

Comments

A NEW CLASS OF EMPLOYEES: FAMILY MEMBERS AIDING THE DISABLED

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I. INTRODUCTION

Under our current employment scheme, relatives who aid their disabled family members are not recognized as employees even though third parties who provide the same services are expressly compensated. This status is based on the traditional model, which imposes upon relatives a duty to take care of their family members. However, as this Comment will show, the traditional view is not only outdated and potentially more expensive, but it fails to provide adequate needs for both the disabled family member and the caretaker relative. Fortunately, there has been recent experimentation among the state and federal governments with overwhelmingly positive results, largely in the form of the Cash & Counseling Project. Furthermore, the judiciary has been more inclined to recognize the need for compensating relatives of the disabled.

Unfortunately, compensation for relatives still remains much more the exception than the rule. The reluctance is partly due to the remnants of a notion of familial duty and more significantly due to concerns about increased financial burdens. However, any concerns regarding increased costs or abuse can be dealt with in the form of strict classifications and close monitoring.

My hope is that one day, all relatives who aid their disabled family members, not just those in experimental groups or those individuals who labor through long-term litigation, will be recognized as employees. While judicial support is of great importance and could eventually lead to this goal, several obstacles make congressional action the best method for

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achieving this goal.

II. THE TRADITIONAL VIEW

While this nation has witnessed great strides regarding employee working conditions and benefits, we have still been reluctant to compensate relatives for the services they provide for their disabled family members. Part of this stems from a notion that relatives have a duty to take care of their family members,¹ and part of this stems from a fear of “exploding public costs for services primarily provided for free.”² The fear is premised on two notions: (1) “the woodwork effect,” a theory that people who are currently not being paid for services will suddenly come forward; and (2) “the substitution effect,” a theory that people will threaten to withhold care unless their demands for payment are met.³

Both explanations for our reluctance to compensate relatives—the notion of familial duty and the fear of exploding public costs—are problematic. First, the familial duty notion is both outdated and impracticable. The traditional family structure has changed immensely over the past few decades as unmarried families, divorced families, and homosexual families have become more prevalent.⁴ Along with this general shift, there has been a greater realization that one family cannot provide everything.⁵ This is most clearly evidenced by the emergence and use of nursing home facilities by working family members who realize that the needs of their loved ones have outgrown the time and effort that the

1. See *NewsHour with Jim Lehrer: Independent Choices* (PBS television broadcast Jan. 4, 2001), available at http://www.pbs.org/newshour/bb/health/jan-june01/cash_counseling.html (noting an objection from the head of one of Arkansas’ agencies on aging, Edward Haas, that “[t]hat’s not what this country is about, paying families to take care of family”); see also Laura W. Morgan, *The Duty to Support Adult Disabled Children*, DIVORCE LITIG., Oct. 1997, at 185, available at <http://www.childsupportguidelines.com/articles/art200003.html> (noting that “[m]ost states have adopted the rule that parents have a common-law duty to support their adult disabled children”).

2. Lori Simon-Rusinowitz et al., *Payments to Families Who Provide Care: An Option that Should Be Available*, GENERATIONS, Fall 1998, at 69, 70, available at <http://www.cashandcounseling.org/downloads/paymentstofamiliesgenerations.html>.

3. NATHAN L. LINSK ET AL., WAGES FOR CARING: COMPENSATING FAMILY CARE OF THE ELDERLY 29–30 (1992).

4. James Georgas, *Family: Variations and Changes Across Cultures*, in ONLINE READINGS IN PSYCHOLOGY AND CULTURE (Walter J. Lonner et al. eds., 2003), <http://www.ac.wvu.edu/~culture/georgea.htm>.

5. See *NewsHour with Jim Lehrer: Independent Choices*, *supra* note 1.

The notion that a spouse or a parent can and should be providing all of this help for free dates back to the poor laws of the 18th and 19th century. We live in a much different day and time, and we should, at the very least, reexamine whether these long-held mores are always appropriate to our own time.

family can provide.⁶

Second, it is debatable whether public costs remain lower under the traditional view. The money spent on paying the relative caretaker is usually money that would be spent elsewhere.⁷ Furthermore, while numerous opponents to compensation for relative caretakers constantly worry about “the woodwork effect” and “the substitution effect,” there is no empirical research verifying these theories.⁸

Most importantly, the tolls are taken elsewhere. There is harm to both the caregiver and the care receiver. Caregivers must often sacrifice their retirement savings and Social Security credits when they leave the workforce.⁹ If they choose not to leave the workforce, they sacrifice their health and well-being.¹⁰ As for the disabled, their needs are not fully met under the current system.¹¹

III. CHANGES FROM THE GOVERNMENT (AIDED BY THE PRIVATE SECTOR)

A. *Prior Changes*

The practice of paying family members to care for their disabled relatives has gradually gained the support of state and federal governments. On the federal level, under the Veterans Administration’s Housebound Aide and Attendance Allowance Program, veterans with disabilities are provided with a cash benefit to pay for personal assistance, which can

6. See Nat’l Ctr. for Health Statistics, Fast Stats A to Z, <http://www.cdc.gov/nchs/fastats/nursing.htm> (last visited Jan. 5, 2006) (stating that, as of 1999, there were 18,000 nursing homes with 1.6 million residents).

7. See Bucks County Dep’t of Mental Health/Mental Retardation v. Pennsylvania, 379 F.3d 61, 68 n.6 (3d. Cir. 2004) (noting that the County actually saved \$5,598 by having the mother provide the therapy); News Release, Cash & Counseling, Model Program that Improves Quality of Life for Elderly Medicaid Beneficiaries and Those with Disabilities Expands to 11 New States (Oct. 7, 2004), available at <http://www.cashandcounseling.org/events/archive/2004100711.html> (noting that, in the Cash & Counseling Project, the consumer-directed option did not cost any more than agency care because there was less spending on nursing homes and other Medicaid services).

8. LINSK, *supra* note 3, at 29–30. Researchers who assessed ten long-term care projects in numerous states were unable to find any evidence of a substitution effect. *Id.* at 30.

9. Simon-Rusinowitz, *supra* note 2, at 70.

10. See S.P. Proctor et al., *Effect of Overtime Work on Cognitive Function in Automotive Workers*, 22 SCANDINAVIAN J. WORK, ENV’T & HEALTH 124, 124 (1996) (Fin.), abstract available at http://www.sjweb.fi/show_abstract.php?abstract_id=120 (concluding that overworking results in “impaired cognitive performance in the areas of attention and executive function” and affects moods as well); Leanne Lehmkuhl, *Health Effects of Long Work Hours* (Aug. 1999), <http://www.web.net/32hours/Health%20Effects%20v2.htm> (concluding that overworking leads to stress, depression, and burnout).

11. These unmet needs will be the focus of this Comment and will be discussed in greater detail later.

include the assistance of a relative.¹² On the state level, as early as 1985, thirty-three states, plus the District of Columbia, permitted some form of public payments for family caregiving.¹³ Currently, six states provide exemptions regarding minimum wage and overtime pay for relative caretakers,¹⁴ and Oregon provides limited pay to spouses.¹⁵

B. *Recent Changes: The Cash & Counseling Project*

The Cash & Counseling Demonstration and Evaluation Project, which was first implemented in 1998, is a policy-driven social experiment initially conducted in three states—Arkansas, New Jersey, and Florida.¹⁶ The project was initiated with the purpose of comparing Medicaid's traditional, agency-delivered services (which currently affect 1.2 million people)¹⁷ to the use of a cash benefit.¹⁸ The Medicaid consumers (the elderly or young adults with disabilities) who are interested in the cash option are randomly assigned to treatment and control groups,¹⁹ with the treatment group operating under a consumer-directed approach to personal assistance

12. Simon-Rusinowitz, *supra* note 2, at 71.

13. *See id.* at 71–72 (noting that Illinois had a Community Care Program and California had an In-Home Supportive Services Program).

14. *See Domestic Companions for the Aged or Infirm*, 3 Empl. Coordinator (RIA) § 10:8 (noting that, when it comes to minimum wage and overtime pay exemption under state law, Montana and North Carolina provide a combined exemption for domestic companions for the aged or infirm; Kentucky has a combined exemption “for any individual employed as a companion by a sick, convalescent, or elderly person, or by the person’s immediate family”; New York and Ohio grant combined exemptions to companions living in the home; and North Dakota provides exemptions for “persons who provide family home care,” meaning “the provision of room, board, supervisory care, and personal services”).

15. Spousal Pay Program, OR. ADMIN. R. 411-030-0080 (2004). Eligibility requires that the disabled member need “full assistance in at least four of the six activities of daily living . . . [that] would require nursing facility placement without in-home support,” and even then, eligible clients must wait on a list. *Id.* at § 411-030-0080(1).

16. While there are slight variations in the three programs, such as the particular department involved or target enrollment number, overall they are very similar. Cash & Counseling, At a Glance (June 30, 2002), <http://www.hhp.umd.edu/AGING/CCDemo/atagance.html>. Since Arkansas was the first state to implement the program (in December of 1998), which they called “Independent Choices,” the majority of the analyses and studies center around this particular program. *Id.* Thus, the references in this Comment will address the Independent Choices Program unless specifically noted otherwise.

17. Leslie Foster et al., *Improving the Quality of Medicaid Personal Assistance Through Consumer Direction*, HEALTH AFF., Mar. 26, 2003, at 162, 163, <http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.162v1.pdf>.

18. This is a public-private project. It is funded by the U.S. Department of Health and Human Services and the Robert Wood Johnson Foundation, and it is aided by the Health Care Financing Administration and the Social Security Administration. *Id.* at 174.

19. Kevin Mahoney et al., Cash & Counseling Demonstration Program Overview, <http://www.hhp.umd.edu/AGING/CCDemo/overview.html> (last visited Jan. 5, 2006). In Florida, children with developmental disabilities are also included. *Id.*

services.²⁰

The program is divided into “cash” and “counseling” in order to address two different sets of concerns. The “cash” portion of the project is directed at increasing autonomy for the disabled and leading ultimately to enhanced satisfaction, while the “counseling” portion is aimed at preventing worse outcomes such as neglect, abuse, or consumer mismanagement of the funds.²¹

Under the current Medicaid system, the disabled face severe limitations on their autonomy; they are forced to rely on “an endless parade of strangers” who can only provide services during agency designated hours and who cannot even take the clients on any types of outings, including shopping trips to buy food or medical supplies.²² Furthermore, most agency caregivers do not understand the client’s ethnic and cultural preferences or even the client’s native language.²³

The “cash” portion of the program attempts to alleviate these deficiencies by providing consumers with a monthly allowance equivalent to what would be spent under traditional Medicaid.²⁴ The consumers then choose: (1) who provides their personal and essential services,²⁵ including a relative (which is strictly forbidden under the traditional Medicaid regime);²⁶ (2) when these services are provided; (3) whether they want to spend the allowance on a variety of other necessities such as drugs (both prescription and over-the-counter) or home modifications that create greater accessibility and less dependence generally on human help;²⁷ and (4) whether they want “to designate representatives (such as family members) to make decisions on their behalf.”²⁸

Opponents of consumer-directed home services had two primary fears: (1) that people with cognitive impairments would have difficulty

20. *Id.*

21. *NewsHour with Jim Lehrer: Independent Choices*, *supra* note 1.

22. *Id.*

23. Simon-Rusinowitz, *supra* note 2, at 71.

24. Press Release, Ohio Statewide Indep. Living Council, Medicaid Recipients Benefit from Directing Their Own Personal Care Services (Apr. 15, 2003), *available at* <http://www.ohiosilc.org/news> (follow “2003 Hot News Archive” hyperlink; then look under April 2003). The average allowance is \$350. *NewsHour with Jim Lehrer: Independent Choices*, *supra* note 1.

25. Typical essential services include bathing, grooming, and meal preparation. Press Release, Ohio Statewide Indep. Living Council, *supra* note 24. The average pay for caregivers in the program is six dollars an hour. *NewsHour with Jim Lehrer: Independent Choices*, *supra* note 1.

26. Spouses and representatives are excluded from being hired in the Arkansas program. Foster, *supra* note 17, at 163.

27. *NewsHour with Jim Lehrer: Independent Choices*, *supra* note 1.

28. Foster, *supra* note 17, at 163.

managing their stipends and fighting off abuse or neglect,²⁹ and (2) that untrained family members would be less equipped than trained professionals to provide the requisite care, such as preventing falls or rotating limbs.³⁰ The “counseling” portion of the program, designed to prevent these harms, pairs participants with a counselor.³¹ The counselor helps them develop acceptable spending plans, advises them about recruiting, training, and supervising workers, and monitors the “satisfaction, safety, and use of funds through initial home visits; monthly telephone calls; semiannual reassessments; and reviews of spending plans, receipts, and workers’ time sheets.”³²

Numerous studies and analyses have been conducted regarding the Cash & Counseling Project, and all have shown overwhelmingly positive results. There is a much greater sense of general happiness and satisfaction by those who participated in the program.³³ This is in part due to the individual tailoring that the program provides. Early risers find it incredibly freeing that they no longer have to wait in bed until an aide can come by, while ethnic minorities appreciate being able to hire someone with the ability and desire to cook ethnic foods.³⁴ However, this is in much larger part due to more reliable and better quality care. When it came to the performance of the caregivers, cash-benefit caregivers were ranked “exceptionally well.”³⁵ They were much more consistent about keeping

29. JANE TILLY & JOSHUA M. WIENER, THE URBAN INSTITUTE, CONSUMER-DIRECTED HOME AND COMMUNITY SERVICES: POLICY ISSUES (2001), available at <http://www.urban.org/UploadedPDF/occa44.pdf>; see *NewsHour with Jim Lehrer: Independent Choices*, *supra* note 1 (“[O]ne woman in the program . . . was effectively victimized by her daughter. . . . [who] was getting the check and spending it and not providing the care.”).

30. Foster, *supra* note 17, at 172–73; see TILLY & WIENER, *supra* note 29, at 21 (noting that Washington requires agency workers to undergo a 22-hour training program and 10 hours of continuing education).

31. Arkansas consumers might receive assistance from multiple counselors while New Jersey and Florida consumers work one-on-one with the same consultant. Cash & Counseling, A Second Glance, <http://www.hhp.umd.edu/AGING/CCDemo/secondglance.html> (last visited Jan. 5, 2006).

32. Foster, *supra* note 17, at 164.

33. This has been indicated both by testimonials and survey evidence. See *NewsHour with Jim Lehrer: Independent Choices*, *supra* note 1 (“They [the agency caregivers] couldn’t take me to the store and I like to do my own shopping. But Kim can take me to the store and she can take me anywhere she wants to [T]his program has been the best thing that’s happened to me since I got sick.”); see also U.S. Dep’t. of Health & Human Serv., HHS Approves Expanded “Independent Choices” in Arkansas (Oct. 2, 2002), <http://www.hhs.gov/news/press/2002pres/20021002.html> (noting that eighty-two percent of participants reported that their lives had improved); Press Release, Ohio Statewide Indep. Living Council, *supra* note 24 (“Program participants were nearly 20 percentage points more likely than the control group to express satisfaction with their lives . . .”).

34. Foster, *supra* note 17.

35. *Id.*

scheduled visits, forty percent more likely to provide the desired transportation, and sixty percent less likely to fail to complete tasks.³⁶ Furthermore, cash-benefit caregivers were much less likely to be rude and disrespectful.³⁷ In the event that they were rude or inadequate, participants actually had authority to deal with the situation.³⁸ Under this program, the participants could fire the people they hired, whereas previously, they could only complain to the agencies and hope to receive a replacement worker.³⁹ When it came to the results on the care recipients, while critics were concerned that the participants would be subject to abuse and lower quality care, the studies have indicated quite the opposite. Overall, the reported incidence of neglect fell by fifty-eight percent.⁴⁰ Specifically, for nonelderly consumers, the likelihood of developing or experiencing worsened bedsores was reduced by more than half, and the likelihood of having problems with shortness of breath was reduced by one-fourth.⁴¹ For elderly consumers, there was a decreased likelihood of muscle contractures.⁴²

C. Future Changes

Due to the Cash & Counseling Project's positive results, other states have become interested in implementing their own similar types of projects, and the federal government and the private sector have been more than willing to help. After all, consumers who get care when they need it consequently have fewer falls, sores, or other problems and thus have generally lower costs.⁴³ Just last year, the Health & Human Services (HHS) department introduced an "Independence Plus" waiver that permits states to operate consumer-directed programs with a minimum of HHS review, and President Bush has proposed a program that would eliminate HHS review altogether.⁴⁴ Furthermore, the Robert Wood Johnson Foundation has expanded the program to provide eleven additional states with \$250,000 grants to replicate the model (but without control groups).⁴⁵

36. *Id.*

37. *Id.*

38. *Id.*

39. *Id.*

40. *Id.*

41. *Id.*

42. *Id.*

43. Cash & Counseling, Evaluation of the Cash and Counseling Demonstration, <http://www.hhp.umd.edu/AGING/CCDemo/ccdemo.html> (last visited Jan. 5, 2006); *see also* U.S. Dep't of Health & Human Serv., *supra* note 33 (noting that hospital costs for participants were eighteen percent lower than non-participants).

44. Press Release, Ohio Statewide Indep. Living Council, *supra* note 24.

45. Cash & Counseling, *supra* note 7. The states are Alabama, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington,

The final report notes, “Independent Choices appears to have tapped a labor source—family members and friends—for people who had been underserved by traditional agencies or who had gone without services.”⁴⁶ Finally, the government seems to be recognizing a new class of employees.

IV. CHANGES FROM THE JUDICIARY

There have been recent, groundbreaking judicial decisions awarding compensation to relatives who directly provided care for their disabled loved ones instead of hiring a third party. Unfortunately, these decisions, while a move in the right direction, impose limitations (mainly to alleviate concerns about potentially increased financial burdens) that prevent family members from realizing the full benefits of a designated class of employees.

Recognizing parent-child compensation schemes appears to present a greater obstacle because parents are required to support their children until they are either eighteen or nineteen years old or have graduated from high school, whichever is earlier.⁴⁷ When it comes to disabled children, the duty is even greater, requiring support even beyond the age of majority.⁴⁸ In reality, however, the compensation is for services provided that are beyond those required of the family member and for which the government would unquestionably compensate a third party (just as it was with the elderly).

A. *The Third Circuit*

In *Bucks County Department of Mental Health/Mental Retardation v. Pennsylvania*,⁴⁹ the Third Circuit held that Barbara de Mora, the mother of a disabled child, should be compensated for the time she had personally spent working with her daughter after Bucks County refused to provide the appropriate services.⁵⁰

In this case, de Mora’s daughter, I.D., was diagnosed with pervasive developmental delay, cerebral palsy, and deafness, qualifying her for early

and West Virginia. *Id.* In Pennsylvania, the anticipated enrollment date is Fall 2005. Cash & Counseling, Pennsylvania’s Cash & Counseling Program, http://www.cashandcounseling.org/about/state_profiles/pennsylvania.html (last visited Jan. 6, 2006).

46. Barbara Phillips & Barbara Schneider, *Moving to Independent Choices: The Implementation of the Cash and Counseling Demonstration in Arkansas 120* (2002), http://www.hcbs.org/files/40/1956/AR_Implementation_report.pdf; *see also* <http://www.cashandcounseling.org/index.html> (noting that a congressional briefing entitled, “Cash & Counseling: Part of the Long-Term Care Answer?” took place on July 29, 2005).

47. Morgan, *supra* note 1.

48. *Id.*

49. 379 F.3d 61 (3d Cir. 2004).

50. *Id.* at 63.

intervention services under the Individuals with Disabilities Education Act⁵¹ (IDEA).⁵² De Mora grew dissatisfied with the service Bucks County was providing under I.D.'s individualized family service plan (IFSP), which provided for only 24.25 hours of physical therapy, speech therapy, occupational therapy, and special instruction.⁵³ She not only wanted additional hours, but she also preferred the Lovaas methodology.⁵⁴ When de Mora's requests for increased hours and the hiring of Lovaas-trained therapist Patricia Laudon were denied by Bucks County, de Mora independently hired Laudon.⁵⁵ Then, when Laudon was unable to spend the requisite amount of time with I.D. and de Mora could not find another person trained in the Lovaas methodology, de Mora underwent training with Laudon so that she would be able to provide her daughter with the Lovaas therapy.⁵⁶ Ultimately, the Pennsylvania Commonwealth Court held that Bucks County should have provided the Lovaas therapy, and in the Third Circuit case, compensation to Laudon for her services was not at issue.⁵⁷

The Third Circuit's decision, one of first impression for the court, was essentially groundbreaking. The court concluded that out-of-pocket expenses should not be a distinguishing factor in determining compensation for services rendered. It being undisputed that Bucks County had to provide I.D. with the Lovaas methodology, "[w]ere the County to have provided I.D. with the discrete trial training in the place of Mrs. de Mora, it would have incurred the cost of implementing discrete trial training for I.D."⁵⁸ Thus, the fact that de Mora happened to be I.D.'s mother should not affect her eligibility for compensation. After all, the time for which she was compensated was "not in the same vein as a mother spending time with her child in the normal course of daily living activities" but instead as a

51. 20 U.S.C. §§ 1400–1487 (2000).

52. *Bucks County Dep't of Mental Health v. Pennsylvania*, 379 F.3d at 62–63. Under Part C of the IDEA, the federal government provides financial assistance to states when they develop and implement a system providing early intervention services such as family training and counseling, special instruction, occupational therapy, physical therapy, psychological services, and social work services. *Id.* at 66. In Pennsylvania, the Office of Mental Retardation of the Pennsylvania Department of Welfare administers the Pennsylvania Early Intervention Program, and Bucks County was the local office responsible for I.D. *Id.* at 63.

53. *Id.* at 63.

54. *See Bucks County Dep't of Mental Health/Mental Retardation v. de Mora*, 227 F.Supp. 2d 426, 427 n.4 (E.D. Pa. 2002) ("Developed by Dr. Ivar Lovaas, Lovaas training is an approach to educating developmentally-challenged children which involves breaking down activities into discrete tasks and providing positive reinforcements for the child.").

55. *Bucks County Dep't of Mental Health v. Pennsylvania*, 379 F.3d at 63.

56. *Id.*

57. *Id.* at 64–65.

58. *Id.* at 65.

Lovaas therapist.⁵⁹ Indeed, Mrs. de Mora held one-on-one workshops with Laudon, read and learned discrete trial training teaching guidelines and books, and was able to provide specific examples of training exercises that she executed.⁶⁰ Furthermore, four other therapists provided affidavits that they observed de Mora performing the Lovaas training and concluded that she was acting as a therapist and not as a mother.⁶¹ While opponents pointed out that, even with all of this training, de Mora was not “qualified personnel” as defined by the IDEA (similar to the objections raised concerning the Cash & Counseling Project, *supra*), the Third Circuit considered the point insignificant given that de Mora’s services filled a void created by an inadequate state-structured program.⁶²

The primary concern the Department had in permitting compensation to de Mora was the potential for increased financial burden.⁶³ The Third Circuit pointed out that, in this particular case, the County actually saved \$5,598 by having de Mora provide the services since de Mora’s time was compensated at twenty-two dollars an hour, while Laudon’s time would have been compensated at forty dollars an hour.⁶⁴ However, the Third Circuit limited the impact of the decision by noting the high aspirations of Congress regarding Part C services and the brief amount of time allotted to achieving those aspirations,⁶⁵ and ultimately by concluding:

[A]ffirming the District Court will not have as far reaching effects as the Department of Public Welfare imagines. Reimbursement under the particular facts of this case will be limited to situations where 1) there has been a violation of IDEA and appropriate private services were provided, 2) the amount of the reimbursement is reasonable, and 3) a trained service provider was not available so that the parent stepped in to act as the trained service provider and not as a parent.⁶⁶

59. *Id.*

60. *Id.* at 63.

61. *Id.* at 74. The therapist is seen as an implementer while the parent is seen as a generalizer. Thus, the implementer teaches the child new tasks while the parent reinforces the training initiated by the implementer. *Id.* at 73–74.

62. *Id.* at 70.

63. The Department urged reversal of the District Court’s decision because the court had identified considerations that would “apply to virtually every successful administrative challenge to an IFSP under Part C.” *Id.* at 75.

64. *Id.* at 68.

65. *Id.* at 73.

66. *Id.* at 75 (citations omitted).

B. *The First Circuit*

While the issue of non-out-of-pocket compensation for family members was one of first impression for the Third Circuit, the First Circuit had decided the issue much earlier in *Hurry v. Jones*.⁶⁷

In this case, the City of Providence refused to provide further transportation services for George Hurry, who suffered from cerebral palsy and mental disabilities and who was confined to a wheelchair by spastic quadriplegia.⁶⁸ The City, which had previously provided George with door-to-door bus transportation to and from school, said it had become unsafe to carry him up and down the steep concrete steps because he had reached a weight of 160 pounds.⁶⁹ Consequently, Mr. and Mrs. Hurry began to transport George to and from school in their van, with Mr. Hurry doing the heavy lifting.⁷⁰

This was yet another instance of the governmental entity failing to provide the requisite care. The Education for All Handicapped Children Act of 1975 (EAHCA) required the school to provide door-to-door transportation to and from school, and the First Circuit noted, "It is clear that if the Hurrys had hired a private agency to drive George to and from school, this expense would have been reimbursable under the EAHCA."⁷¹ The First Circuit ultimately held that, even though the Hurrys had not incurred any out-of-pocket expenses, they should be reimbursed.⁷² "The fact that the Hurrys performed the service themselves rather than hiring someone else to perform it should not bar them from recovering the reasonable value of their time and effort."⁷³ The service the Hurrys provided filled a void and was no different from the service a third party would have provided.⁷⁴ The court's only concern was the possibility of excessive reimbursement, but ultimately the court decided that the reimbursement in this case was "obviously a bare-bones figure, well within any reasonable estimate of fair reimbursement."⁷⁵

67. 734 F.2d 879 (1st Cir. 1984).

68. *Id.* at 881.

69. *Id.*

70. *Id.*

71. *Id.* at 884.

72. *Id.*

73. *Id.*

74. *See id.* ("[I]t cannot be argued that the service in question . . . called for any special skill or training that the Hurrys lacked.")

75. *Id.* The district court had awarded them ten dollars a day for two daily round trips of ten to fifteen miles, which totaled \$4,600. *Id.*

C. *The B.C. Tribunal*

*Hutchinson v. British Columbia (Ministry of Health)*⁷⁶ is a Canadian case, heard before the British Columbia Human Rights Tribunal, holding that a blanket policy prohibiting the severely disabled from hiring family members was discriminatory and that a set of criteria for allowing hiring on a case-by-case basis must be developed. While the case appears less directly relevant to the doctrine in the United States, it is worth examining for several reasons. First, it is considered a groundbreaking decision in Canada that addressed a core issue that is very familiar in the United States.⁷⁷ In fact, the Tribunal alluded to the status of compensation in the United States on more than one occasion.⁷⁸ Second, while this case presented the familiar issue of compensating a family member caregiver, it did so in a unique context: (1) while the case involved a parent-child relationship, the relationship was at a point when the parent had clearly exceeded his duties to provide care for his child—at the time of the hearing, the parent was seventy-one years old and the child was thirty-one years old;⁷⁹ and (2) most importantly, unlike the previous two United States cases, the attack here was much broader. The focus was on the policy rather than an isolated instance of compensation. The challenge that Cheryl Hutchinson and her father, Phillip Hutchinson, brought was one of discrimination. They alleged that the blanket prohibition against hiring family members discriminated against Ms. Hutchinson by impeding her ability “to fully and freely participate in the economic, social, political, and cultural life of our province” and by failing “to promote a climate of understanding and mutual respect.”⁸⁰ They further alleged that the policy discriminated against Mr. Hutchinson because he “was denied an employment opportunity solely on the basis of his family status, and without consideration of his personal attributes and skills.”⁸¹

In 1998, Ms. Hutchinson, a woman with cerebral palsy and

76. 2004 B.C.H.R.T. 58 (June 28, 2004), available at [http://www.bchrt.bc.ca/decisions/2004/pdf/Hutchinson_v_BC_\(Min_of_Health\)_2004_BCHRT_58.pdf](http://www.bchrt.bc.ca/decisions/2004/pdf/Hutchinson_v_BC_(Min_of_Health)_2004_BCHRT_58.pdf).

77. See *B.C. to Appeal Landmark Family Caregiver Ruling*, CBC NEWS, July 14, 2005, http://www.cbc.ca/story/canada/national/2004/07/14/bc_caregiver040715.html (“The ruling was the first in Canada to rule on the rights of the disabled to pay family members as caregivers.”).

78. See *Hutchinson*, 2004 B.C.H.R.T. 58, at 59 (relying on evidence that “noted that in the United States, ‘over half of the states offer some form of financial payment to relatives with varying approaches to eligibility, amount, and purpose’”); *id.* at 70 (noting that “jurisdictions in Canada and the United States which allow relatives to be hired on a limited basis have not suffered undue cost increases”).

79. *Id.* at 3.

80. *Id.* at 35.

81. *Id.* at 38.

quadriplegia who needed twenty-four hour care,⁸² was accepted into the Choices in Supports for Independent Living (CSIL) program.⁸³ The CSIL became very popular because it allowed greater autonomy and choice to a group that had historically been denied such a choice.⁸⁴ Under the CSIL, individuals requiring a high level of care who had the ability to direct all aspects of their care,⁸⁵ received a monthly lump sum to pay the caregiver they chose to hire and to take care of administrative costs involved in being an employer.⁸⁶ The problem arose over the Ministry of Health's policy (which applied to all of its programs, including CSIL) of prohibiting the hiring of family members by adults with disabilities.⁸⁷ In fact, CSIL clients were required to sign an agreement regarding the prohibition.⁸⁸ Ms. Hutchinson had a very difficult time attracting and maintaining a competent caregiver.⁸⁹ One caregiver wheeled Ms. Hutchinson out into traffic, while another refused to get her juice because she did not want to have to take Ms. Hutchinson to the restroom afterwards.⁹⁰ Consequently, Ms. Hutchinson returned to her father, who had been her primary caregiver since she was thirteen years old.⁹¹ Since the policy prohibited Ms. Hutchinson from paying her father, the \$6,000 monthly allowance accumulated in her bank account until she periodically returned it.⁹²

The Ministry's arguments justifying their blanket prohibition were essentially the two same objections we have seen before—the notions of familial duty and the concerns about increased expenses. The Ministry argued that the CSIL was intended to supplement and not to replace the care that relatives already provided for free.⁹³ They argued that it was “the

82. *Id.* at 2.

83. *Id.* at 3. This program is one way by which the Ministry of Health delivers home support services to clients. *Id.* at 5.

84. *Id.* at 5. The Tribunal quoted the CSIL Case Manager's Handbook, which noted, “some clients and their caregivers may wish more choice and control in their lives. The CSIL program, using direct funding for the purchase of home support services, offers eligible clients this greater degree of autonomy.” *Id.*

85. *Id.* at 6.

86. *Id.* at 7.

87. The Tribunal quoted the Ministry of Health's Service Provider Handbook, which stated, “The Continuing Care Division does not provide financial subsidies to family members to care for relatives, either through direct payment to the individual, payment through a Homemaker Agency, or payment as an approved Service Provider.” *Id.* at 1.

88. *Id.* at 6.

89. *Id.* at 8.

90. *Id.*

91. *Id.* at 2.

92. *Id.* at 8.

93. *Id.* at 9. The Tribunal pointed out that the Policy Manual stated, “[I]ndividuals and their families are expected to do as much as they can for a family member without Ministry assistance.” *Id.*

primary responsibility of families to look after their own.”⁹⁴ As discussed earlier in this Comment, this argument is problematic in that Mr. Hutchinson was performing exactly the duties that the hired caregivers had performed—except that he was doing a better job. At the heart of the Ministry’s argument, however, was the concern that the costs would become impossible for the Ministry to bear.⁹⁵ Examining data from the United States and the other seven Canadian provinces that allowed exceptions on a case-by-case basis,⁹⁶ and finding little support from the Ministry’s expert witnesses,⁹⁷ the Tribunal held that these concerns were not bona fide and reasonable justifications for a blanket prohibition.⁹⁸ In addition to awarding damages and backpay (to Mr. Hutchinson),⁹⁹ the Tribunal ordered the Ministry to develop a set of criteria in permitting case-by-case exceptions.¹⁰⁰

Although this was a groundbreaking decision for Canada, and far broader in scope than the Third Circuit and First Circuit decisions, it too has severe limitations. This is partly due to the fact that the issue presented was a narrow one. The parties in *Hutchinson* did not seek an outright claim to familial compensation but instead only sought to acquire a case-by-case analysis.¹⁰¹ Perhaps they were weary that anything more would have been too much, and indeed, their fears were probably valid. The tribunal seemed to stake a great deal of importance on the narrowness of the issue presented.¹⁰² When I first wrote this Comment, I expressed my hopes that this decision would be upheld. Not only had the Ministry filed a stay of the monetary awards, but more importantly, the Ministry had filed an appeal. I am happy to report that the British Columbia Supreme Court denied the

94. *Id.* at 10.

95. *Id.*

96. The Tribunal stated, “There is no evidence that any of the provinces that allow exceptions to the rule have had a problem In Alberta, the evidence is that only four family members out of a caseload of 8,500 clients received payment. In Manitoba, the evidence shows the option is used by a minority of clients.” *Id.* at 58.

97. *See id.* at 63–67 (reviewing the testimony of two witnesses for the Ministry).

98. *Id.* at 68. The applicable Human Rights Code allows a defense when there is a “bona fide and reasonable justification” for the distinction alleged. *Id.* at 45.

99. *Id.* at 77–82. Cheryl Hutchinson was awarded \$8,500. *Id.* at 80. Phillip Hutchinson was awarded \$4,000 for the discrimination, *id.* at 81, and \$105,840 for his lost wages, *id.* at 79.

100. *Id.* at 76. The Tribunal recommended allowing exceptions “in circumstances like the present where the person has extremely high care needs, has made serious and repeated (and indeed ongoing) efforts to find a caregiver, has been unable to do so, and there is a capable and willing family member available to provide such care.” *Id.* at 61.

101. *See id.* at 9 (“What is being challenged is the blanket prohibition against the hiring of family members, without an assessment of the individual circumstances, under CSIL.”).

102. *See id.* at 62 (“Allowing for tailored exceptions does not mean that every individual who provides care for a disabled relative should be paid. It does not even mean that all seriously disabled individuals should be automatically entitled to hire a relative.”).

stay¹⁰³ and upheld the ruling, concluding that the Tribunal did not err in finding discrimination.¹⁰⁴ The Supreme Court also upheld the Tribunal's monetary award, finding it especially significant that the amount paralleled "the average payment made to disabled persons under the CSIL program to fund their care with the voluntary assistance of family and friends."¹⁰⁵ With this victory, I now hope that the next disabled person will seek greater rights until one day they no longer have to wage this sort of battle on top of the daily obstacles they encounter in trying to survive.

V. THE BEST METHOD FOR THE FUTURE

An examination of the Cash & Counseling Project and the various court opinions shows that change is on its way from different directions. While the primary purpose of this Comment is to examine the necessity of recognizing this emerging class of employees, it is also important to consider the best method for achieving this goal.

Essentially, there are two possibilities: (1) judiciary action, and (2) congressional action. The judiciary angle, while certainly vital, takes an ex post approach that has several drawbacks in comparison to the ex ante approach of congressional action.

For one, the judiciary route is much more time-consuming. Cases often take years to work their way through the system.¹⁰⁶ Then, even when a decision is rendered, the victory is uncertain until the appeals route has been exhausted.¹⁰⁷ Furthermore, until the Supreme Court takes up the case, any decisions rendered in one circuit will only be binding within that circuit, and generally, the Supreme Court will not take a case until there is a circuit split.¹⁰⁸ Thus, the amount of time it would take for the United States Supreme Court to recognize this class of employees could be

103. Justice Ralph, in denying the stay, concluded that, even though "there is a reasonable chance Mr. Hutchinson would not be able to repay the award of damages should the Province ultimately be successful," the Hutchinsons would suffer the greater harm. *British Columbia v. Hutchinson*, 2004 B.C.S.C. 1536 (Nov. 24, 2004), available at <http://www.courts.gov.bc.ca/Jdb-txt/SC/04/15/2004BCSC1536.htm>.

104. *British Columbia v. Hutchinson*, 2005 B.C.S.C. 1421 (Oct. 12, 2005), available at <http://www.courts.gov.bc.ca/jdb-txt/SC/05/14/2005bcsc1421err1.htm>.

105. *Id.* ¶ 167.

106. For example, in *Bucks County Dep't of Mental Health/Mental Retardation v. Pennsylvania*, 379 F.3d 61, 64–65 (3d. Cir. 2004), it took approximately three years for de Mora to get her victory. She first filed suit in the Pennsylvania Commonwealth Court in 2001, the case was then heard in the United States District Court for the Eastern District of Pennsylvania in 2002, and the case was finally heard on appeal to the Third Circuit in 2004.

107. Under 28 U.S.C. § 1291 (2000), the courts of appeals have jurisdiction over appeals from all final decisions in the district courts of the United States, and under 28 U.S.C. § 1254(1)(2000), cases in the courts of appeals may be reviewed by the Supreme Court.

108. The 1988 amendment to 28 U.S.C. § 1257 eliminated appeals as of right.

enormous.

Furthermore, even if the Supreme Court were to hear a case on this issue relatively soon, the breadth of the relief would not be nearly as broad as congressional legislation. For example, the case the Supreme Court eventually hears could specifically address compensation in the educational context, or it could address compensation in the Medicaid context. Either way, due to the ban on advisory opinions, the Court would not issue a holding encompassing both situations.¹⁰⁹

Finally, litigation requires individuals to dedicate an enormous amount of resources. Most of the family members who need this employee classification cannot afford to litigate.¹¹⁰

Thus, the better approach would be for Congress to step in. Congressional legislation, while also time-consuming, would take effect much more swiftly than a case winding its way through the appeals process. Furthermore, congressional legislation would not have to rely on the financial commitment and resources of one individual. Finally, congressional action would provide a far greater breadth of relief than an individual case ever could.

VI. CONCLUSION

Currently, many family members face one of three difficult choices: (1) leave their current job in order to fully and efficiently take care of their disabled loved one, but at the expense of earned income and retirement benefits; (2) continue working at their job and continue working with their disabled loved one, resulting in poor health and other effects on the caregiver; or (3) hire a third party who may fail to complete the tasks, treat the disabled family member disrespectfully, and lead the disabled member to feel uncomfortable and inadequate. At a minimum, these hard-working and dedicated family members should be automatically recognized as a class of employees so that they can receive compensation without an uphill battle. This does not mean this classification has to be unduly vague—it can be specific and strict with close monitoring in order to prevent any potential abuses. For example, the class could be limited to family members providing aid to the severely disabled who are willing to participate in ongoing counseling.

109. RICHARD H. FALLON, JR. ET AL., HART AND WECHSLER'S THE FEDERAL COURTS AND THE FEDERAL SYSTEM 79–81 (5th ed. 2003) (discussing the prohibition against advisory opinions in the federal system).

110. Mrs. de Mora, an exception to the rule, was fortunate enough to afford: (1) paying for Laudon for the Lovaas services out-of-pocket, and (2) instituting litigation afterwards to collect her costs from Bucks County. *Bucks County Dep't of Mental Health v. Pennsylvania*, 379 F.3d at 63–65.

While there has been an initial nudge from the government and the judiciary, further congressional action is needed to ensure compensation to everyone. Perhaps then, after an official recognition is given, we can even push for benefits.¹¹¹

111. New York is pioneering efforts to provide family employees with health care and vacation comparable to what they would receive working for local agencies. Simon-Rusinowitz, *supra* note 2, at 74.