenancy, tenancy in common, or similar arrangement, the asset (or the affected portion of such asset) shall be considered to be transferred by such individual when any action is taken, either by such individual or by any other person, that reduces or eliminates such individual's ownership or control of such asset.

(4) A State (including a State which has elected treatment under section 1396a(f) of this title) may not provide for any period of ineligibility for an individual due to transfer of resources for less than fair market value except in accordance with this subsection. In the case of a transfer by the spouse of an individual which results in a period of ineligibility for medical assistance under a State plan for such individual, a State shall, using a reasonable methodology (as specified by the Secretary), apportion such period of ineligibility (or any portion of such period) among the individual and the individual's spouse if the spouse otherwise becomes eligible for medical assistance under the State plan.

(5) In this subsection, the term ‘‘resources’’ has the meaning given such term in section 1382b of this title, without regard to the exclusion described in subsection (a)(1) thereof.

COMBINED CERTIFICATION OF COMPLIANCE

I, Marielle F. Hazen, do hereby certify

1. The ***Brief of Amici*** submitted in this matter complies with the page limitation of Fed. R. App. P.32(a)(7)(A) because it contains less than 7,000 words (word count is 6,999, not including table, certificates and addenda) of proportional type; complies with Rule 32(a)(5)(A) because it uses a 14 point Times New Roman font; and complies with Rule 32(a) because it is double spaced, with required margins on appropriate 8.5 by 11.0 inch paper.
2. The electronic version of this Brief is identical to the hard copy of said Brief.
3. The electronic version of this Brief was checked for computer viruses using Symantec Endpoint Protection prior to transmittal.
4. This Brief was filed electronically on December 13, 2011 with the Office of the Clerk, U.S. Court of Appeals for the Third Circuit, 21400 U.S. Courthouse, 601 Market Street, Philadelphia, PA 19106-1790. Opposing counsel was served electronically via ECF.
5. Ten copies of this were transmitted to the Office of the Clerk via Federal Express on December 13, 2011
6. I am a member of the Bar of this Court.

I hereby certify that the foregoing statements made by me are true.

Dated: December 13, 2011

Respectfully submitted,

s/Marielle F. Hazen
Marielle F. Hazen
Hazen Elder Law
2000 Linglestown Road, Suite 202
Harrisburg, PA 17110
717-540-4332

IN THE UNITED STATES COURT OF APPEALS FOR THE THIRD CIRCUIT

Zackery D. Lewis et al.,	*	
	*	
Appellees	*	
	*	
vs.	*	**No. 11-3439**
	*	
Gary Alexander et al.,	*	
	*	
Appellants	*	

CERTIFICATE OF SERVICE

I certify that I am serving a copy of the brief upon the persons and in the manner indicated below:

Service by ECF electronic filing:

Stephen A. Feldman, Esq.
Feldman and Feldman, LLP
820 Homestead Rd.
Jenkintown, PA 19046

Karen Guss, Esq.
Attorney at Law
2408 Panama Street
Philadelphia, PA 19103

Jason W. Manne
Deputy Chief Counsel
Office of General Counsel
Department of Public Welfare
301 Fifth Avenue, Suite 430
Pittsburgh, PA 15222

Respectfully submitted

s/Shirley Whitenack
Shirley Whitenack
Schenck, Price, Smith & King, LLP
220 Park Avenue, PO Box 991
Florham Park, NJ 07932
973-539-1000

Date: December 13, 2011