Disabled Kids and Their Moms: Caregivers and Horizontal Equity

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I. TWO STORIES

A. Charlie, Eleanor, and Martin

Throughout Charlie’s first year, Eleanor and Martin thought their newborn son was perfect in every way. Not long after he turned one, however, they began to worry. Most of the other children in Charlie’s daycare center smiled and hugged the daycare workers when they arrived and when they left. Charlie never did. The others were beginning to speak, but none of Charlie’s utterances resembled English in any way. Occasionally, he would scream and rock back and forth for hours, and nothing could comfort him. When they walked around the neighborhood, he would get excited about the dogs and birds, but he never interacted with any of the neighbors who tried to speak with him.

When Charlie was two, the few words he had begun to speak disappeared. His outbursts became more frequent. Sometimes he struck out at people, including other children at daycare. The daycare teacher recommended an evaluation, which the pediatrician promptly ordered. The diagnosis was autism, probably on the more extreme end of the spectrum.

Even before his diagnosis, Eleanor and Martin began to change their lifestyle in response to Charlie’s condition. Because his meltdowns and aggressive behaviors were more likely when he was in an unfamiliar situation, they stayed close to home and avoided encounters with people who reacted badly. As Eleanor described it, “I had been isolated to only playing with him at home. We couldn’t even make it to the park to play. No one but family would interact with us.”

Charlie’s disrupted sleep patterns kept his parents up, particularly since he was likely to run out of the house when not supervised.

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Charlie’s daily schedule included appointments with multiple therapists—speech, occupational, physical, applied behavior analysis (ABA), and mental health. Finding competent ones, paying for them, and dealing with the insurance company added to the daily stress. Further, the uncertainty of therapy wore on Eleanor and Martin: “Most of what we have tried has yielded positive results to some degree. I think the ‘disappointment’ tends to come from family and friends’ expectations that your child will be ‘cured’ when you try something new. It’s tiring to constantly explain the incremental progress and why it’s all good . . .”

Until Charlie was five, he spent part of each day in a specialized daycare center. Then he began to attend school in a special part-day program. By that time, Martin could no longer bear the daily stress and difficulties of living with Charlie. When he and Eleanor separated, Charlie lost some of his recently-acquired language. He also became more aggressive at school, so he was required to stay home several days a month after particularly bad incidents.

Eleanor’s employment situation also took a turn for the worse. When they lived together, Martin had dropped Charlie at the daycare center in the mornings. Eleanor could usually get to work early, and her employer was willing to be flexible if Eleanor had to leave early for one of Charlie’s many therapy appointments. Now that Martin was living too far away to get Charlie in the mornings, Eleanor’s daily care responsibilities grew and her time for work shrank. Her employer’s flexibility had limits, and she lost her job. Finding another job proved impossible given her parenting schedule.

With Martin’s child support, Eleanor could pay rent on a small apartment. Regretfully, they put their house on the market. Charlie had been evaluated and approved for Supplemental Security Income (SSI), a means-tested public benefit program available for fully-disabled people who have no history of employment. Until Eleanor lost her job, the family income was too high for SSI; afterward, Charlie qualified for a small monthly stipend. Martin’s health insurance covered some of Charlie’s therapies, but Eleanor had to turn to Medicaid for others. Most of their providers did not accept Medicaid, and Medicaid covered only some of the therapies. Charlie did not cope well with all the changes, and his acting out at school increased in frequency and intensity. Eleanor and Charlie’s rental apartment created new difficulties because Eleanor could not put Charlie-proof locks on the doors and windows without breaching the lease. Her amplified nightly surveillance routine left her even more exhausted during the day. Martin came on weekends so Eleanor could catch up on some sleep, at least when Charlie was not having a meltdown.

Both parents look at their situation with apprehension. At present, they see no better way to care for Charlie. Perhaps even worse, they see no future for Charlie without their ongoing care.

2. Id.
B. Tom and Alice

When Tom’s truck exploded in Iraq, Tom lost an arm and a leg. He also suffered a traumatic brain injury that left him with severe memory problems and seizures. His wife Alice dropped everything to be at his side. After many months in a stateside hospital, his medical conditions stabilized and he returned home. That is when, as Alice puts it, her life “turned a total 180.”

Alice manages Tom's medical care. He cannot bathe or dress himself safely without her assistance. Her notes in his smartphone or computer substitute for his memory. His vulnerability to seizures makes it unsafe for him to drive or to be left alone.

Alice accompanies Tom to medical appointments, makes sure he knows when to take what medications, interacts with the Veterans Administration (VA) about his benefits and care, and helps him with his daily physical therapy exercises. When his prosthetic devices cause him problems, she is the one he depends on to care for the cuts, bruises, swellings and infections. Fortunately, they live relatively close to a VA medical facility. They were also fortunate that Tom’s eligibility for veterans benefits based on one hundred percent disability was established quickly, so he receives a regular income.

When Tom was injured, Alice’s employer continued to pay her until her annual and sick leave days were exhausted, and then kept her accounting job open until she could return. After Tom and Alice returned home, Alice cut back on her work hours. Even the reduced schedule did not provide enough flexibility, so she switched to a job that paid less but where she could come in late or leave as early as needed. Tom’s around-the-clock care-giving needs, however, left Alice too exhausted to keep the job. Quitting meant losing daily contact with her colleagues as well as the satisfaction of work and a paycheck. She hoped to replace some of the mental stimulation by going back to school, but leaving Tom alone for the necessary time was not possible.

With the help of medication, Alice is coping with the stress and depression that she attributes to caring full time for a husband who sometimes bears little resemblance to the person she married. Tom and Alice rarely leave their home because he cannot cope with crowds and noise. Vacations seem out of the question because of how complicated it is for Tom to travel without agitation and discomfort. Their social life revolves around the family members who come to visit; few friends or neighbors have continued their relationships.

II. Refocusing

In the usual ways that we look at disability, these stories have little in common.

4. Id.
One is about a young child on the autism spectrum, while the other is about a veteran with wartime injuries. The child is developing differently from other children, cannot communicate much, and has significant emotional and physical problems. The veteran has suffered the loss of two limbs and a brain injury leaving him with memory and seizure problems.5

If we change the focus to look at the caregivers, however, the stories have much in common. Both caregivers are dedicated to their disabled relatives. Both are women. Both have their lives turned upside down when their loved one unexpectedly needs their full attention. Both suffer emotional and physical stress as well as social isolation. Both leave their employment when their caregiving responsibilities become incompatible with work. Both have succeeded in keeping their loved ones out of an institution.

Eleanor and Alice also share economic difficulties. A significant difference, however, is the degree of their difficulties. Alice, caring for a disabled veteran, shares a standard of living that is comfortable, although it is hardly what she and Tom would have enjoyed had he not been injured. In contrast, Eleanor is caring for Charlie on the edge of poverty. Martin’s standard of living is somewhat higher, but both he and Eleanor have lost their hold on the financial security they would have enjoyed had Charlie not had autism.

The difference in the standards of living of these caregivers is not attributable to their employment status, since both are unemployed. The difference cannot be explained by the caregivers using up resources on extravagant or unjustifiable expenditures. The difference is best explained by public policy decisions to dedicate lots of resources to the support of veterans but to put very little into the support of children, including disabled children. A key point that those policy decisions ignore is that the veteran and the child are not the only ones affected. Caregivers who live with and dedicate their lives to caring for disabled relatives share the same standard of living with those relatives.

This Article’s argument is simple. Public benefits should be available to disabled children and their co-resident caregivers in amounts adequate to ensure that the household standard of living is high enough to reward and appreciate home-based caregiving. The form of this public benefit should be a stipend to the caregiver. Doing otherwise ignores the many benefits conferred on the public by these caregivers. Doing otherwise unfairly puts almost the entire financial sacrifice of caregiving on the individual caregivers. Doing otherwise ignores the profound changes over the last few decades in terms of home care for people for

5. This article considers just two groups of disabled people: veterans and minor children. Other groups of disabled people, such as adults whose disability began during childhood and frail and disabled elderly people, experience many of the same conditions, including institutionalization. Relative caregivers in every group also experience derivative disability. While it is essential to consider how public policy needs to change with respect to these caregivers, I have not addressed those questions in this article because the many variations in the conditions of other groups of care recipients and the public policies affecting them make comparisons overly complex.
disabilities and the importance of paid work for women. And doing otherwise perpetuates unjustifiable differences in the standards of living among caregivers.

This does not mean that public support for each of these households must be identical. Rather, caregiving relatives of people with disabilities should not have to live a life of poverty and economic insecurity. Like caregiving relatives of veterans, caregiving relatives of disabled children should not have to choose between adequate care for the child and adequate food, clothing, and shelter for the family.

III. MOVING TOWARD CHANGE

Eleanor and Alice’s households have different standards of living because they are caring for relatives who are the targets of different public benefits programs. In each program, the target is the disabled member of the family: help is provided for the disabled veteran or the disabled child. In neither program is the family of the disabled person a direct beneficiary of assistance, even where the family is affected by the disability of the targeted member of the family. Fortunately for Tom and Alice, veteran benefits do not ignore the family insofar as the amount of benefits paid to the veteran varies depending on the size of the veteran’s family. Unfortunately for Eleanor, the amount of SSI paid for Charlie does not take into account the presence of his mother in his household except that her earnings, if any, may reduce the amount of Charlie’s benefit. The individualistic design of each program is not uncommon. Given changes in institutionalization practices, employment patterns for women, and treatment regimes for disabled people, however, caregiving family members today do more for disabled relatives and pay a higher price for their time and effort than in the past. As a result, the individualistic approach of veteran benefits, SSI, and similar programs is exacting a higher price from caregivers than it once did.6

In the context of veterans, some change in the individualistic approach to benefits is now visible. In 2010, for the first time in the long history of benefits for veterans, Congress authorized the creation of a stipend payable to relative caregivers of injured veterans.7 According to the Senate Committee on Veterans Affairs, the stipend is needed for three reasons. First, disabled veterans prefer to be at home rather than in institutions. Second, institutionalization is an expensive alternative, so taxpayers benefit from home care. Third, home care is possible only if caregivers are available in the home. If caregivers must sacrifice too much financially, physically and emotionally, they may be unable to keep their veteran

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The Committee concluded that it is unfair to ask family caregivers to make the sacrifices required to keep the veteran at home without providing at least a modicum of financial recognition. Openness to change is also visible in Medicaid benefits for long-term care. For over a decade, states could use Medicaid funds to pay a stipend to family caregivers if the Medicaid recipient decided to put some Medicaid home health care funds to that use. The benefit, originally known as “consumer-directed care,” was developed as an alternative way to deliver personal assistance services to disabled people who needed care but could live outside of institutions. In most such cases, home care services are administered by the Medicaid agency, which determines what services the care recipient needs and designates which home health care agencies are authorized to provide the services.

Consumer-directed care benefits give more flexibility to the care recipient. In its most common form, now known as “Cash and Counseling,” the care recipient is given a budget for home-based services, and the care recipient can then decide, within fairly broad limits, what services to obtain with the funds. Importantly, every state permitting consumer-directed care allows recipients to hire a family member or friend to provide services; recipients are not limited to hiring aides from a home health care agency. Under the Affordable Care Act of 2010, Cash and Counseling is part of Community First Choice Option and may also be part of CLASS, the Community Living Assistance Service and Support Plan.

The consumer-directed home care benefit is a small but growing part of Medicaid’s long-term care programs, with about 17,500 participants in fifteen states in mid-2011. Unlike the VA caregiver stipend, however, it was not developed for the purpose of recognizing and compensating the work of family caregivers. Instead, it was a way for states to use Medicaid funding to replace the state and local funds previously used to assist disabled children and frail or

9. Id. at 5.
11. Id.
15. See Benjamin, supra note 12, at 82-83 (2001) (noting that consumer-directed services were developed based on the idea that disabled persons should be able to live as independently as possible, including making independent choices about which services they receive).
disabled adults leave institutional care or avoid institutionalization.\textsuperscript{16} Program designers decided to pay family caregivers because many communities did not have enough people working as home health aides, and the idea developed despite concerns on the part of some disability advocates, public officials, and policy makers.\textsuperscript{17}

The next three Parts of this Article explore this question: if the reasons offered in support of the veteran caregiver stipend apply with equal force to caregivers of veterans like Alice and to caregivers of children like Eleanor, is there any justification for not creating a publicly-funded caregiver stipend for caregiving parents of children with special health care needs? The first Part explores the similarities and differences in institutionalization practices affecting veterans and disabled children over time, with a focus on whether the preferences of veterans to avoid institutionalization is shared by children and their caregivers.\textsuperscript{18} The second Part compares the costs to the taxpayer of institutional care for each group with the costs of family-provided home care.\textsuperscript{19} The third Part compares the financial, social, emotional and physical burdens experienced by each group of caregivers.\textsuperscript{20}

The comparisons show that the preference for home care over institutionalization does not differ depending on whether the disabled person is a veteran or a child. Furthermore, in both groups, deinstitutionalization is most likely to succeed where better home and community care options have been developed. Costs of institutionalization compared to the costs of family-provided home care are more difficult to estimate, but the likelihood is that family-provided home care is less demanding on the public fisc, even when compared with community care and particularly when compared with institutional care. Finally, the experiences of caregivers in each group have been well-documented, and the differences between the groups are not substantial.

The final Parts of the Article argue that, in light of the preference of each group for home care, the probable cost savings to the public, and the similarities in experiences of family caregivers regardless of who they provide care for, the profound differences in the standards of living experienced by the two groups of caregiver are inequitable and unjustified. The remedy is to fund a stipend for caregiving parents of children with special health care needs that resembles the VA caregiving stipend in situations where the parent’s special caregiving responsibilities diminish or preclude employment outside the home.

\textsuperscript{16} Bruce C. Vladeck, Where the Action Really Is: Medicaid and the Disabled, 22 Health Affairs 90, 91 (2003).
\textsuperscript{17} See Benjamin, supra note 12, at 87-88.
\textsuperscript{18} See infra Part IV.
\textsuperscript{19} See infra Part V.
\textsuperscript{20} See infra Part VI.
IV. HOME CARE V. INSTITUTIONALIZATION

Out-of-home care, or, more generally, institutionalization, was once a relatively common alternative to home and community care for disabled and elderly veterans and for disabled children. Thousands of members of both groups were housed away from their families in public or private residences, many of which housed large numbers of people in poor conditions. Today, institutionalization practices have changed among both groups. Each group has experienced deinstitutionalization somewhat differently and, more for children than for veterans, deinstitutionalization is neither complete nor satisfactory.\(^2\)

Two different forces have joined to advance deinstitutionalization. First, people who were institutionalized and their families have fought hard for the alternative of home and community-based care. For most of them, the clear preference has been to stay at home or, if that is not possible, to move into situations in the community where they can experience life with the fewest constraints practicable.\(^2\) They have carried on their struggle in the courts as well as in other social and political contexts. Their efforts have sometimes coincided with the other important groups engaged in advancing deinstitutionalization: the states and the federal government working to reduce their spending on long-term care.

Beginning in the mid-1960s, lower courts declared unconstitutional the practices of some states of institutionalizing people involuntarily for long periods of time due to their mental health or mental retardation issues.\(^2\) Rather than improve the institutions, most states began to release people into the community, often without much planning or much development of community or home-based support.\(^2\) In 1999, the Supreme Court held in \textit{Olmstead v. L.C. ex rel. Zimring}\(^2\) that undue institutionalization of people with disabilities is a form of discrimination prohibited by Title II of the Americans with Disabilities Act.\(^2\) \textit{Olmstead} has also been applied to people at risk of institutionalization.\(^2\) In response to \textit{Olmstead} and other financial and political incentives to reduce institutionaliza-


\(^{22}\) Colker, supra note 21.


\(^{24}\) Colker, supra note 21, at 1435-48.


tion, many states changed their Medicaid programs to offer at least some services to help people with disabilities stay in their homes. The Affordable Care Act of 2010 added incentives for states to advance the agenda by using more Medicaid dollars for home and community-based care and fewer for institutional care.

The legal, social, and policy movements for deinstitutionalization have made a difference. If one considers only child welfare institutions, the rate of institutionalization of children was probably at its highest during the latter part of the nineteenth and early part of the twentieth century. Between 1923 and 1997, use of child welfare institutions declined by nearly two-thirds. In 1923, the rate of institutionalization for minor children was 331 per 100,000; by 1997, it was 114. Institutionalization has also declined for children with developmental disabilities, from 54,000 people under the age of twenty-one in 1977 to fewer than 3000 in 1998.

The effort to deinstitutionalize children has had its greatest impact on younger children. While today the vast majority of children in institutions and other out-of-home placements are over the age of twelve, more than half of institutionalized children were younger than twelve in 1933. Among other things, younger children have benefitted from changes in federal education law beginning in 1975, which prohibited states from segregating and excluding as


31. Weithorn, supra note 21, at 1450.

32. Paul Lerman, Twentieth-Century Developments in America’s Institutional Systems for Youth in Trouble, in A CENTURY OF JUVENILE JUSTICE 74, 79 (Rosenheim et al. eds., 2002). While institutionalization declined, out-of-home placements of children continued in the form of foster care, increasing from a rate of 189 minor children per 100,000 in 1923 to 601 per 100,000 in 1997. Id. Since foster care placements usually involve compensation for the foster parents, the change may be attributable, at least in part, to the continuing need of parents for financial assistance if they are going to provide care at home for disabled children. Since such support is not provided to parents, their “failure” as compared to foster parents may be more understandable.

33. Vladeck, supra note 16, at 94.

34. Lerman, supra note 32, at 81.
many disabled children from local schools. Laws prohibiting discrimination against the handicapped have expanded the possibility of access to housing and public facilities for families with disabled children. Further, early in the twentieth century, the creation of mothers’ pensions and, later on, Aid to Families with Dependent Children (AFDC), provided a small cash welfare benefit that some impoverished parents could use to keep their children at home. The changes to AFDC enacted in 1996 under the rubric of welfare reform may have reversed that opening, as is explored later.

Despite the rate of deinstitutionalization achieved for younger children, institutionalization of minors persists. At least in recent decades, in fact, rates of institutionalization and other out-of-home placements have risen for older children, especially those with mental health problems. These children and adolescents are no longer placed in child welfare institutions such as orphanages. Instead, they are subject to the juvenile justice system and the neglect and abuse systems, through which many are moved away from their families and placed in institutions, foster care or group homes.

The approach of the Veterans Administration in recent years also emphasizes home and community-based care over long-term institutionalization. Approximately sixty percent of veterans now receiving long-term services are in home or community settings, such as small privately-run care facilities.

35. See Colker, supra note 21, at 1429-30; Arlene S. Kanter, The Law: What’s Disability Studies Got To Do With It Or An Introduction To Disability, 42 COLUM. HUM. RTS. L. REV. 403, 453 (2011); Gary L. Monserud, The Quest for a Meaningful Mandate for the Education of Children with Disabilities, 18 ST. JOHN’S J. LEGAL COMMENT 675, 690 (2004); Erin Phillips, When Parents Aren’t Enough: External Advocacy in Special Education, 117 YALE L.J. 1802, 1807, 1811-14 (2008) (tracing the history of increasing access to public education for disabled children from 1970s, when more than 2,000,000 children were excluded because of disabilities, to the present, when legal changes eliminated exclusion as an option); Laura Rothstein, Strategic Advocacy In Fulfilling The Goals Of Disability Policy: Is The Only Question How Full The Glass Is?, 13 TEX. J. C.L. & C.R. 403, 405 (2008); Mark C. Weber, A New Look At Section 504 and The ADA In Special Education Cases, 16 TEX. J. C.L. & C.R. 1, 5-9 (2010) (arguing that, given limits placed on IDEA and amendments to Title II of the Americans with Disabilities Act, actions under Section 504 of the Rehabilitation Act of 1973 and Title II may provide benefits to increasing numbers of students).


37. See Lerman, supra note 32, at 76.

38. See infra Part VIII.

39. Weithorn, supra note 21, at 1310. Foster care, a form of paid care in a substitute family or group home, has become a substitute for institutionalization for many more children. See Lerman, supra note 32, at 79 (stating that out-of-home placements of children in the form of foster care increased from a rate of 189 minor children per 100,000 in 1923 to 601 per 100,000 in 1997).

40. Weithorn, supra note 21, at 1362-88.


mately 35,000 are receiving long-term care in an institutional setting on any day, the number was almost twice as high in 1999. Of the $2 billion spent by the VA on long-term care in 1998, nearly $1.7 billion was spent for institutional care. A preference for home and community care over institutional care is pronounced among younger veterans returning from Iraq and Afghanistan.

V. FAMILY-PROVIDED HOME CARE BENEFITS THE PUBLIC, REGARDLESS OF WHETHER CARE RECIPIENT IS VETERAN OR CHILD

While the importance of advocacy on the part of disabled people and their families and the mandate in Olmstead cannot be ignored in the story of deinstitutionalization, community and home-based services appealed to state and federal officials because of the possibility of cost savings. Long-term care is an expensive component of an expanding segment of public funding: health care. Delivering that care for fewer dollars is highly desirable. The first question is whether institutionalization is more or less expensive than home- and community-based care. Assuming that the answer is more, as is generally assumed, the second question is whether home-based care provided through home health care agencies is less expensive than self-directed home care, more than half of which is provided by family members. A finding that self-directed home care is less expensive than agency-directed home care would support a conclusion that a program to provide a caregiver stipend to relatives may save taxpayers money.

Self-directed home care may be less expensive than agency-directed home care, although the evidence is not yet clear. The best information seems to come from the Cash and Counseling demonstration program conducted in Arkansas, where officials appear to have kept the closest watch on comparative costs. In Arkansas, as it turns out, the costs for individual recipients to obtain home

43. Id.
45. Id. at 5.
46. BURRIS, supra note 41.
47. Benjamin, supra note 12, at 81.
49. STACY DALE ET AL., MATHEMATICA POLICY RESEARCH, INC., MEDICAID COSTS UNDER CONSUMER DIRECTION FOR FLORIDA CHILDREN WITH DEVELOPMENTAL DISABILITIES, FINAL REPORT (2004); See SIMON-RUSINOWITZ ET AL., supra note 13, at 2.
services were higher initially for self-directed care than for agency-directed care.⁵⁰ This outcome was contrary to predictions, because agencies charge fees. The confounding factor was a failure of the system: care recipients relying on agency-directed care had been receiving fewer hours of service than they were eligible for.⁵¹ Once care recipients could direct their own care, they found ways to get help for more of their authorized hours. Costs, therefore, went up. Arkansas brought the costs down by reducing the money spent for certain support services for self-directed care recipients. With that change, the predicted savings began to occur. Over the course of the nine years of the Cash and Counseling waiver, Arkansas experienced savings of $5.6 million in the costs of providing direct care.⁵² In addition, within the first three years of beginning the self-directed program, nursing home admissions began to decline for care recipients.⁵³ The savings from the decline were sufficient to offset the increased costs of self-directed home care.⁵⁴ Florida’s Cash and Counseling Demonstration Waiver was the only program to include children in its coverage.⁵⁵ As in Arkansas, the costs for family caregivers were higher than anticipated because the children received care for more of the authorized hours rather than for the reduced hours of care previously provided through agencies.⁵⁶ Because the children in the program were less likely “than children in the control group to experience certain disability-related health problems,” the increases “may have been offset by savings on other Medicaid services.”⁵⁷

Another possible source of cost savings may have been states closing institutions that once served children. Calculating cost savings is not straightforward, however, because of “trans-institutionalization,” that is, the process of changing the types of institutions and programs used for children.⁵⁸ Social welfare institutions that once housed young children no longer exist, for example,

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⁵¹ New State Strategies, supra note 10, at 52; see DALE & BROWN, supra note 50, at 71.
⁵² New State Strategies, supra note 10, at 51-52.
⁵⁴ New State Strategies, supra note 10, at 51; see Robert J. Newcomer, Taewoon Kang & Pamela Doty, Allowing Spouses to be Paid Personal Care Providers: Spouse Availability and Effects on Medicaid-Funded Service Use and Expenditures, THE GERONTOLOGIST (2011) (finding that Medicaid expenditures were lower for in-home services when provided by family member).
⁵⁵ See SIMON-RUSINOWITZ ET AL., supra note 13 (stating that about 1000 kids participated in the Florida demonstration Cash and Counseling Waiver program).
⁵⁸ Weithorn, supra note 21, at 1447.
but there have been substantial increases in the public funds for medical care and special education for children, including preschoolers. Fewer older children are placed in social welfare institutions, but many are in juvenile detention facilities, group homes, and foster care, which may be seen as a modern equivalent.  

Cost savings, while important, are only one possible benefit that the public may derive from family-provided home care. At least two others have been studied.

First, family caregivers may pay closer attention to their relative, which helps the care recipient experience better health. Better health should reduce the need for nursing home and hospital-based care, both of which are more expensive than care at home. The Cash and Counseling demonstration programs found that self-directed care, and, more specifically, family-provided care, had a positive impact on reducing the need for hospitalization and nursing home admissions.  

Second, some of the relative caregivers in self-directed care programs decided, based on their experiences caring for family members, that they were willing to take jobs as caregivers to other elderly and disabled people. In recent years, the number of disabled and frail people in need of home care has increased but the numbers of people willing to undertake caring for them has not. When self-care programs entice more people into home care occupations, they benefit not only the original care recipient but also others in need of care.

VI. THE CAREGIVER EXPERIENCE IS SIMILAR, REGARDLESS OF WHETHER THE CARE RECIPIENT IS A CHILD OR A VETERAN

Despite the fact that Eleanor is caring for a child with a developmental disorder and Alice is caring for a disabled veteran, their lives as caregivers are more alike than different. They perform similar caregiving tasks and providing care affects them in similar ways. Studies done by the National Alliance of Caregivers (NAC) document who the caregivers are, what they do, and how their lives change

59. See id. at 1325.
60. See, e.g., New State Strategies, supra note 10, at 51-52 (noting the reduced use of nursing homes by Cash and Counseling participants in Arkansas over a three-year period); Pamela Doty, The Evolving Balance of Formal and Informal, Institutional and Non-Institutional Long-Term Care for Older Americans: A Thirty-Year Perspective, 20 PUBLIC POL’Y AND AGING REP. 3, 3-6 (2010); Newcomer et al., supra note 54 (noting more desirable outcomes for recipients of in-home services where provider was relative paid through Medicaid); Lori Simon-Rusinowitz, Kevin J. Mahoney & Dawn M. Loughlin, Paying Family Caregivers: An Effective Policy Option in the Arkansas Cash and Counseling Demonstration and Evaluation, 37 MARR. & FAM. REV. 83, 96 (2005) [hereinafter Paying Family Caregivers] (finding clients with family worker as opposed to non-family worker “less likely to report a respiratory infection (26% v. 37%, p=.05), bed sores or pressure sores (4% vs. 12%, p=.01), and having fallen (16% vs. 29%, p=.01)”).
61. Paying Family Caregivers, supra note 60, at 102.
62. Id.
because of their caregiving. 63

In the NAC studies concerning children and veterans, at least two-thirds of caregivers in each group are female. 64 More than four-fifths in each group are related to the care recipient, with parents dominating as caregivers for children and spouses as caregivers of veterans. 65 Four-fifths of caregivers for veterans live with the veteran, which is true of nearly two-thirds of caregivers for children. 66

Caregivers of disabled children average thirty hours per week of caregiving time, and one in four spend more than forty hours per week caring for the child. 67 Over two-thirds of caregivers of disabled veterans report spending more than twenty-one hours per week taking care of the veteran, with about two-fifths reporting spending more than forty hours per week. 68 Parent caregivers of disabled children spend an average of 9.5 years on caring for the child, while many caregivers of veterans provide care for more than ten years. 69

Like Charlie and Tom, most of the children and veterans in the NAC studies need help with basic tasks such as getting dressed, maintaining personal hygiene, and eating. 70 Most of the adults also need help getting from one place to another, keeping their home clean, and shopping. Children need caregiving parents to monitor their health, interact with others who do not know how to deal with the child’s condition, and advocate for the child in educational and medical settings, as well as for public benefits. 71 More than half of the parents perform treatment or therapies for learning, emotional or behavioral issues, and give medicines or injections. 72

Caregiving takes a toll on the caregiver, regardless of whether the care recipient is a child or a veteran. Almost twenty percent of people caring for a disabled child report that their health is fair or poor, and over forty percent experience a moderate or high level of physical strain from caregiving. 73 About two-thirds of caregivers for veterans experience high degrees of stress in their lives, compared with about a third of caregivers for children. 74 Like Eleanor and

64. CAREGIVERS OF VETERANS, supra note 3, at 25 fig.3; CAREGIVING IN THE U.S., supra note 63, at 14, 15 fig.7.
65. CAREGIVERS OF VETERANS, supra note 3, at 27 fig.8; CAREGIVING IN THE U.S., supra note 63, at 18 fig.12.
66. CAREGIVERS OF VETERANS, supra note 3, at 27 fig.9; CAREGIVING IN THE U.S., supra note 63, at 36 fig.29.
67. CAREGIVING IN THE U.S., supra note 63, at 22.
68. CAREGIVERS OF VETERANS, supra note 3, at 29.
69. Id. at 28 fig.10; CAREGIVING IN THE U.S., supra note 63.
70. CAREGIVERS OF VETERANS, supra note 3, at 31 fig.15; CAREGIVING IN THE U.S., supra note 63, at 6.
While all young children need some help with these tasks, the NAC study reports on them only when the child needs more help than would be common in children of the same age as the care recipient. Id. at 2.
71. CAREGIVING IN THE U.S., supra note 63, at 6-7.
72. Id. at 6.
73. Id. at 8, 48.
74. CAREGIVERS OF VETERANS, supra note 3, at 17; CAREGIVING IN THE U.S., supra note 63, at 17.
Alice, many find it difficult to maintain much of a social life. Nearly ninety percent of those caring for veterans report spending less time with friends and families, which is also true for sixty percent of those caring for disabled children.  

Financial strain is evident in both groups. Of parents who are caregivers of disabled children, twenty-seven percent report a high degree of financial hardship, which is also true of about half of those caring for veterans. One third of the caregivers of disabled children have sought financial assistance for the child.  

Both groups of caregivers experience financial stress in part because of the difficulties many encounter when trying to satisfy the special care needs of their child or veteran while trying to maintain employment. Nearly seventy percent of each group made a change in their employment because of their caregiving responsibilities. Nearly a third of caregivers of children reduced their work hours or took a less demanding job, as did nearly two-thirds of caregivers for veterans. A fifth of caregivers of children and two-fifths of caregivers of veterans quit work entirely. About three-quarters of caregivers of children came to work late, left early, or took off time from work to handle caregiving responsibilities.  

VII. CAREGIVERS AND EQUITABLE PUBLIC BENEFITS  

Because of public benefits for veterans, Tom and Alice not only avoid living in poverty, their household income puts them at least four times above the poverty threshold. Public benefits for families like Eleanor and Charlie’s, on the other hand, are so low that Eleanor and Charlie cannot achieve a standard of living equivalent to the poverty threshold, even when Martin is paying child support.  

As discussed earlier, three arguments persuaded the Senate that it was time to provide a stipend to some caregivers of disabled veterans. First, veterans prefer home care to institutional care. Second, family-provided home care benefits the public more than institutional care. Third, at a time when most women participate in market work, it is unfair to ask them to make substantial sacrifices in terms of their standard of living as well as the other sacrifices required by their caregiving responsibilities. All three of these rationales apply equally well, as seen earlier, to

75. CAREGIVERS OF VETERANS, supra note 3, at 49; CAREGIVING IN THE U.S., supra note 63, at 9.  
76. CAREGIVING IN THE U.S., supra note 63, at 7 fig.6.  
77. CAREGIVERS OF VETERANS, supra note 3, at 54 fig.36.  
78. CAREGIVING IN THE U.S., supra note 63, at 7.  
80. CAREGIVERS OF VETERANS, supra note 3, at 39 fig.23; CAREGIVING IN THE U.S., supra note 63, at 8.  
82. See CAREGIVERS OF VETERANS, supra note 3, at 39 fig.23; CAREGIVING IN THE U.S., supra note 63, at 9.  
the situations of caregivers of disabled children. Nonetheless, in terms of public benefits and social welfare policies, caregivers of disabled children are given little help, and many more of them risk a low standard of living, including poverty or extreme poverty.

A. Comparative Public Benefits

Some specific numbers help to make plain the large differences. As a fully-disabled veteran whose disability is service-connected, Tom receives tax-free disability compensation each month in the amount of $2823 for a household composed of himself and Alice.\textsuperscript{84} Tom also receives health care through the VA system, including medications, at little cost.\textsuperscript{85} Alice is eligible for the new caregiver stipend, which adds a total of approximately $2000 a month to the family’s income and gives her access to health care coverage through the VA.\textsuperscript{86} If Alice had remained employed, her earnings would have had no impact on Tom’s disability compensation or medical coverage because neither is mean-tested. Under limited circumstances, they could also qualify for an additional “aid and attendance” benefit.\textsuperscript{87}

After Eleanor’s paid employment ended, her household income consists of Supplemental Security Income (SSI) and child support, for a total of $800 a month.\textsuperscript{88} Eleanor and Charlie also receive funds through the Supplemental Nutritional Assistance Program (SNAP) to help them buy food in the amount of $127 a month.\textsuperscript{89} Medicaid covers some of Charlie’s medical expenses, but many providers do not accept Medicaid patients, especially patients like Charlie who are in need of specialized therapies. Martin covers some of Charlie’s medical expenses, which is the major reason that his child support payment is relatively

The group health insurance available through Martin’s employment does not cover family members.

Eleanor is ineligible for cash assistance under Temporary Assistance for Needy Families (TANF) because of Charlie’s SSI. Martin’s child support payments affect the amount of SSI and SNAP the household receives, since both are means-tested. If Eleanor were able to combine paid employment with caring for Charlie and earned more than approximately $1200 a month, some of her income would be deemed available to Charlie, and the SSI benefit would be reduced.\(^91\)

\section*{B. Relative Standards of Living}

In 2010, the poverty threshold for a household of two people was $1223 a month, where the householder is under sixty-five.\(^92\) With a monthly income of $4823, Tom and Alice appear to be living at approximately 394\% of the poverty threshold, although their actual standard of living is somewhat higher because veteran compensation is not taxable. With a total income of $927 a month, Eleanor and Charlie are living at approximately seventy-six percent of the poverty threshold, which puts them halfway between the poverty threshold of $1223 and deep poverty, defined as half of the poverty threshold, or $662.

When it comes to deciding what kind of standard of living the public should help Eleanor and Alice achieve, what distinguishes them from one another is not their effort, sacrifice, or contribution. What distinguishes them from one another is the level of worthiness attributed to the person for whom they provide care. Veterans like Tom get the maximum support because of a keenly felt sense that anyone who fights for this country and risks being killed or permanently disabled is deserving of all the support that the country can afford. Nobody has a quarrel with that proposition. The quarrel is about the support we should provide so that the dedicated people who care for other people with disabilities experience a decent standard of living. In other words, what we do to make sure that caregivers of veterans have a decent standard of living should be the model rather than the exception.

\section*{VIII. SSI and TANF: No Substitute for a Caregiver Stipend}

\subsection*{A. Supplemental Security Income}

Eleanor’s household relies heavily on Supplemental Security Income (SSI). While an important source of income for families with disabled children, SSI

\footnotesize\(^90\) See, e.g., MD. CODE ANN. FAM. LAW, § 12-202(a)(2)(iii) (West 2011) (explaining that presumptively correct child support amount under guidelines may be reduced where parents agree that one parent will make direct payments to provider on behalf of child).

\footnotesize\(^91\) See Soc. Sec. Admin., CHILDREN, supra note 88, at 28.

fails to provide an adequate substitute for a caregiver stipend. It fails at both a theoretical and a practical level.

At the theoretical level, SSI’s problems begin in its definition of disability. For SSI purposes, a child, like an adult, is defined as disabled or not solely based on the physical and mental capacities of the child. 93 Children and adults are not alike, however, in one key way: unlike an adult, no child is capable of self-care. 94 Some adults who have physical or mental conditions that are different from the “norm” are fully capable of self-care so long as the context in which they live does not add barriers. To use Amartya Sen’s famous example as reinterpreted by Martha Nussbaum, a person whose legs cannot support her weight is disabled only if she lacks a wheelchair, if the streets she travels lack curb cuts, and if the places she frequents accommodate only people whose legs are capable of standing and walking. 95 When the community has acted responsibly and made it possible for the person to move about without impediment, the person whose legs cannot support her weight is as capable of mobility as a person whose legs can support her weight. 96

SSI defines disability as existing solely in the person seeking the benefit, just like Sen’s example. But neither approach works fully with children, because children do not operate independently in the world. They operate dependently; they need a caregiver. If the person in need of a curb cut is a child, someone must advocate with the community to create the curb cut. Children are not able to advocate for themselves, so the child who needs the curb cut must depend on some adult to do the advocacy. That advocate is the usually the caregiving parent, who must figure out how to do the advocacy and take time away from other caregiving tasks and from employment to accomplish it. Likewise, a three-year-old in a wheelchair needs more attention from a caregiving parent than a three-year-old on foot because of the additional challenges the wheelchair poses in terms of physical strength and coordination and in terms of judgment—many of the same reasons we do not let young children drive cars. The child’s dependency on an adult is part and parcel of her situation, and it means that the child’s

93. 42 U.S.C. § 1382(c)(a)(3) (2011) (“An individual under the age of 18 shall be considered disabled for the purposes of this subchapter if that individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”); see Sullivan v. Zebley, 493 U.S. 521, 535-37 (1990) (holding that Social Security regulations determining whether a child is “disabled” are invalid because the child is not subject to an analysis of functionality comparable to that done for an adult); Vladeck, supra note 16, at 93 (asserting that the idea of disability is quite variable); Jennifer Pokempner & Dorothy E. Roberts, Poverty, Welfare Reform, and the Meaning of Disability, 62 OHIO ST. L.J. 425, 454-57 (2001); Matthew Diller, Entitlement and Exclusion: The Role of Disability in the Social Welfare System, 44 UCLA L. REV. 361, 363-64 (1996).
94. See Pokempner, supra note 93, at 460.
96. See Nussbaum, supra note 88; Michael Ashley Stein & Penelope J.S. Stein, Beyond Disability Civil Rights, 58 HASTINGS L.J. 1203, 1216-22 (2007).
disability is part and parcel of the adult’s situation as well. SSI’s definition of
disability ignores that interrelationship.

The degree of a child’s dependency varies with age, of course, but it is always
present for children to some degree. The caregiving adult, in Martha Fineman’s
terms, experiences the child’s dependency derivatively.97 While Fineman is
speaking of all children, a child’s degree of dependency increases where the child
has unusual care requirements, such as the diabetic child who needs frequent
monitoring of blood levels and injections of insulin. As the responsibilities of the
caregiving adult for meeting those needs intensify, so does the nature of the
“derivative disability” experienced by the caregiving adult.98

When disability is defined solely around the child’s physical or mental health,
the derivative disability of the parent or other caregiver is ignored. As a result,
many children are found not to be disabled for SSI purposes even though meeting
their special caregiving needs makes it difficult or impossible for the caregiving
parent to earn a living.99 In many situations, employers and community
institutions such as schools and medical providers do not create the equivalent of
curb cuts for the caregiving parents. By not providing paid sick leave, for
example, or by making it time-consuming and difficult to arrange for adequate
special education, employers and community institutions can make it difficult or
impossible for the parent to care for the child without losing or reducing
employment.

At a practical level, SSI is also problematic as a source of financial support for
many households with a disabled child and derivatively disabled parent. In 2006,
1.08 million households with a disabled child received SSI, or about six percent
of all children.100 This seems like a large number, and it is larger than it was in
prior decades, but it is at most about a third of the children who have special

97. Martha Albertson Fineman, Cracking the Foundational Myths: Independence, Autonomy, and
98. Id.
99. The determination of whether a veteran is disabled also turns on the physical and mental situation
of the veteran and not on whether the person caring for the veteran is affected by the veteran’s condition.
38 U.S.C. §§ 1110-1114 (2011). If a veteran is found to be disabled, however, the benefits package takes
into account the impact the veteran’s condition may have on others in the veteran’s household. For
example, the amount of compensation is based on household size. Veterans Compensation Benefits Rate
Tables, supra note 84. So a veteran with a spouse is entitled to a larger monthly benefit than a single
veteran; a veteran with two children is entitled to a larger monthly benefit than a veteran with one, and so
forth. A veteran’s spouse or child does not have to demonstrate financial dependency or any other change
in their lives produced by the veteran’s disability. See 38 U.S.C. § 1115 (2011). Finally, some of the
relatives caring for veterans are eligible for a stipend. U.S. DEP’T OF VETERANS AFFAIRS (VA), supra note
86, at 22-33. The SSI benefit, on the other hand, is solely about helping to satisfy a child’s financial needs.
The amount does not increase if the child’s household includes an unemployed parent, even one who is
unemployed as a result of meeting the child’s special needs, that is, the parent’s derivative disability. In
fact, some of a parent’s earnings may be deemed available to the child and the benefit reduced. SOC. SEC.
ADMIN., CHILDREN, supra note 88.
100. Mark G. Duggan & Melissa Schettini Kearney, The Impact of Child SSI Enrollment on
health care needs. One reason for this is that SSI is an all-or-nothing benefit. That is, it is available only to a person who is one hundred percent disabled. Unlike benefits for disabled veterans, no coverage exists for a child who is ninety percent disabled or thirty percent disabled.

Where a child qualifies for SSI, the benefit can raise the standard of living of the entire household. In effect, the benefit provides a modest substitute stipend for the caregiver as well as support for the child. Households that receive SSI experience an average increase of $400 a month in unearned income, which amounts to an increase in total household income of between twenty and twenty-five percent. Receipt of SSI brings some households out of poverty, lifts others out of deep poverty (that is, household incomes of fifty percent or less than the poverty threshold), and brings slightly wealthier households somewhat further above the poverty line. These are good results, although modest when compared with the financial well-being of households containing a disabled veteran. If SSI were available to children whose disability was less than one hundred percent, more children would qualify and, as a result, more caregivers would enjoy a somewhat improved standard of living.

Another way to improve the economic security of caregiving parents of disabled children on SSI would be to replicate the VA caregiver stipend program in SSI. To a small degree, that happens indirectly through the “Cash and Counseling” program available under Medicaid discussed earlier, since SSI recipients are usually eligible for Medicaid. While many states include something like a Cash and Counseling program in Medicaid, most of these programs focus on older recipients. Further, the payments typically cover only a few hours at a low hourly rate of pay.

If SSI were improved in the ways suggested here, the benefit would be paid to a higher percentage of children with special health care needs. Today, at most one in three children with special health care needs receives benefits. Expanding eligibility would help improve the standard of living for a number of disabled children and their caregivers, but the improvements fall short of the need. Further, because SSI is designed for people with long-term disabilities, even an


102. 38 U.S.C. § 1155 (2011) (establishing that the VA Secretary shall adopt and apply a schedule of ratings of disability ranging from 10% to 100% to reflect reductions in earning capacity).

103. See id. at 881 (showing that poverty is reduced by between 8.5 and 11.9% after SSI receipt begins).

104. See supra Part III.


106. See Kraiem, supra note 105, at 685.

107. Fremstad & Vallas, supra note 101, at 23.
improved program would not cover all children; many children with short-term disabilities have special caregiving needs that impair the labor-force participation of their caregiving parents. For example, some children have chronic illnesses such as asthma that are manageable most of the time. When a child with asthma has a medical crisis, it is likely to be serious but short-lived. Since most low-wage workers have no guaranteed sick leave, paid or unpaid, the crisis may affect the parent's labor-force participation, but the episodic and unpredictable nature of the illness make it quite different from the kinds of long-term disabilities covered by SSI.

B. Temporary Assistance for Needy Families

At present, a caregiving parent whose child does not qualify for SSI has only one alternative source of cash assistance: TANF, a block grant that replaced Aid to Families with Dependent Children (AFDC) in 1996. Over the years, studies have shown a high level of use of TANF and AFDC by parents with sick and disabled children—not a surprise given the effective unemployability of many parents raising children with special health care needs. Most experts now agree, however, that using TANF as a substitute for earnings is not a reliable strategy.

First, TANF's structure is not compatible with the needs of families raising children with special health care needs. Among other things, states are free to decide the level of cash assistance provided under TANF, the number of years (up to five) during which a person is eligible to receive benefits, and what kinds of families are eligible for a waiver from time limits. States are not free to waive the time limit so that all parents receive cash assistance until their child turns eighteen; only a small minority of parents can continue to receive cash assistance under TANF beyond the state's time limit. Further, states are required to have a


certain percentage of the adults in recipient families engaged in specified work activities for a minimum number of hours a week.\textsuperscript{115}

At the level of implementation the families are too often sanctioned for failing to meet the work requirement, or they are discouraged from applying because of program requirements, or they lose benefits because of the time limit. Between a fifth and a fourth of women-headed families in deep poverty who would qualify for TANF do not receive it, and some families that are disconnected from the public benefits system include children with special health care needs.\textsuperscript{116}

During the last reauthorization of TANF, states were released from the requirement of counting parents caring for a sick or disabled child among the parents subject to the work requirement.\textsuperscript{117} The decision was probably grounded in the reality that states simply could not develop affordable programs through which these parents could participate in the labor force.\textsuperscript{118} Families in states that have opted not to require these parents to comply with the work requirement can be secure that they will not lose cash assistance for failing to comply with the requirement.\textsuperscript{119} From the family’s perspective, maintaining eligibility for TANF is not enough for two reasons. First, the parents in almost every state are still subject to the time limits. Recall that the NAC studies disclosed that the average duration of care provided by a parent for a disabled child is over nine years, nearly twice the maximum time limit of five years under TANF.\textsuperscript{120} If a child needs substantial help for an even longer period, TANF time limits become an even greater problem.\textsuperscript{121} Second, states that are relieved of requiring the parents to meet the work requirement are also relieved of the responsibility of helping the parents prepare for any work opportunities that might be compatible with their unusual caregiving responsibilities. When the time limit kicks in, therefore, these parents may have even less preparation for getting work than other parents leaving TANF involuntarily.\textsuperscript{122} From the broader community perspective, allowing states to not count parents of disabled children as work eligible eliminates any incentive states might have had to push for employers to change their practices so that more of these parents could combine paid employment with unusual caregiving responsibilities.

\textsuperscript{116} See Blank, supra note 112, at 186.
\textsuperscript{117} 42 C.F.R. § 261.2(n)(2)(i); see Yoanna X. Moisides, I Just Need Help ... TANF, The Deficit Reduction Act, and The New “Work-Eligible Individual,” 11 J. GENDER RACE & JUST. 17 (2007). It is possible to consider family caretaking as a qualifying work activity, but Congress and states have not been persuaded to do so. See Noah D. Zatz, What Welfare Requires from Work, 54 U.C.L.A. L. REV. 373, 456-63 (2006).
\textsuperscript{118} See Moisides, supra note 117; Pokempner, supra note 93, at 451-53.
\textsuperscript{119} The potential is great for the work requirement to be an insuperable administrative and substantive burden on parents with unusual caregiving responsibilities. See Karen Syma Czapanskiy, Parents, Children, and Work-First Welfare Reform: Where is the C in TANF?, 61 Md. L. REV. 308 (2002).
\textsuperscript{120} Moisides, supra note 117.
\textsuperscript{121} Id.
\textsuperscript{122} Id. at 43-44.
TANF limitations have made SSI a more desirable form of financial aid. As discussed earlier, however, SSI is not a complete answer to the need for a caregiver stipend even if it were available to all TANF families with a special needs child. Eligibility turns on the child having a long-term disability, and the impact of the child’s disability on the caregiving parent’s earnings is irrelevant. A more reliable answer would be to develop a stipend program that works for families with a child whose special health care needs reduce or eliminate the caregiving parent’s participation in paid employment.

IX. HORIZONTAL INEQUITY DEMANDS AN ANSWER

Congress created a caregiver stipend for the caregivers of veterans because veterans prefer not to be cared for in institutions, because home care is more economical for taxpayers, and because it is unfair not to provide some compensation for caregivers who sacrifice much to do the public and private service of caring for their veterans. Caregiving parents of disabled children are in precisely the same situation, yet public benefits policies put the two kinds of households in vastly different economic positions.

Perhaps the most obvious answer to the inequity claim is that the country owes more to veterans than it does to children. Assuming the argument is valid, as most people do, the response is incomplete. Equitable treatment can mean that households with a disabled veteran enjoy a better standard of living than households with a disabled child. An equitable system would not relegate these fundamentally similar households to incommensurably different standards of living.

It may be argued that inequity must be tolerated when economic conditions constrain public expenditures. Assuming the present economic difficulties are not permanent, that argument is time-limited. Further, the argument is incomplete, because it does not examine what should happen at a time when social provision is back on the radar screen. If the equity problem is left unaddressed, funds that become available will continue to be allocated to currently favored groups such as veterans. The situation of groups currently disfavored will not be remedied. The time to talk about equity in public provision, therefore, is always, not only when there is money to use.

The third response is more fundamental. Disabled children live with adult parents, and many of the parents are able-bodied. In this society, able-bodied adults should work, and social provision should not provide an incentive for them not to work. The idea of “disability” is that some people, because of their physical or mental situation, should be excused from participating in the market. The category is a narrow one, designed to exclude people who might be able to participate in the market even if they are not presently doing so.\(^\text{123}\)

\(^{123}\) See Diller, *supra* note 93; Pokemper, *supra* note 93, at 451-53.
As discussed earlier, a caregiving parent of a disabled child is experiencing disability in a derivative manner. That is, the parent’s full or partial exclusion from the labor market is a function of two things: the child’s special need for care and the market’s inability to structure employment for most caregivers of children with special needs. The parent is given a harsh choice: take a job that leaves too little time and flexibility to meet the child’s special needs, or live without wages in poverty or deep poverty.

The caregiver stipend for family members of veterans is a public benefit for able-bodied adults. The stipend is provided because of their derivative disability: without it, they face the choice of working in a job that leaves them too little time or flexibility to meet the veteran’s special needs, or living without wages at the level supported by the veteran’s compensation. Once derivative disability is accepted as the basis for a caregiver’s stipend in the context of those caring for disabled veterans, derivative disability should not be rejected as a basis for a caregiver’s stipend in the context of those caring for disabled children.

A. The Public-Private Partnership

A longstanding objection to paying a stipend to parents of disabled children is that parents should not be paid to do what they have a moral as well as a legal duty to do: take care of their children. This Article does not argue that parents do not owe a moral and legal duty to care for their children or that parents should be excused from that duty if no parental caregiver stipend is created. Caregiving parents surveyed during the Cash and Counseling demonstration project agree, in fact, with the argument that their duty to their disabled children cannot and should not be avoided, just as parents surveyed by the National Alliance for Caregiving (NAC) continue to meet their caregiving responsibilities, regardless of their level of stress and strain.

This Article instead argues for equity. Just as parents owe a duty to care for their disabled children, spouses owe a duty to care for their disabled spouses. In certain circumstances, spouses of disabled veterans can be paid a stipend when they provide the care. Like parents, few of these spouses would shirk their responsibilities in the absence of a stipend. The stipend is justified, however, because the work of relative caregivers is not just a private boon to their relatives; it is also a public boon to society. Because of their work, their relatives stay out of institutions, stay healthier, and put a smaller burden on public systems. Asking

124. See supra Part VIII.
125. See Benjamin, supra note 12, at 87-88.
126. CAREGIVING IN THE U.S., supra note 63 at 2, 5.
relative caregivers to help the public without the public returning some of the favor is taking the argument about the moral and legal duty to care for relatives a step too far, regardless of whether the relative caregiver is a parent of a disabled child or the spouse of an injured veteran.

For some people, an equity argument, however persuasive, is not enough reason to consider a public benefit for family caregivers of disabled children. In their view, the line between home and government is bright, and government should not be doing what family should be doing—taking care of the children.\textsuperscript{128} Of course, most caregiving parents of disabled children fully agree with that view, which helps to explain why relatively few caregiving parents accepted the offer of a stipend in the Cash and Counseling demonstration program in Florida.\textsuperscript{129} Those who did often used their pay for specific items for the disabled child rather than for the specific benefit of the caregiving parent.\textsuperscript{130}

One way to reconcile the norm of unpaid family caregiving with a government-funded caregiver stipend is to step back from the situation of the individual family and ask, as the Senate Veterans Affairs Committee apparently did, what kind of community works well. Perhaps the Committee came to understand that the care of disabled veterans is not now, and probably never was, a function performed solely by the VA. Instead, families, more specifically wives, carry a large share of the burden. When caring for veterans is recognized as both a public and a private function, it becomes appropriate to ask if, as a community, we like the way the public-private partnership is working.\textsuperscript{131} What the Committee saw, when it asked that question, is that the partnership has become unfair. Among other things, assuming that wives should give up jobs and careers to care for disabled veterans was one thing when most wives were not employed outside the home and most families did not depend on their earnings. It is another thing when economic demands and social practices have changed and most women are employed outside the home as well as inside the home throughout their adult lives.

A similar public-private partnership exists around the care of children. While parents and family have the primary responsibility, the public’s role is also substantial. It is the public realm, not the family, that defines the minimal amount of education a child should have, what constitutes adequate medical attention, whether particular people have the rights and responsibilities of marriage and parenthood, and so on. It is the public realm, not the family, that creates and pays for most educational resources, that regulates and pays for most medical provision, and that supplies judicial systems that govern family relationships.


\textsuperscript{129} \textit{Effects of Cash and Counseling}, supra note 127, at 27.

\textsuperscript{130} \textit{Id.} at 30.

When a family’s care for a child falls below minimum standards, the state steps in on behalf of the public, to foster the child directly.\textsuperscript{132}

With welfare reform in 1996, the public decided that its share of the public-private partnership did not necessarily include the support of the households of the poorest children. That decision does not fully extend to the households of children whose disabilities are so great that they qualify for SSI, as discussed earlier. The question remains as to whether that decision should extend to the households of children whose unusual care requirements diminish or eliminate the income-earning capacity of their caregiving parents.

As Congress understood when it authorized the VA caregiver stipend, times have changed for caregivers of disabled people. Less family time is available in the home because only a small percentage of mothers are outside the labor force and most families rely on the income of more than one adult. Caring for a disabled person is more time-consuming because, in many cases, the person in need of care is more medically fragile, sees more medical care providers, and requires more complicated therapies and medications on a daily basis. Further, institutionalization is less common.

Continuing the current version of the public-private partnership means that caregivers of disabled children bear the lion’s share of the care responsibility for the children while they get less than a mouse’s share of public support. They do this at a time when meeting a child’s special care needs has become more difficult and also requires sacrificing some or all paid employment. The allocation of responsibilities is not fair, and it is time for community values to catch up.

B. Equity, Gender and Race

Among the equity claims recognized with the creation of the stipend for caregivers of veterans is one of gender. More than ninety-five percent of the relatives caring for disabled veterans are their wives,\textsuperscript{133} and the vast majority of the caregiving relatives of disabled children are their mothers.\textsuperscript{134} Unpaid family care has traditionally been the job of women. While society has not achieved gender equality with respect to family care, the second wave of feminism has

\textsuperscript{132} See, e.g., \textit{In re Adoption/Guardianship of Victor A.}, 872 A.2d 662 (Md. 2005) (discussing termination of parental rights of parents with respect to child with special care health care needs); Marisa Helene Fisher, \textit{Letter to the Editor: Literature Analysis to Determine the Inclusion of Children with Disabilities in Abuse Interventions}, 33 \textit{Child Abuse \& Neglect} 326, 326 (2009) ("In 2005, Kendall-Tackett, Lyon, Taliaferro, and Little stated that children with disabilities rarely receive protection services because providers are unaware of the increased risk and the specialized needs of this population."); P.M. Sullivan \& J.F. Knutson, \textit{Maltreatment and Disabilities: A Population-Based Epidemiological Study}, 24 \textit{Child Abuse and Neglect} 1257, 1268 (2000) ("Children with disabilities are 3.4 times more likely to be maltreated than nondisabled peers.").

\textsuperscript{133} See \textit{supra} Part VI.

\textsuperscript{134} Id.
made the gendered allocation both more visible and more unacceptable.\textsuperscript{135} A caregiver stipend does not make men and women equally responsibility for family care, of course, but it does recognize and respond to the reality that the practice imposes unequal burdens on the caregiver.\textsuperscript{136}

An equity claim that is not mentioned in the discussions around the veterans’ caregiver stipend is that of race. Given that people of color are overrepresented in the military, however, it seems likely that a disproportionate share of disabled veterans and their caregiving spouses are people of color, at least in recent cohorts. The same is true of disabled children and their parents. Many conditions that result in disabilities in children are more prevalent in communities of color, such as lead poisoning, environmental triggers for asthma, and less access to medical care.\textsuperscript{137} A caregiver stipend might give the households of these children enough income to achieve improved health and well-being. For example, a child with multiple ear infections can lose some or all hearing capacity if the infections are poorly treated. Inadequate access to medical care is more likely to occur in a poor community. Once the hearing loss has occurred, a fully-employed caregiving parent is unlikely to have the time or flexibility to get an early diagnosis and intervention or to make sure the school system is doing everything it can to help the child get an adequate education.\textsuperscript{138} With a caregiver stipend, the parent might have the possibility of accepting a part-time job, at least for a period of time sufficient to get a child diagnosed and to arrange for interventions and education suitable to the child’s capacities.

C. Special Needs Children and Parental Employment

Funding a caregiver stipend for parents of disabled and chronically ill children may relieve the financial deprivation of those families, but it will not help families in poverty that do not happen to include a disabled or chronically ill child. A superior solution would be a public benefits program that leaves no child in poverty.\textsuperscript{139} Even if such a program existed, however, a caregiver stipend for parents of disabled and chronically ill children would still be required in situations such as those at issue here—where the child’s special health care needs diminish or eliminate the parent’s capacity to participate in paid employment. Unless and until employment practices undergo substantial change, these parents will face greater difficulties than other parents when it comes to generating wages to help support their families.

\textsuperscript{135} See generally Joan Williams, \textit{Unbending Gender: Why Family and Work Conflict and What to Do About It} (2000).
\textsuperscript{136} See generally Czapanskiy, \textit{supra} note 6; Singer, \textit{supra} note 128, at 193-97.
\textsuperscript{137} See Pokempner, \textit{supra} note 93, at 435-39.
\textsuperscript{138} See id.
\textsuperscript{139} See Anne L. Alstott, \textit{What Does a Fair Society Owe Children—and Their Parents?}, 72 \textit{Fordham} L. REV. 1941 (2004); Diller, \textit{supra} note 93; Pokempner, \textit{supra} note 93, at 451-53.
A caregiver stipend targeted to families where the child’s need for special care is the reason for underemployment or unemployment may be seen as a kind of “special treatment.” Despite the negative press attached to the idea of special treatment, Ruth Colker has argued persuasively that treating people with disabilities the same as everyone else is not always in the best interests of disabled people, nor is it always what they want. The risk of focusing solely on integration is that we may grow blind to the situations where difference is key to the well-being of the individual. Colker made her argument in situations where government’s action has a direct impact on the disabled person—in special education, institutionalization for mental illness, and voting rights. Because of derivative disability, a similar argument should be credible where government is acting indirectly on the disabled child through the child’s family.

If the special treatment objection holds weight against a caregiver stipend for caregiving parents of disabled children, it should also hold water against a caregiver stipend for caregiving relatives of disabled veterans. The objection does not hold in either context, however, because of the obvious benefit that may accrue to the person receiving care, a key justification for special treatment. Avoiding institutionalization, as discussed earlier, is an impressive benefit. In the case of a stipend for caregiving parents, the Florida Cash and Counseling demonstration project adds additional dimensions. About 1000 children with developmental disabilities were enrolled in the program. Their outcomes were compared with the outcomes of similar children whose parents did not accept payment for any of the hours of care they provided the child.

Children in families with a paid parental caregiver did better in terms of certain important health measures, such as having fewer pressure sores, experiencing less shortness of breath, having fewer bedsores worsen, and suffering fewer urinary tract infections and falls.

It is not difficult to imagine other situations where it could be shown that the disabled child derives a significant benefit from the caregiving parent receiving a stipend. For example, children like Charlie who are on the autism spectrum can make impressive gains and some may even be cured if the child is exposed to intensive and time-consuming therapy regimes early in life. Effective therapy usually requires daily parental input for many hours. Combining that level of care with employment is impossible in most cases. When the therapy works well, however, Charlie is more likely to succeed in the classroom and he may, in time, be able to hold down a job and contribute to society economically as well as

140. Colker, supra note 21, at 1416-20.
141. Id. at 1448.
142. Id.
143. Dale et al., supra note 49, at 4-6.
144. Effects of Cash and Counseling, supra note 127, at 4.
145. Foster, supra note 52.
socially. In the meantime, public support for Charlie’s caregiving parent seems a worthwhile tradeoff.

D. Commodification

A final argument against creating a stipend for the caregiving parent of a disabled or chronically ill child is that family care work should not be subject to commodification.\textsuperscript{147} The claim is that the parent who is getting paid for his care and the child or other relative who is responsible for the payment will come to see themselves as employee and employer, a relationship that is incompatible with the usual connections between close relatives. What the studies of the care and counseling demonstrations showed, however, is that the parents and other relatives who accepted a stipend were not interpreting their role as one of employee in any ordinary sense.\textsuperscript{148} Parents who accepted a stipend appeared to see the money as an additional form of social provision, which allowed their household to enjoy a slightly better standard of living.\textsuperscript{149} Adult recipients of care often saw the payments they made to their relative caregivers almost as a gift that gave the caregiver an opportunity to live a better life. Also, in the usual employer-employee relationship, one would expect a relationship between the amount of pay and the number of hours of work. In the Cash and Counseling demonstration projects, however, the number of hours of care provided routinely exceeded the number of paid hours.\textsuperscript{150} It seems more accurate to describe the pay as an honorarium that allows family caregivers to do what they want to do anyway and feel is necessary but without having to endure some of the financial sacrifice they otherwise experience.

X. CONCLUSION

Disabled and chronically ill children typically prefer to live at home with their parents, who typically prefer to raise their children in their homes. The health and well-being of a disabled and chronically-ill child is usually well-served by parental care. Taxpayers may expend fewer dollars when disabled and chronically-ill children are raised in their homes by their parents. These benefits often come with a cost, however, to the emotional and physical health, social functioning and financial well-being of the child’s parents, particularly the parent who spends more time caring for the child.

A well-designed stipend for the caregiving parents of disabled and chronically-ill children, like the stipend for the caregiving relatives of disabled veterans, is a fair and equitable way to help children reap the benefits of parental care in their

\begin{footnotesize}
\begin{enumerate}
\item See generally Kraiem, supra note 105.
\item See Foster, supra note 127.
\item Id.
\item Paying Family Caregivers, supra note 60, at 99.
\end{enumerate}
\end{footnotesize}
homes, to keep the costs of care more manageable, and to reduce the undue burdens and stresses placed on caregiving parents. The program would cover caregiving parents whose child has unusual health care needs where meeting the child’s needs impairs or eliminates the ability of the parent to participate in paid employment. The stipend would be adequate to ensure that the child’s household does not experience an unreasonably low standard of living.  

Reasonable would mean elevating these families to at least two hundred percent of the poverty threshold after any unusual expenses attributable to the child’s disability or illness are taken into account. Since the stipend is awardable only to parents whose opportunities for paid employment are affected by their unusual caregiving responsibilities, the stipend is in the nature of a wage substitute and should count for the purposes of Social Security, Medicare, workers compensation, and unemployment insurance.

As discussed earlier, a version of the proposed caregiver stipend already exists in Medicaid in the form of the Cash and Counseling program or participant-directed care. While the program represents a breakthrough in terms of some of the arguments against the caregiver stipend, it is a meager and inadequate version of the program that is needed. To begin with, the program is not a mandatory feature of Medicaid. States are permitted to offer it, but they are not required to do so. States can elect whether to cover children in the program, and some cover only adults. They can also elect to cover children with some conditions but not others, and not every state allows parents to be paid. States are not required to make the benefit available to every household that meets the eligibility standard; once the allocated funds are committed, eligible households can be placed on a waiting list. Finally, even those caregivers in families that qualify and are accepted are usually paid only a small stipend, not sufficient to raise the household’s standard of living out of poverty.

A far better model is the program modeled on the one authorized by Congress in 2010 for relatives caring for disabled veterans. Like Cash and Counseling, the caregiver stipend for veterans represents a breakthrough in terms of some of the

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151. If the pay is set too low, there is not only a loss to the household, there is also a risk that the rate of pay for others doing the similar work may decline, and that rate of pay is already quite low. See Kraiem, supra note 105; Mark Sciegaj, Kevin Mahoney & Kristen Simone, State Experiences with Implementing the Cash and Counseling Demonstration and Evaluation Project, 20 J. AGING & SOC. POL. 81, 93 (2008) (retelling that union in New York City objected to cash and counseling demonstration project because of risk of pay cuts affecting agency-based home care workers); Singer, supra note 128, at 196-97.


153. See Kaiser Comm’r on Medicaid and the Uninsured, supra note 28.

154. See id.

155. See Univ. of Minn. Research and Training Ctr. on Cmt. Living, supra note 152, at 7.

156. Id.

arguments against the caregiver stipend. It is preferable for two reasons. First, the
program advances the claims that the public shares at least the financial
responsibility of the family to care for disabled relatives and that the public
should no longer demand that caregiving relatives bear all the costs of care.
Second, the amount of the stipend is adequate to ensure that the households are
sustained at a level well above the poverty threshold even when the caregiving
relative's responsibilities reduce or eliminate opportunities for paid employment.

In times of economic distress and political gridlock, imagining and implement-
ing a public benefit program is a challenge. That challenge pales in comparison
with what caregiving parents of disabled and chronically ill children face.
Economic insecurity is a fact of life for many of these parents. In the best of
times, employment that is compatible with their caregiving is difficult to come by
and even more difficult to keep. In bad times, employers give less quarter. Special
programs to help their children may get cut back by school systems and local
governments, and charitable organizations are strapped. But they persist, and
their children survive. The challenge for the rest of us is to understand what these
parents need and to deliver what they and their children deserve.