Pathologizing poverty: New forms of diagnosis, disability, and structural stigma under welfare reform

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A B S T R A C T

In 1996 the U.S. severely restricted public support for low income people, ending “welfare as we know it.” This led to dramatic increases in medicalized forms of support for indigent people, who increasingly rely on disability benefits justified by psychiatric diagnoses of chronic mental illness. We present case studies drawn from ethnographic data involving daily participant-observation between 2005 and 2012 in public clinics and impoverished neighborhoods in New York City, to describe the subjective experience of structural stigma imposed by the increasing medicalization of public support for the poor through a diagnosis of permanent mental disability. In some cases, disability benefits enable recipients to fulfill important social roles (sustaining a vulnerable household and promoting stable parenting). The status of family members who receive a monthly disability check improves within their kin and neighborhood-based networks, counterbalancing the felt stigma of being identified by doctors as “crazy”. When a diagnosis of mental pathology becomes a valuable survival strategy constituting the basis for fulfillment of household responsibilities, stigmatizing processes are structurally altered. Through the decades, the stigmatized labels applied to the poor have shifted: from being a symptom of racial weakness, to the culture of poverty, and now to permanent medical pathology. The neoliberal bureaucratic requirement that the poor must repeatedly prove their “disabled” status through therapy and psychotropic medication appears to be generating a national and policy-maker discourse condemning SSI malingerers, resurrecting the 16th century specter of the “unworthy poor”.

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Introduction

The past two decades have witnessed dramatic changes in the structure of public aid for the poor in the United States. In 1996, President Clinton signed the Personal Responsibility and Work Opportunity Act, ending “welfare as we know it” and causing a sea change in poverty law — a redefinition and restriction of the basis of public support for our poorest citizens. The dismantling of traditional welfare transfer payments has shifted indigent populations to a form of financial support that is increasingly medicalized — requiring a medical or psychiatric diagnosis to qualify a patient for disability payments. This represents a new approach to the historically ambivalent public responsibility for poverty in the United States, altering it in ways that we must learn to understand and address at the level of public policy and clinical practice.

Welfare, formerly known as Aid to Families with Dependent Children (AFDC), was renamed Temporary Assistance for Needy Families (TANF), capped at a five year lifetime limit for benefits, and given stricter eligibility criteria, including requirements for workforce participation. This shift prompted a crisis at state and city levels as the 5 years limits were reached. Social service bureaucracies scrambled for new ways to provide support for the still very poor and unemployed populations. Social security insurance (SSI) emerged as one of the primary strategies of poverty relief, with a four-fold increase in the annual growth of SSI beneficiaries between 1996 and 1998 and a 50—100% growth in the number of young adult SSI beneficiaries (30—59 years old) by 2000 (Jans, Stoddard & Kraus, 2004; Wiseman & Wamhoff, 2005/2006). Young adults have become the fastest growing group with disability due to chronic conditions (Joffe-Walt 2013; Lakdawalla, Bhattacharya, & Goldman, 2004).
Mental health diagnoses have now become the major drivers of the increase in Social Security beneficiaries. By 1999 over a third of Social Security Insurance (SSI) benefit awards were based on psychiatric diagnoses, making it the largest diagnostic category qualifying awardees for benefits, and this percentage continues to rise (Drake, Skinner, Bond & Goldman, 2009). Furthermore, alcoholism and addiction were eliminated as a qualifying diagnosis in 1996, contributing to an increase in mental health-related dual diagnoses (i.e. substance dependence plus another psychiatric diagnosis) (Davies, Iams, & Rupp, 2000). The proportion of SSI awards based on chronic pain conditions such as musculoskeletal conditions also grew substantially after welfare reform - by 25% between 1996 and 2005 (Deyo, Mirza, Turner & Martin, 2009).

Mental health and chronic pain claims have now become virtually the only avenues available for access to relatively stable benefits. Marcia Angell, former editor of the New England Journal of Medicine, pointed out, “as low-income families experience growing economic hardship, many are finding that applying for Supplementary Security Income (SSI) payments on the basis of mental disability is the only way to survive” (Angell, 2011). Angell raises the question of whether this relationship between structural stressors and bureaucratic pressures to qualify for psychiatric diagnoses foments subjectivities of disability among the poor; that is, to what extent does their receipt of a psychiatric diagnosis shape their personal identities and capacities?

SSI claims based on mental health or chronic pain diagnoses themselves are likely to have serious health consequences because they have been accompanied by a significant rise in the number of Americans prescribed psychotropic medications. These medications rose from 13% of the U.S. population in 1997 to 19% in 2007 (Mark, Kassed, Levi & Vandivort-Warren, 2012) – antidepressant prescriptions increased by 400% between 2005 and 2008 alone (Pratt, Brody & Gu, 2011). Antipsychotic medications are now the third best selling pharmaceuticals as a class, at $13.1 billion in sales for 2007 in the U.S. alone (Crystal, Olsson, Huang, Pincus & Gerhard, 2009). Consumption of antipsychotics is frequently a requirement for continued receipt of SSI benefits, despite the fact that they carry the risk of serious side effects, including obesity, diabetes, and elevated cholesterol (Hudepohl & Nasrallah 2012). The expanded prescription of these drugs also increases the likelihood of diversion to street markets, where pharmaceuticals can generate much needed cash (Maxwell, 2011).

Political and moral economies of stigma

Our research draws on the theoretical approaches of political economy and moral economy to help conceptualize the interaction between macro and micro level policy shifts and associated phenomena; e.g. relationships between social structures and stigma. Political economy, for the purposes of this paper, refers to the macropolitics of influence within political, legal, and economic institutions of a society, including labor markets, capital flows, and institutional and policy level decision-making strategies and negotiations that shape access to political power and financial resources. The relationship of political economy to health is well documented in the literature on social determinants of health (CDC, 2011; Marmot, 2005). Some theorists posit that political economic inequalities not only increase health risks of disadvantaged populations, but predetermine the very mechanisms of risk and causation across populations; they identify social inequalities as the fundamental cause of disease; as the “risk of risks” (Link & Phelan, 1995; Rose, 2001).

Erving Goffman’s (1963) foundational typology of stigma and identity management strategies is compatible with the broader theoretical approach of moral economy, which refers to micro-politics of social value and to the interpersonal strategies that social actors use to influence it. Moral economy draws from a number of political economy influences (Scott 1976; Thompson 1971) as well as applications of Marcel Mauss’ theory of gift exchange obligations among marginalized populations that reveal how dependencies stigmatized by the larger society are, in fact, the basis for respected reciprocities integral to maintaining extended families (Bourgois & Schonberg, 2009; Stack 1975). More recently sociologist Pierre Bourdieu introduced a model of exchange and reproduction of cultural capital (knowledge, education) and social capital (social contacts and social influence) (Bourdieu, 1986); conceiving of them as vital resources that are exchanged, reproduced and legitimized within local moral economies. These theoretical frames add a much-needed structural dimension to Goffman’s concept of stigma, by linking local, interpersonal strategies for managing identities and social value to larger institutional processes of the state, the exercise of power, class relations, and cultural and ideological implications of meaning and value.

As pointed out by scholars of the institutional causes of stigma, structural factors over determine how stigma is experienced on the ground, by politically and economically marginalized groups (Castro & Farmer, 2005; Hatzenbuehler 2011; Parker & Aggleton, 2003; Phelan, Link & Dividio, 2008). In this paper, we use the term the pathologization of poverty to describe the increased necessity for disability benefit-related diagnosis after Welfare Reform. It highlights the unintended negative subjectivity-and-social-network-producing effects of increasingly limited access to Federal and State social welfare benefits that have pressured the indigent to seek clinical diagnoses and accept potentially dangerous medications.

We also ask whether being identified as mentally ill is experienced as stigmatizing on the ground, when it becomes integral to stable survival strategies for poor people in the post-welfare reform era. We examine how these strategies may have important effects on their stigmatization at levels far from the direct experiences of recipients, such as in policy making, and how they may be in contradiction to their perceived experience of vulnerability. Here we draw on Pierre Bourdieu’s (1993) concept of fields, as a system of social positions structured in terms of power relationships. People are affected by multiple overlapping fields, which are hierarchically arranged with local fields generally subordinated to the larger fields that are governed by overarching symbolic power and class relationships. In looking at Welfare Reform and disability, we ask how structures and stigma shape one another: how stigma takes on different meaning and stakes depending on the field in which it is operating (neighborhood resources versus public policy constraints on access to resources). It is the disjunction between the understanding and the rewards and hazards of stigma within and across hierarchically overlapping fields that may be at the crux of what can be conceived of as structural in the processual concept of stigma to elucidate the systemic vulnerability of specific population subgroups (Quesada, Hart & Bourgois, 2011).

Methods

Drawing from two long-term ethnographic field projects in two New York City sites, we present here four cases of study participants who received psychiatric diagnoses qualifying them for disability benefits. The first author (Helena), in her role as a psychiatric resident and fellow from 2005 to 2012, recorded participant-observation and interview data from patients and staff in three Manhattan-based outpatient clinics that provided a range of substance abuse, mental health, and primary care treatment services, as part of a study of the use of pharmaceuticals to treat
addiction (Hansen & Roberts, 2012; Hansen & Skinner, 2012). The study involved intensive long-term follow-up of individual cases, including 127 ethnographic interviews with patients, providers and health system administrators, as well as field observations of clinic activities.

The second author (Philippe) recorded follow-up participant observation and interview data from the social networks of low-income Puerto Rican families residing in East Harlem housing projects that he has been following since 1985 (Bourgois 2003). For this paper, we drew from several dozen hours of audiotapes and over 200 pages of fieldwork notes conducted during visits to the homes and street-corner hang-outs of the network members (N = 30), spanning the years from 2004 to 2012.

Interview transcripts and field notes were analyzed using iterative thematic coding techniques well established in ethnographic analysis, including continuous comparison and a pragmatic adaptation of grounded theory as a method of identifying relevant analytical coding categories (Lingard, Albert, & Levinson, 2008; Reeves, Kuper & Hodges, 2008; Strauss & Corbin, 1998). Field data was triangulated with available primary and secondary data, as well as weekly to monthly confirmatory interviews with study participants to test the face validity of working interpretations.

Four pervasive themes that emerged from the coding and analysis of the data regarding disability payments were delineated based on this coding process: stigma of joblessness versus disease, medicalized subjectivities, SSI through kin networks, and gendered contrasts of disability stigma. Through discussion and consensus among the authors, four cases were selected that narratively illustrated each of these themes. The fieldwork was conducted with recruitment and informed consent procedures approved by the New York University and University of Pennsylvania Institutional Review Boards.

Findings

Inside the clinic: stigma of joblessness versus disease

Lennie

Helena (the first author) first met Lennie, a white Italian-American former janitor, at a public hospital when he was being treated for heroin dependence, HIV, and Hepatitis C. Each morning his emphysematous sister pulled him out of bed and pushed him out of the door toward the clinic for treatment of his drug cravings, crippling abdominal pain, and fatigue. After a few weeks of attempts to pay the clinic out of pocket, his social worker told him to apply for disability. As she explained, disability benefits would help him pay for his sister’s rent in their Queens apartment, and would qualify him for Medicaid coverage.

On this advice, Lennie began the arduous disability application process. First he attempted to complete the paperwork on his own, but with only a high school education and little tolerance for fine print, he eventually hired a law firm that prepared disability applications in exchange for 25% of the backlog of monthly disability checks that he might be awarded. After six months of forms and hearings on how his mental state and chronic pain interfered with his ability to work, Lennie was awarded disability on the basis of depression with psychosis.

Given the 35% first-time disability application success rate that clinic staff cited, Lennie’s disability award was an achievement, but he was not proud of it. He vacillated between blaming himself, blaming the employment market, and blaming the government for having ended up on public support:

“I know how my life is gonna end. I’m gonna commit suicide. They chew you up, use you up, and spit you out in the cold... I’m here without an education. What am I gonna do? The people in the service, coming back from Afghanistan, served their country and they come here and get nothing... (but) I’m to blame. Because I’m a loser. I’m a freaking addict. I came back from the service and all I did was [work in] security. I coulda studied; I coulda done something with benefits, but I didn’t. I did security because it was easy. I was worried about keeping my high.”

Lennie dreamed about returning to work. An army veteran dishonorably discharged when his drug use led him to go AWOL, a childhood friend secured him a union job cleaning a public school in Manhattan. For twenty years he was the most reliable worker in his crew. He used heroin and street methadone daily, but that “gave me the energy to wax the floors twice — I always finished ahead of the others and volunteered to finish their jobs.” At the end of that twenty year stint, however, his experiments combining Xanax and Valium with opiates led him to break a window with his ladder, and he was fired.

In retrospect, Lennie reflected, “Losing my job saved my life. I was so stoked up on opiates I just kept working, I never felt my body. I didn’t notice that I was killing my organs. I’d wake up in the morning and my back was so swollen I couldn’t sit up.” At the time of his SSI award, however, Lennie was so ashamed that he locked himself into his room with Xanax and street methadone with thoughts of finding a new job fading.

A year later, Lennie’s liver was less inflamed, he was off of street drugs, and his HIV viral load was down with regular medication, daily group therapy and meditation. But his struggle to reconcile himself with being on public aid was not over, and it reached a head at a family New Year’s party. Hiding in the corner of his nephew’s suburban living room with a glass of gin, so that he did not have to explain that he was unemployed, he started thinking of suicide. That night he broke three months of sobriety with a hidden stash of Xanax and alcohol, stopping just short of an overdose.

Combing over this sequence of events with his psychiatrist, Lennie said “I think I want to volunteer somewhere. Do something productive. It isn’t as easy as you think to find something.” He threw himself into volunteering, spending three days a week with elderly patients at the Veteran’s Hospital, and cleaning the clinic dining room daily until the floors and countertops reflected his face. Lennie began to see this work as the foundation for his recovery from addiction and depression:

“I’m an old fashioned guy. My neighbor, Bill, was trying to lift something into his apartment. I offered to help him and he said no. I said, Bill, come on, I know you for years, let me help. It’s nothing for me. I guess I have values. That’s it, I have values... You have to grow roots before any shoots or leaves come up. And that’s what I need to do, grow roots.”

Over the months, Lennie became a fixture in the clinic and the Veteran’s Hospital, until one day he failed to appear. Two days passed before his counselor received a call from his sister. He was hospitalized, having lost consciousness in a diabetic crisis. His psychiatrist suspected his antipsychotic medications, which can cause diabetes suddenly, without warning. Lennie had considered tapering off of the antipsychotics just before his hospitalization, but aware that his disability case was up for review, he feared he would lose his benefits if he stopped them.

Lennie’s need to perform disability literally required him to make himself sick by using dangerous second generation antipsychotic medications. This contrasted with Lennie’s self identity as a hard-working man with endless stamina. His already faltering health, combined with his inability to work a paying job and the bureaucratic requirement to declare and demonstrate ongoing disability, gave Lennie a sense of defeat. He adopted the stigmatized...
version of a disabled identity, but he did not attach his stigma to his psychiatric diagnosis; rather, he attached it to his physical inability to work. He reveals the degree to which experienced stigma is a product of local moral economies—which in this case, penalized unemployment over mental illness—reflecting the political economic and symbolic forces producing stigmatizing conditions, such as the benefit requirements to prove cognitive pathology to justify his inability to work, and leading him to take anti-psychotic medications toxic to his body.

Medically interrupted subjectivities

Raul

Sitting at the art table in the clinic’s day program, Raul works uninterrupted for hours after the clinic officially closes, painstakingly pasting and painting pinhead-sized bricks into a collage of a city wall that he has reproduced in dozens of paintings. His last rendition won a State-wide competition for mentally ill artists. In an interview after the show, Raul explained that it represented the actual wall into which he ran on a bike at six years old, cracking his skull open as his mother screamed from their third story window in the projects: “Get up! Get up! I TOLD you not to ride your damn bike!”

Raul was the oldest of twelve children in a second generation Puerto Rican family that was short on affection and long on violence. He last saw his family at the funeral of his second oldest brother, who was killed in a revenge attack outside of a bar. Recounting his brother’s assault in the funeral home, three of Raul’s other brothers brandished their guns. As a teenager, Raul had tired of getting beaten for not taking proper care of his eleven siblings. He left home, taking jobs driving cabs and ambulettes. The owner of his ambulette service, in an effort to boost the work hours of his drivers, introduced Raul to cocaine. As Raul explained it, in the beginning, the cocaine was free, but once Raul and his coworkers got in the habit, his boss started taking $25 per bag out of their weekly checks. Raul’s use of cocaine, then heroin, escalated until he found himself jailed for assault on his girlfriends, without a job, and eventually without a home. The staff in the men’s shelter where he landed referred him to his current drug treatment program.

Within a few months, the clinic staff told Raul they thought he had bipolar disorder. Raul admitted that he had always been an angry person, someone who his coworkers had avoided even before his cocaine use started, but in clinic he threatened other patients who he found tardy and lazy and accused staff members of indulging group members who broke the rules. Raul’s psychiatrist proposed a trial of antipsychotics. The medications would stabilize his moods, treating his bipolar disorder, he said, and bipolar disorder was a diagnosis that could qualify him for disability benefits and permanent housing.

The medications did tranquilize Raul, and his disability checks secured him a private room in a single-room-occupancy recovery house for men. Months went by and the clinic’s art room became the center of Raul’s world. The new peacefulness of his daily life was interrupted only once, by his near explosion in the subway. Raul threatened the employees telling him he could not work in the turnstile, and subway employees told Raul that they would refund his money. Enraged, Raul threatened the employees, interrupted only once, by his near explosion in the subway. Raul landed referred him to his current drug treatment program.

Investing fully in a worthy motherhood/grandmotherhood identity, Esperanza had grown up under conditions of exceptional domestic violence, but primarily directed by men against women: First at the hands of her overprotective, older brothers in rural Puerto Rico and then in a decade-long marriage to an abusive husband. Before fleeing Puerto Rico she had taken revenge on her abusive husband, “I got him back, I stabbed him—only once through—an ice pick”. When her new, East Harlem boyfriend became verbally abusive she suffered an “ataque de nervios” slashing him in the stomach with a kitchen knife. This boyfriend was a second-generation New York-born Puerto Rican, romantically in love with Esperanza, and he recognized that her “over-the-top” violent behavior might qualify her for SSI disability. Instead of pressing criminal charges, consequently, he called the hospital and accompanied Esperanza through several months of psychiatric evaluations that finally ended with a diagnosis of permanent disability for bipolar manic-depression, PTSD and agoraphobia.

This last diagnosis may have been a recent semi-functional adaptation to what East Harlem’s streets were doing to her family: Her oldest son and two oldest daughters had joined The Latin Kings gang and no longer “show their own mother any respect”. She refused to leave her project apartment except to go shopping or to medical/social services appointments during daylight hours. Investing fully in a worthy motherhood/grandmotherhood identity, she became the primary caregiver to her oldest son’s autistic boy, all five of her oldest daughter’s children, and her middle daughter’s two children. She also took care of her younger sister, a chronic crack smoker. In fact, once Esperanza qualified for SSI she helped that addicted sister obtain SSI—for essentially the same diagnoses as her own.

Esperanza also channeled her oldest son’s extreme violence productively and managed to help both him and his autistic son initiate the paperwork for SSI qualification. Eventually, with two SSI
monthly checks in his household based on diagnoses of permanent cognitive disability, her oldest son was able to obtain a section 8 apartment in the South Bronx. In that extremely poor section of New York's inner-city, many landlords preferred renting to cognitively disabled tenants, because SSI disability checks—especially two in one household—represented a more stable source of income than entry-level labor market or underground economy wages. Unfortunately during that process of qualifying for SSI, her oldest son rose to warlord in his branch of the Latin Kings and was sentenced to life in federal prison for multiple cross-state machine gun killings.

Esperanza obtained legal custody of his autistic son and that extra SSI check qualified her for a larger apartment in her housing project complex, enabling her to invite her daughters and grandchildren to come live with her permanently, as couch surfers. She became a model SSI patient, bonding with her therapist through a painful multiyear process of experimenting with multiple heavy doses of over a dozen psychotropic medications:

"I couldn’t cry, for years. I told my therapist that Prozac deadened my emotions. I wasn’t even able to cry when my oldest daughter lost a pregnancy [after being beaten by her boyfriend]. My therapist took me off Prozac little by little. He worked with me and with my medication.

My therapist is good. He got me to where I got the right amount of medication. Now he’s giving me the Seroquel, the Ambien and Paxil—but just a little. I’ve been working with him for 13, no, 14 years."

Gendered contrasts: the balance of masculinity and dependency

Primo

Esperanza’s son-in-law, Primo, grew up in New York city and dropped out of high school to work in a factory in the 1980s, right when New York’s manufacturing sector was plummeting. His first textile factory soon closed down, but he obtained entry-level positions in the growing finance services industry as a messenger boy and Xerox machine operator. None of these positions lasted for more than a few months, however, because his cultural capital skills as a tough, male streetwise inner-city high school dropout, which provided him with excellent violent credibility on East Harlem streets, misfired in the polite, upper-middle class hallways of the office finance sector. Cocaine prices dropped in half during these years and the crack epidemic swept through poor neighborhoods like Primo’s all across the country. Primo, like many of the young men of his generation fell into the “crack epidemic”. He attempted to manage his chronic cocaine consumption habit by becoming a crack house manager. He also began consuming heroin as a nightcap to soften the over stimulating effects of the cocaine and to be able to wake up on time the next day on time to re-open the crackhouse. Opiates became his primary addiction. After several arrests, multiple experiences of violence and one three-year probationary sentence for drug sales, he entered a methadone maintenance program, ceased consuming alcohol, and sought legal employment.

Treatment initiated a cycle of short-term re-entries into the increasingly precarious legal labor market of the mid 1990s through early 2000s: First as a temporary doorman replacement, as “Computer Mr. Fix-it” serving residents of East Harlem housing projects, then his best job with a luxury building management company during the summer months.

Throughout these ups-and-downs, he established a family with Esperanza’s daughter, Jasmine, who worked as a bank teller. Daycare for their two infant sons was prohibitively expensive and Primo was forced to become the caregiver because his computer repairs activities accommodated flexible hours. Primo did, however, joke uncomfortably about being a “Mr. Moms”. He reassured himself that his inability to be the primary source of income for his nuclear family and his obligation to assume the unconventional role of masculine childcare provider were temporary. His official plan was to establish himself as an independent house-repair contractor so that he could earn steadier off-the-books income safe from garnishing.

Primo was unable to reintegrate himself stably into legal off-the-books income generation. Eventually, Jasmine, exasperated by his inability to establish himself as a responsible head-of-household broke up with him. Primo’s world fell apart. His cell phone was disconnected and after several text message and e-mail prompts he sent Philippe an e-mail: “I’m homeless. Its been really tough but what doesn’t kill u makes u stronger & smarter (I hope), looking really hard 4 an apartment...” East Harlem was gentrifying rapidly during these years and, predictably, Primo and his sons were unable to locate a landlord willing to rent to them. Worse yet, when he failed to make the monthly payment on a storage unit on time, he lost several thousand dollars worth of tools he had purchased over the years for expanding his off-the-books handyman business.

Some time into his third year at the homeless shelter, Primo’s communications became more regular and more positive. On a Thanksgiving visit Philippe found Primo in a good mood, having reactivated his computer “Mr. Fix-it” services. Primo explained that, based on a diagnosis of “Bipolar, depression... and schizophrenic", he had finally qualified for a “permanent” SSI mental health monthly disability payment of just over $600 and he expected to at last be able to find a landlord willing to extend him a lease on a Section 8 apartment: [Philippe’s fieldnote]

Primo: “They didn’t want to give me SSI at all at first. I got upset—obsessed and I said ‘if they want to fuck with me, I’m gonna put on an Oscar-winning performance...’ But I was stressin’ ‘cause ever since I started lookin’ for work after 9/11 they been looking more into my record... The felony I got in the [crackhouse] it affected me. All these good jobs I used to get before I wasn’t gettin’ no more. I mean, I need it... I was thinking of my two boys... and I stressed so much that it got to the point that I didn’t care no more. And this one time I got so mad at my social worker that I just started screaming and giving her the finger like this [crouching, contorting his face, and thrusting both]

Mr. Moms

Primo actually felt empowered by the process of receiving a mental illness diagnosis:

“First I only got one year, ‘unable to work’. Then they gave me six months. And I was starting to feel better because I realized they were gonna make me permanent. And one time I almost cracked up laughing, I got scared. That’s when I became a good actor.”

Arguably, Primo began recovering from his mental illness upon realizing he had a chance to stabilize his family economically through a diagnosis of permanent cognitive disability. Primo began to speak openly about his need for SSI as a survival strategy. Nevertheless he always reminded whoever was listening that he was, “...doin’ it for my boys; I got no other choice.” Caseworkers at his shelter continued threatening to evict him; perhaps they were responding to his newly stabilized SSI rent payments: “They can see that I care for my boys. They like that. And they know that the mother gave me legal custody and that there aren’t any apartments out there for us.” Primo was clearly proud of his newfound
institutional legitimacy as a “good father” facilitated by the minimal economic stability of his new disability status.

The punitive neoliberal reaction: non-adherent patients, failing students

More recently, however, a new set of anxieties have emerged in conversations with both Esperanza and Primo due to further social service budget cuts and zero-tolerance drug monitoring. Primo’s clinic shut down, and to maintain access to his SSI check, he had to have his case reopened and undergo urine drug testing. Similarly, Esperanza lost her therapist to cuts and she did not trust her new therapist, a “white woman” who asked her painful questions about her past abuse.

One can read the stories of Primo and Esperanza for their gendered contrasts with regard to stigma. Like Lennie and Raul, Primo feels like a failure for being unemployed/unemployable. In Primo’s case, it was compounded by the stigma of his felony record. Primo also felt his masculinity compromised by having shouldered the primary caretaker role for his sons. His subjectivity maturation from dangerous outlaw drug dealer to self-sacrificing, middle-aged single father approved for social services represented a contradiction that continued to manifest in periodic cocaine binges that appeared to reaffirm his sense of waning masculine, outlaw subjectivity. This conjunction of overlappingly contradictory stigmas arise less from his diagnosis than from the culturally scripted violation of masculine gender roles as a male head of household excluded from legal employment.

In contrast, Esperanza experiences no gender norm stigma for embracing the worthy mother/grandmother caretaker role. Rarely leaving her apartment due to agoraphobia, she always finds herself surrounded by kin and neighbors and has emerged as an almost altruistic hero figure among her family, the residents of her housing project, and even the inmates and guards in her son’s federal penitentiary. Most importantly she assures the stability of her SSI payments by eager compliance with clinical care—including faithful consumption of multiple mind altering/numbing psychotropic medications—to address her history of bloody mobilization of a wronged mother’s/wife’s violent rage. She has become the primary pillar of stability and font of affection for her children and grandchildren. Her intensive clinical/services involvement has provided her with skills to talk to psychiatrists, social workers, pharmacists, and even prison guards. She also accessed vocational training in computer repair. In short, cognitive disability and the stability it provides valorizes Esperanza’s gendered cultural capital as self-sacrificing worthy (grand)mother/wife victim.

As this article goes to press, Philippe received a phone call from Primo who had just been evicted after over three years of “temporary” stable residence from his homeless shelter in East Harlem for multiple minor infractions (entering after curfew, missing social worker appointments, storing too many possessions in his living space). The shelter was undergoing an administrative “efficiency restructuring”. Primo’s primary concern was how his sons would finish the semester at their old elementary school, which was now a distant bus-to-subway commute from their new temporary shelter in an outer borough of New York City.

“The kids were doin’ good in school but now they’re giving me a hard time to get up [in the morning]. It takes at least an hour-and-a-half, two hours, to get to school and they’re goin’ late... [choking tears and clearing throat]

I mean, I feel like I’m in jail, bro. I feel like I’m mandated there [to the distant shelter] and if I break the rules [in a raised voice], ‘You’re done! You get more time! [breaking into a depressed voice] ...or some shit like that.’ That’s what it feels like... real crazy, bro. And now I got to get to their new meetings on time but I also got to pick up the boys two hours away so I miss them or I’m late.”

This latest chapter in Primo and Esperanza’s efforts to stay on disability in an era of political and administrative neoliberal policies to shrink federal and state expenses by weeding out benefit-abusers and restructuring services demonstrates the degree to which moral stigmatization of poor vulnerable unemployed/unemployable populations as “SSI malingerers” in the superordinate public policy field profoundly destabilizes people struggling to survive within subordinated local fields whose distinct set of moral-economic urgencies redefine local understandings of stigma. While Esperanza’s, and, to some extent, Primo’s, neighborhood status was elevated by their resourceful use of disability benefits, the reliability of that strategy is ultimately cut short by agency policies based on stigmatizing views of the worthiness of low income benefit recipients in the more structurally powerful bureaucratic fields of state administrators of social and medical services bureaucracies.

Discussion

The new moral economy of poverty

In our 21st century climate of reduced governmental responsibility for the poor, where income support is often portrayed as fostering chronic dependency and moral weakness, the “end of welfare” has brought with it new (and potentially dangerous) redefinitions of poverty—redefinitions that exacerbate “hidden injuries of class” in America (Sennett & Cobb, 1973). Lennie, Raul, Primo and Esperanza each demonstrate that these new meanings of disability and illness compromise the very physical and mental health strengths and interpersonal assets that they must rely upon to maintain themselves and their families, sharply reducing their ability to navigate the dire consequences of the current neoliberal policy climate that condemns the poor and the unemployed/unemployable.

They are forced to scramble for a new survival strategy in this era of medicalized poverty, which for some has permitted a stable home, a way to avoid street violence, reduce illegal drug consumption and exit the most dangerous echelons of the drug trade, as well as a means to reconnect with children and local community members. The potential stigma of disability and mental illness is reinterpreted as a legitimate responsibility locally among low income people because it is one of the few available routes to stable survival income. Consequently, it generates respect. In the context of poverty, using disability and illness to gain benefits can be interpreted at the street and family level as a marker of competence and social responsibility, or at least as a viable harm reduction strategy in a post-welfare state that offers few alternative solutions to unemployment.

Although these people are using their diagnoses to gain income, a simple reading of their behavior as misuse of public goods does not do them justice. For instance, neat distinctions between “real” and “unreal” disability disintegrate with a closer look. Lennie barely left his room until he got the health coverage and income to treat his emotional and physical pain. Neither Raul nor Esperanza could navigate the world without violence until their rages were therapeutized and medicated. They both learned and successfully utilized the vocabulary and behavioral script of recovery from mental illness. With the stability of SSI income, an almost pathologically depressed Primo became an attentive father, and volatile Esperanza a stable neighborhood matriarch. Without that stability it is not certain that they would have been able to continue navigating the
street economy without coming unglued. What public media portrays as stigmatizing or manipulative might actually be a route to emotional stability in the context of poverty. The perception of a stigma varies by the structural level or emotional stability in the context of poverty. The perception of a stigma as stigmatizing or manipulative might actually be a route to a paradigm whereby Social Security becomes the patriarchal family provider that enables disabled payees to care for home and children. In addition, the contrast of Lennie’s struggle to come to terms with his dependence on a public program, with Primo’s sense of victory at having achieved disability award status, may be due to their divergent work histories and expectations. Lennie was forced to consider disability after losing a salaried, unionized job of over 20 years. Primo had not had a legal job in over fifteen years and was able to supplement his disability checks in the informal economy through occasional drug sales and undeclared computer and janitorial repairs. For both Lennie and Primo, however, dependence on government benefits threatened their social image. Primo’s motivation to work in the informal economy was motivated by a desire to be a competent, masculine provider for his sons.

The political costs of disability payments

SSI-based survival strategies may lead to income, but they are not without costs. The medicalization of poverty leads to new risks, including the iatrogenic side effects of the same pharmaceuticals they must take to qualify for income support. Medicalization also removes focus from attempting to re-enter the labor market. Arguably, it incapacitates people who might otherwise work at least part-time for legal wages. Another cost to the poor of the medicalization of poverty occurs through the growing backlash stigma against SSI applicants reflected in widespread media coverage of social security disability “cheaters” (Blumberg, 2013; Fox News, 2012; Kristoff, 2013; New York Times 2009; Ohlemacher, 2013; Whitman, 2012). This backlash is consistent with many historical cycles of blame and stigma of the “undeserving poor”, from 1960’s policy makers embracing the concept of culture of poverty to 1990’s workplace advocates (Katz, 2011). In its current iteration, this stigma against the unemployed poor has led Federal and State administrators to raise the threshold for SSI applicants, rendering it more difficult for poor people to qualify for SSI, creating a micro-industry of disability lawyers paid on commission (Blumberg, 2013). Paradoxically, this increases stigma against potential “benefit-cheaters”. This is occurring as public health budgets lose funding and clinics prioritize aggressive screening to weed out malingerers—often destabilizing vulnerable patients, as in the case of Esperanza’s emotional turmoil due to her loss of a long-term therapist. International comparisons have similarly shown a correlation of more stringent welfare policies with higher levels of stigma and condemnation of the poor (Contini and Richardi, 2007).

Through the decades, the labels applied to the poor have changed as the language of stigma applied to the poor has been called into question and critiqued. For example, the intergenerational perpetuation of poverty has moved from being attributed to racial weakness, to a culture of poverty, to pathological disability, to malingering. The target population of potential public beneficiaries often demonstrates sensitivity to this stigma, declining to apply for needed benefits because of the attached stigma ( Moffitt, 1983; Stuber and Kronebusch, 2004). Stigma and social structures, however, are dynamic, contextual, and evolve in interaction with one another; stigma can provoke neutralizing strategies among the stigmatized that, in turn, provoke counterstrategies among the stigmatizers.

The full extent and impact of poverty in America are obscured as the common thread linking the groups of people affected by SSI stigma, because the source of their disadvantage is variously labeled race, culture, criminality, disability, dishonesty. For example, mass incarceration has led to the systematic exclusion of crucial data on 8–10 million (mostly minority) men who have been imprisoned over the last 35 years, obscuring the true extent of this nations worsening health and social outcomes among the poor. This is all part of a process that has been termed structural violence, (Castro & Farmer, 2005; Parker & Aggleton, 2003), symbolic violence (Bourdieu, 1997) and subjectification/subjection (Butler, 1997) by which social structures, policies, and institutions devalue target groups of non-normative people or discipline them in coercive and subtle subjectivity-imposing ways. The black box of the experience and process of “stigma” must be unpacked in its specific contexts: what is salient to stigma in a given place and time and across hierarchical fields is not self-evident and may give rise to new structural vulnerabilities.

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