

## Special Needs Trusts/Parent as a Caregiver?

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Frequently, a parent of a child with disabilities provides significant care to that child. Often, the mother is unable to work outside of the home because of the child's care requirements. In determining whether and how much a parent can be paid for care of the child, both the Medicaid and SSI programs must be considered if the child is receiving those benefits.

### *Calef v. Barnhart*

In a troubling case, *Calef v. Barnhart*,<sup>1</sup> payments from a special needs trust to a parent as payment for care to a child with disabilities was held to be unearned income. In that case, the child with disabilities received SSI. The New York court ordered that a personal injury settlement received by the child be placed into a special needs trust and that the trust pay the mother a monthly stipend of \$1,000 because she should not work steadily because of her daughter's medical needs. The Social Security Administration (SSA) determined that the mother's monthly stipend of \$1,000 was unearned income that should have been deemed to her daughter, Heather. Heather's mother appealed arguing that the monthly stipend should be treated as earned income. The SSA Commissioner issued a reconsideration decision that stated in part, "To qualify as *earned* income, income must be from wages or employment. A stipend is not a wage as you are Heather's custodial parent, not her employee. She does not have the authority to direct your work. You are not self-employed as your minor child's care-giver as you are receiving neither a wage, nor income from self-employment, the stipend you receive from the trust fund is *unearned*. The prior decision regarding this matter is affirmed." The U.S. District Court first looked at the Social Security Act, which provides, "For purposes of determining eligibility for and the amount of benefits for any individual who is a child under age 18, such individual's income and resources shall be deemed to include any income and resources of a parent of such individual (or the spouse of such a parent) who is living in the same household as such individual, whether or not available to such individual, except to the extent determined by the Commissioner to be inequitable under the circumstances."<sup>2</sup> The court then examined the Code of Federal Regulations. Earned income includes wages and net earnings from self-employment.<sup>3</sup> Unearned income is defined as "all income that is not earned income."<sup>4</sup> Heather's mother argued that she is self-employed in caring for her daughter. The Regulations defined net earnings from self-employment as "gross income from any *trade or business* that you operate less allowable deductions for that trade or business."<sup>5</sup> The Regulations defined wages as payments to an individual for working as someone else's employee.<sup>6</sup> An "employee" is regarded as anyone who has the status of employee under the usual common law rules.<sup>7</sup> A worker is considered an employee, if the person for whom the work is being performed may tell the

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<sup>1</sup> *Calef v. Barnhart*, 309 F. Supp. 2d 425 (Mar. 24, 2004).

<sup>2</sup> 42 U.S.C. §1382c(f)(2)(A); 20 C.F.R. §§416.1160(a)(2), 416.1160(b)-(d) and 416.1165.

<sup>3</sup> 20 C.F.R. §416.110(a).

<sup>4</sup> 42 U.S.C. §1382a(a)(2)(A).

<sup>5</sup> 20 C.F.R. §416.1110(b).

<sup>6</sup> 20 C.F.R. §416.1110(a).

<sup>7</sup> 42 U.S.C. §410(j)(2).

employee what to do and how, when and where to do it.<sup>8</sup> The court held that Heather's mother did not demonstrate that her daughter or her daughter's special needs trust instructed her in the how, when or where of her tasks or directed her actions as to which chores or activities to perform. Therefore, the income was characterized as earned income. Thus, virtually all of that income had to be deemed to Heather.

### ***Medicaid***

The New Jersey Medicaid Regulations provide that parents shall not be relieved of their duty to support their minor child, if they are capable of doing so. A minor's funds in a trust shall not be expended on routine support, unless the parents' income is insufficient for these expenses.<sup>9</sup> However, the New Jersey State Medicaid Agency has accepted the proposition that providing 24-hour care is extraordinary care, not routine, and allows compensation to the parent. The compensation is limited to the fair market value of similar services in the area and is limited to 40 hours per week.

### ***Supplement Security Income (SSI)***

SSI considerations in paying a parent for care provided to a child with disabilities are more complicated. If the child is over 18, the issue is fairly straightforward. Compensation for the care must be reasonable. If the child is under 18, the issue becomes far more complex.

SSI categorizes income as countable and noncountable, earned or unearned, and cash or in-kind.

### ***General***

The first \$20 of most income received in a month is disregarded. Income is defined as "anything a person receives in cash or in-kind that can be used to meet a person's needs for food or shelter."<sup>10</sup> Certain items cannot be used for food and shelter and are, therefore, not counted as income.<sup>11</sup> Receipt of cash income reduces SSI payments dollar-for-dollar, except for the limited exceptions. As a rule, anything of value received during the month is considered income for the month received and a resource as of the first day of the following month.

Distributions from trusts to the SSI recipient are considered income. Therefore, trustees should make distributions directly to third party providers for goods and services.

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<sup>8</sup> 20 C.F.R. §404.1007(a).

<sup>9</sup> N.J.S.A. 3B:12-43; N.J.A.C. 10:71-4.11(g)1(iii)(2).

<sup>10</sup> 20 C.F.R. §416.1102.

<sup>11</sup> These are found at 20 C.F.R. §416.1103.

## *Earned Income*

Earned income is defined as *wages* before deductions and net earnings from *self-employment*.<sup>12</sup> Twenty dollars per month is excluded.<sup>13</sup> There are certain exclusions from earned income, including federal assistance payments, \$30 per quarter of infrequent or irregular income, and \$65 plus one-half of remaining earned income per month.<sup>14</sup>

## *Unearned Income*

Unearned income is defined as all income that is not earned.<sup>15</sup>

- Examples. Examples of unearned income include alimony, annuities, pensions, and inheritances. Exclusions from unearned income are limited to tuition scholarships, \$60 per quarter of Infrequent and Irregular income, and one-third of child support payments to the child with a disability.
- Infrequent and Irregular Income. Income is received infrequently and irregularly if it is received only once during a calendar quarter from a single source and was not received in the month immediately preceding or subsequent to the month of receipt.<sup>16</sup> Irregular income is income that the recipient cannot reasonably expect to receive.<sup>17</sup>
- Interest and Dividend Income and Certain Gifts. All interest and dividend income on countable resources is excluded. Gifts received that are used for paying tuition or education expenses are excluded from income in addition to grants, scholarships, and fellowships used to pay educational expenses.<sup>18</sup>

## *Deeming*

Under SSI, if a child under 18 lives in the household of a parent, part of the income of the parent is deemed to the child.<sup>19</sup> Deeming rules are complex. Certain steps are followed in the deeming process.<sup>20</sup> First, the income of the ineligible parent is determined. Appropriate exclusions are applied. Second, an allocation is made of an amount for each ineligible child in

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<sup>12</sup> 42 U.S.C. §1382a(a); 20 C.F.R. §416.1110.

<sup>13</sup> POMS SI 00820.500.

<sup>14</sup> 20 C.F.R. §416.1112(b), (c).

<sup>15</sup> 42 U.S.C. §1382a(a)(2); 20 C.F.R. §416.1120.

<sup>16</sup> 42 U.S.C. §1382(a).

<sup>17</sup> 42 U.S.C. §1382(b)(3).

<sup>18</sup> 20 C.F.R. §416.1124(c)(3).

<sup>19</sup> 20 C.F.R. §§ 416.1160(a), 416.1165(g)(7).

<sup>20</sup> 20 C.F.R. §416.1160(c).

the household. In determining the income of the ineligible parent, not all income is included in the deeming process.<sup>21</sup>

If there is only one eligible child claimant, the remaining income of the parent is deemed to the child as the child's unearned income. It is combined with the child's other unearned income and exclusions set forth in §416.1124 are applied to determine the claimant's countable unearned income in the month. This is added to any countable earned income and the total is subtracted from the federal benefit rate for an individual to determine whether the claimant is eligible for benefits.

If there is more than one eligible child, the parental income is divided and deemed equally among those eligible children. Once eligibility is determined, the SSI benefit is determined in the same manner.

If a special needs trust pays income to a parent in exchange for care of a child under age 18 living in the household of a parent, this is a process known as "circular deeming." The income from the trust, which theoretically belongs to the child, is paid to the parent for care and is then deemed back to the child. Since virtually all unearned income is deemed to the child and only roughly 50% of earned income is deemed, it is critical that the payment from the parent to the child be considered earned income. This enables the trust to significantly increase the payment from the trust to the parent.

### ***Care Agreement***

The solution to this problem is a properly-drafted care agreement between the special needs trust and the parent/caregiver. The agreement must clearly provide that the trust is the employer and that the parent is the employee. Duties must be clearly outlined. Under the terms of the care agreement, the parent/caregiver should be instructed by the trust as to the how, when or where the tasks are to be performed and to direct her actions as to which chores or activities to perform. Provision must be made for withholding of FICA and FUTA. Income received by the parent is taxable and must be reported.

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<sup>21</sup> Ineligible income is set forth at 20 C.F.R. 416.1161(a).