

# **UCLA**

## **Disability Law Journal**

### **Title**

Poverty, Welfare Reform, and the Meaning of Disability

### **Permalink**

<https://escholarship.org/uc/item/9kf523f2>

### **Journal**

Disability Law Journal, 3(1)

### **ISSN**

2831-9222

### **Authors**

Pokempner, Jennifer  
Roberts, Dorothy E.

### **Publication Date**

2022

### **Copyright Information**

Copyright 2022 by the author(s). All rights reserved unless otherwise indicated. Contact the author(s) for any necessary permissions. Learn more at <https://escholarship.org/terms>

Peer reviewed

# POVERTY, WELFARE REFORM, AND THE MEANING OF DISABILITY

Jennifer Pokempner<sup>1</sup>

Dorothy E. Roberts<sup>2</sup>

## ABSTRACT

The coincidence of poverty and disability has been widely acknowledged. The focus has been on the degree to which individuals with mental and physical disabilities face poverty because of their exclusion from the labor market and societal discrimination. There has been less concern, however, with the degree to which disability and illness are distributed in ways that reflect gender, racial, and economic inequalities.

Historically, poverty and disability have been addressed by separate governmental agencies and social assistance programs. With minor exceptions, disability has been addressed through programs structured on a social insurance model while poverty has been dealt with by a means-tested public-assistance model. The nature and mode of assistance provided through both models reinforce a social and economic system in which the ideal citizen is a male engaged in waged work that provides sufficient income for family support and who is without responsibility for caretaking work within the home. Because this ideal neither reflects the lived experience of most families nor addresses the structural

---

<sup>1</sup> J.D., University of Pennsylvania Law School, May 2000.

<sup>2</sup> Professor, Northwestern University School of Law; faculty fellow, Institute for Policy Research.

causes of poverty or the inequitable distribution of poverty and disability in society, the development of a new ideal or ethic must be promoted.

In this article, the authors examine the nature of the association between poverty and disability with the goal of encouraging more comprehensive forms of social provision that confront the inequitable distribution of illness and disability as well as the economic and social structures that generate these patterns. These measures would benefit individuals who experience disability or impairment but who also confront the forces that maintain widespread poverty.

#### TABLE OF CONTENTS

I. INTRODUCTION . . . . .	3
II. THE OVERLAP OF POVERTY, RACE, AND DISABILITY . . . . .	15
A. Connecting Poverty, Race, and Disability . . . . .	15
1. Poverty . . . . .	15
2. Race . . . . .	20
3. Gender . . . . .	33
B. Inequality and the Changing Face of Disability . . . . .	38
III. THE STATE'S RESPONSE TO POVERTY AND DISABILITY . . . . .	43
IV. WELFARE REFORM AND DISABILITY . . . . .	54
A. Disabled Welfare Recipients . . . . .	56
B. The Assault on the SSI Children's Program . . . . .	60
V. THE IMPLICATIONS OF "EMERGENT" DISABILITIES FOR SOCIAL POLICY . . . . .	68
VI. CONCLUSION . . . . .	70
A. Reorganization of Care Giving and Waged Work that Includes a Critique of the Meaning of Dependency . . . . .	72

B. Public Policies that Take Macroeconomic Dynamics into Account . . . . .	74
C. Health Promotion as a Central Political Project . . . . .	77

## I. INTRODUCTION

While the coincidence of poverty and disability has been widely noted, the nature of this intersection and the forces that produce it have not been fully explored. Historically, poverty and disability have been treated as separate conditions, addressed by separate advocacy groups, government agencies, and public attitudes. The public welfare system has dealt with poverty, while the social insurance system has dealt with disability.

Public assistance programs have been characterized by the use of means testing and stigma to deter detachment from the waged labor market.<sup>3</sup> Under the social insurance model, assistance is provided from a reserve of funds that were pooled to guard against the risk of economic misfortune.<sup>4</sup> Assistance, however, is predicated upon some attachment to the labor market.<sup>5</sup> The dominant work ideology considers the disabled as deserving of government assistance because their inability to participate fully in the market economy results from impairments outside

---

<sup>3</sup> Matthew Diller, Entitlement and Exclusion: The Role of Disability in the Social Welfare System, 44 UCLA L. REY. 361, 371–76 (1996).

A means-tested program conditions the receipt of public funds on the financial status of the recipient.

<sup>4</sup> Id. at 376–79.

<sup>5</sup> See id.

their control. The poor, on the other hand, are considered undeserving because they are blamed for failing to work. Although disability benefits programs recognize that disability can impoverish people, they obscure the way poverty disables people. The purpose of this article is to examine the nature of the association between poverty and disability as well as its consequences for social policy affecting both disability and poverty. We focus especially on how poverty and disability work to reinforce one another to perpetuate systemic inequalities.

Contemporary models of disability and recent research suggest that the absolute dichotomy between poverty and disability is false.<sup>6</sup> The

---

<sup>6</sup> See generally Nancy E. Adler & Joan M. Ostrove, Socioeconomic Status and Health: What We Know and What We Don't, 896 ANNALS N.Y. ACAD. SCI. 3 (1999) (reviewing research and analytical trends). The definition of disability is neither settled nor static over time. This is true in the realm of social and ideological discourse as well as legal practice. For example, the definitions of disability under the Americans with Disabilities Act of 1990 (ADA), Social Security Act, and various state and federal public welfare programs, differ. Broadly speaking, disability refers to physical or mental impairment that imposes barriers on individuals in functioning in the world of work, public accommodation, social interaction, and activities of daily living. This discussion will not assume a fixed definition of disability and includes a concern with populations that do not meet the criteria for the various legal definitions of disability. See generally Mary Crossley, The Disability Kaleidoscope, 14 NOTRE DAME. L. REY. 621 (1999) (exploring various legal and theoretical definitions of disability and their interactions).

social model of disability focuses on the ways in which people who are physically or mentally different from a norm are disabled by social and ideological forces that manifest themselves in social interactions as well as the very structure of the built world.<sup>7</sup> This analysis reveals the degree to which exclusion and inequality are created by relationships of social power, and applies to disempowered and disadvantaged groups beyond the disabled. The concept of “emergent disabilities,”<sup>8</sup> the growing class of impairments closely linked to poverty, adds a more materialist

---

<sup>7</sup> See Tom Shakespeare, What Is a Disabled Person?, in DISABILITY, DIVERS-ABILITY, AND LEGAL CHANGE 25 (Melinda Jones & Lea Ann B. Marks eds., 1999) [hereinafter DISABILITY, DIVERS-ABILITY] (explaining that the social model of disability “defines disability as a relationship between people with impairments and broader social and economic forces”). This model highlights “the role of environment, systems, attitudes, policy, and law, in rendering members of the population disadvantaged.” Id. at 29. This approach differs from a medical or deficit model of disability, which characterizes a physical or mental difference as a deviation from the norm. For a discussion of disability models and the ADA’s definition of disability, see Deborah Kaplan, The Definition of Disability: Perspective of the Disability Community, 3 J. HEALTH CARE L. & POL’Y 352, 352–56 (2000).

<sup>8</sup> Katherine Seelman & Sean Sweeney, The Changing Universe of Disability, 21 AM. REHABILITATION 2, 2 (1995) (noting changing patterns of disability that emphasize the association between poverty and the risk of disability).

dimension to the social model of disability. Data regarding emergent disabilities and their relation to poverty and disadvantage reveal how the inequitable structure of society produces concrete physical and mental impairments that affect an individual's life chances. Examining the treatment of these "new" (or newly acknowledged) disabilities highlights the overlap of disability with race, gender, and class inequities and exposes the misguided assumptions that underlie our public welfare and social insurance systems. It also suggests that, because the ramifications of illness often keep individuals and families in poverty, the promotion of health should be a greater focus of antipoverty strategies. Similarly, anti-poverty programs that address the inequitable distribution of income should be viewed as programs that promote health.

In addition, a focus on the intersection of poverty, race, gender, and disability can promote a discussion of social provision that is directed at confronting the structural causes of poverty and inequality and attempts to reconfigure welfare's meaning away from degradation and stigma toward health and well-being. Policies addressing disability and poverty must accept the diversity in individuals' physical capabilities, but also must reject unjust social arrangements that cause an inequitable distribution of illness and disability. The mode of analysis mandated by the Americans with Disabilities Act (ADA)<sup>9</sup> can serve as a beginning point in confronting the degree to which physical and ideological forces disable individuals.<sup>10</sup> The ADA acknowledges that people with disabilities have

---

<sup>9</sup>. See 42 U.S.C §§ 12101–12213 (1994).

<sup>10</sup>. Many have noted that the transformative impact of the ADA has not

been excluded from the mainstream of society through discrimination and physical barriers.<sup>11</sup> The ADA requires that public and private entities make affirmative changes in how they interact with and deliver services to persons with disabilities.<sup>12</sup> This affirmative mandate, however, stops short of any changes that would result in “fundamental alterations” of the entity or service provided and would be too burdensome or costly.<sup>13</sup> It is necessary to address how social structures generate illness and disability along gender, race, and class lines. In this way, disability becomes a lens through which poverty and inequality may be examined. Moreover, this analysis suggests that fundamental changes in the economy and the

---

yet been realized. Particularly in the area of employment, few plaintiffs have been successful. Matthew Diller argues that “[r]esistance to the ADA may result from a failure to comprehend and therefore to accept the premises underpinning the statute.” Matthew Diller, Judicial Backlash, The ADA, and the Civil Rights Model, BERKELEY J. EMP. & LAB. L. 19, 22 (2000).

<sup>11</sup>. See 42 U.S.C §§ 12101–12213 (1994).

<sup>12</sup>. See id.

<sup>13</sup>. See § 12111(10) (defining defense of “undue hardship” in the employment context); § 12182(b)(2)(A)(iii) (explaining that failure to make reasonable accommodations in the area of public accommodations can be excused if “the entity can demonstrate that taking such steps would fundamentally alter the nature of the good, service, facility, privilege, advantage, or accommodation”).

provision of social supports are necessary to counter inequitable distributions of wealth, well-being, and physical health.

The need to examine these intersections is particularly urgent as families experience the impact of “welfare reform” resulting from the passage in 1996 of the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA).<sup>14</sup> Under PRWORA; Aid to Families with Dependent Children (AFDC) was replaced by Temporary Assistance to Needy Families (TANF).<sup>15</sup> Many individuals, particularly those who are disabled, or those who are caring for disabled children have not fared well under the “quick work attachment” strategy of TANF, which emphasizes entrance into the workforce regardless of the nature or conditions of employment. First, many parents find it difficult to meet new work requirements and deadlines because they or their children are disabled.<sup>16</sup> The impairments

---

<sup>14</sup>. Pub. L. No. 104–193, 110 Stat. 2105 (1996) (codified as amended in scattered sections of 42 U.S.C.) [hereinafter PRWORA].

<sup>15</sup>. 42 U.S.C. §§ 601–619 (Supp. IV 1998). In contrast to AFDC, which was a federal entitlement, TANF is time-limited assistance not guaranteed by federal right in eliminating AFDC, PRWORA also eliminated the Job Opportunities and Basic Skills Training Program (JOBS), which provided categorical exemptions to individuals meeting the program criteria for disability or who were caring for disabled children. Pub. L. No. 104–193, 110 Stat. 2105, 2112.

<sup>16</sup>. See, e.g., KRISTA OLSON & LADONNA PAVEITI, URBAN INST., PERSONAL AND FAMILY CHALLENGES TO THE SUCCESSFUL TRANSITION FROM WELFARE TO WORK (1996), available at <http://>

they suffer make it difficult for them to find a job that is consistent with their skills and needs. TANF's limitation on the extent to which education and training can count as acceptable "work activities" only exacerbates this dilemma for those with disabilities and for recipients at large.<sup>17</sup> Fur-

---

[www.urban.org/welfare/reportl.htm](http://www.urban.org/welfare/reportl.htm) (documenting the frequency with which the disability of a recipient or family member creates a barrier to accessing and maintaining employment); cf. EILEEN P. SWEENEY, CTR. ON BUDGET AND POLICY PRIORITIES, RECENT STUDIES INDICATE THAT MANY PARENTS WHO ARE CURRENT OR FORMER WELFARE RECIPIENTS HAVE DISABILITIES AND OTHER MEDICAL CONDITIONS 3 (2000), available at <http://www.cbpp.org/2-29-00we1.pdf> (same); RE-CHARTING THE COURSE: FIRST REPORT OF THE PRESIDENTIAL TASK FORCE ON EMPLOYMENT OF ADULTS with DISABILITIES, Presented to the President of the United States (Nov. 15, 1998) (on file with author) (same).

<sup>17</sup>. Under TANF, a state cannot count the involvement of more than thirty percent of recipients in educational or vocational programs toward the monthly participation rate. 42 U.S.C. § 607(c)(2)(D) (Supp. IV 1998). That percentage includes teenage heads of household who are attending an educational or vocational program. § 607(c)(2)(C). States must achieve minimum participation rates to receive federal funds. § 607(a)(l). Further, with some exception, participation in job training for an individual recipient is not to last more than one year. § 607(d)(8). Prior to PRWORA, states had much more freedom in allowing individuals to pursue training programs and post-secondary education while receiving

ther, TANF does little to address the needs of adults who are caring for disabled children. Exemptions from work requirements, if allowed at the state's discretion, do nothing to address the poverty of families caring for disabled children and the particular costs this care imposes. Finally, the abolition of a federal entitlement to public assistance makes the Supplemental Security Income (SSI)<sup>18</sup> childhood and adult disability programs, which remain federal entitlements, more conspicuous sources of family support. SSI is the federal means-tested disability program that provides cash assistance and Medicaid to qualified individuals. While SSI is a means-tested program, it has been superimposed upon the social insurance model of Social Security. It has always been true that the number of applicants for the SSI program grows when there is an economic downturn or recession because more families become economically eligible.<sup>19</sup> As more and more families are pushed below the poverty line, they

---

public assistance. In New York and Massachusetts, for example, changes precipitated by PRWORA resulted in a decrease in enrollment of more than half of the persons receiving public assistance. See Andrew S. Gruber, Promoting Long-Term Self Sufficiency for Welfare Recipients: Post-Secondary Education and the Welfare Work Requirement, 93 NW. U. L. REV. 247, 262 (1998).

<sup>18</sup>. 42 U.S.C. §§ 1381–1383 (1994).

<sup>19</sup>. See, e.g., IRVING HOWARD ET AL., DISABILITY: FROM SOCIAL PROBLEM TO FEDERAL PROGRAM 71 (1980). As will be discussed below, when states administered disability programs through APID aid, the determination of disability was closely tied to evaluations of the

will undoubtedly put pressure on the SSI system as it is the only source of economic and medical assistance for themselves and their disabled children. This pressure reflects the ineffectiveness of our assistance system in responding to economic structures that keep people from leaving poverty and that create particular patterns of disability. Families no longer eligible for TANF and unable to meet the strict criteria for SSI will likely face extreme hardship.

As the SSI childhood and adult disability programs begin to replace welfare for some poor families by default, attacks on SSI mirror criticism traditionally reserved for the welfare system. The growth in the SSI program is viewed as a product of fraud and waste, rather than a reflection of need. The attacks also reflect our limited tradition of positive conceptions of citizenship and freedom and tendency to conceive of rights as formal and negative.<sup>20</sup> While the SSI program rarely raises a family far

---

local economic condition and opportunities available. As Diller notes, this type of analysis allowed the identification of disability to converge with a discussion of structural economic forces which worked against people securing jobs at a living wage. Diller, supra note 3, at 431. In this framework, provision of social aid was less focused on individual deficiency and fault and more on a structural analysis of economic forces and opportunities. Although the amount of assistance received through these programs was not sufficient, these programs at least presented a more comprehensive analysis of poverty and disability. Id. at 431–432.

<sup>20</sup>. See, e.g., David Abraham, Liberty without Equality: The Property-Rights Connection in a “Negative Citizenship” Regime, 21 LAW & SOC.

above the poverty line, the benefits are more generous than those provided under the TANF block grant program.<sup>21</sup> Further, SSI, especially the childhood program, seems to recognize that a successful system of social support must provide sufficient resources and services to enable an individual to successfully encounter the social and labor arenas and achieve family stability. SSI is also attacked because it is one of the last programs of public support structured on a federal entitlement model.

---

INQUIRY 1, 39–40 (1996) (“It appears that only negative liberties exist as rights, whereas affirmative or positive entitlements (or whatever we might call them) exist only as discretionary or revocable privileges.” (emphases in original)).

<sup>21</sup>. 42 U.S.C. §§ 601–619 (Supp. IV 1998). The gap between the cash assistance offered through SSI and welfare programs has progressively grown. In 1997, the maximum amount an individual eligible for SSI could receive was \$484 per month. Most states then supplement this benefit floor. OFFICE OF RESEARCH, EVALUATION AND STATISTICS, Soc. SEC. ADMIN. (PUB. No. 13–11758), SOCIAL SECURITY PROGRAMS IN THE UNITED STATES 84 (1997). In 1997, TANF benefits for a single parent with two children varied from state to state. Benefits most commonly ranged from \$350 to \$450 per month. See L. JEROME GAUAGHERET AL., URBAN INST., ONE YEAR AFTER FEDERAL WELFARE REFORM: A DESCRIPTION OF STATE TEMPORARY ASSISTANCE FOR NEEDY FAMILIES (TANF) DECISIONS AS OF OCTOBER 1997 tbl. 13, at <http://newfederalism.urban.org/html/occas6.htm>.

The attack on the SSI program will only grow as the prevalence of disabilities grows, and the disparity in the distribution of wealth increases due to the contraction of public welfare programs and the decreased likelihood of securing a living wage.<sup>22</sup> Defense of this program is important in the same way that defense of even a meager public assistance program is important. Using disability as a lens through which to examine poverty, however, suggests strategies for launching more comprehensive social programs that confront directly the forces that perpetuate particular patterns of poverty and inequality in our society. It is important to do so before the stinginess and stigma of what we now know as “welfare” invade the SSI system.

The association between poverty and disability in the context of retrenchment in public assistance raises several difficult and related questions: Should families receive disability benefits for children’s needs that are related more to poverty than to a physical or mental impairment? Conversely, why should families have to show that a child is disabled to receive benefits needed to support that child? Is it even possible or productive to sort out the extent to which the disability claims of poor families are related to poverty rather than to impairments traditionally defined as disabilities?

---

<sup>22</sup>. See, e.g., WILLIAM JULIUS WILSON, WHEN WORK DISAPPEARS (1996); THE WORK ALTERNATIVE: WELFARE REFORM AND THE REALITIES OF THE JOB MARKET (Demetra S. Nightingale & Robert H. Haverman eds., 1995).

Rather than attend to the association between poverty and disability, the trend has been to attempt to disentangle the costs and effects of poverty and disability. Elaborate and costly systems have been set up to “determine” whether an individual is disabled according to the definition of the particular program. Disability is supposed to be “treated” through medicine and its effects, through the social insurance systems, while economic need is dealt with through the public assistance system and work mandates. Examining the correlations between class, race, gender and disability brings into focus the degree to which our social insurance, public welfare, and public health systems are out of line with both current economic and family structures. The growing numbers of individuals classified, or self-classifying, as disabled reflects the increase in child poverty, growing disparities in wealth, and an economy and health care system that poorly serve indigent and minority families. The increased pressure on the SSI program, accompanied by an escalated assault, spotlights the overlap of poverty and disability.

These developments demonstrate the need for systems of social support that directly confront the related causes and effects of disability and poverty. They suggest that antipoverty and disability rights advocates should work together to create a common agenda for family support and a more equitable social structure. These advocates should jointly define a notion of social support based on a broader notion of social citizenship that confronts inequalities in wealth and social power affected by race, gender, and physical difference. This approach can build upon the strengths of the ADA and SSI programs to promote an antipoverty and disability rights agenda that is centrally concerned with social justice.

In Part II, we discuss the ways in which disability mirrors social inequality as it intersects with poverty, race, and gender. We explore how this growing overlap is transforming the very nature of disability. Part III discusses the state's response to poverty and disability. While government programs dealing with these two conditions are very different, they are both based on a model of citizenship grounded in waged work without caretaking responsibilities. Part IV examines the impact of welfare reform on poor people with disabilities. We consider the population of welfare recipients who are disabled, as well as the recent attack on the SSI children's program in the wake of welfare reform. Taking into account the association between disability and social disadvantage, Part V discusses the implications of "emergent" disabilities for social policy. We conclude with suggestions for an antipoverty agenda that recognizes these implications.

## II. THE OVERLAP OF POVERTY, RACE, AND DISABILITY

### A. Connecting Poverty, Race, and Disability

#### 1. Poverty

The intersection of poverty and disability has been well-documented.<sup>23</sup> Disability experts have noted that "[p]overty is the primary screening indicator of the many variables that increase the risk of

---

<sup>23</sup>. See generally Paul Newacheck & Neal Halfon, Prevalence, and Impact of Disabling Chronic Conditions in Childhood, 88(4) AM. J. PUB. HEALTH 610 (1998) (documenting the strong association of economic and social disadvantage with elevated prevalence of disability by using the National Health Interview Survey); Adler & Ostrove, supra note 6.

disability.”<sup>24</sup> At both the macro and micro levels, economics critically affect the distribution and nature of health and disability.<sup>25</sup> The main economic factors that affect health are “economic growth and instability (especially recession), economic inequality (including inequality due to structural changes), production processes and consumption of goods that are harmful to health, high-risk social-interaction patterns disproportionately prevalent in the lower socioeconomic strata, and health-care utilization.”<sup>26</sup>

Macroeconomic growth can improve aggregate health through better quality of life and living standards, sanitation, and stability. However, economic growth often creates exposure to toxic and dangerous substances.

---

<sup>24</sup>. Seelman & Sweeney, supra note 8, at 2.

<sup>25</sup>. While industrialization has been associated with general increases in standards of living, it has also been associated with increases in chronic diseases “brought about by increases in consumption of harmful substances, shifts in dietary consumption patterns, sedentary lifestyles, and chemical production.” M. Harvey Brenner, Political Economy and Health, in SOCIETY AND HEALTH 211, 211 (Benjamin C. Amick et al. eds., 1995). In addition, as the environmental justice movement has made particularly clear, the burdens of industrialization have been unequally distributed according to class, particularly race. See generally Regina Austin & Michael Schill, Black, Brown, Poor, and Poisoned: Minority Grassroots Environmentalism and the Quest for Eco-Justice, 1 KAN. J. L. & PUB. POL’Y 69 (1991).

<sup>26</sup>. Brenner, supra note 25, at 211.

Further, while economic growth can assuage tensions resulting from class, gender, and racial inequalities, it cannot resolve them. Instead, the nature of economic growth tends to reflect current social divisions. Thus, many of the burdens of industrialization and economic growth are borne by those with the least resources in our society.<sup>27</sup> One of those burdens is poor health. Those with the least political and economic power are clustered in jobs with more risk and with more exposure to toxins. This population also has less access to housing and environments free of lead and other toxins.

Relative deprivation, in addition to absolute resource deprivation, is associated with poor health.<sup>28</sup> The nature of economic growth may explain the apparent paradox of the growing prevalence of disability despite a seemingly prosperous economy. In our post-industrial economy, wage rates have been detached from real per capita income.<sup>29</sup> The skill and wage structures have become polarized as labor has been increasingly replaced by high-tech machinery and much of the work formally classified as manufacturing has been moved overseas. Thus, it is not simply aggregate wealth, but economic growth accompanied by an equitable distribution of resources, that is correlated with health. This

---

<sup>27</sup>. See id. at 217–18.

<sup>28</sup>. See Michael Marmot et al., Explanations for Social Inequalities in Health, in *SOCIETY AND HEALTH* 203 (Benjamin C. Amick et al. eds., 1995); see also *THE SOCIETY AND POPULATION HEALTH READER: INCOME INEQUALITY AND HEALTH* (Ichiro Kawachi et al. eds., 1999).

<sup>29</sup>. See Brenner, supra note 25, at 212.

correlation points to a perspective that views “industrial, economic and social welfare policies as the essential levers for improving health.”<sup>30</sup>

While the correlation between economics and health is clear, the mechanisms through which poverty and relative deprivation affect health are complex. According to Brenner, however, there is a straightforward feedback mechanism that characterizes this relationship: “(1) low [socio-economic status] involves higher incidence of illness and/or disability due to inequalities in the distribution of material, biochemical, and psychosocial benefits and risks. In turn (2) serious illness and/or disability adversely affects employment possibilities, earnings, and productivity.”<sup>31</sup>

Children living in poverty have a greater vulnerability to conditions highly predictive of disability status. These conditions include: asthma, chronic illness, environmental trauma such as lead poisoning, learning problems, and low birth weight. These conditions can limit a child’s functioning and significantly affect his or her life chances. For example, being born at a low birth weight significantly increases the chance of developing neurodevelopmental disabilities.<sup>32</sup> The long-term effects can include cerebral palsy, mental retardation, learning disorders, and behavior problems. Low birth weight babies are also more susceptible to infections, especially respiratory problems. These disabling effects, in turn, are highly

---

<sup>30</sup>. *Id*

<sup>31</sup>. *Id.* at 220.

<sup>32</sup>. See Tamar Lewin, Learning Problems of Low-Weight Infants Are Broader Than Once Thought, Study Finds, N.Y. TIMES, July 5, 2000, at A14.

associated with conditions related to poverty such as poor nutrition and diet, limited resources, and reduced access to medical care. In short, poverty can place an individual at greater risk for illness and disability as well as intensify their effects.

Finally, our health care system further exacerbates the connection between poverty, illness, and disability. In large part, health care is treated as a commodity. Those with adequate resources are able to purchase adequate, preventative medical care. Although Medicaid and Medicare provide access to medical care to some of the poor, elderly, and disabled, only half of those with incomes below the poverty line are covered by medical assistance.<sup>33</sup> Moreover, even with coverage, access to high quality services is not guaranteed, particularly for minority individuals. Therefore, it is more likely that illness or disability among those with little income will go untreated longer and potentially have severe and unnecessary long-term effects.

---

<sup>33</sup>. RANDE. ROSENBLATT ET AL, LAW AND THE AMERICAN HEALTH CARE SYSTEM 413 (1997).

## 2. Race<sup>34</sup>

Researchers have also demonstrated the intersection of race and disability.<sup>35</sup> According to the 1994–95 Survey of Income Participation, within the 22 to 44 year old age group, the proportion of persons with a severe disability was 5.6 percent among whites not of Hispanic origin, 11.8 percent among blacks, and 6.7 percent among Hispanics.<sup>36</sup> For individuals ages 45 to 54, the percentages were, respectively, 10.5, 18.4, and 15.7.<sup>37</sup> African American children, who are twice as likely as white children to be poor, disproportionately experience illness and disability.

---

<sup>34</sup>. This section provides only a summary sketch of the relationship among race, disability, and poverty. The focus on the status of African Americans and whites represents only a partial picture of these relationships. Examining the health and well-being of other racial and ethnic groups would provide a more comprehensive picture.

<sup>35</sup>. It should be clear from the outset what we do not mean by the intersection of race and disability. We in no way suggest that racial identity predisposes an individual to illness or disability. Rather, the intersection of race and disability occurs because “racial status is highly correlated with social, economic, and political factors.” Newton G. Osborne & Marvin D. Feit, The Use of Race in Medical Research, 267(2) JAMA 275,275,278 (1992).

<sup>36</sup>. JOHN MCNEIL, U.S. CENSUS BUREAU, U.S. DEPT. OF COMMERCE, AMERICANS WITH DISABILITES, 1994–95, at 3 (1997), available at <http://www.census.gov/prod/3/97pubs/p70-61.pdf>.

<sup>37</sup>. Id.

African Americans and other ethnic minorities have higher “rates of childhood diseases such as measles and chicken-pox; chronic diseases such as diabetes, heart disease, and cancer; and communicable diseases such as HIV and tuberculosis.”<sup>38</sup> Further, black infant mortality rates in the United States have consistently been nearly double the white rates.<sup>39</sup> This association stems largely from the color of poverty in America. As Foley and Johnson explain:

We also know, with certainty, that more than any other factor poor health in individuals and populations is correlated directly with poverty. Because blacks as a group continue to have incomes lower than those of whites, they continue to have poorer health status. Poor health is particularly pronounced in American inner cities, where the consolidation of poverty results in a generally harsh and aggravating environment that is increasingly difficult to survive.<sup>40</sup>

---

<sup>38</sup>. Lawrence O. Gostin, Securing Health or Just Health Care? The Effect of the Health Care System on the Health of America, 39 Sr. LOUIS U. L.J. 7, 32 (1994).

<sup>39</sup>. Virginia Davis Floyd, “Too Soon, Too Small, Too Sick”: Black Infant Mortality, in HEALTH ISSUES IN THE BLACK COMMUNITY 166 (Ronald L. Braithwaite & Sandra E. Taylor eds., 1992).

<sup>40</sup>. Marianne Foley & Glenn R Johnson, Health Care of Blacks in Americas Inner Cities, in HEALTH CARE ISSUES IN BLACK AMERICA: POLICIES, PROBLEMS, AND PROSPECTS 212, (Woodrow Jones Jr. & Mitchell F. Rice eds., 1987).

Even controlling for socioeconomic status, however, race is correlated with an increased risk for ill-health and disability. At every level of income, African Americans experience shorter life expectancy and poorer health outcomes.<sup>41</sup> Blacks have a higher mortality rate than whites for eight out of ten leading causes of death, and the gap has been widening.<sup>42</sup> A recent review of data and research indicates the persistence of racial disparities in the incidence of illness and disease, and the likelihood that disease will lead to death.<sup>43</sup>

---

<sup>41</sup> David R Williams, Race, Socioeconomic Status, and Health: The Added Effects of Racism and Discrimination, ANNALS N.Y. ACAD. SCI. 173, 176 (1999).

<sup>42</sup> Id. at 174–75.

<sup>43</sup> THE HENRY J. KAISER FAMILY FOUND., KEY FACTS: RACE, ETHNICITY & MEDICAL CARE § 2 (1999) [hereinafter RACE, ETHNICITY & MEDICAL CARE]; see also THE HENRY J. KAISER FAMILY FOUND., A SYNTHESIS OF THE LITERATURE: RACIAL & ETHNIC DIFFERENCES IN ACCESS TO MEDICAL CARE 6–16 (1999); NAT'L INSTS. OF HEALTH, U.S. DEP'T OF HEALTH & HUMAN SERVS., STRATEGIC RESEARCH PLAN TO REDUCE AND ULTIMATELY ELIMINATE HEALTH DISPARITIES: FISCAL YEARS 2002–2006-DRAFT OCT.6, 2000, at 4–8 (2000), available at <http://www.nih.gov/about/hd/strategicplan.pdf> (reporting racial disparities in health which include a shorter overall life expectancy, and higher rates of cardiovascular disease, cancer, infant mortality, birth defects, asthma, diabetes, stroke, sexually transmitted diseases, oral diseases and

This racial factor in disability stems partly from institutional racism that creates barriers to appropriate medical care and insurance. Further, racism in the job market and housing expose African Americans to more health risks. Data indicate that despite equal education and experience, African Americans are exposed to more occupational hazards and toxins, that they receive lower economic return on education, and that a given level of income may provide less purchasing power to blacks than whites.<sup>44</sup> There is also evidence that the racial disparity in health status results partly from conscious or unconscious discrimination by doctors against black patients.<sup>45</sup> The examples of blacks' inferior medical care are legion. Among Medicare patients, blacks are less likely than whites to receive all of the sixteen most common procedures.<sup>46</sup> Despite their higher rates of heart and kidney disease, African Americans are far less likely than whites to receive aggressive treatments such as bypass surgery, long-term hemodialysis, and kidney transplants.<sup>47</sup> The only four

---

disorders, and mental disorders).

<sup>44</sup>. Gary King & David R Williams, Race and Health: A Multidimensional Approach to African-American Health, in SOCIETY AND HEALTH 93, 110 (Benjamin C. Amick et al. eds., 1995).

<sup>45</sup>. See Williams, supra note 41, at 184.

<sup>46</sup>. Id. at 184.

<sup>47</sup>. Vemellia R Randall, Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans, 3 HEALTH MATRIX 127, 160—61 (1993).

procedures blacks are more likely to receive, such as amputation, all reflect delayed diagnosis or treatment and poorer care.<sup>48</sup>

The incidence and impact of Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome (HIV/AIDS), lead poisoning, and asthma illustrate the close correlation between poverty, racism, and disability.<sup>49</sup> The degree to which these ailments are disproportionately experienced by poor and minority populations highlights the powerful effect of social and economic forces on health and well-being. While these three ailments are extremely complex and involve different symptomologies, they share many characteristics. These ailments are highly influenced by social and physical environments. They are preventable and can be treated effectively, but without treatment can become chronic, debilitating, and even fatal. Further, the complexity of these three ailments challenges traditional models of public health, which focus solely upon the individual and biological aspect of health and illness.<sup>50</sup> Pro-

---

<sup>48.</sup> See Williams, supra note 41, at 184.

<sup>49.</sup> For an analysis of the inclusion of HIV/AIDS in the definition of disability under federal and state law, see generally David W. Webber & Lawrence O. Gostin, Discrimination Based on HIV/AIDS and Other Health Conditions: "Disability" as Defined under Federal and State Law, 3 J. HEALTH CARE L. & POL'Y 266 (2000); see also Bragdon v. Abbott, 524 U.S. 624 (1998) (holding that a woman with asymptomatic HIV infection had a disability for purposes of the ADA's public accommodation provisions).

<sup>50.</sup> Scott Burris, Public Health, "AIDS Exceptionalism" and the Law, 27 J.

fessor Scott Burris, for example, has noted that HIV/AIDS calls for an alternative model of public health that views “health as an attribute of communities in social and physical environments. On this view ill health is a complex phenomenon dependent on an interaction of social, biological, genetic, and psychological factors. Improvements in the population’s health can often be achieved by promoting changes in the social and physical environment.”<sup>51</sup> Because these ailments are so closely aligned with racial and economic inequalities, health-promoting changes in the physical and social environment must be intensely structural and political.

While HIV/AIDS emerged in public discourse as a disease experienced by homosexual, economically stable, white men, the distribution of infection has increasingly been keyed to racial and economic status. For example, in 1991, African Americans were 3.5 times more likely to contract AIDS than whites.<sup>52</sup> African American women were 13.8 times more

---

MARSHALL L. REY. 251,261 (1994).

<sup>51</sup>. Id. at 262.

<sup>52</sup>. Bill Jenkins, AIDS/HIV Epidemics in the Black Community, in HEALTH ISSUES IN THE BLACK COMMUNITY 58 (Ronald L. Braithwaite & Sandra E. Taylor eds., 1992); see also CTRS. FOR DISEASE CONTROL AND PREVENTION, HIV/AIDS AMONG AFRICAN AMERICANS (1999), available at <http://www.cdc.gov/hiv/pubs/facts/afam.pdf> [hereinafter HIV/AIDS AMONG AFRICAN AMERICANS] (African Americans comprise approximately 12% of the population, but make up almost 37% of all AIDS cases reported in the U.S.).

likely to contract AIDS than white women.<sup>53</sup> In addition, African American children were 12.8 times more likely to contract AIDS than their white counterparts.<sup>54</sup> Currently, the most rapid growth of HIV/AIDS is being experienced by minority populations.<sup>55</sup> The growth has been particularly dramatic among African American women and their children.<sup>56</sup> AB of 1995, for African American women, ages twenty-five to forty-four, AIDS

---

<sup>53.</sup> See Jenkins, supra note 52, at 58. “African American and Hispanic women together represent less than one-fourth of all U.S. women, yet they account for more than three-fourths (77%) of AIDS cases reported to date among women in our country.” CTRS. FOR DISEASE CONTROL, HIV/AIDS AMONG U.S. WOMEN: MINORITY AND YOUNG WOMEN AT CONTINUING RISK, at <http://www.cdc.gov/hiv/pubs/facts/women.htm> (last visited Feb. 18, 2001); see also Earl A. Daniels, AIDS among African American Women, at <http://www.gsu.edu/~gs05ead/AIDSandAAF.htm> (last visited Feb. 18, 2001) (stating that cases of AIDS in African American women are twenty times more frequent than in white women and 2.5 times more frequent than in Hispanic women).

<sup>54.</sup> Id.

<sup>55.</sup> See generally HIV/AIDS AMONG AFRICAN AMERICANS, supra note 52 (documenting high rate of growth of the incidence of HIV/AIDS in African American populations); cf. CTRS. FOR DISEASE CONTROL, TRENDS IN THE HIV & AIDS EPIDEMIC 5 (1998), available at <http://www.cdc.gov/hiv/stats/trends98.pdf> [hereinafter TRENDS IN HIV & AIDS] (same).

<sup>56.</sup> Id. at 56.

was the leading cause of death.<sup>57</sup> The disparity has been increasingly dramatic in light of the educational outreach efforts made among homosexual, white, middle-class men, and the progress that has been made in the development of drug therapies.<sup>58</sup>

The risk factors associated with of HIV/AIDS in the African American community have differed from those in white communities. While a majority of the HIV/AIDS cases reported for white men are linked to homosexual risk factors, the prevalence of such cases for African American men is less than fifty percent.<sup>59</sup> About forty percent of the HIV/

---

<sup>57</sup>. THEODORE J. STEIN, *THE SOCIAL WELFARE OF WOMEN AND CHILDREN with HIV AND AIDS: LEGAL PROTECTIONS, POLICY, AND PROGRAMS* 10 (1998). Jenkins adds that because women are more likely to develop conditions not included in the definition of AIDS, they are less likely to qualify for the legal entitlements that would enable early treatment JENKINS, *supra* note 52, at 59. In addition, because reproductive decisions are often bound up in the detection and treatment of HIV for women, the discriminatory treatment that African American and poor women experience in this area must be considered as effective courses of treatment and detection are sought.

<sup>58</sup>. Gostin, *supra* note 38, at 58.

<sup>59</sup>. In 1996, three-quarters of white men diagnosed with AIDS had contracted the disease through homosexual sex, while the figure for African American men was forty percent. Transmission attributed to drug use was thirty-eight percent for African American men and twelve percent for white men. For African American women diagnosed with AIDS,

AIDS cases in African American men are linked to intravenous drug use.<sup>60</sup> For many poor African American and white women, infection has been a result of intravenous drug use or sexual contact with a drug using partner.<sup>61</sup> These higher correlations between drug use and HIV/AIDS however, are surely linked to poverty as well as inadequate medical care and scarcity of drug treatment programs in the communities that are most in need. The effect of the inadequacies of the public health and medical insurance infrastructure are particularly dire for those at high risk for exposure to HIV or who have become infected because early detection and rigidly consistent treatment are necessary for successful treatment. Barriers to treatment exist for African Americans once diagnosed. Research has shown that African American patients were significantly less likely than white patients to have received antiretroviral therapy.<sup>62</sup> Further, despite the success in reducing the perinatal transmission of AIDS through the administration of various drugs during pregnancy and after birth, the majority of perinatally acquired AIDS cases occur among

---

fifty-three percent of the cases were attributed to heterosexual sex. For white women the figure was fifty-one percent. For African American and white women, forty-three percent of AIDS diagnoses were attributed to intravenous drug use. TRENDS IN HIV& AIDS, supra note 55, at 12, 14.

<sup>60.</sup> See Gostin, supra note 38, at 59.

<sup>61.</sup> See id.

<sup>62.</sup> Barbara A. Noah, Racial Disparities in the Delivery of Health Care, 35 SAN DIEGO L. REY. 135, 148 (1998).

African American and Hispanic children.<sup>63</sup> Late detection, inconsistent and inadequate treatment, and exposure to a harsh and insecure environments can be fatal for people suffering from HIV/AIDS.

Poor housing stock and continued patterns of racial segregation have resulted in poor and minority children being at much greater risk for exposure to deteriorating lead-based paint, a major cause of lead poisoning.<sup>64</sup> Forty-nine percent of African American inner city children, for example, are exposed to dangerous levels of lead.<sup>65</sup> Research has also shown that children at nutritional risk are especially susceptible to lead poisoning because absence of important nutrients and developmental needs can enhance lead absorption.<sup>66</sup> In its most recent national health

---

<sup>63</sup>. TRENDS IN HIV & AIDS, supra note 55, at 7.

<sup>64</sup>. Lead poisoning, however, disproportionately impacts African American children at all class levels. See Robert D. Bullard, Leveling the Playing Field through Environmental Justice, 23 VT. L. REY. 453, 467–08 (1999).

<sup>65</sup>. Janet Phoenix, Getting the Lead out of the Community, in CONFRONTING ENVIRONMENTAL RACISM: VOICES FROM THE GRASSROOTS 79 (Robert D. Bullard ed., 1993).

<sup>66</sup>. U.S. GOV'T ACCOUNTING OFFICE, GAO/HEHS-99–18, LEAD POISONING: FEDERAL HEALTH CARE PROGRAMS ARE NOT EFFECTIVELY REACHING AT-RISK CHILDREN 3 (1999) [hereinafter GAO/HEHS]; see generally Herbert L. Needleman et al., The Long-Term Effects of Exposure to Low Doses of Lead in Childhood, 322(2) NEW ENG. J. MED. 83 (1990) (concluding that “exposure to lead in childhood is

survey conducted between 1991 and 1994, the Center for Disease Control (CDC) found that “[t]hree fourths of all children aged one through five [with] elevated blood lead level[s] were enrolled in Medicaid or the [Special Supplemental Nutrition Program for Women, Infants and Children (WIC)] or were within the target population for the Health Center Program,” which targets medically underserved areas.<sup>67</sup>

Lead poisoning can have significant developmental consequences. Neurological, cognitive, and behavioral delays have been associated with moderate to unsafe levels of lead.<sup>68</sup> Based on the CDC survey, it is projected that more than 400 thousand children in or targeted by federal health care programs have undetected elevated blood lead levels.<sup>69</sup> Given this projection, it is likely that many poor children will suffer developmental disabilities whose etiology will not be accurately identified preventing targeted treatment. Treatment for lead poisoning is complex and requires consistent monitoring and follow-up care, which most poor children do not receive. Further, most state Medicaid programs do not reimburse for key treatment services.<sup>70</sup> In recent decades there has been

---

associated with deficits in central nervous system functioning that persist into young adulthood”).

<sup>67.</sup> GAO/ HEHS, supra note 66, at 3.

<sup>68.</sup> NATIONAL LEAD INFORMATION CENTER, LEAD: SOME QUESTIONS AND ANSWERS 11, 14, 19 (Apr. 1993).

<sup>69.</sup> See GAO/HEHS, supra note 66, at 4.

<sup>70.</sup> Id. at 4.

an alarming increase in asthma.<sup>71</sup> Asthma is now the most common chronic disease among American children.<sup>72</sup> Studies show that black and Hispanic children, particularly those who are poor, are especially vulnerable to this disease.<sup>73</sup> This increased risk is largely due to the confluence of the medical condition and the conditions of poverty. Because poor families have less access to quality medical care and expensive medications, and because older and cheaper housing often contains triggers of asthma attacks, such as dust, dust mites, cockroaches, cold air, mold, and mildew, impoverished asthma sufferers also have greater difficulty controlling their condition.<sup>74</sup> Moreover, constant monitoring of the home environment and the child's activities are crucial to containing asthma

---

<sup>71.</sup> See generally Ctrs. for Disease Control and Prevention, Current Trends: Asthma-United States, 1982–1992, 43 MORBIDITY AND MORTALITY WKLY. REP. 952 (Jan. 6, 1995) (documenting steep growth in the reported cases of asthma).

<sup>72.</sup> RACE, ETHNICITY & MEDICAL CARE, supra note 43.

<sup>73.</sup> Sheryl G. Stolberg, Poor Fight Baffling Surge in Asthma, N.Y. TIMES, Oct. 18, 1999, at A1, A18; see generally Paul W. Newacheck & Neal Halfon, Prevalence, Impact, and Trends in Childhood Disability Due to Asthma, 154 (3) ARCHIVES OF PEDIATRICS & ADOLESCENT MED. 287 (2000) (documenting the rise in asthma particularly among minority and impoverished children); Ellen F. Crain et al., An Estimate of the Prevalence of Asthma and Wheezing among Inner-City Children, 94 PEDIATRICS 356 (1994).

<sup>74.</sup> Stolberg, supra note 73, at A18.

exacerbation. This monitoring is costly in terms of time and resources, and is often frustrating given the dearth of affordable housing free of environmental triggers. A recent study showed that the rate of hospitalization for asthma was twenty-one times higher in the more impoverished areas of the Bronx and Harlem than in more affluent areas of the New York City.<sup>75</sup> These results reflect the greater prevalence of asthma among poor and minority individuals as well as the inadequate medical care they receive. When the onset of asthma is in childhood, it can represent a risk factor for other developmental disabilities, particularly when the treatment received is not adequate.<sup>76</sup> Asthma can create limitations in physical activity and can make a child more susceptible to respiratory infections. Asthmatic children frequently miss days of school and often cannot participate in activities with their peers, resulting in social and academic

---

<sup>75.</sup> Id.; see also RACE, ETHNICITY & MEDICAL CARE, supra note 72 (reporting that African American children were three times as likely as white children to be hospitalized for asthma).

<sup>76.</sup> See generally Regina Bussing et al., Prevalence of Behavior Problems in US Children with Asthma, 149 ARCHIVES OF PEDIATRICS & ADOLESCENT MED. 565 (1995) (finding that asthma represents a significant risk factor for the development of emotional and behavioral problems).

losses.<sup>77</sup> Thus, asthma and lead exposure are conditions exacerbated by conditions of poverty that significantly affect children's development<sup>78</sup>

Race and disability, then, are not completely separate sources of disadvantage that parallel each other.<sup>79</sup> Race and disability are overlapping identities that are both related to systemic inequality.

### 3. Gender

Family structure and gender inequalities significantly affect the overlap of disability, poverty, and race. Because poor families are

---

<sup>77.</sup> See generally Paul W. Newacheck & Neal Halfon, supra note 73, at 287 (documenting significant restriction in daily activities, including school attendance for children with asthma).

<sup>78.</sup> Despite the many limitations experienced by asthmatic children, they have been particularly vulnerable to having their SSI eligibility terminated since the changes effected by PRWORA. See generally Chris Palamountain, Children with Asthma Prove Vulnerable to SSI Cuts, XIX(I) YOUTH L. NEWS, Jan.-Feb. 1998, at 1.

<sup>79.</sup> Most of the speakers at the symposium assumed that race and disability were separate categories that could be compared, without considering any relationship between them. One speaker, for example, raised the question whether being black was a greater disadvantage than being disabled. Others compared discrimination on the basis of race and on the basis of disability and considered using the civil rights movement as a model for advocating disability rights. While these projects have merit, they neglect the connection between racism and disability that we highlight in this article.

disproportionately headed by women,<sup>80</sup> women are at greater risk for suffering illness and disability than members of the population at large. Further, a large number of these single mothers are African American.<sup>81</sup> Thus, gender as well as race affects the ability of a family to achieve economic stability. Gender inequalities in the labor market and in caregiving work make the impact of caring for a disabled child or one's own disability more pronounced. Joel Handler notes that "despite the long period of economic growth, the labor market has deteriorated for women, mostly with children, mostly black, and mostly without a high school diploma."<sup>82</sup>

---

<sup>80</sup>. Female headed families compose the majority-fifty-three percent-of poor families in 1999. See JOSEPH DALAKER AND BERNADETTE D. PROCTOR, U.S. CENSUS BUREAU, U.S. DEPT. OF COMM., POVERTY IN THE UNITED STATES 1999 x (2000), available at <http://www.census.gov/prod/2000pubs/p60-210.pdf>; see also JOEL F. HANDLER & YEHESEKEL HASSENFELD, THE MORAL CONSTRUCTION OF POVERTY: WELFARE REFORM IN AMERICA 17 (1991).

<sup>81</sup>. In 1994, single parents accounted for almost sixty-five percent of all black family groups with children present. The heads of these households were predominantly women. STEVE W. RAWLINGS, U.S. CENSUS BUREAU, U.S. DEPT. OF COMMERCE, HOUSEHOLDS AND FAMILIES 23 (1995).

<sup>82</sup>. Joel F. Handler, Low-Wage Work "As We Know It," in HARD LABOR: WOMEN AND WORK IN THE POST-WELFARE ERA 4 (Joel F. Handler & Lucie White eds., 1999).

Further, most of the low-skilled jobs open to these women do not provide the health insurance that is crucial to caring for the health of themselves and their children.

The PRWORA is clearly concerned with gender and recognizes a relationship between poverty and gender. The PRWORA's presentation of the relationship between gender and poverty, however, endorses gender inequality. The law prescribes marriage and a decrease in out-of-wedlock births as the answer to poverty.<sup>83</sup> The PRWORA addresses neither the gender inequality in the labor market nor the unequal distribution of caretaking responsibilities in the home. Nor does it address the structure of the low wage labor market which prevents women and men, whether married or single, from being able to care for their children and their health needs and bring them to a living wage. These omissions disadvantage poor women with disabilities or with disabled children.

Research shows that “[h]aving one child or more with a disability is highly associated with greater poverty in families.”<sup>84</sup> Single mothers with

---

<sup>83</sup>. TANF's purposes include encouraging marriage and reducing the incidence of childbearing out of marriage. 42 U.S.C. § 601(a)(3) & (4) (Supp. N 1998). Assistance can be reduced or eliminated if a woman will not assist in establishing the paternity of a child. *Id.* at § 608(2).

<sup>84</sup>. Mitchell P. LaPlante et al., National Inst. on Disability and Rehabilitation Research, U.S. Dep't of Health and Human Servs., Families with Disabilities in the United States, in FAMILIES WITH DISABILITIES IN THE UNITED STATES 1, 13 (1996) [hereinafter LaPlante].

two or more children with disabilities are at high risk for living in poverty.<sup>85</sup> Women heading poor families frequently have access to the least desirable positions in the labor market and generally are responsible for most of the family's caretaking. Their return in the waged labor market is rarely sufficient to support a family and the work done to care for their family is not valued or compensated.<sup>86</sup> The devaluation of both types of work creates additional costs for the mother attempting to care for a disabled child. These additional costs highlight the gender inequalities which continue to pervade the labor market in terms of wage structures, the devaluation of caregiving work inside and outside the home and the ill-fit between family caregiving and work within the market. Eva Feder Kittay points out that both the gendered nature of poverty and the dependency relationships that exist throughout society have been largely

---

<sup>85</sup>. Id. at 11.

<sup>86</sup>. See Dorothy E. Roberts, The Value of Black Mothers' Work, 26 CONN. L. REV. 871 (1994) (discussing the degree to which women and poor minority women are clustered in the low wage labor market and are also responsible for caretaking work within the home, preventing work from allowing an escape from poverty); see also KATHRYN EDIN & LAURA LEIN, MAKING ENDS MEET: HOW SINGLE MOTHER SURVIVE WELFARE AND LOW WAGE WORK (1997); See generally MARTHA FINEMAN, THE NEUTERED MOTHER, THE SEXUAL FAMILY, AND OTHER TWENTIETH CENTURY TRAGEDIES (1995); GWENDOLYN MINK, WELFARE'S END (1998).

ignored in public debate about welfare and social provision.<sup>87</sup> Kittay documents the degree to which the devaluation of women's caretaking work is particularly harmful to families with disabled children and leaves them exposed to exploitation.<sup>88</sup> The PRWORA makes poor women and their children bear the burden of these inequalities. It suggests that the failure to marry causes poverty and poor outcomes for children rather than an economic structure and gendered division of labor that does not allow waged labor and caretaking to easily coexist or allow TANF recipients to work their way out of poverty. Addressing the overlap of disability and poverty, therefore, must include an analysis of the feminization of poverty that challenges gender and racial inequalities within the labor force, the economy, and the family.<sup>89</sup>

---

<sup>87</sup>. EVA FEDER KITTAY, *LOVE'S LABOR: ESSAYS ON WOMEN, EQUALITY, AND DEPENDENCY* 117 (1999).

<sup>88</sup>. See id. at 131. Kittay argues that "full social citizenship requires that if we are called upon to care [for a child, family member, or fellow citizen], we can fulfill these duties without losing our ability to care for ourselves, and that in caring for another, the full burden of support as well as care for the one dependent on us will not fall upon our shoulders alone. Without such assurance, we have not yet attained the powers and capacities to function as free and equal citizens." Id.

<sup>89</sup>. Brendan Gleeson argues further that a social-materialist analysis of disability suggests a "replacing of the law of value with anew social measurement of economic usefulness." BRENDAN GLEESON, *GEOGRAPHIES OF DISABILITY* 150 (1999). This reconsideration of the

## B. Inequality and the Changing Face of Disability

The growing intersection of poverty, race, and disability is transforming the very nature of disability in America. In 1995 Seelman and Sweeney observed that “the face of the disabled population is changing.”<sup>90</sup> They stated that:

The expanding or new universe of disability is resulting from changing causes and patterns of disabilities which include but are not limited to such conditions as (1) violence and abuse, (2) aging, (3) substance abuse and stress, (4) inadequate prenatal care, (5) low birth weight, (6) adolescent pregnancy and childbearing, (7) poor nutrition, environmental/toxic exposures, such as alcohol, smoking, drug abuse, and lead,

---

“law of value” becomes even more imperative when gender and family structure are added considerations. Lucy A. Williams points out: Economic theories of “productivity” largely do not include the value of unpaid labor as a factor, or as a cost of production, within labor markets [A]n alternative economic formulation can be devised that challenges the coherence of “productivity” or “efficiency,” altering the basic underlying premises in a gender-remedial direction by incorporating into the costs of production a portion of the unpaid labor costs.

Lucy A. Williams, Unemployment Insurance and Low-Wage Work, in HARD LABOR: WOMEN AND WORK IN THE POST-WELFARE ERA 158, 168–69 (Joel F. Handler & Lucie White eds., 1999).

<sup>90</sup>. Seelman & Sweeney, supra note 8, at 2.

sexually transmitted diseases, including pediatric HIV and AIDS, (10) injuries, and (11) child abuse and neglect<sup>91</sup>

The changing face of disability reflects the patterns of poverty and exclusion that exist in society. Fujiura and Yamaki predict that these patterns will produce: “(a) increases in magnitude and rates of disability among those most vulnerable; and (b) greater prominence of what are broadly labeled, ‘socio-environmental’ risk factors as predictors of disability status.”<sup>92</sup> The transformation of disability has intensified as global changes produced a deindustrialized economy and the strength of social conservative ideology has led to the erosion of the welfare state at an unprecedented pace.<sup>93</sup> While the proportion of individuals living in poverty has plateaued over the last decade, the proportion of children living in poverty has grown.<sup>94</sup> In addition, the disparity in the distribution of wealth has dramatically increased. Poverty has consistently been most prevalent among minorities and households headed by women. For example, it is estimated that four in ten African American and Hispanic children are living below the poverty line, with the majority of these in female headed, single-parent households.<sup>95</sup> Along with an increase

---

<sup>91.</sup> Id

<sup>92.</sup> Glenn T. Fujiura & Kiyoshi Yamaki, Trends in Demography of Childhood Poverty and Disability, 66(2) EXCEPTIONAL CHILD. 187, 188 (2000).

<sup>93.</sup> See generally Wilson, supra note 22.

<sup>94.</sup> Fujiura & Yamaki, supra note 92, at 187.

<sup>95.</sup> Fujiura & Yamaki, supra note 92, at 187 (citing JOSEPH DAI.AKER&

in childhood poverty, there has been an increase in childhood disability in the last fourteen years.<sup>96</sup> Children living in poor and single-parent headed families have the highest risk of being disabled.<sup>97</sup>

Because the relationship between poverty and disability is so strong, it is hard to disentangle the additional “cost” of disability from the very struggles related to being poor. With less income, fewer social supports,

---

MARY NAIFEH, U.S. CENSUS BUREAU, U.S. DEPT. OF COMMERCE, POVERTY IN THE UNITED STATES: 1997 (1998), available at <http://www.census.gov/prod/3/98pubs/p60-201.pdf>); see also SARAH STAVETEIG & ALYSSA WIGTON, URBAN INST., RACIAL AND ETHNIC DISPARITIES: KEY FINDINGS FROM THE NATIONAL SURVEY OF AMERICA’S FAMILIES, at [http://newfederalism.urban.org/html/series\\_b/b5/b5.html](http://newfederalism.urban.org/html/series_b/b5/b5.html) (last visited Feb. 18, 2001) (reporting that African Americans have a poverty rate nearly three times as high as whites and that two-thirds of all African American children live in a one-parent home); Mary E. Corcoran & Ajay Chaudry, The Dynamics of Childhood Poverty, 7(2) THE FUTURE OF CHILD. 40, 41 (1997) (documenting that the poverty rates for African American and Latino children were two and one-half to three times the rate for white children and that children living in mother-only families were more than five times as likely to be poor than those living in two-parent families). In 1992, fifty-nine percent of all African American children and seventeen percent of white children lived in female headed families. Id. at 43.

<sup>96</sup> Fujiura & Yamaki, supra note 92, at 192 tbl. I, 194.

<sup>97</sup> Fujiura & Yamaki, supra note 92, at 194.

and less access to comprehensive and preventative medical care, poor people are not only more likely to experience disability and illness, but also less able to treat disabling conditions and to mitigate their impact. Lisbeth B. Schorr and Daniel Schorr vividly describe the complicated interaction of poverty and disability:

The child in a poor family who is malnourished and living in an unheated apartment is more susceptible to ear infection; once the ear infection takes hold, inaccessible or inattentive health care may mean that it will not be properly treated; hearing loss in the midst of economic stress may go undetected at home, in day care, and by the health system; undetected hearing loss will do long-term damage to a child who needs all the help he can get to cope with a world more complicated than the world of most middle class children. When this child enters school, his chances of being in an overcrowded classroom with an overwhelmed teacher further compromise his chances of successful learning. Thus, risk factors join to shorten the odds of favorable long-term outcomes.<sup>98</sup>

Marcia Meyers and her colleagues similarly note the cumulative effects of poverty and disability:

Children in low-income families are more likely to live in poor neighborhoods where they are exposed to heightened

---

<sup>98</sup>. LISBETH B. SCHORR & DANIEL SCHORR, *WITHIN OUR REACH: BREAKING THE CYCLE OF DISADVANTAGE* 30 (1988).

environmental risks. They are more likely to suffer from low birth weight and other complications associated with poor maternal nutrition, health behaviors, and health care. Children in poor families are also less likely to receive the adequate early nutrition, housing, and health care that might help prevent the development of serious disabilities and health conditions.<sup>99</sup>

These observations demonstrate that the relationship between economic disadvantage and disability is more than additive. Even for those whose disability or impairment is less directly linked to poverty, poverty and disadvantage affect the experience of disability. The confluence of disability and poverty are further exacerbated by a health care system that does not adequately serve poor and minority populations.<sup>100</sup> Further, differences in access and treatment continue to exist along racial lines even when socioeconomic status is controlled. Thus, the experience of disability in poor families results in more than just supplemental costs.

---

<sup>99</sup>. MARCIA K MEYERS ET AL., CTR. FOR POLICY RESEARCH, SYRACUSE UNIV., INCOME SECURITY POLICY SERIES, PAPER NO. 16, THE COST OF CARING: CHILDHOOD DISABILITY AND POOR FAMILIES, 4 (July 1997).

<sup>100</sup>. See generally ROBERT M. MAYBERRY ET AL., THE HENRY J. KAISER FAMILY FOUND., A SYNTHESIS OF THE LITERATURE: RACIAL AND ETHNIC DIFFERENCES IN ACCESS TO MEDICAL CARE, (1999) (detailing disparities in health status, access to and quality of care).

If poverty and disability work to reinforce each other and other patterns of inequality, economic and social supports should seek to address both types of disadvantage rather than investing more resources in separating and grading the causes of each. The relationship between poverty and disability suggests that reducing the incidence of both requires more than the provision of meager economic support and the improvement or expansion of health care services. While these are very important aspects of an antipoverty program, our analysis calls for a broader vision of the factors promoting of health and illness, a more structural analysis of the causes of poverty, and attention to the relationship between the two.

### III. THE STATE'S RESPONSE TO POVERTY AND DISABILITY

Historically, the state has responded to poverty and disability in different ways. While the public welfare system addresses poverty, aid to the disabled has been fashioned in the model of social insurance. These responses reflect an unspoken model of citizenship: the waged worker, with access to a decent paying job, and without primary caretaking responsibilities.<sup>101</sup> According to this model, detachment from the waged labor market is deemed socially and morally suspect. When this detachment leads to poverty or is accompanied by illness, this model dictates that assistance be provided in ways that exemplify when this detachment

---

<sup>101</sup>. See Nancy Fraser & Linda Gordon, A Genealogy of "Dependency": Tracing a Keyword of the U.S. Welfare State, in JUSTICE INTERRUPT US: CRITICAL REFLECTIONS ON THE "POSTSOCIALIST" "CONDITION 135 (Nancy Fraser ed., 1997).

is deemed justified and when it is deemed blameworthy.<sup>102</sup> Similarly, the U.S. response to poverty and disadvantage has reflected an ethic of individualism and a virtually unwavering belief in the justness of the market. As a result, a structural analysis of poverty has rarely been pursued as a model for designing government assistance. Such an analysis would require acknowledging the degree to which the state indeed does intervene in the economy in ways that maintain the current racial patterns and class power, and that different forms of intervention could create more equitable social and economic relations.

In addition, the collective and societal costs of poverty to democracy have not been considered a focus of public policy. Because poverty, like wealth, is individualized and attributed to personal merit or fault, it is privatized and depoliticized. The poverty or wealth of individuals or particular groups is perceived as unrelated to broader economic and social structures that have been erected by political choice. As many historians and social scientists have detailed, our bifurcated social assistance systems reflects an assessment of whose poverty and disadvantage is deemed morally acceptable, and reinforces the values and working of a capitalistic market economy.<sup>103</sup> In popular discourse and public policy, the problem of poverty, however, is rarely presented as a matter of collective, political, and constitutional concern, much less a matter of social

---

<sup>102.</sup> See generally MICHAEL B. KATZ, IN THE SHADOW OF THE POORHOUSE: A SOCIAL HISTORY OF WELFARE IN AMERICA (1986).

<sup>103.</sup> Diller, supra note 3, at 367.

justice and ethics. The state's responses to both disability and poverty reflect this limited understanding of social disadvantage.

Nancy Fraser and Linda Gordon interrogate the meaning of dependency that underlies the state's response to disability and poverty:

Why are debates about poverty and inequality in the United States now being framed in terms of welfare dependency? How did the receipt of public assistance become associated with dependency, and why are the connotations of that word in this context so negative? What are the gender and racial subtexts of this discourse, and what tacit assumptions underlie it?<sup>104</sup>

Fraser and Gordon explain a process through which relationships of dependency were removed from the realm of the market and attached to disfavored and excluded groups—women, minorities, the poor, and the disabled.<sup>105</sup> While the waged laborer became the model of the independent citizen, the non-waged and “dependent” worker was deemed to be outside the acceptable economic and political realm and therefore “dependent.”<sup>106</sup> This model of citizenship has meant that disability and productivity have been defined in reference to waged work.

In our bifurcated model of social assistance, disability has traditionally placed people in the category of those excused from the labor force and entitled to government assistance. This model holds that the cause

---

<sup>104</sup>. Fraser & Gordon, supra note 101, at 122.

<sup>105</sup>. See id. at 1261–31.

<sup>106</sup>. See id. at 131.

of disability is typically beyond the control of the individual. Accordingly, the disabled are not blamed for their inability to fit in the social structure or to achieve economic well-being and are therefore considered “worthy” of social assistance in a fairly dignified manner. If they have previously participated in the waged labor market or can clearly demonstrate their inability to do so, receipt of aid neither challenges the valued norms of work nor the rules of the capitalist market economy. It follows from this reasoning that it is only when individuals’ needs are deemed “faultless” that they are able to remain “both . . . citizen[s] and in need.”<sup>107</sup> In contrast, the poor, whose need is considered their own fault, receive only meager aid and on terms that stigmatize and seek to prod them into the waged labor market regardless of the conditions of entrance.<sup>108</sup> Our welfare and disability policies and debates have been structured and limited by these categories.

Matthew Diller notes that U.S. social policy has moved toward an exclusionary approach to disability.<sup>109</sup> This approach makes the focus of disability policy the delineation of rigid boundaries between the category of the disabled and the residual category of “able-bodied” poor. Deborah

---

<sup>107.</sup> DEBORAH A. STONE, *THE DISABLED STATE* 24 (1984).

<sup>108.</sup> The concept of less eligibility has been most widely popularized by FRANCES FOX PIVEN & RICHARD A. CLOWARD, *REGULATING THE POOR: THE FUNCTIONS OF PUBLIC WELFARE* (2d ed. 1993) (explaining that the terms of public assistance are always calibrated so that they provide less than the lowest paying waged labor).

<sup>109.</sup> Diller, supra note 3, at 364.

Stone elaborates that the state's definition of disability has been central to the nature of the welfare state: "The very notion of disability is fundamental to the architecture of the welfare state; it is something like a keystone that allows the other supporting structures of the welfare system and, in some sense, the economy at large to remain in place."<sup>110</sup> In this sense, policies regarding disability and poverty have been interdependent rather than distinct.

It was not until 1974 that a means-tested disability program-Supplemental Security Income (SSI)-was created. SSI is a federally-funded public assistance program for the elderly and disabled. The program provides federal aid, gauged to the consumer price index, that can be supplemented by the states. Prior to that time, states administered their own means-tested disability assistance program, Aid to the Permanently and Totally Disabled (APTD).<sup>111</sup> Because APTD programs were based on the public assistance model, the definition of disability was more inclusive, making the line between disability and other causes of disadvantage and unemployment less distinct, and making the connection between economic structure and poverty more clear.<sup>112</sup> As with the public assistance model, however, the level of benefits was very low.

The very form of the SSI program embodies the tension between theories of assistance based on social insurance and public welfare. The SSI program is a means tested program placed within the social

---

<sup>110.</sup> STONE, supra note 107, at 12.

<sup>111.</sup> 42 U.S.C. § 1351 (1994) (repealed 1974).

<sup>112.</sup> See Diller, supra note 3, at 364.

insurance model of Social Security.<sup>113</sup> The legitimacy of the Social Security model stems from the attachment of recipients to the labor force. Because Social Security is in part: financed by payroll taxes, the public regards recipients' benefits as earned.<sup>114</sup> In contrast, no attachment to the workforce is required for SSI eligibility.<sup>115</sup> Because eligibility is

---

<sup>113.</sup> Id. at 443–44.

<sup>114.</sup> Diller, supra note 3, at 380; Dorothy E. Roberts, Irrationality and Sacrifice in the Welfare Reform Consensus, 81 VA. L. REY. 2607, 2620 (1995).

<sup>115.</sup> Several programs have been implemented to encourage recipients of SSI and SSDI to enter or re-enter the workforce. These programs confront the contradictions embedded in our bifurcated model of social assistance: how can work be permissible for recipients of disability benefits when their qualification for aid was based on a determination that they are unable to work? The Ticket to Work and Work Incentives Improvement Act [hereinafter Ticket to Work Act] is the most recent of these programs. It was passed by Congress and signed by President Clinton in late 1999. Pub. L. No. 106–170, 113 Stat. 1860 (1999) (codified at 42 U.S.C.A. § 1320b-19 (2000)). The Ticket to Work Act is to be phased in over a four year period and is a voluntary entitlement program that applies to individuals receiving SSI and SSDI. Recipients opting to take advantage of this program can access vocational and rehabilitative services. Possessing a “ticket” allows the individual more flexibility in trying to enter the workforce without an automatic loss of SSI or SSDI or medical coverage.

means-tested, implicit in the SSI program is a belief that poverty and disability somehow interact. The program arose out of a desire to supplement the incomes of Social Security recipients and to recognize the needs of those who could not support themselves because of physical and mental impairments. The SSI program also emerged from Richard Nixon's failed welfare reform bill in 1972.<sup>116</sup> Nixon's reforms were based on a negative income tax model of assistance and proposed a national guaranteed income that could be supplemented by the states.<sup>117</sup> While Nixon's Family Assistance Program, which would have replaced AFDC, failed, the assistance program for the impoverished elderly and disabled, SSI, was passed.<sup>118</sup>

Along with meeting the medical and functional requirements for disability, SSI recipients must meet income criteria. The allowable income and asset limit is higher than for welfare, but the connection with poverty is nevertheless maintained. At the same time, because the program was designed to reflect the social insurance model, it also maintained the line between the disabled and those not excused from the labor market. The disability determination process makes clear that only medically determinable impairments justify being excused from work. This extensive adjudication process demands voluminous medical evidence<sup>119</sup> to insure

---

<sup>116.</sup> See Diller, supra note 3, at 434.

<sup>117.</sup> Id.

<sup>118.</sup> Id.

<sup>119.</sup> As discussed in Part II, poor and minority individuals often have limited access to consistent and quality medical care. In such situations

that the individual's failure in the labor market is due to medical causes rather than any other "private" matters.<sup>120</sup> Thus, while the terms of SSI are much more favorable than public assistance, the eligibility process is extremely intrusive and rigorous, and one in which the "definition of disability and the means to determine it became critically linked."<sup>121</sup>

As part of a social insurance scheme, the SSI program has helped to hide the overlap between poverty and disability. It has also reinforced the exclusive model of the worker-citizen and the devaluation of the poor through the public assistance system. As Diller argues, the exclusionary and medicalized definition of disability supported by the SSI program facilitates the vilification of welfare recipients because it fosters the assumption that they are able to work, but simply refuse to do so, despite ample data to the contrary.<sup>122</sup> Therefore, the "individual whose age, lack of education, and lack of skills make it impossible to obtain work, but who suffers from no medical impairment, is not only denied benefits, but is subject to being labeled a malingerer because no benefit program legit-

---

accumulating sufficient medical evidence for the disability determination process can be difficult.

<sup>120.</sup> See Diller, supra note 3, at 388.

<sup>121.</sup> STONE, supra note 107, at 28.

<sup>122.</sup> See Diller, supra note 3, at 451; see generally KATHRYN EDIN & LAURA LEIN, MAKING ENDS MEET: How SINGLE MOTHERS SURVIVE WELFARE AND Low WAGE WORK (1997) (documenting that most welfare recipients do work, but are not able to secure jobs that would allow them to escape poverty).

imates these causes of unemployment “<sup>123</sup> The logic underlying the SSI program similarly perpetuates the view that there are a sufficient number of jobs available to permit all families who want to work to rise above the poverty line. Finally, SSI’s rigid and exclusionary definition of disability leaves many individuals with functional impairments that do not rise to SSI’s criteria with limited sources of cash and medical assistance to address their needs and to promote self sufficiency. The state thus polarizes disability and poverty in a way that harms the recipients of both public assistance and social insurance.

Disability benefit programs seem to acknowledge the fact that disability can leave someone in poverty. These programs, however, do not address the way that poverty creates disabilities. While the meaning of disability includes the belief that disability is caused by forces outside the individual, this has not led to a thorough examination of all the forces that have grave consequences for the health of an individual or community. In particular, the definition of disability has failed to embrace a community-centered view of health that takes into account the unequal distribution of health risks and disability.<sup>124</sup> The disability rights movement, therefore, has not advocated for broad reforms in health or welfare policy.

---

<sup>123.</sup> Diller, supra note 3, at 460.

<sup>124.</sup> The environmental justice movement has adopted a community-centered and structured approach to the problems of poverty and ill health. This movement has noted the degree to which broader economic and social forces affect individual health and well-being, thus making structural change central to improving individual and

In contrast to the medical model of disability that is integral to the SSI program, the ADA<sup>125</sup> begins with the proposition that much of the disablement and exclusion that persons with physical and mental impairments suffer are created by social reactions and structures rather than medical conditions alone. This model places responsibility on private and public actors to make services and facilities accessible to those with physical and mental impairments. Congress stated that the purpose of the ADA is to “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”<sup>126</sup> The ADA proceeded from the premise that discrimination and failure to make “reasonable modifications” in structures and the way services are delivered is what has prevented more inclusion.

---

community well-being. As Robert D. Bullard explains, “[t]he impact of redlining, economic disinvestment, infrastructure decline, deteriorating housing, lead poisoning, industrial pollution, poverty and unemployment are not unrelated problems if one lives in an urban ghetto or barrio, rural hamlet, or on a reservation.” Leveling the Playing Field through Environmental Justice, 23 VT. L. REV. 453, 454 (1999). Cynthia Hamilton has further noted that an environmental justice perspective makes large scale “economic democracy” important to individual and community health. Coping with Industrial Exploitation, in CONFRONTING ENVIRONMENTAL RACISM: VOICES FROM THE GRASSROOTS 66 (Robert D. Bullard ed., 1993).

<sup>125</sup>. 42 U.S.C. §§ 12101–12213 (1994).

<sup>126</sup>. § 12101.

While the ADA's model of disability centers on inclusion, SSI's model of disability centers on exclusion and differentiation<sup>127</sup>. Diller makes clear, however, that the ADA and SSI are not necessarily at odds; instead, these programs address different problems that can be framed as disability. The ADA underlines the degree to which social norms, rather than individual impairments and characteristics, are responsible for social exclusion. It seeks to integrate those who are "otherwise qualified" and would likely participate in mainstream activities but for discrimination based on erroneous assumptions or the failure to make reasonable accommodations. In contrast, SSI recipients are assumed not to be otherwise qualified. It is assumed that even with reasonable accommodations, they would not be able to work. But even while the ADA mandates affirmative action to facilitate the inclusion of those with physical and mental impairments, it does not demand that social and economic structures fundamentally change. Rather, the ADA mandates that structures expand to make more room for variation but only when such expansion is not too costly or burdensome.<sup>128</sup> Thus, reasonable accommodations must be made for the otherwise qualified individual, but changes and supports need not be provided for individuals who are not otherwise qualified. For example, the ADA does little for an individual with neurological impairments resulting from lead poisoning, who has few

---

<sup>127</sup>. Matthew Diller, Dissonant Disability Policies: The Tensions Between the Americans with Disabilities Act and Federal Disability Benefit Programs, 76 TEX. L. REV. 1003, 1030 (1998).

<sup>128</sup>. See supra note 13 and accompanying text.

marketable skills. As with the SSI and public welfare programs, the structure of the political economy is left unquestioned as a force responsible for exclusion and disadvantage.

As Diller notes, the “full promise of the ADA can only be realized if the full range of barriers that confront people with disabilities are addressed.”<sup>129</sup> This would include a recognition of a broader range of physical and mental impairments, as well as impairments such as skill deficiencies. To bring together the strengths of the ADA and SSI would mean recognizing the centrality of socioeconomic forces in both the creation of disabilities and the promotion of health and well-being. The social structural analysis encouraged by the ADA should not be contained in the realm of disability. Because disability and poverty overlap, a policy that addresses the disadvantage and discrimination experienced by the disabled must be embedded in broader antipoverty policies.

#### IV. WELFARE REFORM AND DISABILITY

Although disability is critically relevant to welfare policy, until recently there has been little research into the extent and impact of disabilities and chronic illness among welfare recipients.<sup>130</sup> Disability rights advocates have emphasized that many disabled persons are poor because

---

<sup>129.</sup> Diller, supra note 127, at 1080.

<sup>130.</sup> MARCIA K. MEYERs ET AL., CTR. FOR POLICY RESEARCH, SYRACUSE UNN., INCOME POLICY SECURITY SERIES, PAPER No. 12, WORK, WELFARE, AND THE BURDEN OF DISABILITY: CARING FOR SPECIAL NEEDS OF CHILDREN IN POOR FAMILIES, 2 I30 (Apr. 1996).

of the current design of the labor market or employment discrimination.<sup>131</sup> The ADA addresses this concern by mandating certain structural and architectural changes and prohibiting discrimination of those otherwise qualified for particular positions of employment. There has been little focus, however, on how poverty creates disability and how the burdens of poverty and disability perpetuate patterns of inequality. Welfare reform has also had an impact on the public's perception of the SSI children's program.<sup>132</sup>

---

<sup>131.</sup> Harlan Hahn, Advertising the Acceptably Employable Image: Disability and Capitalism, in 'THE DISABILITY STUDIES READER 172 (Lennard J. Davis ed., 1997) (explaining an economic model of disability that focuses upon vocational limitations).

<sup>132.</sup> Welfare reform has had negative effects on both the adult and childhood programs of SSI. We focus on the childhood program because it has been subject to greater attacks and because it represents a particular challenge to our limited models of social provision. As discussed in Part III, the payment of childhood SSI benefits seems to reflect a recognition that the costs of poverty and disability for a family are cumulative. Assistance is provided to the family on the child's behalf despite the child's detachment from the labor force. The childhood program, therefore, offers a beginning point from which to envision more comprehensive programs of social support for families that do not fit the constricting model of the male waged laborer without caretaking responsibilities.

## A. Disabled Welfare Recipients

The ADA fails to help many disabled adults who are not otherwise qualified for a particular job with an accommodation. Although the ADA applies to programs and benefits as well as employment, it is not yet clear what affirmative response to disability it mandates within the welfare law. It is clear that welfare law has not adequately addressed the degree to which having a disabled child affects the economic status of the family, particularly in a single parent household. For example, the response of many states to disabled welfare recipients has been to exempt them from the five year limit on assistance through inclusion in the “hardship exception,” which can include only twenty percent of a state’s public assistance population or by exempting them from work requirements based on state policy.<sup>133</sup> This exemption addresses neither the barriers to self sufficiency faced by a disabled adult nor the additional burdens of an adult caring for a disabled child because the exemptions are rarely accompanied with

---

<sup>133</sup>. TANF allows states to exempt no more than twenty percent of the average monthly number of families to which assistance is provided from the sixty month limit “by reason of hardship or if the family includes an individual who has been battered or subjected to extreme cruelty.” 42 U.S.C. § 608(a)(7)(C) (Supp. N 1998). Exceptions to work participation requirements are determined by the states. See generally’ TERRI S. THOMPSON ET AL., STATE WELFARE-TO-WORK POLICIES FOR PEOPLE WITH DISABILITIES: CHANGES SINCE WELFARE REFORM (1998).

any supportive services that may assist in confronting the barriers to self sufficiency faced by many of these recipients.

Nor have the effect of a child's disability on family income and the prevalence of disability and illness among recipients of public assistance been a focus of the contentious debate surrounding welfare reform. This omission surely undercuts the effectiveness of social reform as it ignores the real barriers many individuals face when attempting to support their families. Research shows that the presence of one or more children with disabilities or chronic illness has a significant impact on the economic well-being of families.<sup>134</sup> The data also demonstrate that adults with both severe and nonsevere disabilities were less likely to be working and more likely to have lower earnings when they did.<sup>135</sup> Among the 13 million people ages 22 to 64 who received means-tested cash, food, or rent assistance in 1996, 50.6 percent had either a severe or nonsevere disability and 40.3 percent had a severe disability.<sup>136</sup> Moreover, although the disability rate is high among program recipients, most people with a severe disability did not even receive cash benefits from an assistance program.<sup>137</sup>

---

<sup>134.</sup> See generally LaPlante, supra note 84 (examining the well-being of families which include individuals with disabilities).

<sup>135.</sup> JOHN MCNEIL, U.S. CENSUS BUREAU, U.S. DEPT. OF COMMERCE, AMERICANS WITH DISABILITIES, 1994–95, at3 (1997), available at <http://www.census.gov/prod/3/97pubs/p70–6l.pdf>.

<sup>136.</sup> Id.

<sup>137.</sup> Id.

Recent research on welfare reform also reveals that many of the women who have not been able to transition to work or who have been sanctioned because of failure to comply with work requirements have disabilities—most commonly learning disabilities or are caring for a child with disabilities.<sup>138</sup> These individuals have been classified as hard to serve. A report by the Center on Budget and Policy Priorities states that one-fifth to one-half of center TANF recipients who are not working report health problems; one-fifth to two-fifths of parents no longer receiving TANF and not working report disability or illness as the barrier to work<sup>139</sup>. For example, learning disabilities and mental disorders were also found to be prevalent among TANF recipients.<sup>140</sup> Further, the Second Annual Report to Congress on TANF states that:

[Although] there are no completely reliable estimates of specific family needs among welfare families, . . . recent studies suggest that as many as 27 percent of adults in the case-load have a substance abuse problem; up to 28 percent have mental health issues; up to 40 percent have learning disabilities or low basic skills; and up to 32 percent are current victims of domestic violence.<sup>141</sup>

---

<sup>138</sup>. Id.

<sup>139</sup>. SWEENEY, supra note 16, at 3.

<sup>140</sup>. Id.

<sup>141</sup>. ADMIN. FOR CHILD. AND FAMILIES, TEMPORARY ASSISTANCE FOR NEEDY FAMILIES (TANF) PROGRAM: SECOND ANNUAL REPORT TO CONGRESS 140 (Aug. 1999), available at <http://www.acf>.

Because a large portion of people making up this hard-to-serve population have low basic skills,<sup>142</sup> these individuals are even more disadvantaged by TANF's limitations on the number of people who can attend educational and vocational programs while still being counted in the state's participation rate.<sup>143</sup>

Mental and physical disabilities as well as child care burdens are often what make people hard to serve by policies emphasizing quick attachment to work. It is important to the coherence of the welfare and disability programs that welfare recipients are deemed capable to work regardless of whether they are able to maintain employment and regardless of whether decent jobs and quality child care are available. This may be the reason that administrators prefer calling those having difficulties under the quick attachment model hard-to-serve and "hard-to-place" rather than disabled, unemployable, or underemployed given the current labor market. As noted above, preserving the distinction between welfare and disability programs deters an investigation of the coincidence

---

[dhhs.gov/programs/opre/director.htm](http://dhhs.gov/programs/opre/director.htm).

<sup>142</sup>. See FREDRICA D. KRAMER, WELFARE INFORMATION NETWORK, 2(5) THE HARD-TOPLACE: UNDERSTANDING THE POPULATION AND STRATEGIES TO SERVE THEM (Mar. 1998), at <http://www.welfareinfo.org/hardto.htm>.

<sup>143</sup>. A. Johnson & A. Meckstroth, Ancillary Services to Support Welfare to Work, MATHEMATICA POLICY RESEARCH (June 1998). For an explanation of the limited degree to which educational activities can be counted as "work activities," see supra note 17 and accompanying text.

between poverty and disability that critiques inequalities in the market economy and social structure.

## B. The Assault on the SSI Children's Program

As the SSI program has grown, the children's program has come under increasing attack.<sup>144</sup> The attachment of public assistance to work

---

<sup>144</sup>. In 1974, after the first year of the SSI program, children made up less than 2 percent of the caseload. 1998 GREEN BOOK: BACKGROUND MATERIAL ON DATA ON PROGRAMS WITHIN THE JURISDICTION OF THE COMMITTEE ON WAYS AND MEANS, § 3 at 298, available at <http://www.welfareacademy.org/research/1998.html> [hereinafter GREEN BOOK]. In December of 1980, they made up 5.5 percent of recipients. Id. As of December 1996, children made up 15.4 percent of the over 6.6 million SSI recipients. Id. The increase in child recipients has accompanied increases in the adult population of recipients. Id. at 302. In addition, the increase in child recipients is also a result of the 1990 Sullivan v. Zebley decision, 493 U.S. 521 (1990), which added a functional component for children that paralleled the functional/vocational analysis for adults. GREEN BOOK, supra, § 3 at 299. The number of children receiving SSI more than doubled between 1989 and 1992 for several reasons: changes in the regulations to insure compliance with the Social Security Act, legislated outreach, and a recession, which allowed more families to meet the income criteria. See NAT. ACAD. OF SOC. INS., RESTRUCTURING THE SSI DISABILITY PROGRAM FOR CHILDREN AND ADOLESCENTS: REPORT OF THE COMM. ON CHILDHOOD DISABILITY OF THE DISABILITY POLICY PANEL

underlies the controversy over whether disabled children deserve economic support through the SSI program. Because SSI and Social Security Disability Insurance (SSDI)<sup>145</sup> were envisioned as replacements for paid labor for those who could not work, children recipients—who are not obligated to work—do not fit easily into the worker-citizen model exemplified by social insurance and public welfare schemes.

The children's SSI program was tacked onto the SSI legislation near the time of its passage with little discussion. However, in its 1971 report, the House Ways and Means Committee stated that:

[D]isabled children who live in low-income households are certainly among the most disadvantaged of all Americans and . . . are deserving of special assistance in order to help them become self-supporting members of our society. Making it possible for disabled children to get benefits under this program, if it is to their advantage rather than under the

---

12 (Jerry L. Mashaw et al., eds. 1996) [hereinafter RESTRUCTURING]. Increases in the diagnosis of mental impairments, including mental retardation and attention deficit hyperactivity disorder, accounted for more than two-thirds of the growth in awards. GREEN BOOK, supra, at 302. Program growth slowed in 1994, and has continued since the enactment of PRWORA, which narrowed the definition of disability for children. RESTRUCTURING, supra, at 1.

<sup>145</sup>. See 42 U.S.C. § 423. SSDI is the disability program for individuals eligible for social security who are under the age of sixty-five. Thus, eligibility is contingent upon attachment to the labor force.

programs for families with children, would be appropriate because their needs are often greater than those of nondisabled children.<sup>146</sup>

Despite this initial recognition of the cumulative costs of poverty and disability, it did not take long for attacks on the program to emerge.<sup>147</sup> In part, this is because of the disjuncture between the premise of the childhood SSI program and the model of assistance maintained by the adult SSI and public assistance programs. The attacks in Congress and the media have centered around allegations of fraud and questions about the legitimacy of a program that does not require recipients to have an attachment to the labor market. For example, Christopher M. Wright, writing for the Cato Institute and testifying in Congress, has alleged that “[g]aming the childhood disability system has become an epidemic” and

---

<sup>146.</sup> U.S. HOUSE OF REPRESENTATIVES, SOCIAL SECURITY AMENDMENTS OF 1971, REPORT OF THE WAYS AND MEANS COMMITTEES, H.R. REP. No. 92-231, pt. 1, at 146-48 (1971).

<sup>147.</sup> Attacks on the children’s program came soon after attacks on the granting of SSDI to adults on the basis of drug and alcohol addiction and the granting of SSDI to immigrants. Despite the different issues involved in each of these attacks, they have been linked together, in Christopher Wright’s words, as creating a “black hole” in the welfare system. See CHRISTOPHER.M. WRIGHT, CATO INST., POLICY ANALYSIS NO. 224, SSI: THE BLACK HOLE OF THE WELFARE STATE, POLICY ANALYSIS No. 224, at <http://www.cato.org/pubs/pas/pa-224.html> (Apr. 27, 1995) [hereinafter WRIGHT, BLACKHOLE].

that “[f]raud appears to be deeply rooted within the culture of the program.”<sup>148</sup> Wright transplants the image of the welfare queen into the childhood SSI program through a litany of anecdotes of fraud unsupported by concrete data. Wisconsin Representative Gerald Kleczka’ and Michigan Representative Nick Smith, who proposed the elimination of SSI program for children under age 16, have made similar accusations.<sup>149</sup> Wright and others supplemented their allegations of fraud by describing SSI as “crazy money” easily received by families who coach their children to act out or even present disabled children as “ringers” to stand in

---

<sup>148.</sup> Id.; see also Supplemental Security Income Fraud Involving Middlemen: Hearing Before the Subcomm. on Oversight, House Comm. on Ways and Means, 103rd Cong., 223–27 (1994) (statement of Christopher M. Wright).

<sup>149.</sup> Testimony Concerning SSL: Hearing Before the Subcomm. on Human Res., House Comm. on Ways and Means, 103rd Cong., LEXIS, Federal Document Clearing House Congressional Testimony File (1993) (statement of Rep. Gerald D. Kleczka) (citing anecdotal evidence to support claims of fraud and abuse of the SSI program for children); Testimony on the Supplemental Security Income Program: Hearing Before the Subcomm. on Human Res., House Comm. on Ways and Means, 104th Cong., LEXIS, Federal Document Clearing House Congressional Testimony File (1995) (statement of Rep. Nick Smith) (same); see also H.R. 3913, 103rd Cong. (1994) (bill proposed by Nick Smith to eliminate SSI benefits for children under age 16).

for their own children to win benefits.<sup>150</sup> While there was little to no support for these allegations, they resonated in a climate where attacks on social programs, particularly those associated with welfare, are common.

Kenneth S. Apfel, the Commissioner of Social Security, recently stated that there is a need “to strengthen the legitimacy” of the childhood SSI program.<sup>151</sup> His comments reflect the belief that while the SSI program should respond to the needs of disabled children and their families, the legitimacy of the program relies on a clear demarcation between disability and “mere” need. Enhancing this legitimacy, he argued, includes clarifying and strengthening eligibility criteria to better identify the disabled according to official standards.<sup>152</sup> This way of defining SSI’s legitimacy does not address the multilayered problems that lead individuals and families to seek assistance and the greater focus on the program as the effects of welfare reform become more salient.

A report completed by the Committee on Childhood Disability of the National Academy of Social Insurance notes further that, given the disparity between welfare and disability benefits, “there are concerns that policies providing income support to low-income families of children with disabilities may pose an incentive to poor families to have their children

---

<sup>150.</sup> WRIGHT, BLACKHOLE, supra note 14.

<sup>151.</sup> Kenneth S. Apfel, Address at the National Dialogue on SSI Childhood Disability, Hosted by the National Academy of Social Insurance, at <http://www.ssa.gov/pressoffice/ChildDis03.html> (Mar. 9, 2000).

<sup>152.</sup> See RESTRUCTURING, supra note 144.

classified as disabled.”<sup>153</sup> Rather than interpreting this fact as either a reflection of the overlap of poverty and disability or evidence that public assistance benefits are too low to allow a family to survive, government officials see it as a weakness in the SSI program. As Jane L. Ross, Director of Income Security Issues of HHS, puts it, SSI is perceived as a “high-risk” area.<sup>154</sup>

In the past decade, a major reason for growth in the SSI rolls has been an increased number of younger recipients with mental impairments who have limited work histories, not fraud.<sup>155</sup> Rapid growth in the number of children receiving SSI benefits has further contributed to changes in the program’s character. This increase parallels the growth in childhood poverty and increased reports of disability in the population at large.<sup>156</sup> This

---

<sup>153.</sup> Id. at 8.

<sup>154.</sup> Federal Programs “At Risk” for Fraud and Abuse: Hearing Before the Subcomm. On Oversight, House Comm. on Ways and Means, 105th Cong., LEXIS, Federal Document Clearing House Congressional Testimony File (1997) (statement of Jane L. Ross).

<sup>155.</sup> See RESTRUCTURING, supra note 144 at 9 (stating that 837,000 children were receiving SSI in 1994). In October of 2000, 855,900 children under the age of eighteen received SSI. OFFICE OF POLICY, Soc. SEC. ADMIN., HIGHLIGHTS OF SUPPLEMENTAL SECURITY INCOME DATA, OCTOBER, 2000, at <http://www.ssa.gov/policy/programs/ssi.html>.

<sup>156.</sup> Fujiura & Yamaki, supra note 92, at 187 (documenting that “[p]overty increasingly is a phenomenon of children” by analyzing National Health

increase also follows the Supreme Court's decision in Sullivan v. Zeb-ley,<sup>157</sup> which required that the Social Security Act contain a provision for childhood disability that mirrored the adult functional standard. Putting the childhood program in compliance with federal law increased the number of child recipients. The increased prevalence of disability in poor and minority populations<sup>158</sup> has put more pressure on the SSI program, making it susceptible to the type of criticism that has been traditionally leveled at the public assistance system. The childhood disability program is becoming an easy target, in part, because the traditional rationale for social insurance—some attachment to the work force does not exist for children.

While these charges were backed up by little evidence, they had great currency in public debate and generated much investigation of the childhood disability program. The most comprehensive study was completed by the National Academy of Social Insurance. In its report, "Restructuring the SSI Disability Program for Children and Adolescents," the Committee on Childhood Disability explained that "[a]ny evidence of coaching or 'gaming the system' is extraordinarily thin—and appears to be based on anecdotes or perceptions of dubious benefit claims, which upon investigation are found to have been denied."<sup>159</sup> Despite this finding, the committee still considered whether vouchers or direct services would be

---

Service data from 1983 to 1996).

<sup>157</sup>. 493 U.S. 521 (1990).

<sup>158</sup>. Fujiura & Yamaki, supra note 92, at 187.

<sup>159</sup>. RESTRUCTURING, supra note 144, at 2.

a preferable substitute for the cash assistance provided by SSI by creating more control over recipients' use of assistance. In the end the committee concluded that changing the form of assistance would result in excessive intrusion into families' lives as well as increased administrative costs. The committee considered the cash assistance essential because "without these supports, disabled children would be at a much greater risk of losing both a secure environment and the opportunity for integration into community life, including the world of work"<sup>160</sup>

The criticism of childhood disability benefits stems not only from children's lack of attachment to the labor force, but also from their mothers' sometime detachment from waged work. Implicit in the attack on childhood disability benefits is a devaluation of the caregiving work performed by mothers of disabled children. Receipt of SSI benefits for children can enable a mother to forego or limit work to care for a disabled child and pay for the additional costs entailed in this care. Even with receipt of SSI benefits, however, most families remain at or below the poverty level. Critics of the childhood SSI program view the mothers of child recipients more like undeserving mothers receiving TANF than like SSI recipients who have been determined to be unable to work. The perceived association between the mothers of SSI recipients and mothers receiving TANF is reinforced by the disproportionate number of African American women in both groups.<sup>161</sup>

---

<sup>160.</sup> Id. at 19.

<sup>161.</sup> See supra Part III.

## V. THE IMPLICATIONS OF “EMERGENT” DISABILITIES FOR SOCIAL POLICY

The growth in childhood disability associated with poverty and the changing nature of disabilities are manifestations of societal injustice. The public debate about these developments has focused instead on the increase in SSI application and receipt as a reflection of fraud and abuse.<sup>162</sup> The growth of physical and mental impairments that are correlated with poverty and disadvantage, such as HIV/AIDS, asthma, cognitive problems resulting from lead poisoning, and effects of low birth weight and lack of prenatal care, suggests that we are beginning to confront a new “universe” of disabilities that challenge existing models. Researchers have called this burgeoning group of impairments “emergent” disabilities.<sup>163</sup> These disabilities are not really new, but their increasing prevalence requires a new mode of analysis. Their apparent “emergent” nature reflects traditional models of medicine, which tend to ignore the social context of health and illness. Although poverty and disability have always been related, issues of social justice and economic equity have received too little attention in public health policy or health care delivery. Emergent disabilities place inequality at the center of these discussions.

Recognizing that disabilities are often caused by inequitable allocations of wealth and power implicates the state in creating disability, not just reacting to impairments in ways that disable. It also acknowledges that poverty and inequality can impede development in ways that make

---

<sup>162.</sup> See, e.g., WRIGHT, BLACKHOLE, supra note 147.

<sup>163.</sup> See Seelman & Sweeney, supra note 8, at 2–13.

it virtually impossible to succeed in mainstream society. The concept of emergent disabilities opposes the traditional understanding of poverty that has guided social policy—the assumption that poverty is created by individual failing or cultural pathology. Unlike the traditional model of welfare and disability, the discussion of emergent disabilities critiques the workings of the market rather than reinforcing its principles as neutral and inherently just.<sup>164</sup>

Addressing emergent disabilities requires making positive rights central to social policy debate. Negative liberty, or the freedom from government intervention, does little to cure the causes of disability or improve the well-being of those with disabilities. Under a positive view of liberty the state is obligated to correct conditions that create impairments and to remove barriers to full participation in society. Jerome Bickenbach writes:

The salient feature of the condition of inequality among people with disabilities is that it typically consists of limitations on their freedom to participate in the full range of social roles and ways of living. Their freedom is . . . usually limited . . . by failures to provide the resources and opportunities needed to make participation feasible . . . . The denial of positive freedom is characteristic of the disadvantages experienced by people with disabilities.<sup>165</sup>

---

<sup>164</sup>. See STONE, supra note 107, at 26–27.

<sup>165</sup>. Jerome E. Bickenbach, Minority Rights or Universal Participation: The Politics of Disablement, in DISABILITY, DIVERS-ABILITY, supra note

The promotion of health and well-being are important to our notion of political community, as well as personhood. The non-random distribution of ill-health and disability highlights the inequitable results of social policies that fail to enable many individuals to participate fully in the political and social spheres. The interplay of race, poverty, and disability, highlights the degree to which state action creates and intensifies patterns of illness and impairment that reflect inequitable social and economic structures. Recognizing this dynamic requires, as a matter of social justice, state action that affirmatively addresses the structures that hinder full participation in society even for those not considered disabled. Finally, such an analysis demands a system of social provision that abolishes the traditional dichotomy between poverty and disability.

## VI. CONCLUSION

The intersection of disability and social inequality demonstrates the need for a more diverse model of citizens' contributions to society that creates entitlements to adequate social and economic support. The opposition between work and disability and the denigration of all relationships of dependency are at odds with the way most people live their lives. Welfare and disability programs have been superimposed upon a market structure that reflects the inequalities in our society. Because it is precisely this system that creates the patterns of poverty and unequal distribution of disability and illness, disability and antipoverty programs that leave these structures intact will neither help individuals escape poverty nor allow them to fully enter the political and social world as valued

citizens. Our analysis of disability and systematic disadvantage highlights the need to integrate disability policies into a more comprehensive antipoverty agenda that fosters economic and social justice.

In 2002, the Personal Responsibility and Work Opportunity Reconciliation Act will expire. This provides an opportunity to propose alternative forms of social assistance that address the causes of poverty and the inequitable distribution of illness and disability. Using disability as a lens to examine poverty and programs of assistance provides guidance in identifying many of the areas that must be addressed. The problems disabled persons and their families experience are often related to the problems faced by poor persons in our current economic and welfare system. Claims to public assistance need not be based upon work force attachment. Rather, justifications for public assistance and welfare should emerge from our goals for political community and citizenship. Resulting policies should rely on an ethic that seeks to “replac[e] the law of value with a new social measurement of economic usefulness that would allow for the valuation of a greater range of productive work.”<sup>166</sup> Depending on the nature of those visions, assistance could be based upon “notions of reparations for past injustice or collective responsibility for current inequalities,” the requirements of democracy and political participation, and the requirements -of personhood and bodily integrity.<sup>167</sup> We propose the following measures to achieve this alternative vision.

---

<sup>166</sup>. BRENDAN GLEESON, *GEOGRAPHIES OF DISABILITY* 150 (1999).

<sup>167</sup>. Dorothy Roberts, *The Only Good Poor Woman: Unconstitutional*

A. Reorganization of Care Giving and Waged Work that Includes a Critique of the Meaning of Dependency

As discussed above, the traditional notion of citizenship has been attached to an idealization of waged work in the market. This privileging of waged work continues to have racial and gendered implications, particularly for poor families. Work within the home has not been deemed work worthy of remuneration or political import. Further, gender and racial inequities in the job market make the experience of work for poor women less satisfying and less likely to provide family support. The degree to which these factors help maintain patterns of poverty and disability call for a reevaluation of what constitutes work and activities that are socially valuable. The work of Kittay,<sup>168</sup> Fineman,<sup>169</sup> and Fraser and Gordon<sup>170</sup> highlights the degree to which the idealization and articulation of “independence” reflects class, racial, and gender inequalities. The model of the free and autonomous citizen is usually the white male, well-employed, without caretaking responsibilities. This model obscures citizens’ involvement in relationships of dependency with family members, friends, and employers. Dependencies, however, shift throughout a person’s lifetime and can be inevitable or created. They are not inherently bad or good. Despite the insightful analysis of these authors, it is extremely difficult to discuss relationships of dependency without invoking

---

Conditions and Welfare, 72 DENY. U. L. REY. 93, 946–48 (1995).

<sup>168</sup>. See supra notes 87–88, and accompanying text.

<sup>169</sup>. See supra note 86, and accompanying text.

<sup>170</sup>. See supra note 101, and accompanying text.

negative images. In fact, the welfare mother has become the archetype of depraved “dependency.” This climate of debate leaves little room for differentiating between the relationships of dependence and interdependence that allow persons to thrive and function successfully, and those which have negative effects. These limitations are particularly damaging for disability policy. For those with physical or mental impairments, dependence on others is often a necessity. For poor women caring for children, disabled or not, the devaluation of this caregiving work places them in a position of created dependency.

The polarized discussion of dependency and independence has limited the reserve of possibilities from which an antipoverty program that addressed disability could emerge. For Fraser and Gordon, this tracks the opposition created in U.S. theories of citizenship that oppose contract and charity as the viable forms of political and social interaction.<sup>171</sup> The dominant civil model of citizenship has viewed relationships in terms of contractual exchanges and rights in terms of property relations.<sup>172</sup> By re-evaluating the role of relationships of dependency and interdependency in social and political functioning, more equitable and comprehensive social policies may emerge.

The Women’s Committee of I00, for example, recently proposed a set of policies that address women’s poverty by calling “attention to the

---

<sup>171</sup>. Nancy Fraser & Linda Gordon, Contract Versus Charity: Why is There no Social Citizenship in the United States?, 22(3) SOCIALIST REV. 45, 47 (1992).

<sup>172</sup>. See id. at 63.

special economic vulnerability arising from the caregiving responsibilities that women often assume.”<sup>173</sup> The proposal provides for replacing TANF with a guaranteed income for caregivers with minor children and other dependents.<sup>174</sup> It also suggests further reforms to current public benefits that value women’s caregiving work, including universal access to higher education and skill-building training programs, universal health care, inclusion of caregiving work as part of individuals’ work history, and a care giver tax credit.<sup>175</sup> These measures would make it more likely that work and childcare responsibilities can coexist and that employment can help families escape poverty. These policies will also benefit individuals with disabilities.

#### B. Public Policies that Take Macroeconomic Dynamics into Account

While economists have noted that we have entered a post-industrial era in which economic opportunity and the wage structure have vastly been altered, public policy with respect to the poor has not changed. As Sanford Schram notes, the transformation to a post industrial economy has been accompanied neither by any theory of post industrial ethics nor by a discussion of whether a new theory is needed.<sup>176</sup> Schram

---

<sup>173</sup>. WOMEN’S COMMITTEE OF 100, PROJECT 2002-AN IMMODEST PROPOSAL: REWARDING WOMEN’S WORK TO END POVERTY, at <http://www.welfare2002.org> (last visited Jan. 5, 2001).

<sup>174</sup>. Id.

<sup>175</sup>. Id.

<sup>176</sup>. SANFORD F. SCHRAM, AFTER WELFARE: THE CULTURE OF POST INDUSIRIAL SOCIAL POLICY 149–53 (2000).

argues that, on the contrary, any discussion of ethics” in social policy has focused upon the need to return to “traditional” values.<sup>177</sup> This trend seems counterproductive and dangerous, particularly for poor families.

The emphasis on waged labor in the welfare law takes little account of the availability of employment and the potential of that employment to support a family. In addition to the reorganization and revaluation of work proposed above, public policy must include macroeconomic interventions that provide either employment at a living wage that takes into consideration childcare responsibilities or provide social provisions that reflect inequalities in the market that perpetuate gender and race discrimination in the wage structure. Further, because of the correlation between health and economic structure, equity in economic provision as well as in public health requires economic regulation that promotes well-being more broadly. The state should intervene in the economy to promote a more equitable distribution of wealth and of family caretaking responsibilities just as it currently intervenes in the economy to facilitate growth in certain sectors of the economy and to effectively burden others. Intervention in the economy, through subsidies and incentives, are common, but because they typically maintain current patterns of wealth and power they are not recognized as affirmative state action.<sup>178</sup>

---

<sup>177.</sup> Id. at 149.

<sup>178.</sup> While state intervention and the provision of subsidies is often most readily identified in the administration of public assistance programs, the state clearly acts in other affirmative ways that affect economic and family structure. The state acts to support current patterns of wealth and

Finally, we should abolish the welfare system's artificial separation of the disability category from other groups that fail to achieve well-being in the market economy<sup>179</sup>. As Diller recognizes, "A noncategorical minimum income system would obviate the need for a disability category in the first

---

well-being through such measures as corporate tax breaks and financial assistance and by maintaining levels of unemployment that affect wage-rates and conditions of employment.

State intervention and subsidy can be direct and indirect. Martha Fineman argues that we all live subsidized lives. Martha A. Fineman, Cracking the Foundational Myths: Independence, Autonomy, and Self-Sufficiency, 8 AM. U. J. GENDER SOC. POLY & L. 13, 22, 23 (1999). She explains that "a subsidy is nothing more than the process of allocating collective resources to some persons or endeavors rather than other persons or endeavors because a social judgment is made that they are in some way 'entitled' or the subsidy is justified." Id. She argues that a subsidy is provided "by the uncompensated labor of others in caring for us and our dependency needs." Id. at 23. In this formulation, subsidies can take the form of wealth and resource transfers, but also the form of policies that influence the structure of families, work, and the economy to affect the choices made and the burdens borne by certain individuals. Fineman continues that "subsidies are hidden when they are not called subsidy (or welfare, or the dole), but termed 'investments,' 'incentives,' or 'earned' when they are supplied by government." Id.

<sup>179</sup>. See Diller, supra note 127, at 1080.

place.”<sup>180</sup> Economists and sociologists have suggested plans for a progressive negative income tax and minimum income programs that can result in maintaining a productive economy while creating a more equitable distribution of wealth.<sup>181</sup> These plans must be taken seriously as 2002 approaches.

### C. Health Promotion as a Central Political Project

Health is central to enabling people to pursue their livelihood and exercise their fundamental rights and privileges; it is essential to aspects of personhood and bodily integrity.<sup>182</sup> Lawrence Gostin and Rene Bowser contend that “health is basic to all human endeavor and, therefore, may be regarded as a foundational justification for governmental action.”<sup>183</sup> The promotion of health is also an essential role of government because it can be meaningfully attained only through collective action.<sup>184</sup> Gostin further states that:

---

<sup>180.</sup> Id.

<sup>181.</sup> See, e.g., Fred Block & Jeff Manza, *Could We End Poverty in a Postindustrial Society?: The Case for a Progressive Negative Income Tax*, 25 POL & SOC’Y 473 (1997).

<sup>182.</sup> See Rene Bowser & Lawrence Gostin, *Managed Care and the Health of a Nation*, 72 S. CALL. REY. 1209, 1223 (1999).

<sup>183.</sup> Id.

<sup>184.</sup> Gostin, supra note 38, at 12. Gostin defines health broadly to include “improvement in the quality of life, ‘compression’ of morbidity and suffering, and the extension of active or well- functioning life-expectancy.”  
Id.

When illness or disease are preventable, or when pain and disability can be alleviated, the government's failure to act is conspicuous. Persons whose morbidity and suffering could have been prevented or lessened through reasonable government intervention may understandably argue that they count less, that their dignity is undermined by governmental inaction.<sup>185</sup>

As the overlap of disability, race, and poverty shows, the government's failure to act reflects a pattern in U.S. policy and law that undervalues the health of poor and minority populations through regulation of reproduction and denial of access to health care.<sup>186</sup>

Acknowledging the association between disability and systemic disadvantage also supports a broader notion of health that views access to health care as only one among many areas of social and political engagement that must be improved to promote individual and societal well-being. This conception of health resembles theories of positive liberty that obligate the government to facilitate individual selfdetermination, as well as citizens' collective efforts to install more just and egalitarian economic, social, and political structures.<sup>187</sup>

---

<sup>185.</sup> Id. at 13.

<sup>186.</sup> See generally DOROTHY ROBERTS, KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY (1997).

<sup>187.</sup> Id. at 308–12. These state obligations could be supported systematically by Fourteenth Amendment guarantees as well as a reinterpretation of the Thirteenth Amendment. See William Forbath, Why

\*\*\*

The unequal distribution of disability and the link between disability and social inequality suggest the need to re-imagine social policies and advocacy agendas addressing both poverty and disability. Antipoverty and disability rights struggles must confront the poverty-related causes and impact of disability, as well as the difficulties faced by single mothers who are disabled or care for disabled children. Antipoverty strategies should focus more on disability issues and on health promotion. Disability rights strategies should focus more on the promotion of economic, racial, and gender justice. This approach challenges the traditional dichotomy between disability and poverty that has helped to perpetuate the dominant conception of welfare and calls for radical changes in our systems of social support.

---

is This Rights Talk Different from All Other Rights Talk? Demoting the Court and Reimagining the Constitution, 46 STAN. L. REV. 1771, 1788 (1994).

