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CONSUMER DIRECTION IN MEDICAID LONG TERM CARE: AUTONOMY, COMMODIFICATION OF FAMILY LABOR, AND COMMUNITY RESILIENCE

DANIELA KRAIEM*

I. Introduction	672
II. Background: Medicaid and Long Term Care.....	676
A. What and Where is Long Term Care?	676
B. The Need for Long Term Care Will Increase Dramatically in the Future.....	678
C. Families Cannot Sustain the Current Levels of Unremunerated Care.....	679
D. Medicaid, the Largest Funder of Long Term Care, is Moving Towards Consumer Directed Long Term Care Because of Autonomy Concerns and a Shortage of Labor	681
1. HCBS Beneficiaries Lack Autonomy.....	683
2. HCBS Programs Lack Adequate Labor Supply	684
3. Consumer Directed Long Term Care in the Medicaid Home and Community Programs Increases Both the Pool of Available Long Term Care Workers and	

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Consumer Autonomy.....	688
III. Consumer Direction Expands the Labor Pool for Medicaid Home and Community Based Services by Commodifying Family Labor.....	691
IV. Consumer Direction Increases Autonomy in Long Term Care, But at What Cost?.....	695
A. Neoliberal Autonomy as Consumer Choice Obscures Our Dependence on Both Family and State.....	696
1. Autonomy as consumer choice pits the interests of the consumer against the interests of their family member caretakers.....	698
2. Autonomy as consumer choice allows the state to shed its role as both regulator and employer.....	699
B. Autonomy Creates a Positive Human Right for Beneficiaries, but it Disembeds Long term Care Workers from the Regular Workforce.....	701
1. Consumer direction makes organizing and collective bargaining in long term care more difficult.....	704
2. The commodification of family labor carries opportunity costs for the worker.....	706
V. Grounding Consumer Directed Long Term Care in Community Resilience Rather Than Autonomy.....	710
A. A Resilience Frame Embeds Long Term Care Consumers in Community.....	713
B. A Resilience Frame Re-embeds Caretakers in the Workforce...	714
C. Supporting Resilient Caretaking Communities Strengthens Long Term Care for Everyone.....	716
VI. Conclusion.....	717

I. INTRODUCTION

Long term care—assistance when we are elderly, frail, or have a disability—is a basic human need. Families, the private market, communities, and the state all play roles in ensuring that these essential needs—help with bathing, eating, transportation, self-care, and housekeeping, not to mention companionship and belonging—are met. There is nothing natural about the allocation of responsibility for care. Roles differ from place to place, and change over time. Who manages decisions about care reveals, for example, whether members of a society perceive that a frail elderly person or a person with disabilities is capable of being autonomous. Who bears the benefits and burdens of care illuminates the role and nature of the family, including gendered dynamics within

households and intergenerational compacts between households. How we compensate and regulate caretakers who work inside our homes, or how we compensate members of our families who provide care, illustrates how and whether we believe that home and market operate under distinct rules, even when the boundaries between them prove to be porous.

The past thirty years in the United States have brought remarkable transformations in the organization of long term care. Although female family members still provide the lion's share of long term care in this country, the government has gradually taken an increasing role in providing long term care for the frail elderly and persons with disabilities.¹ Like other forms of public assistance, the form of help from the state has changed over time, reflecting shifting notions about the best method for delivering services given limited resources, as well as the evolution of American society itself. Initially, the Medicaid program, the largest public funder of long term care, paid only for institutional care, such as nursing homes or hospitals. By the early 1980s, advocates began to demand that Medicaid provide some long term care services in peoples' homes, so that they could age in place or live independently. Most recently, State Medicaid Programs have been experimenting with a model of "consumer direction," a voucher program in which beneficiaries use government funds to purchase long term care assistance on the private market.² One fascinating aspect of consumer direction is that beneficiaries tend to hire family members to provide care, thus returning the family back to the center of the discussion, albeit this time in the context of a free market-driven program funded by the state.

I argue that while the new trend towards consumer direction in long term care has some benefits, it also creates significant negative consequences that advocates and policy makers should be attentive to before this service delivery model becomes more widespread. I begin the article in Section II by describing how the consumer directed model, which has been heavily

1. Not all persons who are elderly or who have disabilities require long term care. For the purposes of this article, I am referring to those who do require some form of long term care. The term "persons with disabilities" encompasses children with special needs, non-elderly adults with disabilities, elderly persons with disabilities, and the frail elderly. Of course, the needs of each of these communities (and indeed of individuals within those communities) are diverse.

2. I use the term "consumer directed long term care" in this article to denote government funded programs in which the beneficiary has both employer authority (the power to hire and fire their aides) and budget authority (the power to allocate some of his or her stipend towards goods and services, according to a preapproved plan). See generally Pamela Doty et al., *New State Strategies to Meet Long Term Care Needs*, 29 HEALTH AFF. 49, 50 (2010) (describing states' efforts to implement various long-term care programs). There are multiple terms for similar kinds of programs, which include "Cash and Counseling," "self-directed long term care," "person-directed long term care," "consumer-directed personal care assistance services" ("CD-PAS"), and "individualized care," among others.

influenced by both neoliberal economic theory and progressive human rights discourse, emerged in response to two concrete problems in the long term care delivery system: dissatisfaction with services and a severe labor shortage. Beneficiaries in the Medicaid funded in-home care programs complained that they lacked autonomy because a Medicaid Home Health Agency controlled the hiring, firing, training, and scheduling of the aides they rely upon. Further, many agencies could not find adequate staff to provide high quality, culturally appropriate care. These problems are significant enough that they are a matter of public concern. The current labor shortage of in-home care workers will grow more acute in the near future. The Census Bureau estimates that the number of older persons in the United States will increase from 35 million people to 87 million people between 2000 and 2050.³ Geographic mobility and the need for most women to work outside of the home make it increasingly difficult for family members to provide unpaid care. Because Medicaid is a federal government program, undocumented immigrant labor cannot supplement the regularized labor force, as occurs in private pay situations.

Consumer directed long term care programs address the question of autonomy by transforming “beneficiaries” into “consumers” who may use their funds to hire any worker to care for them. Consumer direction transforms the passive Medicaid beneficiary into an active consumer who will carefully manage her limited benefit as though it were private property. Simultaneously, state funding of consumer directed long term care might also be seen as an entitlement to services that maximize the self-determination of people with disabilities.

Consumer direction addresses the shortage of labor by opening up new labor pools. Consumers can tap into the labor of friends and family members who are not career caretakers but are willing to work caring for someone they know. Many, if not most, consumers hire family members with their stipends. The significance of this, which I explore in detail in Section III, should not be understated: consumer directed long term care is the first potentially large scale, state-funded commodification of family care work in the United States.

At the core of this article is Section IV, in which I ask what happens when the rhetoric of the “autonomy of the individual,” which generates much of the political support for this program, meets the reality of the commodification of family labor, in the context of a state program under pressure to contain costs. I argue that the autonomy arguments underlying

3. See RICHARD W. JOHNSON ET AL., MEETING THE LONG TERM CARE NEEDS OF THE BABY BOOMERS: HOW CHANGING FAMILIES WILL AFFECT PAID HELPERS AND INSTITUTIONS, URBAN INSTITUTE 1 (2007), available at www.urban.org/UploadedPDF/311451_Meeting_Care.pdf (estimating population growth using 2004 U.S. Census figures).

support for consumer directed long term care from both political conservatives and liberals mask how decisions that we make about long term care affect our family members, our care workers, and our communities in concrete and immediate ways. When the beneficiary and the worker are likely to be family members, and may even be part of the same nuclear household, it is misleading to consider only *individual* autonomy. In the aggregate, decisions about long term care policy determine the shape of our society—and have significant effects on gender, race, and class-based inequalities. From this vantage point, I see Medicaid long term care policy as a site of governance of both the family and the market; while it appears in the form of a public benefit, it shapes the legal regulation and norms of family life in particular ways, structures employment, remuneration and work around specific principles, and has consequences that reach far beyond the intimate relation between the caretaker and care receiver.⁴

I argue that while that consumer direction has tangible benefits, shifting employer authority to the beneficiary in while simultaneously commodifying family labor also has specific negative consequences, several of which I discuss in detail. A focus on autonomy as consumer choice is rooted in the assumption that people may be disembedded from their families and that pitting the interest of the consumer-as-employer against that of the family-member-as-worker is possible, and would not have a negative effect on the relationship. In the meantime, the state sheds its obligations as a regulator of quality of care and no longer has to provide for even the most basic labor and employment benefits or protections for the workers. Consumer directed long term care reduces workplace protections for people who work in private homes—rather than for an agency-based employer—and for employees who are family members. These reduced workplace protections dislodge the workers from their position in the regularized labor force. This leaves already vulnerable workers, who are disproportionately low-wage earning women of color, in an even more precarious position than before. The focus on autonomy as a positive human right, while a vital component of the movement for rights for persons with disabilities, blinds us to effects on the capabilities and rights of the paraprofessional and family care workers. By scattering employer authority across all consumers, consumer direction undermines

4. See Janet Halley and Kerry Rittich, *Critical Directions in Comparative Family Law: Genealogies and Contemporary Studies of Family Law Exceptionalism*, 58 AM. J. COMP. L. 753 (2010). Long term care policy functions as an aspect of “Family Law 2” (legal regulation of the family outside of the laws of matrimony, divorce and custody, which often reinforce the family as special or exceptional) as well as “Family Law 3” (those laws which operate in deep background to how family lives are structured and experienced). See *id.*

the nascent attempts by long term care workers to bargain collectively for better pay and improved working conditions and benefits. The option to provide care for a family member who is elderly or who has a disability, while possibly the best option in the short term, poses significant long term opportunity costs for the disproportionately female family member caretakers who are not participating in the regular labor force.

In the final section of this article, I take up the question of how to conceptualize a program that honors the dignity and self-determination of persons with disabilities, while not imagining them as mere market participants who are disembedded from their families and communities. Instead of focusing on autonomy, I propose a lens of “community resilience” to design and evaluate programs for long term care. The role of the state should be to build the resilience of these caretaking communities by ensuring workplace protections for all workers, connecting caretaking units to each other and to outside services so that they are not providing care in isolation, and finally, remaking communities so that they understand caretaking and supporting the elderly and people with disabilities as part of community life, rather than an individual undertaking.

II. BACKGROUND: MEDICAID AND LONG TERM CARE

This article is about consumer directed long term care within the Medicaid program. Consumer directed options within Medicaid are only a small part of the much larger patchwork of the efforts of multiple actors to meet the needs of the frail elderly and persons with disabilities.⁵ In this section, I will give a cursory overview of long term care in the United States and introduce the new consumer directed long term care option under the Medicaid program.

A. What and Where is Long Term Care?

“Long term care” is an umbrella term for services to meet the medical and non-medical needs of people who, due to advanced age or disability, cannot care for themselves. Long term care commonly consists of assistance with either or both the “activities of daily living” and the “instrumental activities of daily living.”⁶ It takes place in institutional

5. There is no single system for long term care in the United States, no single government agency that oversees long term care, and no universal entitlement to ensure that everyone has the long term care they need. *See generally* Terence Ng et al., *Medicare and Medicaid in Long-Term Care*, 29 HEALTH AFF. 22, 26 (2010) (describing several of the programs that provide funding for long term care in the United States and the lack of coordination among them).

6. *See* CONG. BUDGET OFFICE, FINANCING LONG-TERM CARE FOR THE ELDERLY 2 box1.1 (2004), available at <http://www.cbo.gov/ftpdocs/54xx/doc5400/04-26-LongTermCare.pdf> (defining long term care). Activities of daily living are basic physical abilities, such as “eating, getting in and out of bed, getting around inside the

settings, such as nursing homes. It also occurs in private homes, or wherever people live.

Home-based long term care can range from basic assistance with remembering medications to bathing, dressing, feeding, basic medical care (such as changing bandages, monitoring health, etc.), more complex medical care (catheters, injections, etc.), and providing transportation. Of course, the needs of the elderly and persons with disabilities are diverse. Even the needs of individuals are not static.⁷ Each recipient of care is differently situated and empowered with regard to age, race, ethnicity, class, gender, sexual orientation, gender identity, and other social structures.⁸ These factors influence where, how, and from whom people receive long term care.⁹

There are four major sources of funding for long term care: out of pocket expenditures,¹⁰ long term care insurance,¹¹ unremunerated care by family; and public funding. Only nine percent of people have long term care insurance policies, and paying out of pocket for full time long term care

home, dressing, bathing and using the toilet.” *Id.* “Instrumental activities of daily living” are the functions necessary for living independently, such as “heavy housework and laundry, preparing meals, shopping for groceries, getting around outside, getting to places that require either driving or taking public transportation, managing money, using the telephone, and taking medications.” *Id.*

7. Most people use a variety of long term care services over time as their need for care changes. Care needs may increase over time, as a person ages and becomes increasingly frail. Conversely, care needs may decrease, especially for children or non-elderly adults with disabilities, as they learn new skills or acquire home modifications or assistive technologies that make independent living more feasible. *See id.* at 13-14; *see also* JOHNSON ET AL., *supra* note 3, at 3.

8. *See* Nancy R. Hooyman & Judith G. Gonyea, *A Feminist Model of Family Care: Practice and Policy Directions*, 11 J. WOMEN & AGING 149, 153 (1999).

9. For example, women tend to outlive men and remain healthier for longer. Thus, even women who were once married are less likely to receive long term care from a spouse in their own homes than men who are similarly situated with regard to race or class. A woman may provide long term care for her husband, who is likely to die before she does. She then must rely upon others (usually female adult children) for her long term care. *See id.* at 150.

10. People with disabilities or their families pay for approximately \$45 billion in long term care services, including nursing homes and home-based care. This amounts to twenty-seven percent of long term care costs “out of pocket.” Richard W. Johnson, *The Strains and Drains of Long-Term Care*, 10 AM. MED. ASS’N J. ETHICS 397, 398 (2008).

11. Approximately nine percent of Americans above the age of 55 have private long term care insurance. JOHNSON ET AL., *supra* note 3, at 2. In 2004, private insurance covered about \$6 billion, or four percent, of long term care expenses. CONG. BUDGET OFFICE, *supra* note 6, at 4. Insured persons often find that insurance is inadequate to cover expenses. *See id.* Uncertainty about insurer solvency and premium instability, as well as other problems in the long term care insurance market, make purchasing insurance unattractive to many consumers. *See id.* at 17-21. The availability of government-funded long term care through the Medicaid program also renders long term care insurance less attractive, especially for people of modest means. *See id.*

over many years is unrealistic for most people.¹² This means that the two primary sources of long term care funding are public funding and unremunerated care by families.

Long term care is labor intensive, which means that it is costly, even if the workers are not paid at all or if the workers' wages are low.¹³ For example, a nursing home costs five to eight thousand dollars per month.¹⁴ In-home long term care is generally less expensive, but varies with the needs of the recipient and does not account for the cost of room and board. In 2004, Americans spent \$135 billion on long term care for older adults¹⁵ and \$206.6 billion on adults with disabilities in 2005.¹⁶ In addition, families provide the equivalent of around \$375 billion in unremunerated care per year.¹⁷

B. The Need for Long Term Care Will Increase Dramatically in the Future

Often termed a "crisis," the increasing needs of the large baby boomer generation as they age will drive up demand for long term care services.¹⁸ The number of older persons in the United States will increase from 35 million people to 87 million people between 2000 and 2050.¹⁹ The number of people over 85, who typically require the most long term care resources,

12. See JOHNSON ET AL., *supra* note 3, at 2.

13. See CITIZENS FOR LONG TERM CARE, LONG-TERM CARE FINANCING AND THE LONG-TERM CARE WORKFORCE CRISIS: CAUSES AND SOLUTIONS 1, 3, 7 (2002), available at http://www.directcareclearinghouse.org/download/CLTC_doc_rev1.pdf (noting that the relationship between public funding levels, wages and the quality of long term care is complex).

14. LAWRENCE A. FROLIK & MELISSA C. BROWN, ADVISING THE ELDERLY OR DISABLED CLIENT § 14.01[1] (2d ed. 2009).

15. See CONG. BUDGET OFFICE, *supra* note 6, at ix (estimating that approximately \$15,000 was spent per "impaired senior").

16. See U.S. DEP'T OF HEALTH & HUMAN SERV., PAYING FOR LONG TERM CARE: OVERVIEW (2010), available at http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx (last visited July 30, 2010) (explaining that this number excludes the cost of care provided by family and friends).

17. See Carol Levine et al., *Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care*, 29 HEALTH AFF. 116, 116 (2010) (estimating that "thirty-four million family caregivers, the majority of them women, provide seventy-five to eighty percent of long-term care in the community").

18. See generally KATHRYN G. ALLEN, U.S. GEN. ACCOUNTING OFFICE, GAO-05-564T, LONG TERM CARE FINANCING: GROWING DEMAND AND LOSS OF SERVICES ARE STRAINING FEDERAL AND STATE BUDGETS 12 (2005), available at <http://www.gao.gov/new.items/d05564t.pdf> (estimating that the number of people relying on Medicare, Medicaid and Social Security will double by 2040); DAVID M. WALKER, U.S. GEN. ACCOUNTING OFFICE, GAO-02-544T, LONG TERM CARE: AGING BABY BOOM GENERATION WILL INCREASE DEMAND AND BURDEN ON STATE BUDGETS 10 (2002), available at <http://www.gao.gov/new.items/d02544t.pdf> (detailing the economic challenges associated with the aging of 76 million baby boomers).

19. See JOHNSON ET AL., *supra* note 3, at 1.

will quadruple between 2000 and 2050, rising from 4 million to almost 21 million people.²⁰ Even in fairly conservative estimates, which assume a steady and substantial decline in levels of disability among the elderly, “the number of older adults using paid home care will increase by three-fourths between 2000 and 2040 and the number in nursing homes will increase by two-thirds.”²¹ Non-elderly persons with disabilities are also using personal assistance services at an increased rate.²²

C. Families Cannot Sustain the Current Levels of Unremunerated Care

The demographics of the baby boom do not tell the entire story. There is also an increased need for state funded long term care because female family members appear to be unable to sustain, much less increase, the high levels of long term care they already provide.²³ By far, the most significant sources of long term care for people with disabilities in all stages of life are their families. Some researchers estimate that family caretakers provide almost eighty percent of all long term care in the United States.²⁴ A quarter of all workers report that they care for an ailing parent.²⁵ The amount of work required to care for family members can be considerable. Seventeen percent of family caretakers report that they provide care for forty hours per week or more.²⁶

The other part of this story is rooted in the immense transformation of the work and home lives of women in the United States over the past half century, just as life expectancy is rising and creating an increased demand for long term care. Both men and women provide unpaid family care.²⁷

20. See *id.*; U.S. CENSUS BUREAU, U.S. INTERIM PROJECTIONS BY AGE, SEX, RACE AND HISPANIC ORIGIN tbl.2a, available at <http://www.census.gov/ipc/www/usinterimproj/> (last visited Nov. 3, 2010). While not all of the elderly are disabled, sixty-nine percent of those who are 65 or older will develop disabilities before they die, and thirty-five percent of those are expected to enter a nursing home. Peter Kemper et al., *Long-Term Care over an Uncertain Future: What Can Current Retirees Expect?*, 42 INQUIRY 335, 342 (2005).

21. See JOHNSON ET AL., *supra* note 3, at 1.

22. See PARAPROFESSIONAL HEALTHCARE INST., THE PERSONAL ASSISTANCE SERVICES AND DIRECT-SUPPORT WORKFORCE: A LITERATURE REVIEW 3 (2003), available at http://www.directcareclearinghouse.org/download/CMS_Lit_Rev_FINAL_6.12.03.pdf. (suggesting that the need for home health care will increase as the number of young people with disabilities grows).

23. JOHNSON ET AL., *supra* note 3, at 6.

24. See LEE THOMPSON, LONG-TERM CARE FIN. PROJECT AT GEORGETOWN UNIV., LONG-TERM CARE: SUPPORT FOR FAMILY CAREGIVERS [ISSUE BRIEF] (2004), available at <http://ltc.georgetown.edu/pdfs/caregivers.pdf>.

25. NANCY FOLBRE, INVISIBLE HEART 37 (2001).

26. See NAT'L ALLIANCE FOR CAREGIVING & AARP, CAREGIVING IN THE U.S. 44 fig.20 (2004), available at <http://www.caregiving.org/data/04finalreport.pdf>.

27. See METLIFE, THE METLIFE STUDY OF WORKING CAREGIVERS AND EMPLOYER HEALTH CARE COSTS 10 (2010), available at <http://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-working->

However, women provide the vast majority of unpaid care, and using the term “family” caretakers masks the fact that women experience the negative financial and emotional effects of caretaking more than men.²⁸ Without discounting the extraordinary contributions many male caretakers make to caring for family members, it is safe to say that wives, mothers, and female adult children provide most unpaid home care for adults with disabilities.²⁹ Parents, largely mothers, provide unpaid family care for children with disabilities.³⁰ The gendered nature of the work is in part the result of the fact that women appear to provide more care related to immediate physical needs that cannot be scheduled at the convenience of the caretaker, such as feeding and dressing, while men engage in other important, but less time-bound tasks such as home maintenance, financial planning, and providing transportation.³¹ Elderly women, who are more likely to rely upon a non-spouse for care, might also prefer that intimate tasks, such as bathing, be performed by a female family caretaker.

Researchers have found that “the demand for paid services will likely rise in the future as the opportunity cost of care from adult children—especially daughters—grows.”³² The fact that most women now work outside of the home, either by choice or economic necessity, limits the amount of unpaid labor that is available.³³ Unremunerated (largely female) caretakers become “derivative dependents.”³⁴ A person who spends her time providing care for another person instead of earning money must find another source of support.³⁵ But relying upon a mate for support during a period of derivative dependency is less and less possible, as most families require two incomes to maintain a middle class standard of living.³⁶ Wage

caregivers-employers-health-care-costs.pdf. *See also* Hooyman & Gonyea, *supra* note 8, at 153.

28. *See* Hooyman & Gonyea, *supra* note 8, at 150; FOLBRE, *supra* note 25, at 37.

29. *See* JEANNETTE TAKAMURA & BOB WILLIAMS, DEP’T OF HEALTH & HUMAN SERVS., INFORMAL CAREGIVING: COMPASSION IN ACTION 5 (1998), *available at* <http://aspe.hhs.gov/datcp/Reports/carebro2.pdf>.

30. *See* EXEC. SUMMARY AND ACTION PLAN—SLOAN WORK AND FAMILY RESEARCH NETWORK PANEL MEETING AT BOSTON COLLEGE: WORK-FAMILY ISSUES FOR EMPLOYED PARENTS OF CHILDREN WITH DISABILITIES 3, *available at* http://wfnetwork.bc.edu/pdfs/Disability_Panel_Summary_0908.pdf (last visited Nov. 3, 2010) [hereinafter SLOAN WORK AND FAMILY RESEARCH NETWORK PANEL MEETING].

31. *See* Hooyman & Gonyea, *supra* note 8, at 152. This tendency should not be naturalized, but rather understood as the product of multiple factors, including the gendered structure of the workforce, societal and cultural expectations based on gender, state policies that shape family life and other forces. *See id.*

32. JOHNSON ET AL., *supra* note 3, at 7.

33. *Id.*

34. *See* MARTHA FINEMAN, THE AUTONOMY MYTH 41-45 (2005) (describing the gendered nature of derivative dependency).

35. *See id.* at 46.

36. *See generally* ROBERT B. REICH, THE WORK OF NATIONS: PREPARING

stagnation over the long term has meant that families do not have the resilience to tolerate long periods of time with only one income.³⁷ This is even more acute for single earner households, which simply do not have the option of trading paid work for unpaid care work.³⁸ Even if this were not an issue, people are more geographically mobile than they used to be, which means that many people do not live close to the family members who require help.³⁹

D. Medicaid, the Largest Funder of Long Term Care, is Moving Towards Consumer Directed Long Term Care Because of Autonomy Concerns and a Shortage of Labor

State and federal governments together provide the largest share of cash funds for long term care. When an individual does not have personal resources, sufficient unpaid family care or insurance to cover long term care needs, Medicaid is the payer of last resort.⁴⁰ Medicaid pays for at least one half of all nursing home care in the country.⁴¹ This is a significant expenditure; one third of all state and federal Medicaid funds are spent on long term care.⁴²

Medicaid is a means-tested program with complex funding and eligibility rules.⁴³ In general terms, Medicaid recipients are poor.⁴⁴

OURSELVES FOR 21ST CENTURY CAPITALISM 208-24 (1992) (arguing that growing wealth inequalities mean that wage earners will suffer declining standards of living); ELIZABETH WARREN & AMELIA WARREN TYAGI, THE TWO INCOME TRAP: WHY MIDDLE-CLASS MOTHERS AND FATHERS ARE GOING BROKE 1-14 (2003) (arguing that family incomes are almost entirely committed to necessities, such as home and car payments, health insurance, and education costs).

37. See Hooyman & Gonyea, *supra* note 8, at 155.

38. *Id.* at 156.

39. FOLBRE, *supra* note 25, at 37.

40. It is worth noting that Medicare (as opposed to Medicaid) does not, strictly speaking, pay for long term care. Medicare will pay for a limited amount of skilled care after a hospital discharge, including some home care. See 42 U.S.C. § 1395x(m) (2006) (stating that home health services include part time nursing care, physical or occupational therapy, and home health aides that do not visit more than eight hours a day or a total of 28 hours a week). However, this generally does not include personal care services (such as cooking or transportation) and is often only available while there is a need for skilled care (meaning the types of services provided by a professional nurse) and not the care that a family member or paraprofessional could provide. While Medicare has become a de facto long term care program for some people, it is not a program that individuals can *plan* on using to fund their care.

41. FROLIK & BROWN, *supra* note 14, § 14.01[1].

42. BRIAN BURWELL ET AL., THE URBAN INSTITUTE, MEDICAID LONG-TERM CARE EXPENDITURES IN FY 2005 1 (2006), available at <http://www.urban.org/url.cfm?ID=311451>.

43. See generally FROLIK & BROWN, *supra* note 14, §§ 13.02, 13.03[1]-[4] (noting that eligibility for benefits is restricted to persons with non-welfare income below a certain level). Federal and state governments jointly fund the program. *Id.* § 14.01. While state rules regarding Medicaid eligibility vary widely, recipients fall into several general categories. The first are people deemed “categorically needy.” The

Millions of Americans, even those who have not previously been low-income, are deemed eligible for the program because of the costs associated with long term care.⁴⁵

Because it is such a large funder of long term care, Medicaid rules and policies affect millions of the elderly and persons with disabilities. Up until the early 1980s, Medicaid would pay for institutional long term care, which meant that most people who required state subsidized long term care wound up in nursing homes, institutions, or other congregate care living facilities.⁴⁶ Not all people with disabilities needed or wanted to live in institutions, and it is an extremely expensive option.⁴⁷

To combat institutional bias as well as save significant funds, some states now offer Medicaid Home and Community Based Services (“HCBS”), which can be thought of as nursing home diversion programs under a federal waiver.⁴⁸ HCBS programs vary from state to state, but

categorically needy are extremely poor and have an additional qualifying condition, such as age, blindness, or other disability. 42 U.S.C. § 1302 (2006); *see* 42 C.F.R. § 435.4 (2010) (defining categorically needy individuals as “families and children, aged, blind, or disabled individuals, and pregnant women . . . who are eligible for Medicaid”). The federal government requires states that participate in the Medicaid program (which is all states at this time) to cover the categorically needy. 42 C.F.R. § 435.4. The second category are the “optional categorically needy,” which includes people who might not otherwise qualify for coverage, but whom the state elects to cover. These rules are complex and contain numerous exceptions. The last large category of Medicaid recipients is those who are deemed “medically needy.” The medically needy are people who are aged, blind or disabled, but who, despite having incomes above the low threshold for categorical eligibility, have medical costs that they simply cannot absorb. FROLIK & BROWN, *supra* note 14, § 14.02[4]. Medically needy recipients have enough income that they are not categorically needy. However, they must “spend down” their income by using virtually all of that income to pay for the cost of their medical expenses. Medicaid will then pick up the rest of the costs. *Id.*

44. Many people enter nursing homes as private pay residents, but exhaust all of their assets and wind up relying on Medicaid to cover the costs of their long term care. FROLIK & BROWN, *supra* note 14, § 14.01[1].

45. *Id.*

46. Home and community-based services were available for Medicaid-eligible individuals who would otherwise need nursing home care if the state opted to offer that option since 1981. Pub. L. 97-35, Aug. 13, 1981, 95 Stat. 357; 42 C.F.R. §§ 441.300-310 (2010) (permitting states to offer home and community-based services to individuals under a Medicaid waiver program). *See, e.g.*, FLA. STAT. ANN. § 409.9102 (West 2010) (establishing a long term care program for the state of Florida); FLA. ADMIN. RULE 690-157.201 (2009) (approving standards for Long-Term Care Partnership Program); ALA. ADMIN. RULE NO. 560-X-10-.01 (2009) (defining long term care provisions for Alabama residents).

47. *See, e.g.*, *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 593-94 (1999) (describing a claim in which the plaintiff alleged that the State placed her in a segregated institution rather than a community based rehabilitation program despite her desire to live independently).

48. Until recently, states operated HCBS programs under a waiver. *See* 42 U.S.C. § 1915(c) (1981) (permitting states to operate HCBS programs under a waiver of statutory requirements); 42 C.F.R. §§ 441.300-10(2010) (outlining requirements for obtaining a waiver under 42 U.S.C. § 1915(c)). *See generally* Andrew I. Batavia, *A Right to Personal Assistance Services: “Most Integrated Setting Appropriate”*

many offer case management, homemaker services, adult day care, respite care, or home health aides to assist the recipient under what is called the “Agency” or “Medical” Model.⁴⁹ Agency model services usually include the assistance of a long term care worker employed by a private home health agency that contracted with Medicaid to provide the service. Significantly, the agency is the aide’s employer and sets the caretaker’s hours, terms and conditions of employment, and is responsible for training, hiring, and firing the aide(s). Caretakers under most HCBS waiver programs must be supervised by a Registered Nurse, and may not be legally liable family members of the participant, which means that they may not be the spouse or parent of the recipient.⁵⁰

Although many Medicaid beneficiaries are satisfied with their agency-based HCBS experience, two significant problems arose with the service delivery model: concerns about beneficiary autonomy and a shortage of labor. In the next sections I will explore each of these problems, and discuss how consumer direction arose to address them.

1. HCBS Beneficiaries Lack Autonomy

Many beneficiaries complained that they lacked autonomy within the HCBS system because they could not dictate when the aide would come to assist them or with what activities they would assist them, and because they had no way to insist that the aide provide services in a culturally appropriate manner.⁵¹ In the agency model, the Medicaid beneficiary has no control in the selection, training, directing, and firing of the person who enters their home and performs what may be extremely intimate caretaking tasks, including changing adult diapers, bathing, and feeding. While a recipient may complain about a particular aide, it is up to the agency to fire and replace the aide. The recipient does not control the aide’s working hours, which may result in a mismatch. For example, an aide may work a full eight-hour day, providing care from nine until five. However, the recipient may require assistance getting into bed. The aide might need to put the recipient to bed at five in the afternoon, before she leaves for the evening. Other aides may not be attentive to religious or culturally

Requirements and the Independent Living Model of Long-Term Care, 27 AM. J.L. & MED. 17, 24-25 (2001) (explaining the process under which states can apply for a federal waiver to supply HCBS services under the Medicaid Program).

49. Batavia, *supra* note 48, at 21.

50. See 42 C.F.R. § 440.167(a)(2) (2010) (restricting payments to legally liable family members under Medicaid HCBS programs); LAURA BATES, MICHIGAN FAMILY IMPACT SEMINARS, MICHIGAN PROGRAMS TO SUPPORT FAMILY CAREGIVERS 26, 29 (2005), http://familyimpactseminars.org/s_mifis09c04.pdf.

51. See Marshall B. Kapp, *Enhancing Autonomy and Choice in Selecting and Directing Long-Term Care Services*, 4 ELDER L.J. 55 (1996) (arguing that patients lack control over services in traditional HCBS programs).

determined needs of the recipient—such as the desire of the recipient to keep her kitchen kosher or eat halal meat.

2. HCBS Programs Lack Adequate Labor Supply

The second major problem that arose in the Medicaid HCBS programs is a dire shortage of paraprofessional home-based long term care workers at all skill levels.⁵² In 2008, the U.S. Bureau of Labor Statistics estimated that 1.5 million workers were employed as personal and home health aides. In 2000, the Office of Disability, Aging and Long-Term Care Policy estimated that the “direct care workforce” provided care to at least fifteen million people.⁵³ The number of workers will have to increase by forty-eight percent, or at least one million more workers by 2014.⁵⁴ The paraprofessional health care worker shortage has serious consequences for families as well as the person with disabilities. For example, in a 2000 study, forty-six percent of parents with a child eligible for home health services could not find adequate workers or services for their child.⁵⁵

Agencies that contract to provide Medicaid-funded long term care workers suffer from the severe labor shortage, especially for recipients who

52. I use the term paraprofessional long term care workers to include people working under a variety of occupational titles or descriptions. These include home health aide, home care worker, personal services assistant, and direct-care worker, among others. The U.S. Bureau of Labor Statistics recognizes two broad categories of paraprofessional health care workers who are likely to work in private homes. Home Health Aides “provide routine, personal healthcare, such as bathing, dressing, or grooming, to elderly, convalescent, or disabled persons in the home of patients or in a residential facility.” U.S. BUREAU OF LABOR STATISTICS, DEP’T OF LABOR, OCCUPATIONAL EMPLOYMENT STATISTICS, HOME HEALTH AIDES (2009), *available at* <http://www.bls.gov/oes/current/oes311011.htm>. The Department of Labor defines personal and home care aides as workers who “help people who are disabled, chronically ill, or cognitively impaired and older adults who . . . live in their homes or in residential facilities instead of in health facilities or institutions.” Duties include basic housekeeping tasks such as making a bed and keeping the home sanitary and safe for the client. U.S. BUREAU OF LABOR STATISTICS, U.S. DEP’T OF LABOR, OCCUPATIONAL EMPLOYMENT STATISTICS, HOME HEALTH AIDES AND PERSONAL AND HOME CARE AIDES (2009), *available at* <http://www.bls.gov/oco/ocos326.htm>.

53. See U.S. DEP’T OF HEALTH & HUMAN SERVS., THE FUTURE SUPPLY OF LONG TERM CARE WORKERS IN RELATION TO THE AGING BABY BOOM GENERATION (2003), *available at* <http://aspe.hhs.gov/daltcp/reports/04cfpk02.htm#note1> (indicating that 12.1 million people received long term care, including 6.4 million people aged 65 years or over and 5.7 million people aged under 65 years).

54. See JUTTA ULRICH, THE U.S. DIRECT CARE WORKFORCE—AN OVERVIEW 2 (2007), *available at* https://www.azdes.gov/CMS400Min/uploadedFiles/DAAS/direct_care_workforce_united_states.pdf (citing Bureau of Labor Statistics data).

55. See LESLIE FOSTER ET AL., U.S. DEP’T OF HEALTH & HUMAN SERVS., THE EFFECTS OF CASH AND COUNSELING ON THE PRIMARY INFORMAL CAREGIVERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES 6 (2005), *available at* <http://www.cashandcounseling.org/resources/20060120-105320/ddkidpic.pdf> (explaining that forty-six percent of parents were either dissatisfied with services or needed services but could not obtain them).

live in rural or high crime areas, live in communities with poor public transportation, do not speak English, or need care outside of normal working hours.⁵⁶ Agencies suffer from an extremely high rate of aide turnover.⁵⁷ The problem is especially acute in federally funded long term care programs, because they cannot rely upon the labor of undocumented immigrants, who provide an unknown but significant portion of the low wage labor in the private long term care market.

Unfortunately, there is not much to draw new workers into a career in long term care, and the prospects for improving the employment outlook are poor. Wages are low, and benefits nearly non-existent.⁵⁸ The work can be difficult and dangerous. There is close to no regulation or employment protection, not even a guarantee of minimum wages or maximum work hours.⁵⁹

Despite the severe labor shortage, wages have resisted the laws of supply and demand and remained stagnant over the past decade. In 2007, the inflation-adjusted median hourly wage for all direct care workers was \$10.48. Inflation adjusted wages for home care workers have actually declined to under \$8.00 per hour.⁶⁰ Thirty-six percent of home health care workers are uninsured.⁶¹ Forty-one percent of all home care workers live in households receiving public benefits like Medicaid, Food Stamps, child care, energy, or transportation assistance.⁶²

Racially-coded gender stereotypes play a strong role in keeping wages low and working conditions poor. As a subset of domestic workers, long term care workers suffer from being too far inside the private (feminine) sphere to be regulated. Long term care work, like other work inside the

56. *See id.* at 10 (surveying parents of children with special needs eligible for in-home long term care).

57. *See generally* CITIZENS FOR LONG TERM CARE, *supra* note 13, at 12-15 (describing the turnover rates as high as one hundred percent).

58. *See id.* at 1-2.

59. *See* 29 C.F.R. § 552.6 (2010) (exempting companionship workers from wage and hour protection).

60. *See* PARAPROFESSIONAL HEALTHCARE INST., WHO ARE DIRECT-CARE WORKERS? (2010), *available at* http://www.directcareclearinghouse.org/l_art_det.jsp?res_id=299610. If employed full time, year round, the median annual earning for a home health aide was approximately \$20,000, while a personal and home care aide earned \$18,480. *Id.* However, only fifty-seven percent of direct care workers are employed full time, while forty-three percent are employed part time or only part of the year. *Id.* Fifty-four percent of personal and home care aides worked part time or for only part of the year. *Id.*

61. *Id.* at 3. Only half of personal and home care aides have employer-based health coverage. Many of the remaining home care workers likely receive their health coverage through Medicaid. *Id.*

62. Forty-five percent live in households under two hundred percent of the federal poverty line and fifteen percent live under one hundred percent of the federal poverty line. *Id.* at 2.

home, is not perceived as productive work; it is not work that enriches capital.⁶³ Long term care workers perform “emotional work” that is underpaid because, like in other female-dominated professions such as teaching or child care, the work is supposed to carry its own rewards.⁶⁴ Further, in the past there was a perception that domestic work was temporary, easy, and less dangerous than other types of female employment, especially for white women who worked only until marriage. Popular perception placed white domestics safely inside the private sphere of the household, rather than in the rough and tumble public sphere of the market.⁶⁵

On the other hand, when domestic workers are not white, they are perceived as too far outside of the regularized workforce to merit full labor and employment protection. During the New Deal, domestic service became increasingly associated across the country with women of color, in particular Black women.⁶⁶ Currently, the paraprofessional home care work force is made up largely of women of color. Approximately ninety percent or more of direct care workers (including those in institutional as well as home-based settings) are female.⁶⁷ Approximately thirty percent are

63. See Peggie R. Smith, *Aging and Caring in the Home: Regulating Paid Domesticity in the Twenty-First Century*, 92 Iowa L. Rev. 1835, 1839 (2006) [hereinafter Smith, *Aging and Caring*].

64. See generally Aihwa Ong, *The Gender and Labor Politics of Postmodernity*, 20 ANN. REV. ANTHROPOLOGY 279, 286-89 (1991) (describing how gender inequality is perpetuated when women are expected to accept lower wages for stereotypically feminine jobs which involve a great deal of caretaking activity in addition to other tasks).

65. Notwithstanding this historical perception, private homes are not necessarily safe places for workers. Domestic workers experience high rates of violence and harassment in in-home settings. See METROPOLITAN ACTION COMMITTEE ON VIOLENCE AGAINST WOMEN & CHILDREN, DOMESTIC WORKERS & LIVE-IN CAREGIVERS EXPERIENCING WORKPLACE SEXUAL VIOLENCE AND HARASSMENT 4 (2008), available at http://www.owjn.org/owjn_2009/Images/pdfs/Domestic%20Workers.pdf.

66. Smith argues that the sharply declining rates of white women in domestic service during the period of the New Deal, meant that “structuring domestic service as a regulated employment relationship on behalf of Black women received limited public support.” Smith, *Aging and Caring*, *supra* note 63, at 1857. She notes:

There was little concern that they too would shun domestic service for alternative job opportunities, given that “state-sanctioned discrimination not only precluded them from making inroads into an increasing number of occupations available to white women but also routed them into domestic service.” Racial and regional politics strongly influenced the question of whether New Deal labor legislation should extend to domestic service workers. As various scholars have concluded, the decision to exclude them hinged on a Southern agenda bent on maintaining a cheap labor supply and preserving the status quo of white domination.

Id. (citations omitted).

67. In contrast, approximately fifty-six percent of the entire U.S. workforce is female. U.S. BUREAU OF LABOR STATISTICS, LABOR FORCE STATISTICS FROM THE CURRENT POPULATION SURVEY 195 tbl.2 (2009), available at <http://www.bls.gov/cps/cpsaat2.pdf>; CITIZENS FOR LONG TERM CARE, *supra* note 13, at

African American and fifteen percent either of Hispanic origin or other workers of color.⁶⁸ Twenty percent of the home care workforce speaks a language other than English in the home.⁶⁹

Depending on the client, paraprofessional home care work can be extremely demanding. Paraprofessional home care workers suffer from much higher than average rates of workplace injury, higher in some regards than stereotypically dangerous settings such as coal mines and steel mills.⁷⁰ Home health workers must lift patients unassisted and often do not have control over their working environments, which leads to a greater risk of injury than their nursing home counterparts.⁷¹

Exclusions of long term care workers from basic labor and employment regulation reinforce the low status, poor wages, and dangerous working conditions of this vulnerable workforce.⁷² The Fair Labor Standards Act (“FLSA”) explicitly exempts from minimum wage and maximum hours rules “any employee employed in domestic service employment to provide companionship services for individuals who (because of age or infirmity) are unable to care for themselves”⁷³ They are also excluded from the

10.

68. See CITIZENS FOR LONG TERM CARE, *supra* note 13, at 10; see also U.S. GEN. ACCOUNTING OFFICE, GAO-01-750T, NURSING WORKFORCE: RECRUITMENT AND RETENTION OF NURSES AND NURSE AIDES IS A GROWING CONCERN 22 tbl.2 (2001), available at <http://www.gao.gov/new.items/d01750t.pdf>.

69. See Smith, *Aging and Caring*, *supra* note 63, at 1848.

70. See *id.*, at 1884-85 (noting that risk of injury among home care workers is greater than that of nursing home workers).

71. See PARAPROFESSIONAL HEALTHCARE INST., HEALTH CARE FOR HEALTH CARE WORKERS, THE INVISIBLE CARE GAP: CAREGIVERS WITHOUT HEALTH COVERAGE 3 (2008), available at <http://hchcw.org/wp-content/uploads/2008/05/phi-cps-report.pdf>; PARAPROFESSIONAL HEALTHCARE INST., HEALTH CARE FOR HEALTH CARE WORKERS, FACT SHEET: MICHIGAN, CAREGIVERS WITHOUT HEALTH CARE (2006), available at <http://hchcw.org/wp-content/uploads/2008/05/hchcw-fact-sheet-mi.pdf>.

72. See 29 C.F.R. § 552.6 (2010) (exempting companionship workers from wage and hour protection); see also *Long Island Care at Home, Ltd. v. Coke*, 551 U.S. 158, 162 (2007) (confirming that companionship workers are exempt from wage and hour protection under FLSA); Charles P. Sabatino & Dr. Simi Litvak, *Liability Issues Affecting Consumer-Directed Personal Assistance Services—Report and Recommendations*, 4 ELDER L.J. 247, 289 (1996) (describing how home care workers are unprotected by various labor and employment laws); Hila Shamir, *Between Home and Work: Assessing the Distributive Effects of Employment Law in Markets of Care*, 30 BERKELEY J. EMP. & LABOR L. 404 (forthcoming 2010) (describing how home care workers are unprotected by various labor and employment laws); Smith, *Aging and Caring*, *supra* note 63, at 1860 (describing how home care workers are unprotected by labor and employment law).

73. Over the years, domestic service, including the work of nannies and housekeepers, has gradually come under minimal federal labor and employment law protection. Since 1974, most domestic workers have been protected by the federal minimum wage, and most domestic workers who do not live-in are protected by maximum hour rules. 29 U.S.C. § 213(a)(15) (2006). However, while the general gradual trend has been towards increased coverage of domestic workers in general, home-based care workers remain almost completely outside of federal wage and hour

National Labor Relations Act (“NLRA”), which protects the rights of workers to engage in collective bargaining.⁷⁴ Home care workers employed directly by families or who work for small agencies are not covered by the Family and Medical Leave Act (“FMLA”)⁷⁵ or Title VII of the Civil Rights Act of 1964 (“Title VII”).⁷⁶ State Workers’ Compensation statutes do not cover many home-based long term care workers.⁷⁷

3. Consumer Directed Long Term Care in the Medicaid Home and Community Based Programs Increases Both the Pool of Available Long Term Care Workers and Consumer Autonomy

“Consumer directed long term care” is a type of HCBS program designed to mitigate the labor shortage and autonomy concerns associated with agency-based home health care.⁷⁸ Consumer direction in Medicaid-

protection. Long term care workers provide “companionship services” and are thus exempt from coverage. *Id.* Companionship services include:

fellowship, care, and protection for a person who, because of advanced age or physical or mental infirmity, cannot care for his or her own needs. Such services may include household work related to the care of the aged or infirm person such as meal preparation, bed making, washing of clothes, and other similar services. They may also include the performance of general household work: *provided, however*, that such work is incidental, *i.e.*, does not exceed 20 percent of the total weekly hours worked

29 C.F.R. § 552.6 (2010) (exempting companionship workers from wage and hour protection) (emphasis added). The FLSA exempts from coverage paraprofessional home health workers, even though workers in the most closely analogous category, “babysitters,” are exempt from coverage only if they work on a “casual” basis. That is to say, “casual” babysitters are exempt from coverage, but paraprofessional babysitters (such as nannies) are covered by the statute. In contrast, paraprofessional home health workers are exempt from coverage, even when they are not employed on a “causal” basis. Smith, *Aging and Caring*, *supra* note 63, at 1862.

74. See 29 U.S.C. § 152(3) (2006) (excluding individuals employed in the domestic service of any family or person at his home or any individual employed by his parent or spouse from employee status for purposes of the NLRA). See *generally* Shamir, *supra* note 72 (stating that all “in-home care workers are excluded from the coverage of the NLRA”).

75. See 29 U.S.C.A. § 2611(2)(b)(ii) (2010) (excluding the employees of businesses with under 50 workers from FMLA coverage).

76. See 42 U.S.C. § 2000e(b) (2006) (excluding employees of businesses with under 15 workers from Title VII).

77. See, *e.g.*, CAL. LAB. CODE § 3351(d) (West 2009) (excluding employees who provide personal services from Worker’s Compensation coverage); FLA. STAT. ANN. § 440.02(17)(1)(1) (West 2010) (providing that domestic servants in private homes are not covered under Workers’ Compensation Statutes); N.J. STAT. ANN. § 34:15-36 (West 2010) (not extending Workers’ Compensation to domestic servants or household employees unless specifically covered under a homeowners policy).

78. See 73 FED. REG. 57854, 57855 (Oct. 3, 2008) (defining self-directed care as “a service delivery mechanism that empowers individuals with the opportunity to select, direct, and manage their needed services and supports identified in an individualized service plan and budget plan”). Goals of consumer directed programs include the following:

[d]elay or avoid institutional or other high cost out-of-home placement by

funded long term care “represents a major paradigm shift in the delivery of publicly funded home and community-based services.”⁷⁹ Instead of having a Medicaid contracting agency organize and oversee long term care services, the beneficiary receives a stipend to purchase his or her own care on the private market.⁸⁰ A popularized alternative name for consumer directed long term care is “Cash and Counseling.” As this name suggests, the program has two basic components. Essentially, these programs are a cash allocation to elderly persons or persons with disabilities, which the recipient can use to purchase goods or services related to long-term care, coupled with some assistance from the state, or counseling, in managing their services.

Consumer directed long term care programs are spreading across the country.⁸¹ In 2005, Congress created the statutory authority for states to

strengthening supports to individuals or families; [r]ecognize the essential role of the individual or family in the planning and purchasing of health care supports and services by providing individual or family control over an agreed upon resource amount; [e]ncourage cost effective decision-making in the purchase of supports and services; [i]ncrease individual or family satisfaction through the promotion of self-direction, control, and choice . . . ; [p]romote solutions to the problem of worker availability; [p]rovide supports including financial management services to support and sustain individuals or families as they direct their own services; [a]ssist States with meeting their legal obligations under the Americans with Disabilities Act (ADA) and the U.S. Supreme Court’s *Olmstead* decision; and [p]rovide flexibility for States seeking to increase the opportunities afforded individuals and families in deciding how best to enlist or sustain home and community services.

Id.

79. JANET O’KEEFFE, CASH AND COUNSELING, IMPLEMENTING SELF-DIRECTION PROGRAMS WITH FLEXIBLE INDIVIDUAL BUDGETS: LESSONS LEARNED FROM THE CASH AND COUNSELING REPLICATION STATES i (2009), available at <http://www.cashandcounseling.org/resources/20090202101712/CCReplicationReportFinal.pdf>. Over the past twenty years there have been a bewildering array of attempts by states to implement self-directed models for the provision of Medicaid or state-funded long term care. See, e.g., DIANE BRAUNSTEIN, NAT’L GOVERNOR’S ASS’N, STATE-FUNDED HOME AND COMMUNITY-BASED SERVICE PROGRAMS (2001), available at <http://www.nga.org/Files/pdf/031901SERVICEPROG.pdf>; see also PAMELA DOTY & SUSAN FLANAGAN, U.S. DEP’T OF HEALTH & HUMAN SERVS., HIGHLIGHTS: INVENTORY OF CONSUMER-DIRECTED SUPPORT PROGRAMS (2002), <http://aspe.hhs.gov/daltcp/reports/highlght.htm> (detailing 139 programs offering consumer directed home and community-based support services nationwide as of 2002).

80. This kind of program goes by many names, including consumer directed long term care, Self-Directed Long Term Care, Cash and Counseling, and Consumer Directed Personal Assistance Services (“CD-PAS”). Each of these reflects ideological choices about the program. Because this article focuses on the use of the term “consumer” to describe the user of services, I will use “consumer directed long term care.”

81. The Robert Wood Johnson Foundation funded pilot programs to study “Cash and Counseling” implementation in Alabama, Florida, and New Jersey. BARBARA PHILLIPS ET AL., MATHEMATICA POLICY RESEARCH, INC., LESSONS FROM THE IMPLEMENTATION OF CASH AND COUNSELING IN ARKANSAS, FLORIDA AND NEW JERSEY iv (2003), available at <http://www.cashandcounseling.org/resources/20051202-163649/Gsswltc%20sharedcashandcounseling.orgLibrary%20ResourceImplementation>

provide “self-directed personal assistance services” in their Medicaid State Plans without requiring an additional Medicaid waiver.⁸² The Department of Human Services (“DHS”) anticipates that additional states will add self-directed programs to their Medicaid State Plans in the near future. The Patient Protection and Affordable Care Act, popularly known as “Health Care Reform” in 2010, created additional monies and incentives for states to implement consumer direction in long term care.⁸³

The cash component gives recipients the “budget authority” to manage the government funds used for their long term care.⁸⁴ In the Medicaid program, there are limits to the freedom granted to the participants. Unlike other cash public benefits, such as Temporary Assistance to Needy Families (“TANF”) and Supplemental Security Income (“SSI”), states impose restrictions on the goods and services the recipient can purchase with state funds. Each expense must be planned for and approved in advance. Examples of typically allowed expenditures include hiring of a personal care assistant, housekeeper, or companion, making home modifications, obtaining transportation services, or purchasing prepared meals or other goods and services. Participants in demonstration studies of consumer directed long term care purchased items like ramps, lift chairs,

3states.pdf. It later provided funding and research support for eleven more states to develop programs under the new waiver templates. In 2004, an additional twelve states implemented replication projects to follow up on the Cash and Counseling demonstration models. Although the programs in the United States are unique in several regards, there is a worldwide trend towards adoption of consumer directed long term care programs. *See generally* MICHAEL FINE, A CARING SOCIETY? CARE AND THE DILEMMAS OF HUMAN SERVICES IN THE 21ST CENTURY (2006).

82. 42 U.S.C. § 1396n(j) (2006); 73 FED. REG. 57854, 57855 (Oct. 3, 2008) (defining self-directed care as “a service delivery mechanism that empowers individuals with the opportunity to select, direct, and manage their needed services and supports identified in an individualized service plan and budget plan”).

83. *See generally* Patient Protection and Affordable Care Act, PUB. L. NO. 111-148 (2010). The 2010 Health Care Reform legislation included two reforms of particular relevance to this article. The Community First Choice Option will provide incentives to states to amend their HCBS state plans to provide community-based attendant services and supports. 42 U.S.C. § 1396n(k) (2006 & Supp. 2010). The Community Living Assistance Services and Support Act (“CLASS Act”) establishes a new national voluntary insurance program for purchasing community living assistance services and support. 42 U.S.C. § 30011 (2006 & Supp. 2010).

84. In keeping with the philosophy of consumer direction, beneficiaries are presumed capable of handling many of these obligations. Some early commentators expressed concerns about the ability of beneficiaries to complete these tasks. Beneficiaries may designate a personal representative to assist them with these tasks. The demonstration studies generally noted that many beneficiaries could manage their obligations and planning, and that those who felt that they could not or did not want to opt to have a representative (usually a family member) assist them. RANDALL BROWN ET AL., MATHEMATICA POLICY RESEARCH, INC., CASH & COUNSELING: IMPROVING THE LIVES OF MEDICAID BENEFICIARIES WHO NEED PERSONAL CARE OR HOME AND COMMUNITY-BASED SERVICES 36 (2007), available at <http://www.rwjf.org/files/research/0807casfinalcrosscutting.pdf>. This assistance is, of course, unremunerated care by a family member.

and microwave ovens, although the low amount of the benefit often limited the purchases they could make.⁸⁵

Participants spend the vast majority of funds under these programs to pay for caretakers to help them with meals, personal care, shopping, and the like. Along with the “budget authority,” many of these programs transfer “employer authority” over caretakers to the recipient.⁸⁶ Caretakers do not need to work for an agency to provide home health services. Because the participant does not go through an agency to hire caretakers, he or she is responsible for the hiring, firing, and training of workers.

The second component to these programs is the “counseling” element. While the consumer direction model is premised on the idea that that the elderly and persons with disabilities are capable of directing their own care, program administrators have come to recognize that not all participants have the skills needed to manage budgets, the obligations of an employer, or long-term financial planning. States offer varying forms of support in locating, selecting, training, and paying vendors.⁸⁷

III. CONSUMER DIRECTION EXPANDS THE LABOR POOL FOR MEDICAID HOME AND COMMUNITY BASED SERVICES BY COMMODYING FAMILY LABOR

Under consumer direction, the consumer is responsible for locating his or her own long term care workers—freeing the state from this obligation. Importantly, many consumer directed long term care programs explicitly allow participants to hire relatives, even those such as parents or spouses who are already legally obligated to provide support.⁸⁸ While there have

85. See generally BARBARA PHILLIPS & BARBARA SCHNEIDER, MATHEMATICA POLICY RESEARCH, INC., ENABLING PERSONAL PREFERENCE: THE IMPLEMENTATION OF THE CASH AND COUNSELING DEMONSTRATION IN NEW JERSEY 72 (2003), available at <http://aspe.hhs.gov/daltcp/reports/enableppes.htm>.

86. O’KEEFE, *supra* note 79, at i. Additionally, caregivers in most cases do not need to be supervised by a Registered Nurse, as is usually the case in agency-based home health care. See, e.g., WASH. STATE DEP’T OF HEALTH, NURSING CARE QUALITY ASSURANCE COMM’N, CAREGIVER’S FREQUENTLY ASKED QUESTIONS, http://www.doh.wa.gov/hsqa/professions/nursing/Caregiver_FAQ.htm (last visited Nov. 20, 2010).

87. Assistance can range from giving basic information about hiring an assistant to serving (or contracting with a vendor to serve) as the fiscal agent, and processing the caretaker’s payroll, including withholding. The state or state contractor in its role as fiscal agent will typically cut the checks to pay the vendors or service providers. The cash and counseling states all provide fiscal services (in some cases for a fee) to handle payroll and withholding for caretaker employees. In New Jersey, for example, one of the original Cash and Counseling Demonstration states, not one participant requested to be their own fiscal agent for purposes of payroll and withholding. See PHILLIPS & SCHNEIDER, *supra* note 85, at 93.

88. See 42 U.S.C. § 1396n(j)(4)(B) (2006) (stipulating that under a self-directed plan, an individual is permitted to hire individual(s) to assist in providing such services and may hire any individual capable of providing such tasks, including legally liable

been a number of state-funded programs that have allowed payment to legally liable family members, in general this has not been the norm and was not allowed under previous Medicaid regulations.⁸⁹ States do not have to enact this option, but it appears that many will.⁹⁰ This new legally liable caretaker rule represents a major shift in law relating to caretaking and support.⁹¹

The option to hire a worker without going through an agency has a specific effect: demonstration studies of experimental consumer directed programs show that the majority of beneficiaries hire members of their own families.⁹² Consumer direction increases the labor supply by tapping into the labor of friends and family members who are unlikely to work for a home health agency but who may be willing to care for a relative with a disability. It may also bring into the system a small portion of family caretakers who are already providing care without being paid.⁹³ It is important to note that consumer direction increases the labor supply by tapping into new pools of labor rather than improving wages and working conditions to make the profession more attractive. On the contrary, it has negative effects on the workforce, which I will discuss in detail in Section IV.

Putting aside for the moment concerns about the specific effects on labor force, the commodification of family labor alone is significant, as it is largely unprecedented in American social policy. Organizations representing family caretakers have been advocating for many years to allow family members to receive payment for providing long term care.⁹⁴

relatives).

89. See 42 C.F.R. § 440.167(a)(2) (2010) (restricting payments to legally liable family members under Medicaid HCBS programs).

90. See, e.g., FLA. STAT. ANN. § 409.221 (West 2010) (providing payment for care provided by family member).

91. Under the common law, contracts for wages for housework by a spouse were unenforceable. Katherine Silbaugh, *Turning Labor into Love: Housework and the Law*, 91 NW. U. L. REV. 1, 32 (1996). The principle has remained intact in a range of modern cases, from prenuptial agreements to contracts to provide care in exchange for consideration in a will. It also presumes, at least in the case of spouses, that housework could not constitute consideration because it was already presumed as part of the marital relationship. While this might not apply to parents of minor children, the principle reflects an understanding that caregiving labor is a component of kinship and relationship, rather than a form of productive labor. *Id.*

92. BROWN ET AL., *supra* note 84, at 36.

93. Program administrators initially expressed concerns about a potential for the “woodwork” effect. See, e.g., Briana Bunn, *A New Class of Employees: Family Members Aiding the Disabled*, 8 U. PA. J. LAB. & EMP. L. 505, 506 (2006). There has been little evidence of people signing up for Medicaid simply to gain access to consumer direction monies for their unpaid family caretakers. BROWN ET AL., *supra* note 84, at 36. However, in some cases, there is evidence of family caretakers turning some of their unpaid work into paid labor through the program. *Id.*

94. See, e.g., THOMPSON, *supra* note 24, at 7 (arguing that financial compensation

Some feminist theorists have advocated for the commodification of care work in general, highlighting its significance to the economy and emphasizing that housework and care work are indeed work.⁹⁵ The move not only to allow the state to pay family members to provide care, but also to create a system in which this does not require that the family member become an employee of a home health agency, is both welcome and long overdue.⁹⁶

The significance of transforming family members and friends into paid home based care workers under Consumer Directed Care cannot be understated Traditional agencies may struggle to hire enough aides to meet demand. Hiring family and friends taps a source of assistance usually unavailable to traditional agencies Analysis of interview data for Arkansas indicates that the treatment group members were much more likely than control group members to receive paid care. This finding is consistent with tapping the “labor supply” of family and friends.⁹⁷

On the other hand, by using quotation marks around the term “labor supply” of family and friends in the above quote, the author telegraphs the general discomfort with conceiving family as a labor supply or care work as something that family members could or should commodify.⁹⁸ Keeping in mind that consumer directed long term care would not function without the infusion of family labor, the authors of the demonstration summary note, “[I]n all three of the Cash and Counseling programs, consumers had difficulty hiring a worker if they did not have a relative or friend to hire.”⁹⁹ In Arkansas, for example, after nine months in the program, sixty-six percent of participants who had hired a paid caretaker, reported that they had hired a relative.¹⁰⁰ These relatives were likely not people available to provide care through an agency; they were “new” paraprofessional home-based care workers. Only fifteen percent of Florida caretakers for adults reported not knowing the “consumer” prior to being hired to care for them, while in New Jersey, this figure was ten percent, and in Arkansas was as

to family caretakers helps strengthen care because it provides more resources to be used for care of the recipient).

95. See, e.g., Clare Ungerson, *Social Politics and the Commodification of Care*, 4 SOC. POL. 362, 362 (1997).

96. See, e.g., Bunn, *supra* note 93, at 505 (arguing for increased payment to family members who care for persons with disabilities).

97. BROWN ET AL., *supra* note 84, at 36.

98. On feminist debates regarding commodification, see generally RETHINKING COMMODIFICATION: CASES AND READINGS IN LAW AND CULTURE 271-302 (Martha M. Ertman & Joan C. Williams eds., 2005).

99. PHILLIPS ET AL., *supra* note 81, at 18.

100. CASH AND COUNSELING DATA AND ANALYSIS SYSTEM, MATHEMATICA POLICY RESEARCH, ARKANSAS NINE MONTH DATA (2005), <http://198.87.1.54/default.asp?go=Interactive%20Analysis>.

low as five percent.¹⁰¹ Within this group, the proportion of caretakers who were family members was also strikingly high. In Florida, fifty-eight percent of paid caretakers for adults were family members.¹⁰² In New Jersey, this figure rose to seventy percent, while in Arkansas, a full seventy-eight percent of paid caretakers were related to the “consumer.”¹⁰³ This is in stark contrast to the agency-based control group, which reported that less than five percent of paid caretakers were related to the Medicaid beneficiaries or provided unpaid care to them prior to the demonstration in all three states.¹⁰⁴

Proponents of consumer directed long term care also point to two additional benefits provided by tapping into the family and friend labor pool that may or may not be met through the current system of agency-based home health care: increased supply of culturally sensitive or appropriate care¹⁰⁵ and increased supply of care in hard-to-serve locations or non-traditional hours.¹⁰⁶ Eighty-three percent of consumers of self-directed care in Arkansas, for example, reported that they were satisfied with their caretaker’s schedule, as opposed to only sixty-nine percent in the agency-based control group.¹⁰⁷ In Arkansas and New Jersey, non-elderly consumers were more likely than the control group to receive personal care assistance during non-working hours (weekdays before 8:00 a.m. or after 6:00 p.m. or on weekends).¹⁰⁸

101. STACY DALE ET AL., MATHEMATICA POLICY RESEARCH, INC., EXPERIENCES OF WORKERS HIRED UNDER CASH AND COUNSELING: FINDINGS FROM ARKANSAS, FLORIDA AND NEW JERSEY 12 tbl.1 (2005), available at <http://aspe.hhs.gov/daltcp/reports/workerexp.pdf>.

102. *Id.*

103. *Id.*

104. *Id.* at 11.

105. Georgia Burke & Katharine Hsaio, *Older Women of Color and the Challenge of Regulating Cultural Competence*, 43 CLEARINGHOUSE REV. 27, 36 (May/June 2009) (noting that good implementation of self-directed delivery options under Medicaid personal services would “tackle the issues of language, cultural competence . . .”). In this article I do not address whether Medicaid beneficiaries using consumer directed funds to hire workers either can or should be able to discriminate on the basis of race, ethnicity, religion or gender in the name of finding a culturally competent aide. These are thorny questions which deserve more space than I can dedicate to them in this article.

106. NATHAN L. LINSK ET AL., WAGES FOR CARING: COMPENSATING FAMILY CARE OF THE ELDERLY 191 (1992).

107. LESLIE FOSTER ET AL., MATHEMATICA POLICY RESEARCH, INC., EFFECT OF CONSUMER DIRECTION ON ADULTS’ PERSONAL CARE AND WELL-BEING IN ARKANSAS, NEW JERSEY AND FLORIDA 41 (2005), available at <http://aspe.hhs.gov/daltcp/reports/adultpcw.htm>.

108. *Id.* at 38 tbl.21.

IV. CONSUMER DIRECTION INCREASES AUTONOMY IN LONG TERM CARE,
BUT AT WHAT COST?

Even though the labor shortage is the most pressing issue in long term care, it is not the problem most cited when discussing the need for long term care reform. The most significant political argument for consumer direction is the lack of autonomy in agency-based HCBS programs. But, autonomy is a slippery concept that bears exploring in the context of long term care. Upon closer examination, we can see that there are different neoliberal and progressive iterations of autonomy operating in the rhetoric underlying consumer direction. In this case, they come together in a single policy discourse to make this program appealing to most of the American political spectrum.

In the first version, which resonates with neoliberal economists and policymakers, lack of autonomy creates a learned helplessness in which the passive beneficiary depends upon the “nanny state” to send aid. This version assumes an obliviousness to cost on the part of the beneficiary, which, in a fiscally conservative frame, leads to overuse of the resources.¹⁰⁹ In the second iteration, which resonates strongly with a human rights-based frame, a lack of autonomy results in a lack of control over basic bodily and household functions. While a person may be living in her home, she is no longer the mistress of her house.

Consumer direction purports to solve all of these problems by eliminating the HCBS Agency and making the beneficiary the employer of her aides. In the next two subsections I describe the two versions of autonomy that are married in this program, and in each section I will address the effects highlighted by each iteration of autonomy. I argue that when the commodification of family labor (described above) meets these autonomy discourses, the family caretakers and paraprofessional workers become invisible, disembedded from their place in the regularized workforce. The power of the autonomy discourse distorts our understanding of the relationship between caretaker and care recipient so that we see it as disembedded from the lived reality of the people involved. I argue that that any program for long term care that fails to address the interests of the caretakers and the fundamentally relational nature of those interests will remain unsustainable, trading the weaknesses and hidden costs of the agency-model HCBS program for the new ones of consumer direction.

109. See Batavia, *supra* note 48, at 21.

A. Neoliberal Autonomy as Consumer Choice Obscures Our Dependence on Both Family and State

Consumer directed long term care funded by Medicaid appears to be something of an oxymoron: a neoliberal welfare program. In reality, it is a political compromise between free market principles and the need to fill the gap in long term care created by demographic pressures and the entrance of most women into the paid labor force. In its purest form, neoliberalism rejects exactly the kind of transfers inherent in consumer direction—the forced redistribution of income tax-based general revenue funds, without regard to efforts of the beneficiary to earn those benefits.¹¹⁰ However, consumer direction is an expression of a softer version of neoliberal ideology termed the “ownership society,” which libertarian thinkers promoted during the presidency of George W. Bush.¹¹¹ By replacing the regulation-heavy (not to mention expensive) nursing-home model with one that plays to the rhetoric of individual choice and limited budgets, consumer directed long term care manages to appear to be a conservative answer to the pressing social welfare problem of an aging population.

In this ideological compromise, the state provides social welfare benefits, but people enact a performance of autonomous consumption of the benefit rather than behaving as passive beneficiaries.¹¹² The state expects Medicaid beneficiaries to manage their benefits as though they were private goods in the free market, using allotted benefits to maximize their own self-interest. Because the consumer is looking out for him or herself, there is no need for state regulation for quality.¹¹³ Finally, the risks of success and failure are borne entirely by the “consumer” of the benefit. In this, consumer directed long term care is the sibling of efforts to privatize Social Security,¹¹⁴ impose consumer direction in health care,¹¹⁵ and provide school vouchers.¹¹⁶

110. See Rojhat B. Avsar, *A Critique of ‘Neoliberal Autonomy’: The Rhetoric of Ownership Society*, 37 F. FOR SOC. ECONOMICS 125, 128 (2008) (citing F.A. HAYEK, *THE CONSTITUTION OF LIBERTY* 295 (1978)).

111. *Id.* See also DAVID BOAZ, CATO INSTITUTE, *THE POLITICS OF FREEDOM: TAKING ON THE LEFT, THE RIGHT AND THREATS TO OUR LIBERTIES* 27 (2008).

112. See FINEMAN, *supra* note 34, at 39; MARSHALL B. KAPP, *THE LAW AND OLDER PERSONS: IS GERIATRIC JURISPRUDENCE THERAPEUTIC?* 98 (2001); Avsar, *supra* note 110, at 128.

113. See Marshall B. Kapp, *Ninny Clients of the Nanny State? Selective Paternalism in Public Benefits Programs for Older Americans*, 6 GEO. J.L. & PUB. POL’Y 191, 193 (2008) (arguing that consumer direction will result in a need for less quality regulation).

114. Avsar, *supra* note 110, at 128; KAPP, *supra* note 113, at 158.

115. MargaretAnn Cross, *Consumer-Directed Health Care: Too Good to be True?*, *MANAGED CARE*, September 2003, available at http://www.managedcaremag.com/archives/0309/0309.cdhc_main.html.

116. See generally KAPP, *supra* note 113, at 109 (pointing to consumer direction in

A number of Medicaid consumer directed long term care programs pointedly and deliberately use the term “consumer” rather than “beneficiary.”¹¹⁷ This creates a powerful framework that hides the means-tested nature of the program. In the “ownership society,” market participants, those who own and control their retirement portfolios, homes, and small businesses, reign supreme.¹¹⁸ As one commentator notes with regard to long term care services,

[i]n the purchase of any products or services, ordinarily the important operational details (the who, what, when, where, and how specifications) of financing, handling, and delivery are largely within the control of whoever is paying the bills. When an individual product purchaser or service recipient personally pays, that person is *respected* as a consumer and economically empowered to negotiate the specifics of the transaction, at least to the degree that there exists a competitive marketplace of product and service merchants seeking business in the individual’s geographical location.¹¹⁹

In contrast, of course, is agency-based HCBS or institutional model long term care, in which the beneficiary is a passive recipient. In Agency model contexts, the state sends out an aide to provide care at the time and pay rate that the state and aide negotiate. Because he or she receives care, but not choice about that care, the beneficiary exists in a realm outside of the marketplace. The moral hazard and learned helplessness created by government planning and oversight of long term care diminishes the fundamental status of the elderly and persons with disabilities as full members of the polity.¹²⁰

Transforming the beneficiary into an active consumer (putting aside the fact that the state is giving them the money in the form of a need-based welfare benefit) restores them to full citizenship. Consumers are rights bearing social citizens, inasmuch as they now possess individual property and, by extension, individual property rights.¹²¹ Capitalism has no role for

long term care as part of a general trend which should also include consumer direction in other social programs).

117. See, e.g., ROBERT APPLEBAUM & IAN M. NELSON, EVALUATION OF THE CASH AND COUNSELING PROGRAM IN ILLINOIS (2009), available at <http://www.cashandcounseling.org/resources/20090311140801/EvaluationoftheCashandCounselingPrograminIllinois.pdf>; FLORIDA DEP’T OF ELDER AFFAIRS, CONSUMER-DIRECTED CARE PLUS, available at <http://www.edcplus.org/docs/brochure.pdf> (last visited Nov. 10, 2010); IOWA DEP’T OF HUMAN SERVS., DEVELOPING CHOICES, EMPOWERING IOWANS (2006), available at <http://www.cashandcounseling.org/resources/20060113-144803/IowaFAQ.doc>.

118. See Avsar, *supra* note 110, at 128.

119. KAPP, *supra* note 113, at 193 (emphasis added).

120. *Id.* at 217.

121. See FINEMAN, *supra* note 34, at 15; Bryan S. Turner, *Outline of a Theory of Human Rights*, 27 SOCIOLOGY 489, 492 (1993).

the elderly and people with disabilities. They are non-productive. But, perhaps by making them consumers, consumer direction salvages or perhaps even creates a role for them. This framing reflects a market-based culture and recognizes that in the United States our power as consumers is perhaps more significant than other forms of collective or political action.¹²² This frame has some compelling elements to it, not least of which is a vision of the elderly and persons with disabilities as full-fledged members of society, receiving care with which they are satisfied.

1. Autonomy as consumer choice pits the interests of the consumer against the interests of their family member caretakers

On the other hand, the neoliberal autonomy rhetoric masks that the vast majority of beneficiaries are receiving care with which they are satisfied because they are receiving care from their friends and family, not necessarily because they are suddenly “autonomous.” It is not that they are making choices from a vast array of potential sources of care. For the most part, consumers who did not have a friend or family member to take care of them could not participate in the program.¹²³ It is not their autonomy that creates the satisfaction—on the contrary, it is their interdependence that creates the satisfaction.

If beneficiaries are satisfied, why should we care about the rhetoric surrounding the program? Because the neoliberal vision of autonomy as consumption hides something else—it undermines the very interdependence that the elderly and persons with disabilities enjoy. It points to a weakness in neoliberal ideology in general, which is that neoliberalism generally fails to appreciate that markets are embedded in social relations.¹²⁴

A social citizenship premised only upon our ability to purchase services in the free market presents a very impoverished vision of community.¹²⁵ Neoliberalism pretends that, as a rational consumer, the beneficiary is free to ignore the potentially negative costs to either the other person at the end of this supposedly arm’s length transition or society. Acting like a rational consumer means maximizing benefits and limiting costs. In the context of a fixed stipend it means one thing very clearly—keeping wages as low as possible.

122. *See generally* ULRICH BECK, *POWER IN THE GLOBAL AGE* 7 (2005) (arguing that the power of consumers and the logic of consumption is replacing formal political processes in a way that is potentially deeply undemocratic).

123. BROWN ET AL., *supra* note 84, at 95.

124. *See generally* KARL POLANYI, *THE GREAT TRANSFORMATION: THE POLITICAL AND ECONOMIC ORIGINS OF OUR TIME* (Amereon Ltd 1999) (1944).

125. *See* ROBERT REICH, *SUPERCAPITALISM* 5, 7 (2007).

What does an emphasis on keeping wages as low as possible mean in a situation in which a person hires a family member to provide care for them? It means that we are pretending that the interests of the consumer and the interests of the worker can be severed from each other and treated as oppositional. It means that we can imagine an arms-length transaction with a person who is accepting the position not only for wages, but possibly in part out of love and/or obligation. It leads to seeing the two as entirely separate, rather than as inexorably linked.¹²⁶ It elides how the relationship between caretaker and care recipient is just that: a relationship between real people with histories and futures and with shared economic interests. Economic reductionism also elides the love that some people feel for each other, the deep sorrow at the illness of a loved one, the extraordinary burden disability can place upon a family. It buries the guilt or negativity or exhaustion that are almost inevitable in caretaking relationships. It hides how the economic life of the family is inseparable from its emotional life.

2. Autonomy as consumer choice allows the state to shed its role as both regulator and employer

Autonomy expressed as consumer choice reduces the role of the state. The consumer, not the state, is the employer of record for all purposes under such a program. The state collects taxes and then acts only as a fiscal agent, cutting checks and ensuring paperwork is filed.¹²⁷ Whether this is viewed as a positive or negative development is entirely normative; it depends on how we conceptualize what the proper role of the state is in these specific circumstances.

The reduction of state control in the day-to-day delivery of long term care might reduce bureaucratic interference with tasks that implicate intimate bodily functions of the beneficiary.¹²⁸ For example, if the beneficiary controls the working hours of the worker, then he or she can make choices about which services they provide and which they ask others to assist them with or handle on their own. This might lead to a caretaker providing services highly valued to the beneficiary but which are less based

126. This is reminiscent of attitudes towards pregnant women. See Dawn Johnsen, *A New Threat to Pregnant Women's Autonomy*, 17 HASTINGS CENTER REP. 33, 36 (August/September 1987).

127. See BARBARA PHILIPS & BARBARA SCHNEIDER, MATHEMATICA POLICY RESEARCH, INC., CHANGING TO CONSUMER-DIRECTED CARE: THE IMPLEMENTATION OF THE CASH AND COUNSELING DEMONSTRATION IN FLORIDA 75 (2004), available at <http://aspe.hhs.gov/daltcp/reports/>.

128. See Deborah Stone, *For Love nor Money: The Commodification of Care*, in RETHINKING COMMODIFICATION: CASES AND READINGS IN LAW AND CULTURE, *supra* note 28, at 271 (arguing that the bureaucratization of care disrupts the caretaker-receiver relationship).

on medical needs than would be allowed under the agency model. For example, a beneficiary could decide that having an aide take him or her to a weekly church service is more important to them than assistance with bathing.

On the other hand, decreased state control over care is linked in the American legal system with decreased state regulation over all aspects of the caretaker-care receiver relationship. If the state is no longer the employer, it does not bear liability for abuse of the beneficiary or responsibility to monitor quality of care.¹²⁹ In the free market, the consumer should simply choose another caretaker if the care offered by one is inadequate.¹³⁰

If the state is no longer the employer, it also sheds its responsibility to protect the worker, in more ways than one. First, the state itself is no longer a party to the transaction and therefore cannot be held to have violated labor and employment laws with regard to the worker.¹³¹ More insidious is that consumer direction shifts the workers from being employees of an agency (likely an entity that employs enough workers to bring them under the coverage of many federal labor and employment laws) to being workers employed in private homes by individuals (who are much less well protected). As a result, paraprofessional workers who work in consumer directed settings will lose a number of fundamental workplace protections the state affords agency workers, thus making the workers even more vulnerable than before. For example, although agency-based long term care workers are generally (albeit poorly) protected by occupational health and safety regulation, those employed by a private individual in a home are not covered at all.¹³² Many state workers' compensation statutes do not cover workers employed in private households, while many cover domestic workers employed by an agency.¹³³ Some state minimum wage and maximum hour laws cover agency-based long term care workers, while those same state laws may not cover workers employed in private homes.¹³⁴

129. Sabatino & Litvak, *supra* note 72, at 258. Thank you to Ann Shalleck for pointing out that any costs for preventing or punishing neglect or abuse are then buried in the Adult Protective or Criminal Justice systems.

130. See KAPP, *supra* note 113, at 192.

131. See Sabatino & Litvak, *supra* note 72, at 258-60.

132. See 29 C.F.R. § 1975.6 (2010) (exempting domestic workers in private homes from coverage under Occupational Health and Safety Act). See also Peggie R. Smith, *Home Sweet Home? Workplace Casualties of Consumer-Directed Home Care for the Elderly*, 21 NOTRE DAME J.L. ETHICS & PUB. POL'Y 537, 549-50 (2007) [hereinafter Smith, *Home Sweet Home?*].

133. Smith, *Home Sweet Home?*, *supra* note 132, at 549.

134. See, e.g., KEN. REV. STAT. ANN. § 342.650 (2010) (stipulating that domestic workers or companionship workers employed in a private home would not be covered by Workman's Compensation Statutes, but yet the same workers would be covered by such laws if they were employed by an agency).

Workers in private homes also lose coverage under Title VII of the Civil Rights Act of 1965, the FMLA, and the FLSA.¹³⁵ This means that anti-discrimination laws do not protect them and they do not have a federally protected right to unpaid family or medical leave and do not have a right to unionize.

Family members who serve as consumer directed long term care workers find themselves with even fewer protections. For example, even in states where long term care workers employed by an individual are covered by workers' compensation, a family member might be excluded from coverage, even though they run the same high risks of on-the-job injury as other workers.¹³⁶ Parents and spouses are not eligible to receive unemployment compensation if their family member lays them off.¹³⁷ Family member workers may not be eligible for state disability programs.¹³⁸

B. Autonomy Creates a Positive Human Right for Beneficiaries, but it Disembeds Long Term Care Workers from the Regular Workforce

Despite its emphasis on market-based solutions, reduction of the role of the state and the power of the consumer, consumer direction is not exclusively a neoliberal concept. On the contrary, the original demand for autonomy in long term care emerged out of the movement for the civil and human rights of persons with disabilities.¹³⁹ As Ruth Lister notes,

135. 29 U.S.C. § 28-2601(2)(B)(2) (2006) (covering only employees who work for an employer with 50 or more employees within 75 miles of the worksite under the FMLA); 29 U.S.C. § 206(f) (2006) (denying domestic workers the same minimum wage protections as other employees); 29 U.S.C. § 207 (2006) (exempting domestic workers from maximum hour protections); 42 U.S.C. § 21-2000e(b) (2006) (covering only employees who work for an employer who has over fifteen employees under Title VII).

136. *See, e.g.*, IDAHO CODE ANN. § 72-212(4) (2010) (exempting members of an employers family from Workman's Compensation, if desired); OKLA. STAT. tit. 85, § 2.6 (2010) (exempting employers with fewer than five employees from workers' compensation scheme).

137. *See, e.g.*, HAW. REV. STAT. § 383-7(f)(20) (2010) (excluding family member employees from unemployment insurance coverage). While it might sound odd, there are numerous scenarios in which one might be "laid off" by a family member. For example, the beneficiary might lose Medicaid coverage or move to a nursing home, a child with a disability might start to receive school-based services, or a beneficiary might pass away.

138. *See, e.g., id.* § 392-5 (denying state disability benefits to family member employees).

139. The pressure initially arose out the *disability rights* movement. Because the elderly and persons with disabilities both receive long term care from the Medicaid program, there is a considerable amount of cross-pollination between the movements in the United States. However, the movements are distinct, and may represent different interests in other contexts. For more on the emerging international movement for civil and human rights of elderly persons, see generally Diego Rodriguez-Pinzon & Claudia Martin, *The International Human Rights Status of Elderly Persons*, 18 AM. U. INT'L L. REV. 915 (2003).

“[A]ccording to the independent living movement, independence stems from the ability to control the assistance required. The dependence that results from the lack of such control is . . . corrosive of disabled people’s rights as citizens.”¹⁴⁰ Autonomy then moves beyond a negative right to be free from state interference, which fits into the neoliberal human rights paradigm, into the much more progressive territory of positive rights.¹⁴¹ In a positive rights paradigm, the state should give persons with disabilities the resources to exercise autonomy because individual self-determination is a human right, not because their consumer behavior will lead to better outcomes. For example, the new U.N. Convention on Rights of the Disabled (which the U.S. has signed but not ratified) specifically lays out the right to “have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from the community.”¹⁴² The declaration of a right to “have access” presumes a measure of state involvement in providing the resources.¹⁴³

The United States started to move in this direction even prior to the signing of any international treaty to that effect. Title II of the Americans with Disabilities Act, as interpreted by the United States Supreme Court in the case of *Olmstead v. L.C.*, requires the government to provide publicly-funded long term care services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”¹⁴⁴ Under *Olmstead*, home and community-based settings must be made available to Medicaid beneficiaries whenever reasonable.

The disability rights movement extended this line of reasoning, arguing that living independently in home and community-based programs requires

140. Ruth Lister, Justice, Equality and Dependency: A Critical Social Policy Perspective, Presented at Symposium on Nancy Fraser’s Work (Mar. 22, 2003), <http://www2.warwick.ac.uk/fac/soc/sociology/rsw/researchcentres/gender/news/pastevents/symposium/listner>.

141. See CHAVA WILLIG LEVY, RESEARCH & TRAINING CTR. OF INDEPENDENT LIVING, UNIV. OF KANSAS, A PEOPLE’S HISTORY OF THE INDEPENDENT LIVING MOVEMENT 6 (1988), available at <http://www.independentliving.org/docs5/ILhistory.html>; see also World Institute on Disability, Timeline of the International Independent Living Movement, <http://www.wid.org/programs/international/timeline-of-the-international-independent-living-movement-1> (last visited Nov. 20, 2010).

142. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/Res/61/106, art. 19 (Dec. 6, 2006).

143. See Samuel Bageustos, *The Future of Disability Law*, 114 YALE L.J. 1, 79 (2004).

144. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 592, 596 (1999) (quoting C.F.R. § 35.130(d) (2010)).

consumer direction.¹⁴⁵ This framing proved successful. When the federal government finally allowed experimentation with consumer direction on a large scale (as part of the Bush Administration's Independence Plus waiver program) policy makers made implicit reference to the positive right to supports for autonomy by invoking the Americans with Disabilities Act and the *Olmstead* decision in the "goals" of the program.¹⁴⁶

The autonomy discourse of the movement for independent living is powerful and persuasive. However, it contains within it a paradox that highlights why autonomy is ultimately a poor frame for long term care policy. Consumer directed long term care, by pulling so heavily on autonomy-as-individual-self-determination, blinds us to the people on the other side of the equation. An autonomy paradigm—even one deeply rooted in human rights—that rests on a system in which women of color and family caretakers receive wages and benefits so low that they themselves are eligible for public benefits, with little or no health and safety regulation despite dangerous working conditions, is ultimately not rooted in social justice. As Fineman writes, "[B]y relying on the myth of the autonomous individual, the formal equality model fails to address substantive inequalities and differential allocations of privilege produced by our institutions."¹⁴⁷ Neoliberals can at least pretend that low wages and poor working conditions are irrelevant in a supposed free market for labor. After all, no one is forcing people to work in long term care. But, for a progressive movement based in human and civil rights principles, ignoring the worker on the other side of the equation should not be possible.¹⁴⁸ Much like we cannot countenance a feminism blind to the injustices of race and class, I argue that we should not ground a movement for the rights of persons with disabilities in the exploitation of others, especially when those others are overwhelmingly low-income women of color and low-income female family members of all races.

The elimination of the agency as employer of record for even some long

145. See Batavia, *supra* note 48, at 19 (arguing that a "more integrated setting" requires consumer direction, like that available to persons who can purchase services on the private market); see also Andrew Batavia, *The Growing Prominence of Independent Living and Consumer Direction as Principles in Long Term Care: A Content Analysis and Implications for Elderly People with Disabilities*, 10 ELDER L.J. 263, 264-65, 267 (2002) (stating that consumer direction has proven a highly satisfactory model in various studies); United Nations Enable, *Declarations and Reservations*, available at <http://www.un.org/disabilities/default.asp?id=475> (last visited July 30, 2010) (listing the declarations of various countries that give persons with disabilities presumption of legal capacity and ability to choose their own care).

146. 73 FED. REG. 57854, 57855 (Oct. 3, 2008).

147. Martha Albertson Fineman, *The Vulnerable Subject: Anchoring Equality in the Human Condition*, 20 YALE J.L. & FEMINISM 1, 19 (2008).

148. JENNIFER PARKS, NO PLACE LIKE HOME: FEMINIST ETHICS AND HOME HEALTH CARE 93, 97-111 (2003).

term care workers has consequences for all long term care workers which should be of particular concern for civil and human rights advocates. I divide these effects into two categories, which I will discuss in turn. First, consumer direction will freeze the low wages and poor benefits of paraprofessional long term care workers by reducing the ability to organize for better wages and by creating disincentives for family member workers to seek better wages for themselves. Second, the family members who undertake care work, even when paid under consumer direction, incur opportunity costs not captured in the wages paid by the program. In the long run, this diminishes the capabilities of the caretakers.

1. Consumer direction makes organizing and collective bargaining in long term care more difficult

Consumer directed long term care, by having the beneficiary serve as the sole employer, undercuts one of the only mechanisms low wage workers have for improving their working conditions: unionization. While unionization is not without complicated politics, agency or public authority-based care workers in state Medicaid programs have had some success by unionizing. When they have done so, they have achieved higher wages and improved working conditions.¹⁴⁹ For example, workers represented by SEIU Health Care Michigan recently won a \$.50/hour raise, despite the poor economic climate. As the union's website noted, "this is the third raise home care workers have won since uniting together in SEIU and most workers have seen their pay rate rise by nearly [forty percent]."¹⁵⁰ Importantly, in a number of places, unionized workers have bargained for health insurance coverage and other benefits.¹⁵¹ They have also used their resources to oppose cuts in long term care funding and their political clout to agitate for long term care reform.¹⁵²

Under the consumer directed model, collective bargaining by long term care workers is much more difficult. First, the NLRA excludes domestic

149. See Howard S. Berliner et al., *Health Care Workers Unions and Health Insurance: The 1199 Story*, 31 INT'L J. OF HEALTH SERVICES 279, 281 (2001); Kristin Jenkins Gerrick, *An Inquiry into Unionizing Home Healthcare Workers: Benefits for Workers and Patients*, 29 AM. J.L. & MED. 117, 128 (2003) (outlining both benefits and challenges posed by unionization of home care workers).

150. Service Employees International Union, *Home Care Workers Win Raise!*, <http://www.seiuhcaremi.org/hcw/Default.aspx> (last visited Nov. 3, 2010).

151. See Service Employees International Union, *About SEIU UHW*, <http://www.seiu-uhw.org/about/> (last visited Nov. 3, 2010); Service Employees International Union, *As National Bargaining for 100,000 Union Members at Kaiser Permanente Begins . . . SEIU Members Tell Kaiser: Keep Your Hands Off Our Healthcare Benefits* (Apr. 7, 2010), <http://www.seiu-uhw.org/2010/04/as-national-bargaining-for-100000-union-members-at-kaiser-permanente-beginsseiu-uhw-members-tell-kai.html>.

152. Berliner et al., *supra* note 149, at 283-85.

workers employed by a “family or person at his home.”¹⁵³ This means that workers employed by a beneficiary have no right to bargain collectively for better working conditions or higher wages, though all of the funds used to pay for their wages comes from a single source, the state’s Medicaid program.¹⁵⁴

Even without the legal impediments, collective bargaining would be unlikely under consumer direction. First, under consumer direction, the beneficiary, not the government entity, sets the wages and any other benefits. There is no central employer to set uniform wages, and so collective bargaining is not useful. Further, the presence of large numbers of friends and family members (even if they were not a majority of care workers) creates a sub-set of workers who are very unlikely to be interested in unionizing the field. Because they are interested in working for only one beneficiary, and not staying in the care work field long term, they are unlikely to see themselves as having a stake in the long term care workforce or in the field more generally. While those workers might engage in advocacy on behalf of his or her friend or family member, and perhaps even for increased long term care funding overall, it is unlikely that they have the kind of “intentionality” about the choice of long term care as a career that would propel them to collective action with other workers. In fact, these workers may be unlikely to think of themselves as professionals at all, instead seeing their work as an extension of their caretaking obligations for which they receive a small remuneration. While these workers are vital to the beneficiary they care for and to the functioning of the system as a whole, their presence decreases the effectiveness of one of the only tools workers have for raising the wages and improving working conditions enough to make the profession more attractive.

In the end, the move from agency as employer to beneficiary as employer may harm beneficiaries as well as workers by reducing the supply of paraprofessional long term care workers. Paraprofessional long term care workers who work for agencies already suffer from poor working

153. See 29 U.S.C. § 152 (2006) (excluding any individual employed in the domestic service of any family or person at his home, or any individual employed by his parent or spouse from coverage under the NLRA). See generally Smith, *Aging and Caring*, *supra* note 63, at 1873-75 (describing the domestic worker exclusion).

154. The ability to select a worker alone, however, does not have to be fatal to workers’ ability to unionize. California has for many years allowed some beneficiaries to select their own workers under the state’s Medicaid home health program. Workers circumvented the lack of NLRB protection by lobbying for the creation of public authorities which serve as the employers of record for purposes of collective bargaining for wages and benefits. Several unions represent workers across the state, including those employed under the quasi self-directed model. However, in California, the program is not fully self-directed, in that the county sets caretaker wages and the number of hours of care, not the individual beneficiaries. See CAL. WELF. & INST. CODE § 12306.1 (2010) (setting wage and hour rules for home health care workers under California’s Medicaid program).

conditions and low wages. These conditions are exacerbated when the beneficiary is the employer, and the worker loses almost all labor, employment and health and safety protection. Absent collective bargaining, it is difficult to see how long term care workers will ever achieve the wage increases needed to make the field attractive enough to a sufficient number of documented workers to solve the long term care worker shortage.

2. The commodification of family labor carries opportunity costs for the worker

At a practical level, consumer directed long term care can function as wage replacement for family caretakers who opt to take payment to provide care instead of participating in the regular labor force. In this scenario, the program brings in more money to the family unit, which was otherwise losing the opportunity to earn income by providing the care. Supporters of lifting the legally liable relative ban point to the lost wages of family members who provide unpaid care work instead of engaging in paid labor.¹⁵⁵

The benefits of a wage-replacement scenario are most likely to emerge in cases involving care by legally liable relatives, such as parents or spouses, who might otherwise work outside the home. Many parents who have children with significant special needs find that working outside of the home is logistically impossible and thus suffer a direct loss of income as the result of having at least one wage-earner in the house occupied in caring for the child with a disability, rather than bringing income into the house.¹⁵⁶ The replacement of wages is likely to be especially significant for low-income single parents, who find it impossible to live on the meager benefits offered by SSI, but who cannot hold down traditional employment due to their child's needs. The parent/spouse worker will also pay Federal Insurance Contribution Act ("FICA") taxes, thus receiving Social Security credit for the years they provide paid care.¹⁵⁷

There are other intangible reasons why a family member might decide to receive payment for the care rather than hire an outside aide. For example, the increased flexibility and ability to direct the care of a child with a disability might decrease conflicts that can arise between the interests of children with special needs and their parents or other family members. It

155. Lori Simon-Rusinowitz et al., *Payments to Families Who Provide Care: An Option That Should Be Available*, 22 GENERATIONS 69, 71-72 (Fall 1998).

156. See SLOAN WORK AND FAMILY RESEARCH NETWORK PANEL MEETING, *supra* note 30, at 3.

157. See I.R.C. § 3306 (2006) (requiring workers who are the parent or spouse of an employer to pay Federal Insurance Contribution Act taxes if they are over 21 years of age).

might just be simpler, which as anyone who has had to juggle and schedule multiple aides to care for a family member will say is no small benefit. The parent or spouse would not have to manage the paperwork for an outside worker or locate, hire, train, or fire the worker. Some family members might appreciate additional time with the disabled or elderly family member. Certainly in the case of mothers staying home to take care of their own children, they are conforming to cultural expectations of good mothering in that they are caring for their child, rather than hiring another person to do so.

Finally, parents and spouses might worry less about the quality of care they can provide. While quality of family caretaking versus care by another person will differ from case to case, a parent might worry much less about the quality of care he or she provides. In extreme cases, the parents might not be able to find another suitable caretaker, and at least receiving payment for caring is better than having no caretaker and no other employment. This is most likely to be true for the hardest to serve families, who are more likely to be non-English speaking, care for a person with severe disabilities or live in rural or high crime areas or regions without public transportation.

For example, in its Cash and Counseling Demonstration project, Florida allowed parents to receive payment for the care they provided for their children with developmental disabilities so long as that care was beyond the care typically provided a child of the same age.¹⁵⁸ In the demonstration study, about twenty percent of primary caretakers opted to become paid caretakers through the program.¹⁵⁹ While the reasons for choosing this option differ for each family, it appears that opting to become a paid caretaker correlated very strongly with two factors: unmet need for care prior to enrolling in the program and higher benefit levels.¹⁶⁰ The caretakers who opted to be paid for their caretaking were also less likely to be married, perhaps indicating that another wage earner was not available in the household.¹⁶¹ For some families, the level of disability was

158. FOSTER ET AL., *supra* note 55, at 3. The children enrolled in the program were between 3-17 years old and qualified on the basis of need as well as a diagnosis of low intelligence quotient, cognitive disability, autism, spina bifida, cerebral palsy, or Prader-Willi syndrome, as well as limitations in their ability to self-care. *Id.*

159. *Id.* at 17. It is also worth noting that thirty-eight percent of parents reported that the primary reason they did not become paid caretakers is that they did not know this option was available to them under the program. *Id.* at 18.

160. *Id.* Caretakers who reported that their child was not getting enough help with personal care at baseline were 2.58 times more likely to become paid caretakers. *Id.* at 33 tbl.C.4. Caretakers of children who had benefits of \$500 or more per week were 3.4 times more likely to become paid caretakers than those who had children who received benefits of under \$150 per week. *Id.*

161. *See id.* at 18.

sufficiently high that caring for the child was intensive (and thus likely to disrupt other paid employment), they could not find another satisfactory care worker and/or the wages earned by the family caretaker were enough to make a difference to the family. Both the paid and unpaid caretakers in the demonstration study reported increased satisfaction with their child's care and their own lives, but these effects were even greater for the paid family member caretakers.

The implications of the policy change for some extremely vulnerable families might be positive in the short term, as they are able to care for their children or spouse while still bringing in income to the family.¹⁶² However, there are also significant negative consequences for the worker. The transfer of sole employer responsibility to the beneficiary places legally liable relatives in an even worse position than other workers in what is already a low wage, low benefit job.

Like many other long term care workers, nuclear family member workers will not receive a paid vacation. However, the effects of this may be more pronounced for nuclear family member workers who live in the same home and are likely providing unpaid care as well. This might turn an already overwhelming job into literally around the clock care, with no weekends, vacations or respite. There is nothing to stop a beneficiary from hiring more than one worker, thus providing respite for their family member caretaker. However, given the complexities of hiring even one worker and the desire to keep what little monies the benefits provide in the family, it is possible that this will not be an option for many families.

Also worth considering are the less tangible, but in the long term possibly more important, opportunity costs lost to a person who gives up outside paid employment to provide care, even if that care is minimally paid. Although some observers have argued that paying nuclear family members for their care work makes up for at least some of the opportunity cost of providing care,¹⁶³ I argue that the wage alone may not sufficiently account for the entire opportunity cost to the family member worker. It also is important to note here that these opportunity costs are borne almost exclusively by women, and in particular by women who are already low-income.

What are the opportunity costs not covered by the wages provided to the

162. See, e.g., FINEMAN, *supra* note 34, at 54 (arguing that a reallocation of economic help to caretaking units, along with structural support, would allow for those who "work for wages and work for either love or duty do not have to compromise one to do the other").

163. See, e.g., Lori Simon-Rusinowitz et al., *Payments to Families Who Provide Care: An Option That Should Be Available*, 22 GENERATIONS 69, 71-72 (Fall 1998), available at <http://www.cashandcounseling.org/resources/20051202-155025/paymentstofamiliesgenerations.pdf>.

caretaker? Family caretakers are likely missing the opportunity to work in a field of their choosing, build a résumé, climb a career ladder, and develop their skills and potential. In a way, a concern for the needs and desires of the family member worker turns the autonomy argument on its head. The “autonomy” of the beneficiary results in a reduction in opportunity to develop the capabilities of the caretaker.¹⁶⁴ For family member caretakers, working in long term care is not a chosen career.¹⁶⁵ They are caring for a specific individual (their child or spouse) and are not engaged in the intentional career development that could lead from low-wage long term care work to higher wage work in the medical or another related field. This has significant class implications, as a low wage earning woman is more likely to find the option of paid care work more attractive than a woman who has the potential to earn more than minimum wage.¹⁶⁶

Barriers to re-entry in the workforce in any field other than long term care work would likely be the same as though the family member had not been compensated for her work. “I was home caring for my severely disabled child” or “My elderly mother needed me” is not a résumé builder, especially if the break in paid employment is for more than a few years. High earning women suffer a thirty-seven percent loss of “earning power” if they take three years off from work.¹⁶⁷ There is little reason to believe that the loss of long term earning power would be any different for women who took a low wage job as a care provider for a family member.

Consumer direction transforms family care work from unpaid labor into poorly paid labor. We have commodified, but continue to undervalue, the work. These may indeed be families who cannot get adequate care otherwise, who might benefit from the infusion of extra cash into the household, and who would certainly welcome the reduced hassle and worry about hiring care workers. However, the same families, the least resilient, need the most investment in their future over the long haul. These families need to locate and be able to remain in jobs with health benefits, vacation time, and sick leave. Parents who care for children with severe disabilities who may require care over their entire lifetime may find themselves choosing between long term planning and short term survival. While being very helpful in the short term, the payment of wages for care work does

164. See Hooyman & Gonyea, *supra* note 8, at 161 (arguing that women who leave paid employment to be caretakers, even temporarily, are often “locked into a lower socioeconomic status throughout their lives”).

165. See *id.* (emphasizing the need for caregiver choice and agency).

166. See JOHNSON ET AL., *supra* note 3, at 7 (“[I]n a study of determinants of home care use, frail older people with high-earning adult children received less unpaid care from their offspring and more care from paid sources than those whose children has worse labor market prospects.”).

167. Sylvia Ann Hewlett & Carolyn Buck Luce, *Off-Ramps and On-Ramps: Keeping Talented Women on the Road to Success*, 83 HARV. BUS. REV. 43, 46 (2005).

little to increase the long term resilience of the family and may leave them even more vulnerable in the end.

V. GROUNDING CONSUMER DIRECTED LONG TERM CARE IN COMMUNITY RESILIENCE RATHER THAN AUTONOMY

Whether the caretaker family member benefits from the arrangement or not, constructing consumer directed long term care around the principle of “autonomy” carries steep costs. If nothing else, the consumer direction demonstration projects show us that, for many people, there is no such thing as an “autonomy” that does not account for people’s position inside of families. Market-based solutions that emphasize the need for each individual to invent her or his own solution to the challenge of aging or disability are inadequate to the task of simultaneously solving the crisis of labor, the need for self-determination, the sustainability of the entire system of long term care, and the impact that care work has on the people who provide care.

What would happen if instead we started to understand the “market” for long term care as one that is embedded in social relations? If the discourse around autonomy creates overly narrow boundaries for understanding how to provide for inevitable aging and disability, then what discourse in the United States might open up new spaces, ones in which the dignity of the beneficiaries are unified with a sustainable framework for the caretakers?

One conceptual frame worth exploring is that of community resilience.¹⁶⁸ Framing the question of long term care as one of community resiliency might provide a way out of the false dichotomy between of the needs of the “consumers” of care and of the “providers” of care created by the autonomy discourse. In this section, I take up the question of how we might use the resources of the state to create the community resiliency that will enable families and communities not only to rise to the challenges created by the need to care for vulnerable members, but also to become stronger as a result.

Resiliency, like autonomy, is often framed in individual terms.¹⁶⁹ Enhancing resiliency, for example, may be framed as providing a person with reeducation so that he or she can meet the challenges of earning a living in a changing economy. Thinking about resiliency in this way

168. I began to explore resilience in response to a call for participation for an Emory Law School Feminism and Legal Theory Project workshop, organized in March 2010 around the theme of resilience. I thank Martha Fineman and the other organizers for allowing me to participate in that forum and for their helpful feedback.

169. See Rachel Davis et al., *A Community Resilience Approach to Reducing Ethnic and Racial Disparities in Health*, 95 AM. J. PUB. HEALTH 2168, 2169 (2005) (noting that most approaches to eliminating health disparities focus on individuals rather than on communities).

presents community as nothing more than a collection of atomized individuals, each of whom is struggling alone to meet his or her own needs. This vision of community resembles something more of a marketplace, where individual actors (“market participants”) compete. Resilient individuals find ways to meet their needs, while less resilient and less competitive individuals in this community do not. Differential outcomes, while unfortunate for the losers, are fair as long as each individual is free to participate and choose how he or she will participate in the same marketplace. When we think of community in this way, we give little attention to how winners and losers are connected to each other and fail to consider how resiliency is fundamentally relational.

More recently, “community resiliency” (as opposed to an individual resiliency) has started to make its way as a concept from ecology to the social sciences. Community resilience is the ability of communities to thrive despite the presence of risk and change.¹⁷⁰ This conception of community resilience is rapidly taking hold in the field of sustainable development, especially with regard to the capacity of communities to withstand climate change and natural disasters.¹⁷¹ It also recognizes that all communities, and all persons within those communities, are vulnerable.¹⁷² Martha Fineman writes that “[U]nderstood as a state of constant possibility of harm, vulnerability cannot be hidden. Further, while institutions such as the family may provide some shelter, they are unable to eliminate individual vulnerability and are themselves vulnerable structures susceptible to harm and change.”¹⁷³

The immense social change created by the full transition to a capitalist labor market, with its need for a mobile labor force, the entry of women into the paid labor force, increasing longevity, and the large size of the baby boom generation places immense pressures—a social climate change—on both families and the state as they try to meet the need for long term care. Aging, disability, and increased wage labor are not disasters.¹⁷⁴

170. David Godschalk, *Urban Hazard Mitigation: Creating Resilient Cities*, 4 NAT. HAZARDS REV. 136, 137 (2003) (defining a resilient city as one that can sustain networks of physical and human systems that can survive breakdowns, change, and external influences).

171. See, e.g., ATIQ AHMED, US AID/ASIA, CONCEPTS AND PRACTICES OF “RESILIENCE”: A COMPILATION FROM VARIOUS SECONDARY SOURCES 19 (2006).

172. See Fineman, *supra* note 147, at 11.

173. *Id.*

174. As Nancy Hooyman and Judith Gonyea note,

a feminist analysis challenges the status quo and stresses the absolute necessity of changes in social institutions, attitudes and values to improve women’s lives. Accordingly, feminists do not define demographic and social changes, such as the growth in the percent of the older population or the large-scale entry of women in the paid labor market as “problems.” Instead a feminist

But, they do present immediate challenges that create stress on a system and a need to reallocate resources within a community while often engendering change. All of these forces together create a need for resilient caretaking communities that can adapt in the face of change while retaining their essential character and continuing to perform their valuable functions.

Resiliency and autonomy do not operate in opposition. Being embedded in a resilient family or community should not mean that an individual does not have choices within that context or even the choice to leave that context. Two important components of community resiliency are diversity and redundancy, both of which operate to create more choice.¹⁷⁵ The more resilient various community structures are, the more options an individual might have for having his or her needs met. Real autonomy, then, is the ability to make more than one choice.

Systems with multiple nodes are less likely to fail because the failure of one component does not cause the entire system to fail.¹⁷⁶ In the context of long term care, this means having more than one option for long term care and not expecting any single structure to meet all needs. Creating diversity and redundancy dictates that we look to multiple, local forms of care rather than a one-size-fits-all solution. This supports, rather than reduces, autonomy in the long run. It also can serve to diffuse the work of long term care, and, if designed specifically to do so, counteract the tendency of long term care systems to rely so heavily on the unpaid or low paid work of women.

For the purposes of this Article, I only consider how community resilience might be a useful concept in consumer directed long term care.¹⁷⁷ I propose that by placing three principles at the heart of any program for home-based long term care, we will start creating the kind of community resilience required to meet the demands for long term care. As a threshold matter, long term care programs must re-embed the elderly and people with disabilities in family and community. Second, long term care programs must re-embed paid caretakers within the labor market and protect the interests of unremunerated caretakers. And finally, programs should emphasize social cohesion by broadening the definition of the caretaking community and recognizing that civil society can complement the state, the family, and the market in providing consumer-directed long term care. I

model is oriented toward fundamental systemic changes that accord greater societal recognition of the work of caring and assure flexibility and choice for both those who require care and those who provide it.

Hooyma & Gonyea, *supra* note 8, at 151-52 (internal citations omitted).

175. Godschalk, *supra* note 170, at 141.

176. *Id.* at 140-41.

177. There are, of course, many other issues raised by this framing in the area of long term care more generally, which I hope to see addressed in other projects.

touch upon each of these briefly in turn, largely to provide direction for future research in this area.

A. A Resilience Frame Embeds Long Term Care Consumers in Community

The first step in applying a community resiliency frame to consumer directed long term care is to reposition caretakers and persons with disabilities within a larger community. As an initial matter, we should stop promoting policies that pit the interests of the beneficiaries against those of the workers who care for them, because this framing hides the nature of interdependence. If we conceptualize the caretaker-care receiver as a unit (rather than a consumer and provider operating in opposition), we see that supporting caretakers inures to the benefit of both.¹⁷⁸ Further, if we see the caretaker-care receiver relationship as one node in a complex system, then we might begin to imagine a network of possibilities for supporting long term care.

For example, in a community resiliency frame, we can more clearly see the benefits of supporting family caretakers, even those paid for their work under a consumer directed long term care program. Often it is the sheer number of tasks—ranging from food to mobility to medical care—involved in intensive long term care that overwhelm family caretakers. To borrow another metaphor from ecology, families are overfished. Advocates for family caretakers have been asking for years for increased respite programs, assistance with transportation, and other services.¹⁷⁹ New federal funding may expand some of these programs, but advocates agree that more support is needed.¹⁸⁰

Step two would be to stop seeing caretaker-care receiver dyads as independent units that operate in isolation. The supports that do go to family caretakers now flow to individual caretakers, as though each caretaker must reinvent the wheel of how to balance long term care needs with the needs of other members of the family, in addition to work.¹⁸¹ Many programs focus on “individual solutions” (i.e., if caretakers learn to

178. See generally FINEMAN, *supra* note 34, at 43.

179. See NAT’L FAMILY CAREGIVERS ASSOC., A FAMILY CAREGIVER SPEAKS UP: IT DOESN’T HAVE TO BE THIS HARD (2007), available at http://www.nfcacares.org/pdfs/caregiver_advocacy/family_friendly_caregiver_legisl.pdf (identifying 15 bills that would improve the working and living conditions for caregivers).

180. See Paula Span, *In Obama’s Budget, Help for Caregivers*, N.Y. TIMES, NEW OLD AGE BLOG (Feb 3, 2010), <http://newoldage.blogs.nytimes.com/2010/02/03/in-obamas-budget-help-for-caregivers/> (calling an investment of \$102.5 million in caretaker-related programs a “drop-in-the-bucket” when compared to the size of the entire federal budget).

181. See Hooyman & Gonyea, *supra* note 8, at 157 (arguing in favor of a systemic approach as opposed to an individual approach based solely in psycho-educational interventions).

operate more efficiently and become more skilled at coping, their stress will be reduced) versus systemic change (i.e., the development of more effective delivery models).”¹⁸² This model may even inadvertently reinforce gender-based inequities in the allocation of caretaking, since their focus is to “help caregivers adjust to unavoidable burdens.”¹⁸³

If we stop thinking of people as atomized individuals who must solve the dilemma of how to obtain care for themselves or thinking of families as discrete units that must allocate the burdens of care within and between their members, a number of new possibilities for state action to support long term care come into focus. Caretakers who see themselves as part of a community of people facing similar challenges might be more able to suggest and advocate for collective solutions that address the underlying structural forces that create caretaker stress. For example, the National Association of Family Caregivers advocates for a number of policy changes to better integrate family caretakers into the community, including: integrating the concerns of family caretakers into federal health, long term care, and social service policy-making; lowering the threshold for deducting medical expenses; providing Social Security “credits” of deemed wages for caretaking; allowing caretakers who lose health insurance because they leave the workforce to buy into group health; extending COBRA for caretakers; allowing Medicare to pay for more of the supplies often needed by the frail elderly; increased funding for respite care; expanding paid and unpaid family medical leave; increased training; and increasing support for care coordination.¹⁸⁴

B. A Resilience Frame Re-embeds Caretakers in the Workforce

A focus on community resilience dictates that the labor practices that underpin the entire long term care system must be sustainable. It weakens the entire edifice if home health agencies, long term care institutions, and individual consumers are constantly grappling with high turnover and lack of continuity.

The state can support the long term care workforce, at least in the consumer direction context, by re-assuming its responsibilities vis-à-vis the workers. There are models for doing so without destroying what is valuable about consumer direction—the ability to control the identity of workers and their working hours and the hiring of willing family member

182. *See id.*

183. *See id.* (discussing how counseling interventions which focus on individual behaviors as opposed to social structures may reinforce gendered notions regarding caretaking).

184. NAT’L FAMILY CAREGIVERS ASSOC., PRINCIPLES, PLANS, AND POLICY RECOMMENDATIONS (2009), available at <http://www.thefamilycaregiver.org/pdfs/0809policystatement.pdf> [hereinafter NAT’L FAMILY CAREGIVERS ASSOC., PRINCIPLES].

workers. For example, California has moved to a public agency model in which consumers self-direct their care, but the public agency serves as employer of record for other purposes.¹⁸⁵ This would bring home-based long term care workers, including family member workers, under the protection of many important federal and state employment laws, including the FMLA¹⁸⁶ and Title VII of the Civil Rights Act of 1965.¹⁸⁷ Under such a system, workers compensation coverage could also be made available, and workers would be eligible for Unemployment and State Disability benefits in a manner comparable to other workers in their State.

Having the state assume a regulatory role would not solve all of the legal discrimination faced by long term care workers. Even long term care workers employed by a public agency or other state entity are not covered under the minimum wage and maximum hour rules under the Fair Labor Standards Act. However, this is a relatively simple regulatory fix, and the Department of Labor has already drafted (but never implemented) the proposed regulations that would enable such a change. Likewise, Congress could solve the lack of coverage under the federal NLRA.

More complex than simply bringing home-based long term care workers on par with almost all other workers would be accounting for opportunity costs borne disproportionately by female family members. Severing the age-old connection between gender and caretaking will be challenging. Raising wages and status can help, but likely only up to a point. The rest is transformation of culture that cannot take shape so long as our current conceptions of community, the relative value of work and gender-based wage inequalities persist. It is naïve to think that we can overcome all of that at once. It also elides the very real matter that most of the elderly are women, and they may prefer a female caretaker over a male one for reasons of modesty. However, like child rearing norms, norms about caring for the elderly or persons with disabilities are not static, and the nagging effects of gender inequality require our attention.

Ensuring that family member workers are compensated for all hours of care, and providing sufficient remuneration so that workers can contribute to their own retirement savings, health insurance, paid vacations, and unemployment coverage might ameliorate some of the more concrete lost opportunity costs. Family caretakers could also be offered training so that they could translate their experience working with a family member into a

185. See CAL. WELF. & INST. CODE § 12301.6 (West 2010) (establishing public agencies as employers of record for In Home Supportive Services workers).

186. See 29 U.S.C. § 2611(2)(b)(ii) (2006) (excluding businesses with less than 50 employees from FMLA coverage).

187. See 42 U.S.C. § 2000e(b) (2006) (excluding businesses with less than 15 workers from Title VII coverage); see also NAT'L FAMILY CAREGIVERS ASSOC., PRINCIPLES, *supra* note 184.

career in the nursing or medical profession either in conjunction with or after their work as a family caretaker. While this would not appeal to all family caretakers, there might be some who benefit greatly from the opportunity, especially those low wage workers who might be able to later obtain jobs in a rapidly growing field.

C. Supporting Resilient Caretaking Communities Strengthens Long Term Care for Everyone

Broadening societal notions of who is responsible for long term care in a community creates diversity and redundancy. This in turn supports autonomy and resilience. Largely absent from discussions of consumer directed long term care is the presence of civil society, or members of local communities which could create diversity and redundancy in the system. This does not need to be the case. There is nothing in consumer direction that dictates reliance on only family, state, or private market. States that offer a Medicaid consumer directed long term care option should consider shoring up community involvement in long term care for several reasons. First, families are not appropriate locations for care for all consumers, and people who do not have sufficient family support often end up falling back upon more expensive institutional care. Second, even for those who have family care, it is often not enough. Finally, strengthening community involvement in long term care will carry ancillary benefits to the entire community.

Family care is not available to all for a variety of reasons. For some, families are sites of violence and oppression. For other families, the work of long term care may be more than they can or want to bear given the other needs of their family members and the demands of work. Others live far from their families. Further, placing responsibility within family (especially without extensive community support) serves only to reinforce the existing gender norms regarding who will provide what type of care.

Considering community resilience allows us to find a role for the state in supporting community groups that fill the gaps left by families and the private market. Religious groups and community groups can play an even larger role than they do now to fill the niches where persons with disabilities need support, but the private market and families cannot quite meet the need. For example, consumers could opt to spend their long term care stipends on services, such as errand running or shopping services, rather than asking their paid aide or an unpaid family member to help with these tasks.¹⁸⁸ However, those services do not exist in many communities. Thus, a role for the state might be to subsidize such a service or find other

188. See 42 U.S.C. § 1396t (2006) (including chore services within the list of personal care services a consumer may choose as part of an HCBS program).

ways to encourage community groups to create one. The private market has created those services in some markets, but in others, state subsidy might be required to seed them or ensure that they are available to all. In another example, families with similar diets could pool consumer directed long term care funds to hire a cook to provide culturally appropriate meals for elders who live alone, which would eliminate a source of stress for some beneficiaries who would otherwise be uncomfortable with a caretaker from outside of their ethnic or religious community. Support of groups that encourage social interaction, while not exactly “long term care” in the traditional sense, create the kind of social support that enables people to go on living independently for as long as possible. Finally, states should consider ways to help people who do not have family members to locate long term care workers, either by maintaining clearinghouses or lists.¹⁸⁹

These supports also assist people outside of the Medicaid system with long term care. There are numerous examples of community-cohesion enhancing models for caring for the frail elderly and persons with disabilities: walking scale neighborhoods; apartments with elevators in them within walking distance of a park, library, community center, town square, or school; public transit on demand; easy access to fresh foods and healthy prepared meals; nearby basic medical facilities; community visits by trained medical professionals for assessments. As proponents of Universal Design point out, making changes to benefit people with disabilities often benefits the entire community. The state can play a vital role in seeding these kinds of improvements and projects, while encouraging multiple, local and dynamic action by communities.

VI. CONCLUSION

Long term care touches upon deep questions about what it means to be autonomous or resilient and what it means to live in a community. Creating a just and sustainable system for providing long term care means coming face to face with the heavily gendered nature of care work and the race-based inequalities that pervade low wage long term care work. It means addressing the multiple pressures on families who already provide most of the care for their vulnerable members. It means confronting the demographic changes that mean that more and more people will need long term care in the coming years, while the pool of available labor remains low. It means placing the dignity of persons with disability at the center of the conversation without losing sight of the human rights of others.

I have mixed feelings about the turn toward consumer direction in long

189. *See, e.g.,* CTR. OF MEDICAID & STATE OPERATIONS, STATE OF DELAWARE ATTENDANT SERVICES WAIVER APPLICATION, *available at* <http://www.cashandcounseling.org> (last visited Nov. 3, 2010).

term care. On the one hand, I understand the connection between human dignity and the ability to make basic decisions about one's day-to-day existence. Those decisions have to include some measure of control over who touches our bodies, enters our homes and plays a vital role in our lives. Consumer directed long term care recognizes that the elderly and people with disabilities should have this control over their lives. Perhaps even more importantly, it recognizes that they are capable of exercising it.

On the other hand, the move in the direction of vouchers in lieu of a robust social welfare program is a part of a continuing trend to shed state responsibility for provision of basic human needs. It is rooted in an attempt to impose free market principles even though, given the extraordinary amount of unpaid labor that is foundational to the system, there is no such thing as an undistorted free market for long term care.

In this article, I have attempted to point to the specific legal and policy consequences created by the switch from state-controlled in-home care to consumer directed (but state-funded) care in the United States. My purpose is to show how implementing policies that shift responsibility for arranging care away from the state and toward the family and market has real consequences for caretakers and the people who depend upon their care. The consequences of moving to consumer direction include a loss of state quality control oversight, elimination of even the most basic employment protections, such as anti-discrimination laws and occupational health and safety, disruption of the ability to access ordinary workplace protections, such as unemployment or disability insurance, a destruction of any potential for collective bargaining, and unaccounted for opportunity costs for family member workers. The raced and gendered nature of these ill effects cannot be ignored, as most of them fall upon the low-income women of color who make up the long term care workforce, or upon female family members who already bear the brunt of caretaking labor.

Because I support the basic dignitary interests of the elderly and people with disabilities, and because I see how the ability to hire a family member might benefit especially vulnerable families, I cannot reject consumer direction out of hand. However, I also resist the market-based framework that disembods people from relationships and community and creates the laundry list of negative consequences for workers and family members. Since I can neither accept nor reject consumer direction entirely, I have struggled to create a new framework for considering long term care that preserves the dignitary aspects of consumer direction, while not forgetting that people who need care are members of families and communities who are affected by their actions. This is not a mere exercise in writing the "solutions" section traditional to law review articles. It is a genuine, if preliminary, attempt to reframe in-home long term care. Community resilience, which I explore in this article, is one attempt at such a

reframing; there may be other frames worth exploring. Instead of thinking of long term care in a competing rights framework in which the caretaker is pitted against the person who needs care, I challenge myself and others to imagine a long term care system which increases community cohesion, that reduces the stresses on families while retaining their vital economic and affective functions, and that recognizes the dignity of both the people who need care and the people who provide it.