

Barriers to Health Care
for
Women Who Have Been Incarcerated

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Executive Summary

This exploratory study was designed to investigate structural and personal factors that present barriers to health care access for women who have been incarcerated. Through in-depth interviews with thirty women identified through the Massachusetts Parole Board's Transitional Housing Program, the study looked at women's pre-incarceration, incarceration and post-incarceration health care experiences. Systematic examination of these experiences suggests that access to appropriate health care interventions could reduce rates of incarceration and recidivism.

Many of the women interviewed for this study recall childhoods disrupted or compromised by physical or sexual abuse, learning disabilities and struggles in school, early drug or alcohol use, and early exits from home. While most of the women did have stable family doctors as children, only one third of the women received therapy or counseling as children or teenagers, and almost two-thirds of the women were arrested for the first time by age 19.

As adults, their lives have been characterized by combinations of mental illness, physical and sexual abuse, homelessness, unemployment, drug or alcohol addiction, and involvement with the criminal justice system. Overall, their self-reported health status is poor both in terms of numbers and complexities of problems.

- ❖ 43.3% of the women test positive for Hepatitis C
- ❖ 23.3% of the women suffer from asthma
- ❖ 100% suffer from depression, anxiety or mental illness (in addition to drug or alcohol addiction)
- ❖ 96.7% use drugs or alcohol

Three factors were found to be associated with especially poor health profiles:

- ❖ Leaving home at an early age because of physical or sexual abuse
- ❖ Homelessness
- ❖ Having been made uncomfortable by words or actions by a medical provider

Barriers to accessing appropriate health care exist pre-incarceration, during incarceration, and post-incarceration. Some of these barriers have to do with the women's own backgrounds, health, lifestyles and capacities.

- ❖ Drug or alcohol use that interferes with pursuing and following-up medical appointments
- ❖ Insecure housing and frequent moving from one housing arrangement to another
- ❖ Difficulties keeping track of records and paperwork
- ❖ Learning disabilities
- ❖ Limited self-management skills

Other obstacles have to do with the structure and nature of the health care system. Commonplace situations (such as waiting for appointments) that irritate or moderately impede many Americans, often become insurmountable barriers for women who may be

struggling with multiple physical and mental health issues, homelessness, chaotic lives, substance abuse and learning disabilities.

- ❖ The cost of medical care
- ❖ Fragmented care
- ❖ Lack of coordination of care between prison and pre- and post- release health care providers
- ❖ Lack of accessibility of services
- ❖ Long waits for services both in and outside prison
- ❖ Discontinuous coverage by health insurance (including Medicaid)
- ❖ Inappropriate and insensitive treatment at the hands of some providers

Taken together, the meaning of the personal and structural barriers is that women with complex health problems often find themselves unable to navigate a complicated, under-funded, fragmented, and sometimes antagonistic system.

Many programs in Massachusetts serve the health care needs of women involved with the criminal justice system. The key recommendations that arise from the present research focus on the need for continuity of care, a medical home base, a PCP – both inside prison and outside, and a medical caseworker committed to helping women organize their health and health care issues over an extended time.

Introduction¹

America's prison population is substantially less healthy than the general population. Prisoners have higher rates of HIV infection, hepatitis C infection, tuberculosis, chronic lung disease, musculoskeletal disorders, and STDs than Americans who are not incarcerated. Studies suggest that as many as 40% of all seriously mentally ill people in the United States may be incarcerated. Over half of U.S. prisoners have a diagnosable drug use disorder and one quarter suffer from an alcohol abuse (Anno 2000; Cohen 2000; Peters 2000; Weisman 2000).

The health profile of women inmates is particularly distressing. A recent Massachusetts Public Health Association study found that "[Incarcerated] women exhibit higher rates of many health problems than men" (2003:3). Nationally, women inmates have higher rates of HIV infection and other sexually transmitted diseases than male inmates, higher rates of drug use disorder, and are in greater need of mental health services.

While prison conditions certainly contribute to some of these health challenges, poor health status often pre-dates incarceration, and in many cases may be a critical part of a trajectory that leads to incarceration and recidivism (Chesney-Lind 2003; Richie 2003). While earlier studies report on the poor health status of incarcerated women, no studies have tracked the health histories of incarcerated women over the life-course. In other words, while a variety of studies point to some sort of long-term relationship between poor health and involvement with the criminal justice system, there are no previous studies that explore that relationship over the life-course.

Based on in-depth interviews with thirty women recently released from incarceration in Massachusetts, the research on which this report is based set out to identify where and when in the life course the poor health trajectory begins and / or accelerates, and at what points in the life-course medical or other interventions could potentially halt or decelerate that trajectory. The picture that emerges from the women's narratives is complex and dynamic. The health care resources available to these women often are insufficient, inappropriate, unacceptable, and fragmented. But it is also the case that they do not always take advantage of health care services that have been offered. Lack of motivation, impatience with waiting as well as long waiting lists at many programs and facilities that provide care to uninsured people, chaotic living situations that make it difficult to keep track of paperwork, drug use, transportation costs, childcare issues, stigma, fear, lack of understanding of the referral process and reluctance to be involved with governmental agencies are common reasons for not following through on health care referrals. Women with limited income, small children, psychological problems, or language difficulties, women who have been sexually abused may be fearful of male providers, and women with histories of incarceration or drug histories may be concerned that providers will look down on them.

Delays in diagnosis, sporadic treatment and lack of follow-up care keep many of the women in this study locked into their poor health status. Poor health, in turn, makes it difficult for them to hold jobs, pay rent, take care of their children, and refrain from criminal activities such as drug use and prostitution that contribute to their poor health. Prison medical services are heavily used by the women of this study. However, the typically short length of each incarceration – compounded by long waits for prison medical services and the spread of

¹ We wish to thank Mike Way, Jennifer Young and Nicole Pritchard of the Boston Rescue Mission for helping us connect with the women interviewed for this study. We also thank Edith Silvas for her helpful comments on the draft of this report. Funding for this project was provided by Suffolk University's Summer Research Stipend.

infectious diseases in prison – means that prison simply is part of the larger landscape of on-again-off-again fragmented care that the women experience throughout their adult lives.

In addition to the human suffering resulting from untreated or sporadically treated illness, the economic costs of coping with an increasingly ill prison population are daunting. Numerous studies by health economists show that the costs of preventing and managing chronic illnesses are far lower than the costs of responding to crises – both medical and criminal that result from unmanaged physical and mental illnesses (Institute of Medicine 2002).

Goals of the Study

The poor health status and compromised access to and utilization of health care services by women involved with the criminal justice system has been well-documented. However, no previous research has taken a holistic, life-course perspective regarding barriers to appropriate medical services.

Immediate goals of the present study are:

- ❖ To better understand interactions between involvement with the criminal justice system and health status for women throughout the life course.
- ❖ To identify pivotal points in women's life courses at which health care interventions could be particularly useful in terms of avoiding involvement with the criminal justice system.
- ❖ To better understand the post-incarceration health care needs of women.

Long-term goals of this study are:

- ❖ To better serve the health care needs of women who are at risk for involvement with the criminal justice system so as to reduce likelihood of incarceration.
- ❖ To better serve the current health care needs of women who have been incarcerated so as to decrease rates of recidivism.

Methodology

In-depth interviews were conducted with 30 women identified through the Transitional Housing Program coordinated by the Massachusetts Parole Board. Twenty-eight women were residents of the Boston Rescue Mission; two resided at the McGrath House. Length of stay in the transitional housing ranged from 1 day to 3 months at the time of the interview.

A semi-structured questionnaire explored the current and past health, health care, and access to health care of women who recently had been released from incarceration. All interviews were administered by the Principal Investigators. The questionnaire was developed based on extensive review of the correctional health care literature, previous work by Sered among uninsured Americans, research on female offenders by Norton-Hawk and the input of Kira Dunn, the Parole Board's Director of Re-entry and Tina Hurley, Parole Board Women's Services Specialist. The study was approved by Maureen E. Walsh, Chair of the Massachusetts Parole Board. IRB approval was granted by Suffolk University.

Each interview lasted approximately 60 minutes. Participation in the study was voluntary. Identifying information was removed from the interview records, and interviewees were told that they could decline to answer any question that they found intrusive or troublesome, and could terminate the interview at any time. Thirty-one women were asked to

participate. One woman declined. Interviewees were provided with a \$15 MBTA pass as a token of appreciation for taking the time to participate in the study.

Interviewees were asked a variety of open-ended questions regarding their health and health care histories such as, “What are some of the factors that have made it easier / harder for you to take care of your health?” and “Has it ever happened that you couldn’t afford medical care when you needed it? If so, what did you do?” Their answers were not verified through external records, which, in any case, tend to be fragmented and partial given that many of the women interviewed have been in and out of a large number of correctional facilities, treatment programs, emergency rooms, clinics, halfway houses, and shelters. The quoted remarks of the interviewees have been lightly edited to remove repeated use of words such as “like,” stammers, redundancies, and off topic comments such as, “Is it okay if I chew gum?”

In addition to the open-ended questions, a variety of specific demographic and health questions eliciting ‘yes’ or ‘no’ answers were asked. This included offering the interviewees a list of illnesses and asking which they have ever experienced. Quantitative data were entered in the Statistical Program for the Social Sciences (SPSS). Frequency analysis, descriptive statistics and correlations were calculated. Scale data were recoded to nominal to facilitate the analysis of significant relationships. Qualitative data were coded separately by each researcher to ensure the validity of the findings.

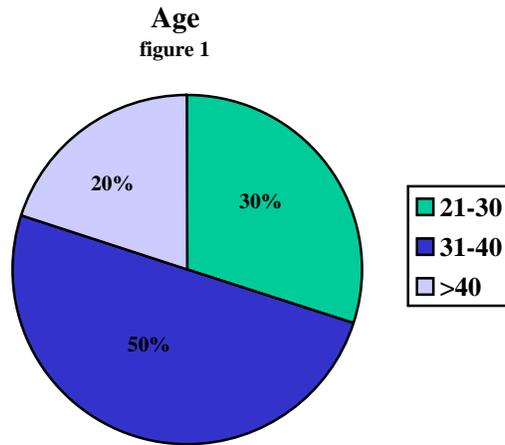
Limitations of the current study

Issues of representativeness are raised by this research. The research was conducted primarily at one transitional housing facility in a large urban center. It is possible that women accepted at this facility are not representative of all women who are being released from a Massachusetts correctional facility. Women who are not under parole supervision or are released to other facilities may have vastly different medical conditions and health care histories. Additionally, this information may not be generalizable to other states. Massachusetts may provide better or worse access to health care over the life course.

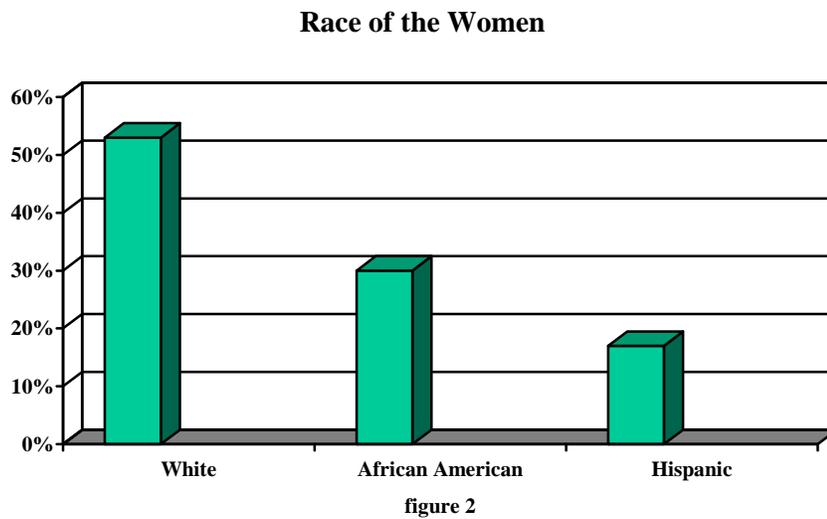
Questions regarding the validity of the data are also raised. The researchers had to rely on the truthfulness of the women’s responses. Memory lapses, drug-induced mental impairment, and intentional misrepresentation of their medical, criminal, and family history may reduce the validity of the data. Records that were available in the women’s file lacked consistency and thus were not a valid source to confirm or refute individual responses.

Sample Characteristics

The median age of the sample is 35 with ages ranging from 21 to 47 years.



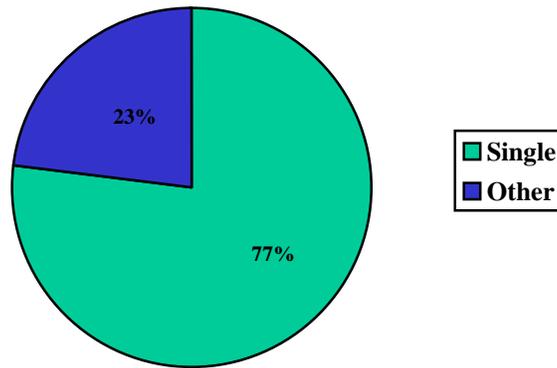
The majority of the women are white (53%), African American (30%) and Hispanic (17%).



Over 75% of the women were single, never married.

Marital Status

figure 3



The women are often under-educated. On average the women completed a little over 11 years of schooling. However, 50% did not graduate from high school. Post high school education included various levels of college courses, technical schools, and on-the-job training programs.

Educational level

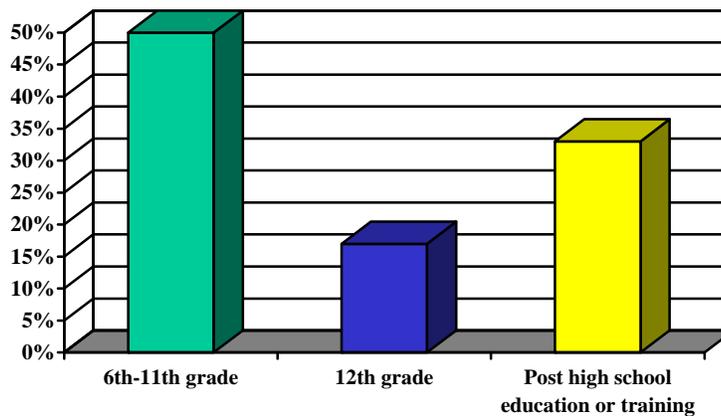
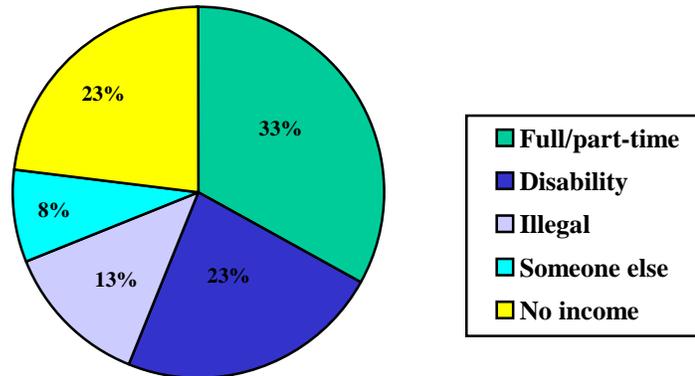


figure 4

The women are often under or unemployed. Prior to their most recent incarceration only 33% were employed either full or part-time. Twenty-three percent had no regular source of income.

Source of Income
figure 5



While slight variations do exist, the demographic characteristics of the sample are comparable to the characteristics of female inmates under the supervision of the Massachusetts Department of Corrections (D.O.C.) as of January 1, 2006. The average age of the female D.O.C. population was 36 years, the largest percent was white, more than half were never married and 48% did not complete high school.

Health and Health-shaping Experiences Over the Life Course

Childhood

Forty percent of the women were raised by both parents. Most of the remaining women were raised by their grandparents, usually their grandmother, or by one parent only, usually their mother.

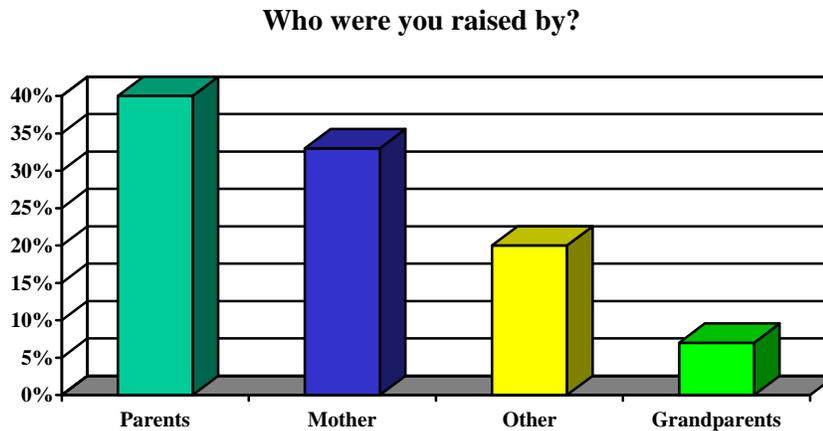


figure 6

- Fifty-seven percent of the women reported that they had no particular health problems in childhood.
- Of those who reported childhood health problems, the most common illness was asthma, which was suffered by 23.3% of the women.
- Ninety percent of the women recall having a family doctor or clinic they regularly visited for medical needs.

Many of the women shared narratives that root their current mental and physical health problems, as well as their correctional and substance abuse issues, in the respondent's early years. On-going histories of physical and sexual abuse were reported.

“When my father was drunk he would beat the kids.... I was sexually abused by my parents' friend when I was eight years old.... [Later in life] I have been beaten up [several times] by strangers.”

“[I was abused by my] father from age three. [Now] one of my sisters cuts her body. My other sister is dead – murdered by her boyfriend.”

“I was sexually abused by my uncle from age eleven. Touching me and oral sex. My grandmother supposedly didn't know about it. I never went to the emergency room. I was afraid to go. One time a guy [boyfriend] hit me so bad – I was in the hospital for six weeks. Broken ribs, eyes, nose, bruises all over my body... He spent three years in jail for that... I am

always in abusive relationships with every man... I used to think it's okay that men hit me because that's how they show love."

"I had thirteen years of everything [physical and sexual abuse] with my husband. He went to jail three times because of it.... Also, I was raped when I was thirteen."

"I was raped at age thirteen. I passed out drinking and when I woke up a former boyfriend was raping me. I didn't report it because I was drunk and thought it wouldn't do anything to report it.... After that I was afraid. In general I have paranoid delusions, I don't trust many people."

"I was with my boyfriend from 7th to 10th or 11th grade. He was psycho, crazy, raped several girls. There was abuse, physical, mental, emotional and sexual. He beat me up, knocked my teeth out and split my head open [the scars are visible on her forehead.] That was the start of my problems. I lost my friends because of my boyfriend ... he raped other girls too. He always called me 'fat, chunk, chunky' and that started my anorexia and bulimia. I was down to 79 pounds at one point."

- Of the women interviewed, 48% started serious use of illegal drugs before age 18 and 36% before age 14.
- Peer pressure and social settings in which friends were experimenting with drugs were the most frequently stated reasons for beginning drug use.

Age First Drug Use

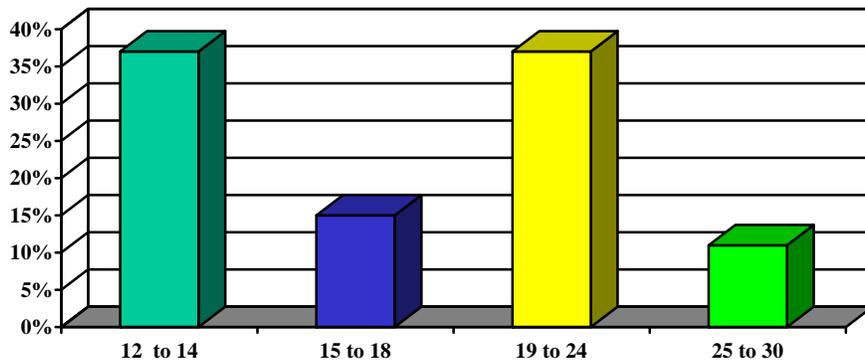


figure 7

Why First Drug Use

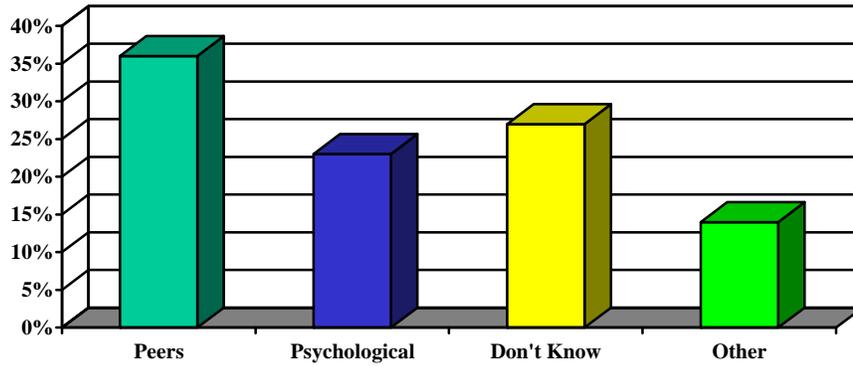


figure 8

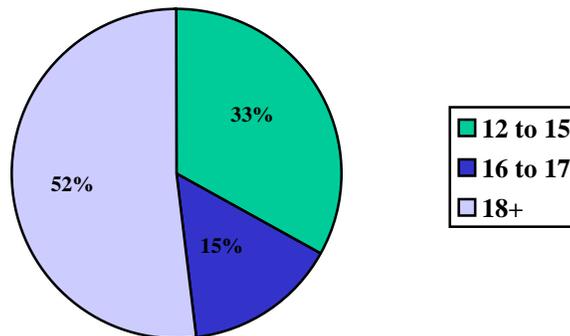
Several women explicitly linked their early entry into substance use to physical or sexual abuse at home.

“First time I picked up a drink I got bold and told my father I’d go to the police if he toughed me again, and he never did. So I thought alcohol was the magic elixir, my magic potion.”

Most of the women left home at an early age. One-third had left by the age of 15, and 48% were on their own before the age of 18.

Age Left Home

figure 9



Twenty-nine percent left home as minors because of physical or sexual abuse by an uncle, father or step-father.

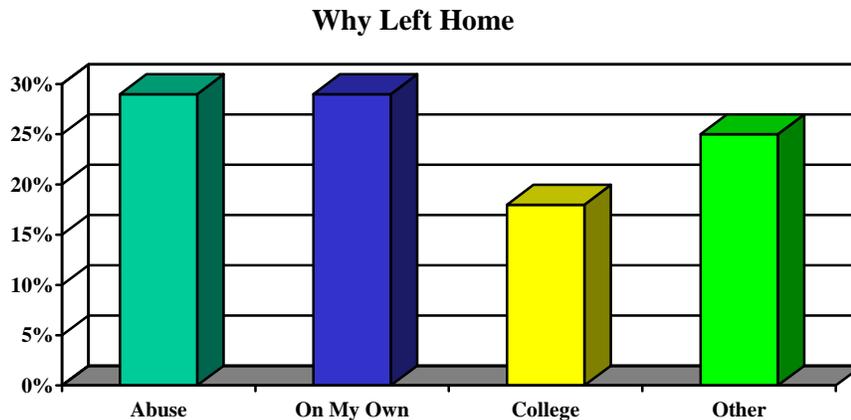


figure 10

The implications of these childhood experiences are long-term. Using a physical illness severity scale (described below) the current health status of the interviewees was assessed. *The girls who left home because of abuse were twice as likely to have moderate to severe health problems than girls who left home for other reasons.*

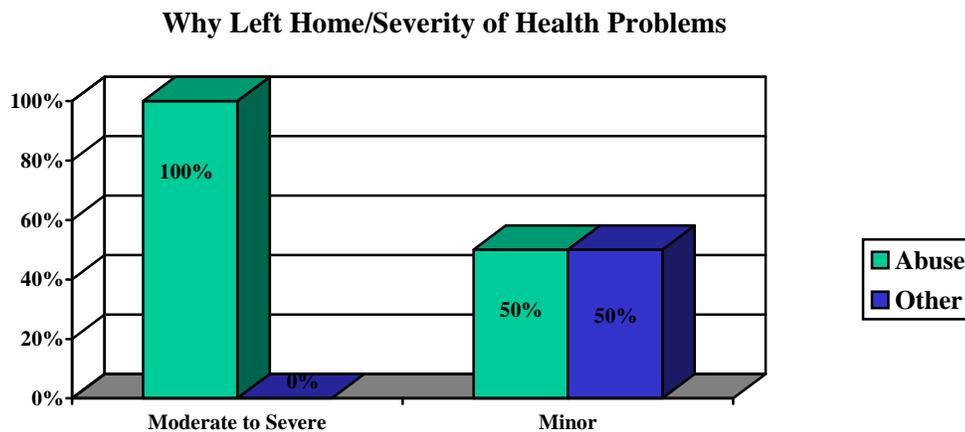


figure 11

School did not provide much of a sanctuary for the women in this study.

- *Thirty percent of the interviewees report having learning disabilities.*

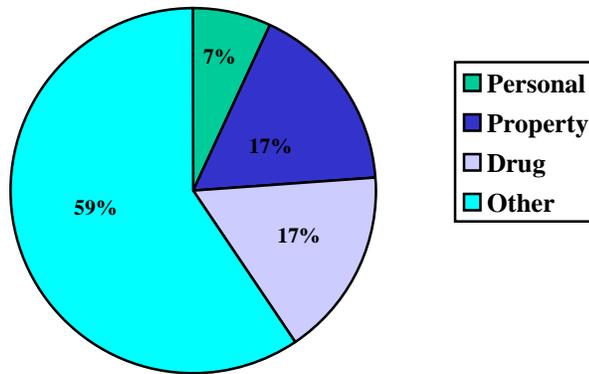
AE was in special education all through school. "I was a slow learner, uncomfortable. In tenth grade I wasn't learning anything so I quit. Now [recently] they diagnosed me with ADHD and said I'm not capable of sitting in a classroom. If they had diagnosed me with this I

would have learned something in school. Now what I know I learned on the street. I went to Job Corps but couldn't concentrate there. In school, we were just 'the bad kids.'"

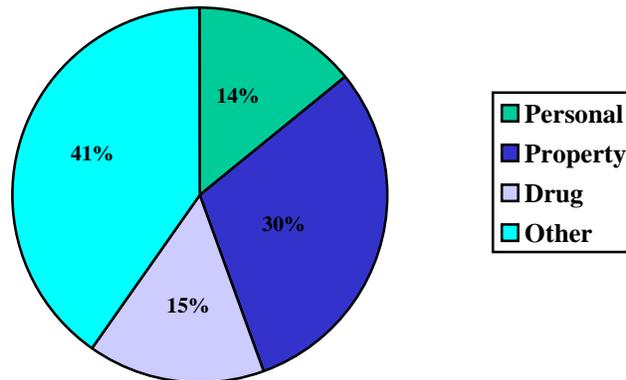
BJ recalls, "When I was going to school I had big problems with learning. I still do. I can't really read. My reading improved in jail and detox. I'm always scared to go to job interviews, job applications, training programs because I'm afraid I can't do it." While the cause of her learning disabilities is unknown, it is noteworthy that this interviewee was diagnosed with childhood lead poisoning, which, according to government studies, may lead to learning disabilities.

For many of the women of this study, childhood struggles with abuse, drugs, alcohol and school led to early entries into the criminal justice system. Forty percent were arrested for the first time before the age of 18. First arrest typically was for drinking in public, trespassing, prostitution, driving under the influence, shoplifting, or having an open container of alcohol. The median age for first incarceration in a state or county facility was 25 years; ages ranged from 17 to 42 years. Incarceration often resulted from the commission of more serious crimes, but still a rather large percentage were involved in non-violent, drug or property crimes.

Criminal Offense First Arrest
figure 12



Criminal Offense First Incarceration
figure 13



Adulthood

ABUSE

The abuse that characterized their childhood often continued into adulthood.

Ninety percent of the women have experienced violence or abuse. The consequences of the abuse include physical and emotional problems such as miscarriages, broken bones, substance abuse, and post-traumatic stress disorder (PTSD).

Women inmates are more likely than women in the general population to have experienced physical or sexual assault (Chesney-Lind 2003; Richie 2003; Alarid and Cromwell 2006). Victims and survivors of domestic and sexual violence frequently experience long-term reactions of fearfulness, anxiety, and confusion, chronic fatigue, sleep disturbances, phobias, depression, substance abuse, feelings of powerlessness, and a variety of somatic symptoms. Overall, women with a history of victimization by rape and other abuse perceive their health less favorably than other women and report more symptoms of illness across virtually all body systems (Koss 1994).

“One time a guy [boyfriend] hit me so bad – I was in the hospital for six weeks. Broken ribs, eyes, nose, bruises all over my body.”

“I was in an abusive relationship with boyfriend. I was afraid for my life. What is weird is he now works over at XXX court.”

“My son's father beat me up. I had a restraining order against him [but they were incarcerated in the same facility] which made me very afraid.”

“My son's father gave me a broken jaw, fractured rib, cracked head [she indicates a big scar on top of her head]. I didn't go to the hospital - I was drugged. I was in two abusive relationships. My first boyfriend, in the 7th grade, I had two kids by him. By the time I was eighteen he abused me. He punched me around. He was an alcoholic and would want to fight me when he was drunk. It was about control - he wants to control women.”

“My boyfriend and johns tried to overdose me by giving me too many meds of Fentanyl.”

“I was raped three times and beaten up [I don't know how many] times. How I was treated after made it worse. [In 2003 when she was raped the rapist was let go]. They told me, ‘You're not emotionally stable enough to bring to the grand jury.’ A few months later the police called me and told me that the man raped another girl and he was put in jail.”

PHYSICAL ILLNESS

Overall, this population of women is in poor health. Based on their responses to questions about specific illnesses as well as open-ended questions about physical and dental health issues, only 23.3% reported two or fewer problems.

Number of Physical Illnesses

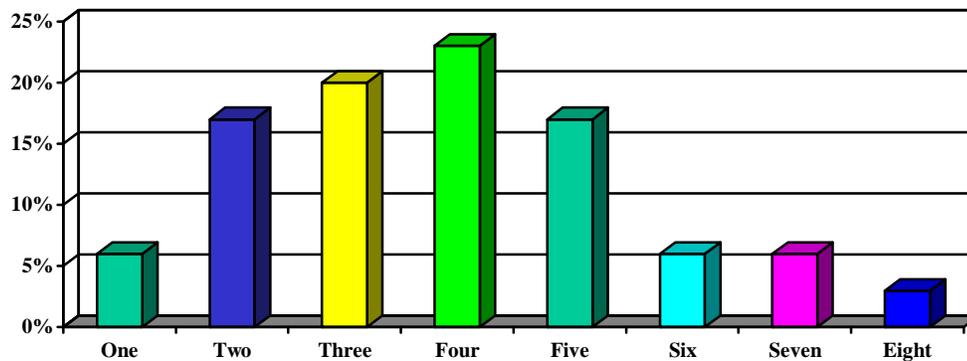
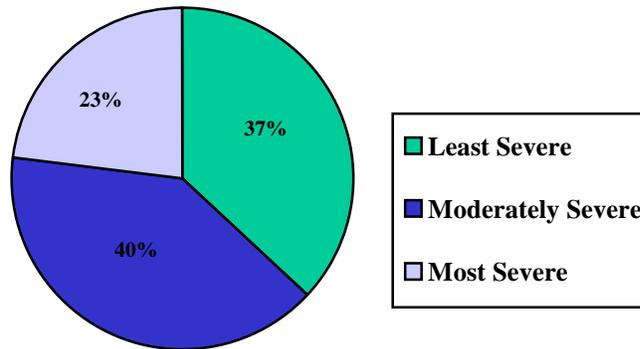


figure 14

Not all illnesses are equally serious or incapacitating, thus each interviewee was coded by assigning a scale of 1 – 3. Since none of the women have good physical health, we assigned a rating of 1 to women who have minor health problems. A rating of 2 was assigned to women who have one major problem or a substantial number of minor problems. The rating of 3 was given to women with seriously incapacitating health problems or with two or more major problems. For the purposes of this rating assessment only physical ailments were considered.

Health Severity Index

figure 15



Hepatitis C is the most common physical illness. Other physical illnesses include gynecological problems (such as ovarian cysts), asthma, and chronic pain.

Physical Illnesses

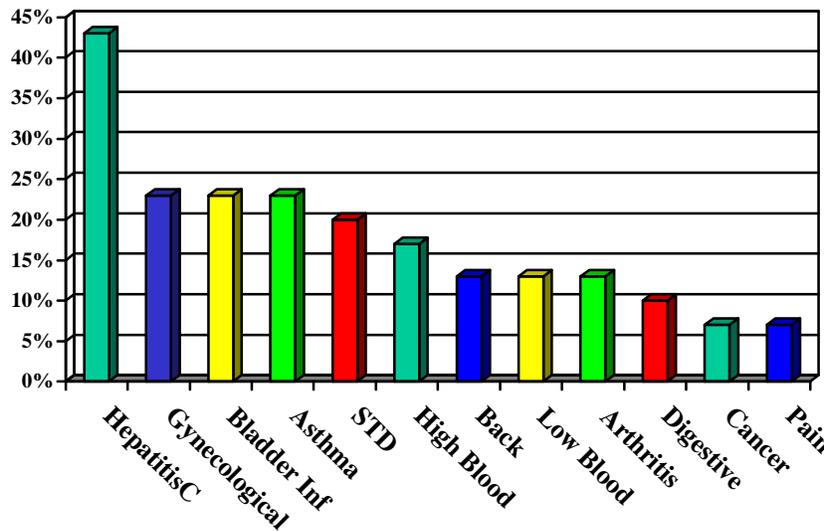


figure 16

DENTAL PROBLEMS

Dental problems were cited by 90% of the interviewees.

In many cases these problems are severe enough to lead to chronic pain, disfigurement, and repeated trips to the emergency room.

“[My teeth are] horrible. I need to see a dentist. All my teeth problems are from crack use. My teeth are getting transparent. I saw a dentist in pre-release [but that’s all].
 “I had 6 root canals. I lost all of my bottom back teeth. Probably from drinking sweet drinks.”
 “I need a root canal right now. Fillings have fallen out and not been replaced. It is very painful.”
 “I only have three teeth missing.”
 “Four teeth have been knocked out.”

MENTAL ILLNESS AND SUBSTANCE USE

For most of the women, their physical disorders interlock in complex ways with their traumatic histories, challenging living situations, mental health issues, and substance abuse.

Mental Illness

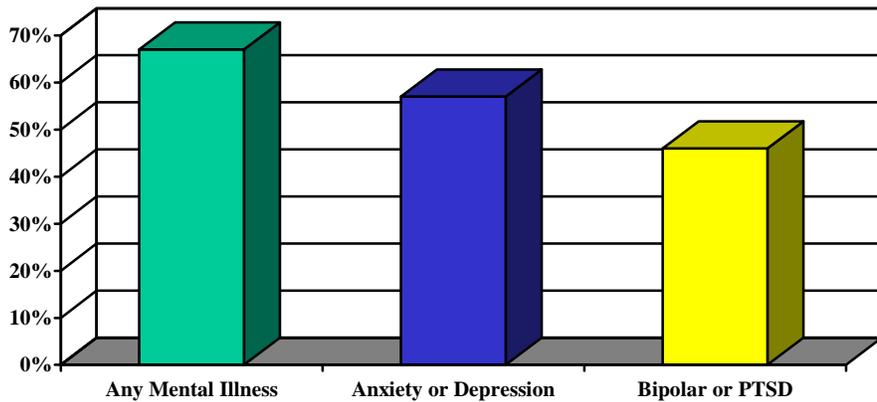


figure 17

Substance Abuse

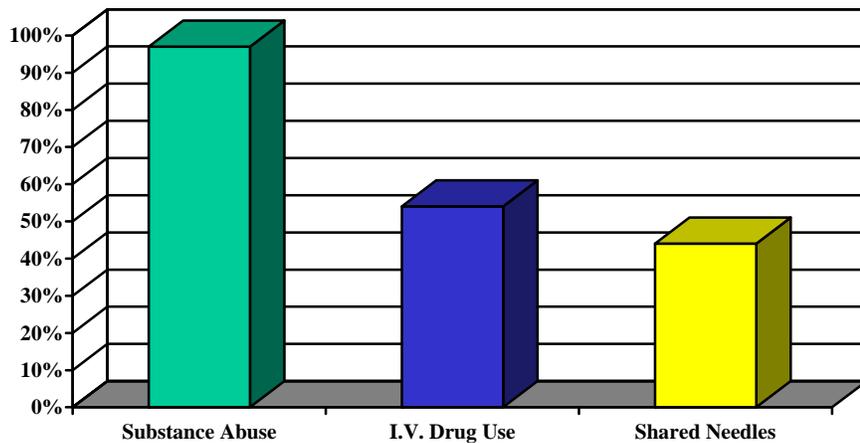


figure 18

AA relates that she was healthy until 2003, “and then fell apart.” That year she was raped, contracted Hepatitis C the one and only time she used intravenous drugs, and was assaulted by a man who punched out two of her teeth. Her Hepatitis C is highly symptomatic. She suffers from severe sciatica caused by passing out when drunk. She has experienced numerous injuries including a concussion caused by a beating. AA was first diagnosed with anxiety / depression at age 19. More than ten years later, at age 30, she was diagnosed as bipolar.

BB has tested positive for Hepatitis C since age 20. Her condition, which is sporadically monitored, is highly symptomatic, causing pain in her sides, fatigue, and periodic jaundice. While Interferon would be the standard medical intervention, she cannot take Interferon, which can cause suicidal feelings, because of her history of depression, anxiety and drug use. While in prison she was found to have HPV and was told her she needs a coloscopy, which she has not yet had. She also suffers from severe migraines for which she sometimes is treated with Demerol shots. BB explains that, "When I'm using [drugs] I don't have migraines, when I'm clean I get them." She has coped with mental illness “my entire life,” making several suicide attempts beginning at age 16. "I make mountains out of molehills. For example, if I'm turned down for a job I can get suicidal." Twice the suicide attempts were severe enough for her to end up in the ICU. Not all of her injuries have been self-inflicted, BB also has been hit by a car and been involved in a major car accident.

CC has a history of injury, domestic violence, trauma, sexual abuse, and drug abuse. She experiences anxiety and depression and has been diagnosed as bipolar. She has been offered medication but has chosen not to take it. DD has a 7 cm. cyst on her right ovary that causes severe menstrual cramps and heavy bleeding. She also suffers from Hepatitis C, an ulcer, frequent bladder infections, repeated kidney stones, and high blood pressure (the last reading she recalls is 180 / 100).

DD has Hepatitis C that she caught from using shared needles. She has been on Interferon and that has cleared it - her blood tests are good now. She suffers from PTSD in the wake of horrible and long term abuse from her boyfriend when she was a teenager. She was in a serious car accident. She has attempted suicide and has a history of anorexia and bulimia. She has arthritis and severely limited use of her hand as a result of severing many tendons in a suicide attempt.

PREGNANCY, CHILDBIRTH AND MOTHERHOOD

The constellation of disrupted childhoods, physical and sexual abuse and substance use forms the backdrop to their experiences of pregnancy and childbirth. The women report high rates of complications during pregnancy and childbirth, high rates of premature births, and an assortment of problems having to do with babies born addicted to heroin or other drugs.

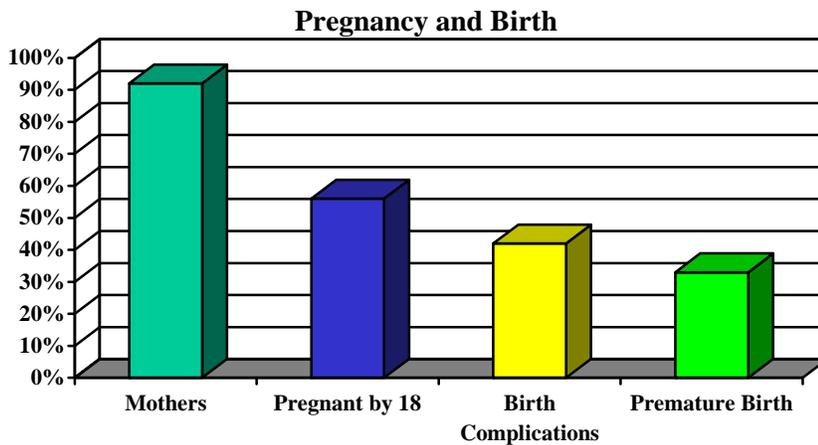


figure 19

AP explains that while pregnant she was on methadone and on the run from a warrant but wanted to wait until the baby was born to go back to jail. She was getting pre-natal care at XXX Clinic when she learned that the clinic was going to call the police because of the outstanding warrant. “So I had no choice but to go to the street and run, and so I was on heroin [rather than methadone]” for the duration of the pregnancy.

BA recalls, “With my second baby I used [drugs] the whole time. Didn’t really have much [prenatal care]. He was premature. When my water broke he was born. I was trying to steal something and they caught me or tried to. I tried to get away. I yelled ‘I’m pregnant.’ The saleswoman let me go but the store officer caught me and pushed me to the ground. My water broke.”

HOMELESSNESS AND PROSTITUTION

Fifty-two percent of the women were homeless or living in shelters before their most recent incarceration.

This too is part of the larger picture of physical and emotional vulnerability. Using the scale of 1 – 3 (described above) for assessing the overall physical health status of interviewees, *women who were homeless before their recent incarceration were in substantially poorer health than the women who had stable housing arrangements.*

Homelessness/Severity of Health Problems

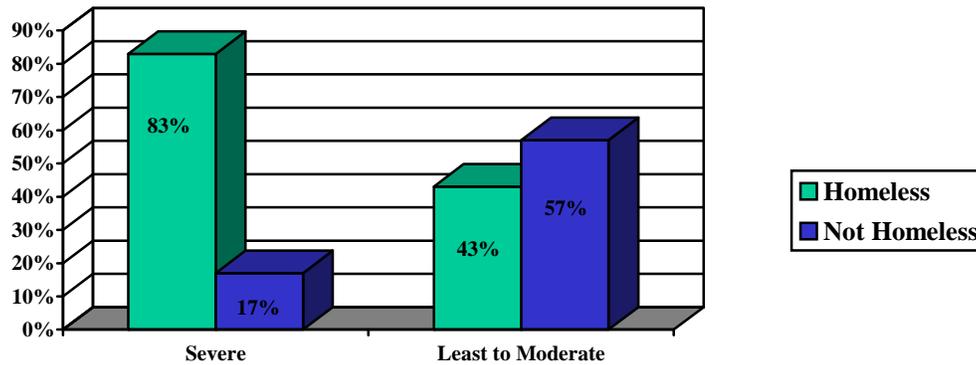


figure 20

America's homeless population is sicker than other Americans. Jahiel (1992) summarizes a number of local studies: From 33% to 48% of homeless respondents reported their health to be poor or fair, compared to 18% to 21% of the general population. Rates of arthritis, asthma, diabetes, elevated blood pressure and a myriad other chronic conditions are far above the average in homeless populations. Jahiel notes a high rate of other trauma-related diagnoses (such as lacerations, fractures, and head traumas) and a frequency of rape victimization that in some areas is reportedly 15 times higher than in the general population. According to a study conducted by the Community Health Advisory Information Network at Columbia University's School of Public Health, at any given time, one out of four people living with HIV in New York City is homeless or marginally housed.

"I was homeless after my mother said I couldn't come home. I had no income. But I had men who took care of me and that's why they was abusive."

"When I was in the street whoring – [I was] raped many times, I can't even count how many... I went to the police. They do the exam and the hospital and then send you back out."

- Thirty percent of the women report that prostitution – a notoriously dangerous and unhealthy occupation -- has at some time been their primary source of income.
- Typically, those women turned to prostitution because of substance abuse problems.

Incarceration

For the women of this study, their most recent incarceration was not an aberration in their life course: The women tell of lives spent on probation, parole, in halfway houses and detoxification programs, in homeless shelters and on the streets. Thus, health experiences during their most recent incarceration are not treated as a watershed moment in their lives. For the most part, the health issues they deal with begin before they are incarcerated, carry on

during incarceration, continue post-incarceration, and are still relevant at the time of the next incarceration. Still, many of the women identified ways in which women's health is negatively affected while in prison.

- 73.3% of the respondents say that women who have been or are incarcerated have more health problems than other women.
- Respondents particularly noted Hepatitis C (46.2%), mental illness (34.6%), MRSA (34.6%), and diabetes (23.1%) as common health problems among incarcerated women.

EE spoke in some detail about the health issues she saw in prison. "HepC, HIV, liver disease, abscesses from shooting dope, poor dental care - no teeth. Health problems because of the way some of them have been living. The situation in prison. It is hard to get accustomed to it. The confinement, structure, food, you're a number. The first time I lost 48 lbs in 3 months. The prison food is disgusting. And really small portions. It is not enough food. Women augment it with food from the canteen, and this isn't very healthy food and women who don't have money can't do this. A lot of the younger women in prison go insane and cut themselves up, they start fighting because they can't handle the situation. In prison they don't help you. You have to ask for toilet paper. Demeaning. Degrading. Some women can't handle it."

FF made similar comments. "Oh my gosh, yeah [women in prison have more health problems]! HIV positive, hepatitis, MRSA, psychiatric issues, teeth. They're lucky if they have some [teeth]!... Also, in jail women gain weight out of boredom. This is bad for their self-esteem."

A number of interviewees noted that it is not uncommon for women to become sicker – or at least more symptomatic – in prison.

HH explains, "A lot of women didn't know they were sick until they got to jail because they were running the streets with drugs. A doctor on the outside? What was that to them?"

Detoxification from drugs or alcohol in prison gives rise to a variety of symptoms.

According to JJ, "[In prison there are] more STDs. Lots of PTSD. Many women had childhood sexual abuse and teen rape. They become addicts to block the feelings. Then they commit crimes to get drugs or because they don't know what they are doing when on drugs. Then they go to jail. In jail many women suffer from bad and frequent headaches. This is because they are coming off drugs, smoking and caffeine."

KK clarifies, "Mentally, emotionally, and physically. They have a lot of illness – HIV, Hep A, B, C. STDs. Cancer, diabetes, depression. When you are on the street using drugs you don't go to see the doctor, but when you go clean in jail your body reacts and sicknesses comes popping out all at once."

It is important to note that several women identified ways in which their health improved in prison. For the most part, women felt that their health improved because they stopped using drugs while in prison.

"The detox has made me better - I'm not using."
"In jail I exercised a lot. I went to the gym all the time. My health improved in jail. There was a lot of fruit to eat there."
"I'm clean and gained my weight back."
"I'm sober. In jail I exercised."

Health Care Experiences Over the Life Course

Childhood

- 82% of the interviewees recall having a regular family doctor while growing up.
- 87% of the women who recall having a family doctor said they were comfortable with that doctor.

However, *not a single interviewee mentioned that the doctor was helpful or advocated for them regarding the physical and sexual abuse they experienced.* The only specific comment about a family doctor was negative. "I hated him [family doctor.] I thought he was a pervert." She clarified that he didn't do anything in particular to indicate that he was a "pervert," but because of her father's abuse she didn't trust male doctors.

The women recall a great deal of use of the emergency room. Most typically, these visits were for accidents, injuries or asthma. Similar to their recollections of their family doctors, most of the women felt they were treated reasonably well at the emergency room. However, none mentioned that an emergency room doctor or nurse noticed or intervened regarding the physical and sexual abuse.

Studies show that because of the ongoing and injurious nature of violence toward women by male partners, abused women often visit physicians repeatedly with increasingly severe physical traumas. Despite the repeated trips to physicians, however, inquires rarely are made into the cause of the injuries and the history of victimization underlying the physical trauma may never be identified (Koss 1994).

According to Massachusetts law, physicians who attend, treat or examine victims of rape or sexual assault are required to report the case to the police but may not identify the victim.

Despite their difficult childhoods and histories of abuse,

- 63.3% of the interviewees did not see a therapist while growing up.

- Of those who saw a therapist, only 45% report finding the sessions helpful.
- None of the interviewees mentioned telling a therapist about the sexual abuse or receiving a helpful response.
- Often, going to a therapist meant one or a couple of visits with no continuity of care.
- Sometimes therapy was not pursued because the parents did not follow up.
- In other cases the child services system was too fragmented to follow up.
- Sometimes a particular therapist with whom a good bond had been created moved on.

Adulthood

HEALTH MAINTENANCE

The majority of the women reported some access to preventative medical care as adults in the 5 years before incarceration. However, most qualified their answers by noting that when they were actively “using” or “running the streets” they didn’t take care of basic health needs.

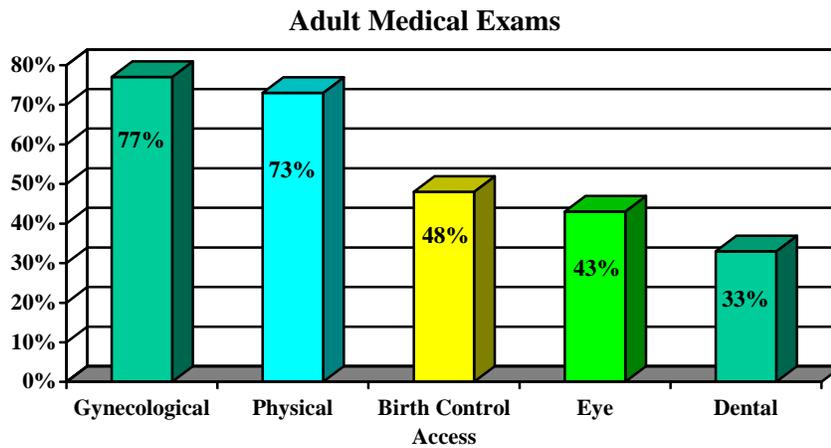
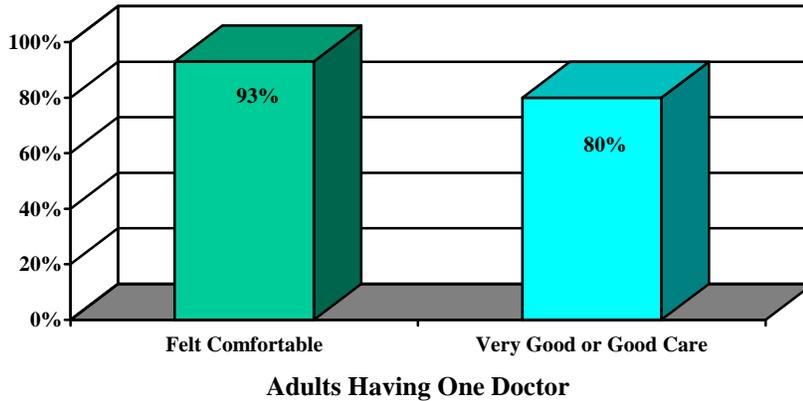


figure 21

Fifty-seven percent had one doctor or medical home base. For those who report having a regular doctor, the assessments of the care they received were very positive.

Assessment of Health Care in Adulthood

figure 22



MEDICATION

The women of this study make copious use of legal medications. Common over-the-counter medications include various pills for headaches and menstrual cramps. Prescription medications most often were taken for anxiety, depression, and asthma.

Regular Licit Drug Use

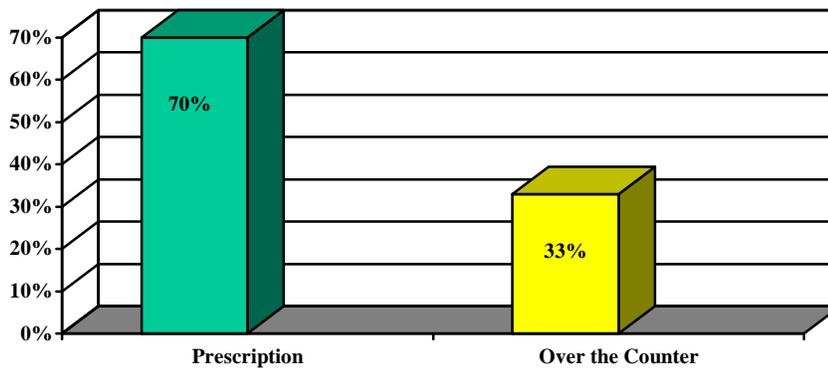


figure 23

HOSPITALIZATION

Despite dealing with many serious medical conditions, the women of this study have not been hospitalized particularly often (note: this does not include residential detoxification facilities).

Number of Hospitalizations

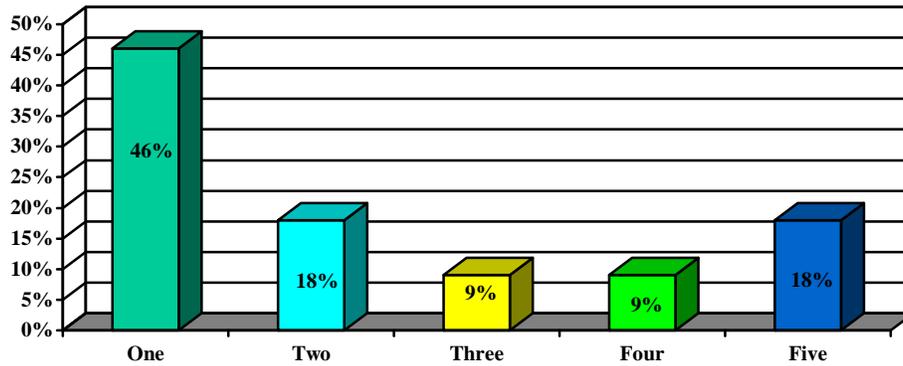


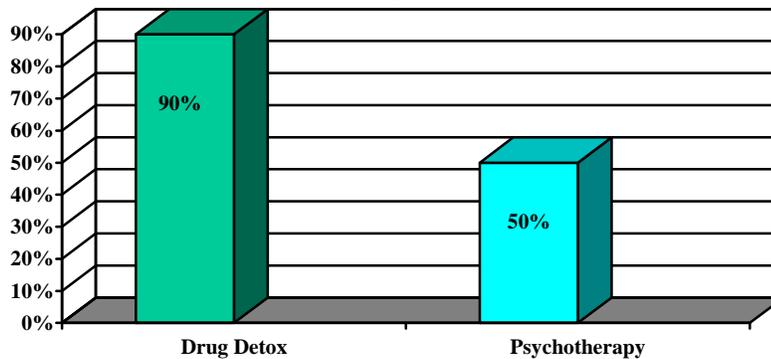
figure 24

Reasons for hospitalizations include: embolism, kidney infection, cyst removed, asthma, pneumothorax, injury, knee surgery, mental illness, suicide attempts, surgery on infected finger, broken ribs (as a result of abuse), blood infection, pneumonia, asthma, ectopic pregnancy, car accident, UTI, and drug overdose.

DETOXIFICATION AND PSYCHOTHERAPY

Prior to Incarceration

figure 25



Women Who Had Detox or Psychotherapy

Regarding both detoxification and therapy the interviewees generally reported on-and-off services.

MM has been in and out of therapy for many years. She went to therapy “pretty regularly until jail.” Some of the therapists have been helpful, some not. “It seems like once I get used to a counselor they have to leave and stop seeing me.” She spoke about one therapist whom she felt really was helping her, but that one had to leave the clinic she was working at and so she couldn’t see her anymore.

Other women had similar experiences with therapy.

"Whenever I go it's two times and that's all. I end up either using [drugs] or I back off."
 "It was great, but then she left and I did not like the person who replaced her so I never went back"
 "Treatment ...was not helpful. I felt drowsy from the pills."

DENTAL CARE

Many of the women reported difficulties accessing dental care. These difficulties include:

- long waiting lists
- lack of insurance
- dental office requirements for payment upfront
- inconsistent Mass Health policies regarding dental coverage
- trouble following up on appointments

Interviewees report a variety of ways that they cope with untreated dental needs. In addition to self-medicating dental pain, some interviewees go to the emergency room when they have severe abscesses. The emergency room typically does not treat the dental problem beyond prescribing antibiotics.

One woman shared a particularly frustrating story.

"My dentures need cleaning - I paid for the cleaning at Gentle Dental before jail but didn't have a chance to keep the appointment." She is not sure if the payment made upfront over a year ago still will be honored.

- Those women who do manage to access dental care usually are satisfied with the level of care (72.2% said they are satisfied).

Incarceration

During incarceration, especially for women incarcerated for six months or more, physical and other routine exams and assessments are common.

Medical Exams in Prison

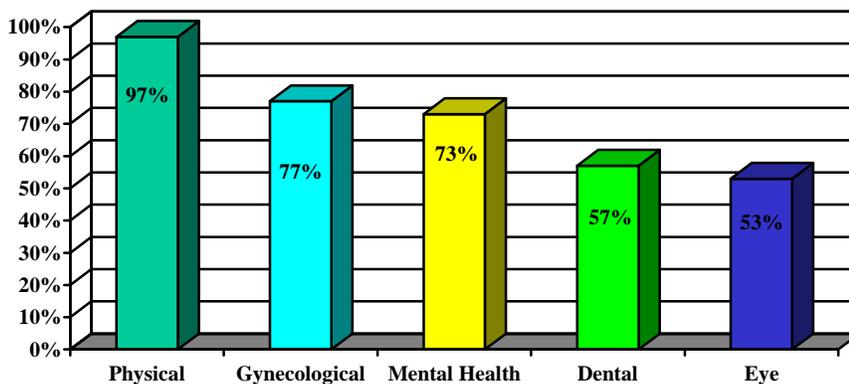
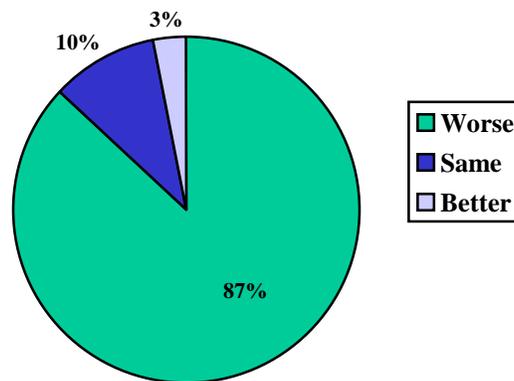


figure 26

While the women interviewed mostly appreciated the exams and assessments in prison, they felt that the overall quality of medical care in prison is worse than outside.

Prison Compared to Non-Prison Health Care

figure 27



Emergency medical treatment in prison received praise from several of the women. However, the more chronic problems identified in the medical exams often were not treated. For example, while many of the women saw dentists while in prison, the dentist diagnosed cavities but did not fill them.

“If it was an emergency it was treated well and quick.”

Many of our interviewees felt that the medical system in prison is permeated by an air of suspicion and that this comprises the quality of care.

“She [the doctor] assumed we were all out to abuse her meds. For the first several weeks there I couldn't get Motrim - I had to wait.”

“The prison system always thinks you're lying when you tell them you are ill. They think you are trying to get out of something. They will simply let you die. They don't care.”

“We need treatment, not punishment. It just drags us down. It's harder to hold onto my recovery when I'm in jail because when you're told you're nothing but a felon you lose your positive attitude and get knocked down.”

MRSA²

Interviewees singled out the diagnosis and treatment of MRSA as problematic.

AG was diagnosed in prison with MRSA without benefit of a culture. She was treated with three separate courses of antibiotics but it didn't go away.

² MRSA, Methicillin-resistant *Staphylococcus aureus* is a serious antibiotic-resistant staff infection that in recent years has spread in hospitals, barracks, locker rooms and prisons. Common symptoms include pus-filled boils and rashes.

GG explains, “Because of the mix of people in prison all put in close together, diseases spread. Women with contagious diseases are not kept separate from other women.... Especially MRSA. They put bandages on women’s arms to cover the rashes.”

BD relates, “When you have MRSA they wait till it has pus. When someone [at MCI was showing signs of illness] we would get something sharp and lance the boil, clean it up and let it heal. We take care of each other.”

WAITING

Most of the women were troubled by the waiting time to see a doctor or nurse for a new problem, and by the long wait for follow-up treatments in prison. While many Americans feel frustrated by waiting to see medical providers, several aspects of the respondent’s life experiences make that waiting particularly difficult.

- Many of the women live with chronic **and** acute physical **and** mental distress.
- Many of the women **somatize** (express through their bodies) the traumas of abuse in their lives.
- Many of the women are insecurely housed and move frequently. They know from experience that delays in medical attention often mean no medical attention.
- Prisoners are 100% dependent on the prison medical system for care. Prisoners cannot go to the bathroom medicine cabinet and treat their own problems with over-the-counter remedies.
- While in prison many of the women feel powerless concerning their lives and their children. Waiting for medical attention exacerbates these feelings with feelings of powerlessness over their bodies.

QQ explains that, “Some of the nurses and doctors are good, understanding, caring. Some are bad, bitching about the women in jail. In jail the lady [doctor, nurse] found something in my titty. She said I should have a mammogram but they didn’t send me for it. Now I’m scared to go.” QQ had an eye exam while in prison and they told her she needs glasses but she didn’t get them because it took too long. “I’m not going to fight with the system. You always lose. You’re just numbers. In jail the doctors and nurses don’t take care of people the way they are supposed to.... The waits are too long – two or three weeks after you put in a medical slip – and it has to go to this person and then that person and then the highest person to give permission won’t be there so you wait and by the time you see the doctor you are all screwed up.... I feel tired most of the time. I think I have anemia, but maybe I’m just overwhelmed. They say I need to take iron but I don’t have any. In jail medication is like a fight – constantly. They always say they ran out and have to order more. They say ‘You have to understand, there are 700 of you [who need medicine].’”

PP recalls that at Dartmouth House of Corrections the medical staff was “terrible.” She was on the list to see a gynecologist from April when she arrived. Eight months later she still had not been seen despite giving in numerous request slips. “They pacified me with a nurse who said I had a yeast infection and gave me a cream.” It was not a yeast infection and the cream didn’t help. One time, “I was deathly sick for eleven days and the nurse said it was a virus. I had a terrible headache the entire time [she points to the back of her neck - a typical

sign that a patient should be tested for meningitis] but didn't see a doctor." She also put in a slip to see a therapist because she was having "problems with anger and fighting. I saw the therapist one time and he said he'd come back and do light therapy but he never came back."

Waiting for glasses presented a particularly difficult problem for a number of women.

"In jail they take your contacts and glasses away and you are blind. You need to go through the jail for new glasses and it takes two months."

DETOXING AND MENTAL ILLNESS

Medical care in prison is complicated by the fact that many of the women detox when they arrive in prison. Several women, including women with histories of suicide attempts, recall that they were taken off their psychiatric medication in prison. "I could have committed suicide."

"In jail you detox - everyone does. Your immune system shuts down and you get sick. The prison medical services are not set up for that. It's a joke. You're lucky if they see you. It's hard even to get a Tylenol."

"I was cut off from all my meds when I arrived in prison. Even for Tums I needed a sick slip and you give it in and then don't hear anything, and then more slips, and nothing. Women who are detoxing in prison wait two months to see a psychiatrist.. [She explains that this is a matter of policy - they make them wait until the prison is sure they are completely finished, though the detoxing does not take anywhere near that long.] "Mentally ill girls are put into solitary.... My therapy was stopped when I went to prison."

"It took so long to get seen. It took 3 months to get on psyche meds."

PREGNANCY AND CHILDBIRTH

Pregnant inmates are in particular need of medical services. Interviewees generally praised the availability of pre-natal care in prison. However, the very nature of incarceration presents serious problems for pregnant women and for mothers.

SS recalls that the pre-natal care in prison (Framingham) was good, but she gave birth handcuffed to the bed. "It was horrible... The nurses were not nice – they looked down on you." SS did not receive postpartum care because she left prison three days after giving birth. She was sent to a rehab / reentry facility and the baby was kept behind.

RR became pregnant while in a detox / halfway program. The baby was born in prison on methadone but otherwise healthy. RR feels that the prenatal care in prison was good and the way she was treated during childbirth was very good. She had been upgraded to "mother and child" so she was not shackled during the birth. The baby stayed in prison with her for three months, "and then they took her. It was so hard when they took her. It killed me."

Re-entry

At the time of the interviews, only 50% of the women were enrolled in Mass Health. This number may not be particularly reliable: Several of the women answered that they “think” they are on Mass Health but they are not sure.

Mass Health Enrollment

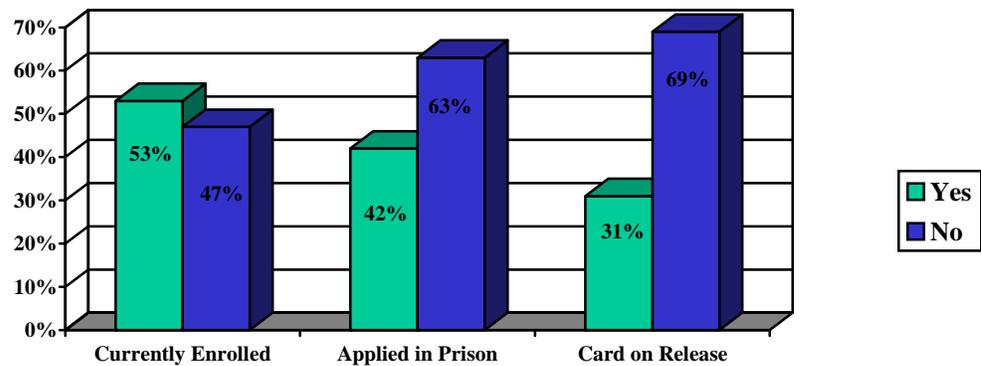


figure 28

Very few of the women reported any sort of arrangement for medical services upon release from prison.

“I was taken off my psych meds when I got to prison. It was wrong to take me off but it turned out okay. I coped okay in prison. However, now that I'm outside of jail and off medication I'm feeling overwhelmed.”

AL needs to see a doctor to get her psychiatric medication prescription renewed. She has made phone calls but cannot find anyone who will take a new patient earlier than six months from the time of the call. She knows she needs to continue looking.

Other women made similar comments regarding their medication.

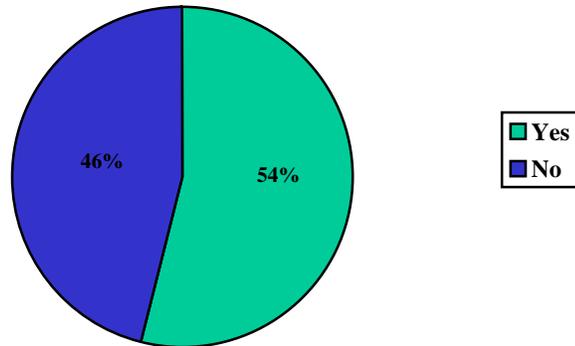
“I am not taking [my medication] as I [am] supposed to so that I won't run out. I am trying to take it every other day.”

“I have 7 days left but can't get a doctor's appointment to get more. I was at the ER for [a] punctured eardrum and asked the doctor there but he said no.”

“They give you 30 days - no refill for mental health meds. But to see a doctor who can write a new prescription you have to wait two to three months, so you run out of pills.”

Were You Given an Adequate Supply of Prescription Medication?

Figure 29



Supply of Prescription Drugs

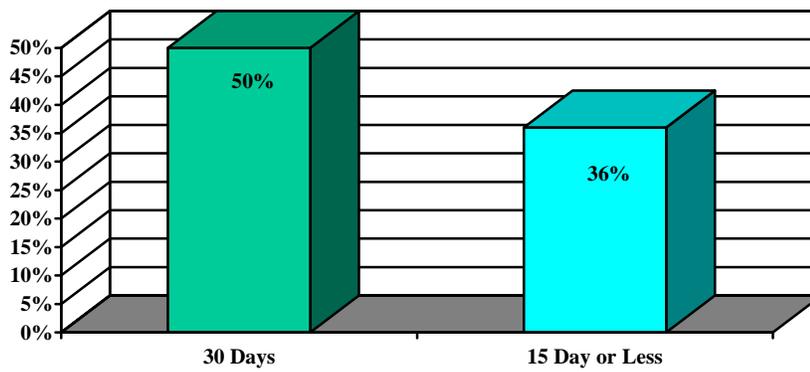


figure 30

Barriers to Health Care Utilization

Interviewees' health and health care experiences were organized along a chronological life-course axis. Similar barriers exist, to greater or lesser extents, at every stage of the life course. Indeed, *many of the barriers are most insurmountable at transition points from one life-course stage to the next.*

Some of the barriers have to do with the women's own backgrounds, health, lifestyles and capacities. Other barriers have to do with the structure and nature of the health care system and how women with drug and incarceration histories may be treated by some providers and services. Taken together, these barriers mean that women who are particularly needy and often incapacitated in one way or another must deal with a complicated, under-funded, fragmented, and sometimes antagonistic system.

Complex Physical and Mental Health Problems

Women with a history of having been sexually assaulted are likely to make twice as many physician visits per year as non-victimized women. The outpatient medical expenses incurred by the most severely victimized woman may be more than twice as high as expenses incurred by non-victimized women. One watershed study found that, "Victimization severity was the single most powerful predictor of total yearly physician visits and outpatient costs, exceeding the predictive power of age, ethnicity, self-reported symptoms, and morbidity-related injurious health behaviors" (Koss et al 1994: 182).

Most of the women interviewed deal with constellations of physical and mental health problems. Often, medical treatment is difficult to manage because the various medications they need are contra-indicated, medication protocols are too complicated to follow during periods of homelessness, or certain medications are inappropriate for individuals with a history of substance abuse.

Because AD has Hepatitis C, she cannot take most of the medications she needs to treat her bipolar disorder. "They've tried many drugs on me but I can't tolerate them. I think I've actually made more suicide attempts while on medication than while off it."

Learning Disabilities and Limited Self-Management Skills

For many of the women, managing their complicated health and personal issues is exacerbated by learning disabilities. For these women, navigating the complexities of the health care system may present insurmountable challenges.

AF explains that she has been labeled "slow" since she was a child. She feels that she is not slow, it's more a matter of ADHD and learning disabilities. Aside from school problems, her childhood and young adulthood were relatively untroubled. In fact, her life was more or less healthy until age 23. At that point, her mother – who always "took care of me" -- moved back to her country of birth. Within that year, AF became pregnant, the baby's father died, she started using drugs, and then was arrested for assault and battery (resisting arrest). At this time she has given birth to six children, has been homeless over much of the past several years, and is fighting to get custody of her baby whom she desperately wants to raise.

AB was diagnosed bipolar in 2001. She has suffered from back problems since 2000, anxiety since 1993, drug abuse since 1975, chronic bladder infections because she was born with only one kidney, gonorrhea and Chlamydia (several times), and asthma since 1970. AB also has struggled with severe learning disabilities ever since she was run over by a car as a child. At the time, she was taken to an emergency room where doctors diagnosed internal bleeding and pressure on the brain, and gave her outpatient treatment. AB reflects, "It caused my memory loss and made school harder. I already had a hard time in school. I haven't ever left home. Mother died two months ago, I still have the apartment. My brother and boyfriend live with me. Mother always did everything for me. Not sure how I am going to handle taking care of myself. My mother was always there. I don't know how to pay bills even."

Chaotic Lives and Moving Around

Many interviewees identified their own life-style, including substance abuse, as factors that impeded accessing health care.

- "Drugs and a chaotic life."
- "I didn't follow through on things like that."
- "I applied for Mass Health but didn't follow up so didn't have anything."
- "I was an addict and let things go."
- "I went [to a therapist] once but then didn't follow through with more appointments."
- "I did not keep the appointments [with the therapist] because I was using [drugs]."

A corollary of their chaotic lives is that most of the women were very mobile, with periods of homelessness interspersed with stays in one facility or another. The result of these temporary living arrangements is that appointments are not kept and records gets lost. HIPAA regulations present additional obstacles to helping the women keep track of diagnoses and treatments that they have received at the many facilities they have visited over their lives.

"I have to request my medical records. They got lost in transit when they moved me from prison to jail."

Periodic incarceration further impacts women's health care in that it disrupts protocols that were in process prior to incarceration. Regimes of medication are interrupted, laboratory tests that were conducted are never analyzed, and diagnostic procedures are terminated before effective treatment program can be established.

AE is diabetic and suffers from frequent, severe headaches. Her doctor scheduled an MRI for her last year but she then was arrested and it never was carried out.

Many of the women describe similar disruptions in medical care.

"I haven't gotten to see her [the therapist]. I made an appointment then went to jail. I will be seeing about the bipolar this week."

"I was starting to go to doctors and had all of that [check ups] done when I was working at XXX. The nurses there told me to get my big, hard stomach checked out. Fibroids. But then I went to prison... I want to go back to that job but they won't take me back."

Fragmented Medical Care

Because most of the women deal with complicated medical and psychiatric conditions, they do tend to access a great deal of health care service. However, because of their chaotic lives, frequent moves and complex conditions, as well as the limited resources available at any given time at any given facility, it is not uncommon for the women to have been treated in dozens of different programs, clinics and facilities.

Fragmented Care: One Woman's List of Providers, Hospitals, Detox Programs, Rehab Programs, Clinics and Services (according to her recollection)

Adcare Hosp in Worcester - detox and outpatient care
St Elizabeth - detox, pain clinic, outpatient care
Faulkner Hospital - detox and outpatient therapy
Norcap in Foxboro – outpatient and in patient (about 5 times between 1996 – 2004)
Bournewood in Brookline
Baldpate Psych Hosp in Georgetown (3 or 4 times)
Brockton Hospital detox
Arbor Hospital
Boston CAB
New Bedford CAB
High Point (Plymouth) approx. 4 times
Hello House in Boston
Lowell House
BRM
Glennis Sheehan House in Tewksbury
Edwina Martin in Brockton
Stepping Stone in New Bedford
Starr Detox in Fall River (approx. 4 times)
Women's Hope – Dorchester
Shattuck Hospital
NEMC – pain clinic and urology
Gynecologist at MGH
Boston Medical Center outpatient
Norwood Hospital
Good Samaritan for ER and for detox
Lahey Clinic in Burlington
MCI prison doctor
Private primary care doctor in Wellesley
MGH – psychiatry
Private doctor addiction specialist in Canton
Emergency Rooms: BMC, Brigham and Women's, MGH, NEMC

Quotas and Long Waits

Waiting for medical care and treatment while in prison was the most common complaint. Delays led to situations where women receive preliminary diagnoses of serious conditions while in prison, yet they are released before a treatment plan is set in place.

NN is a slim woman with a large, hard, swollen distended stomach. “It took two weeks for them to do an exam, pap. The nurse thought I was pregnant. She scheduled me for Shattuck Hospital for an ultrasound. Four months later they finally did the ultrasound. The doctor said they would fax the results the next day. I kept asking because I was worried but was not given the results. It took the nurse 27 days to call me in for the ultra sound results. Three months later they send me for a CT scan, though the doctor said to do an MRI. Huge fibroids, 4 and a half centimeters, like a 4 month fetus. They said maybe I should have a hysterectomy.” NN was released from prison with no follow-up.

TT tells how the prison clinic received lab results indicating that she is infected with HPV but relayed the results to her two weeks later -- on the very day that she was released! “They [the nurse] told me I definitely would get cancer and that I need to take care of this right away.” However, the prison health system did not offer her any care nor did the nurse offer to make phone calls for her to set up an appointment to follow up with a doctor after her release.

Quotas, waiting and denial of services happens outside of prison as well. This is especially likely to be the case for psychotherapy and for detoxification programs.

“I asked at the clinic for a counselor but they said they're packed up.”

“I was cut short during my detox [by Mass Health]. They said I passed my quota for detox. They call that a ‘red flag.’”

Bureaucracy

While it is likely that many of the interviewees were eligible for Mass Health but did not follow through on enrolling, it also is the case that their chaotic life-styles and frequent moves made it difficult for them to follow through and keep track of paperwork. At every stage of applying and setting up appointments there are waits which, for these women, present serious obstacles.

Several women commented that it is easier getting care in jail than out of jail because on the outside they often don't have an address to which their Mass Health card can be mailed.

“I think my [Mass Health] card was sent to wrong address.”

“I think my [Mass Health] card is with the half-way house I was in before [prison].”

Typically, if a Mass Health card is sent back by the post office, Mass Health unenrolls the applicant.

Other women were stymied by rules they did not understand, time limits on eligibilities, or demands for documents that they did not have.

“It was too hard trying to explain to Mass Health that I'm a citizen but can't prove it [she is missing the necessary documentation].

“I had Mass Health for one year and then it was cancelled.... I didn't renew.”

“I was put on a waiting list for Mass Health. Never got it because I was supposed to reapply and never did because I went back to drugs.”

“You call, they put you on hold, they take too long to get you what you need. I need letters, documents saying that I can't work because of being a victim of violent crime.”

While systematic questions about their understanding of the new health coverage law in Massachusetts were not asked, none of the women suggested that they had heard of the changes either while in prison or since release. Indeed, as we noted earlier:

Less than half of the women even applied for Mass Health while in prison and only four women actually received their Mass Health card immediately upon release.

Cost

No systematic studies have been conducted of pre-incarceration access to health care services. However, research has documented that non-married women and poor women are less likely than other women to be covered by employment-based health insurance and therefore less likely to benefit from consistent medical services (Sered and Fernandopulle 2005). Women involved with the criminal justice system are disproportionately poor and non-married, thus less likely to have had dependable health care coverage prior to incarceration. Upon release from prison, women face an additional set of obstacles to managing their health. With a record of incarceration, women find it difficult to secure employment (Boutwell, Kendrick and Rich 2006). Jobs that are available are often low-wage, part-time, seasonal, or temporary; positions that rarely provide health care benefits. Existing state care programs for the indigent may not be sufficient to meet the needs of this population. According to a recent Massachusetts Public Health Association study, “The incarcerated population [in Massachusetts] is sicker and much less likely to have received medical care in the community than those who have not been incarcerated” (2003:4).

Cost constitutes a significant barrier to health care for the women of this study. Despite the fact that employment based health insurance is the normative health care financing track in the United States, very few women in this study have held employment based insurance during the five years prior to their most recent incarceration. Furthermore, considering their complex and serious health problems, very few have been granted Medicare through SSI Disability. Medicaid (MassHealth) is the primary financier of health care for these women. More than one woman said, “I'm grateful for Mass Health.”

Still, many of the women fall through the cracks and report being uninsured.*

* This chart reflects the women's estimates of their health insurance status over the five year period preceding their most recent incarceration. Most of the women had spotty coverage. Very few of the women were covered for the entire five year period.

Health Care Coverage Prior to Incarceration

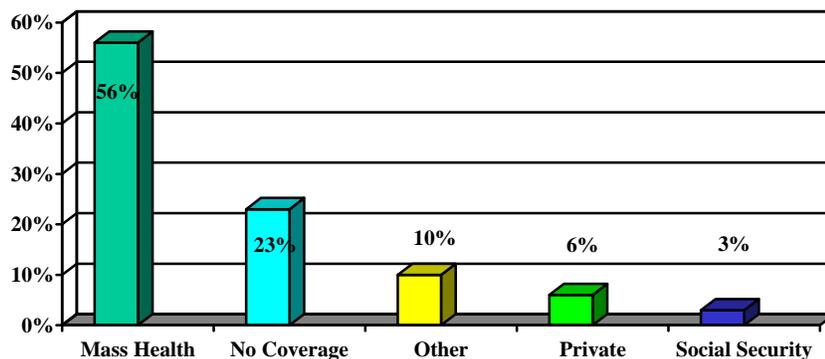


figure 31

Thirty-eight percent of respondents said there have been times they needed medical care but could not afford it.

AH had employment based insurance while working but after she lost her job she was uninsured. She paid for a few appointments but then couldn't afford them. She is supposed to have pap smears every six months because the doctor found that she has pre-cancerous cells, but she couldn't afford pap smears for quite a while before she went to prison.

Providers Issues: Insensitivity, Stigma and Harassment

While women who were identified in the emergency room as having been hurt or beaten tended to be treated quite well, it often was the case – both for girls and for women – that medical providers did not notice and did not ask about abuse.

Interviewees elucidated ways in which medical providers had made them feel uncomfortable. In some instances, medical providers conveyed their distaste for women “like them” who become pregnant. Sometimes, these comments are twinged with racism.

AN saw a gynecologist after a miscarriage. “He said, after putting the light on me, ‘Boy this was my lucky day!’ and then he said, ‘You really didn't want this baby did you?’ I have tried to see only women gynecologists since then [since] I was abused as a child.”

“When I was pregnant and a doctor saw me he said, ‘That's disgusting!’”

Several women report that medical providers treat them with suspicion, assuming that they are trying to trick doctors into giving them narcotics or that they are thieves.

“I had a blood clot and went to the ER. [They] thought I was looking for pain meds and sent me away and told me to stay off the street. I went to Lowell General and they found the embolism and I was hospitalized for two months.”

“Dr. XXX accused me of stealing. I used to see Dr. XXX. The secretary's wallet was missing. They accused me of stealing it. They searched my house. The wallet was found in the secretary's car. Nothing was stolen. They apologized but I never went back.”

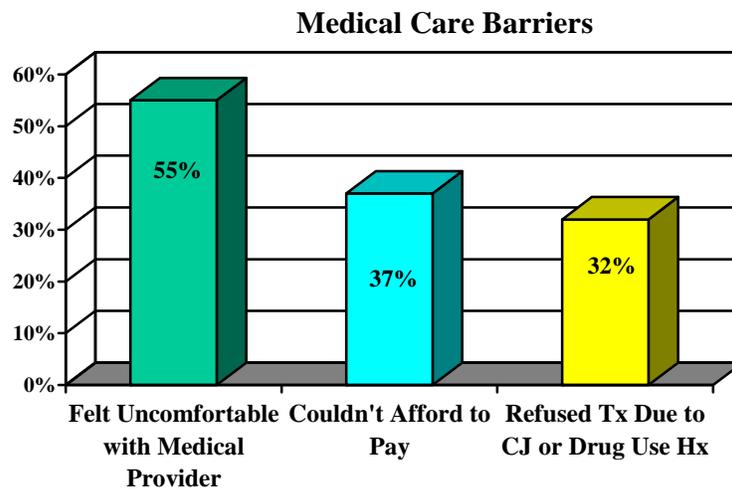
Several of the women reported sexually inappropriate comments or behaviors on the part of medical staff.

AM tells how a psychiatrist to whom she was sent assumed that, because of her drug history, she worked as a prostitute. AM, however, did not work in prostitution and told him that she did not. “He talked about sexual topics that were inappropriate and in an inappropriate way.”

BK recalls, “[When I was a teenager] I went to the doctor for a UTI [urinary tract infection]. He sent the nurse out of the room and molested me.”

Although most providers do behave properly, histories of sexual abuse present significant barriers for many of the women.

AE, who has four large visible gaps where teeth are missing, explains, "If the dentist is a man I can't stand it and I run out. I can't stand a strange man putting hands on me."

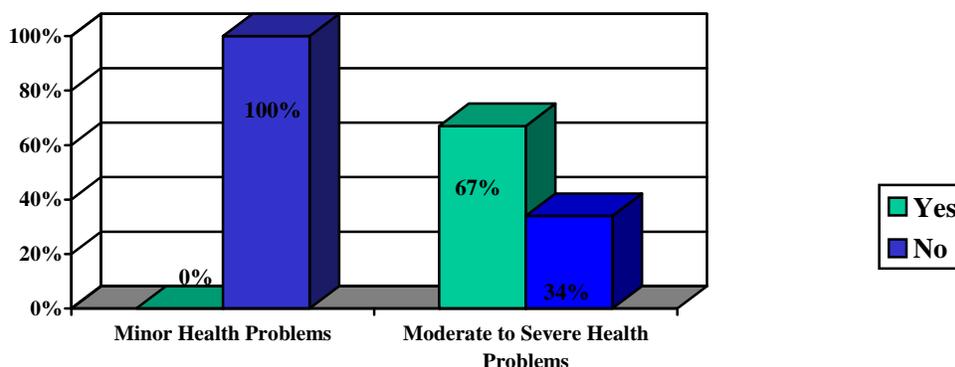


Reasons for Not Accessing Medical Care

figure 32

Women who report having had an experience in which a health care provider made them feel uncomfortable tend to present poorer health profiles.

Has a Medical Professional Ever Made You Feel Uncomfortable/ Severity of Health Problems



Severity of Health Problems

figure 33

Programs, Practices and Strategies that Facilitate Health Promotion Over the Life-Course: The Women Speak Their Minds

“It would have helped if there had been something like the cancer van [mobile testing van] for women on the streets and doing stuff [drugs] like I was doing. Bring the health care to them. We're drugging and don't feel pain so we can't tell [that there is a health problem]. The distance makes it hard [to go to the doctor.] It's like - 'I'm too high to walk.' I've been out in the cold and doing things I shouldn't be doing, and that's hurt my health.”

While this study was designed to identify the barriers that prevent or make it difficult for women in the criminal justice system to access appropriate health care services, we think it is crucial to note that the women themselves often have survival strategies that help them maintain their health, a variety of appropriate services are available to the women, and they often do make use of those services.

Interviewees were asked a series of questions aimed at eliciting what they feel has made it easier for them to take care of their health. Their responses offer insight into successful policies and programs as well as into beneficial structural conditions.

Availability and Continuity of Services

A first set of responses highlights the availability of various kinds of care and help.

- “Mass Health. I have been on it for three years - they simply put it on hold while I was in prison.”
- “Boston Medical Center.”
- “I go to doctors and to the hospital OFTEN. I run to the doctor with any problem.”

- “In XXX (town) the police put me on a crisis list.” [This meant that when she was picked up the police could quickly access her history and take her to an appropriate facility.]

Avoiding Prostitution

A second set of responses have to do with life choices and lifestyles of the women.

- “[What makes it easier for me to maintain my health?] Not having multiple sex partners.... Counterfitting is healthier!”
- "I've had lots of jobs. Larceny is safer than prostitution!"
- "I wasn't out there like that. How they prostitute. I only sold drugs... You can't sell and smoke drugs at the same time.”

Avoiding Drugs

A third set of responses have to do with substance abuse issues faced by the women..

- “I was an addict and let things go.”
- "My problems with substance abuse led to arrest, problems with DSS and getting a job."
- "Drugs make it more difficult.... I don't keep appointments... I am always chasing something.”

Family

A fourth set of responses focuses on family relationships.

- “I love my kids.... My kids saved my life. They are my only family.”
- “I am trying to stay well for my son.”
- “My kids [all well-functioning adults] - I know they need me and love me and I don't want to let them down."
- "My family!! Without my family I'd be on the street. When I'm sick my mother makes me go to the doctor."

Recommendations

The ultimate goal of this study is to better serve the health care needs of women who are likely to be or have been incarcerated. In this section we identify programs and policies that could positively impact their health status by facilitating healthy behaviors and by eliminating barriers to medical care. Many of these recommendations fall into the category of expanding or improving policies and programs that already are in place. Several of the recommendations provide a novel approach.

Continuity of Care

These women have complex medical problems, complicated histories, limited capabilities to organize their personal and medical lives, and constant disruptions in terms of housing, family and other aspects of life. Thus, in many cases appropriate services are available; still, the women interviewed are not able to access them in a consistent way. In short, while the various recommendations may be useful, the key recommendation is the need for a

systematic program that helps the women transcend the piecemeal care that results from the fragmented health care system and their own disrupted lives. This recommendation recognizes that many of these women are not, and never will be, able to navigate the complex health care system on their own.

Many of the women we interviewed could benefit from a permanent health care advocate or caseworker who helps them manage their health and health care needs before, during and after incarceration.

Such a caseworker potentially would save substantial sums of money by heading off situations in which:

- ❖ Expensive tests are repeated
- ❖ Treatment plans are developed but never executed
- ❖ Medications that are contra-indicated are given by providers who do not know the women's history
- ❖ Appointments are made but not kept
- ❖ Prescriptions and medical equipment is misplaced during moves between facilities
- ❖ Therapy begins but is terminated prematurely

For the medical caseworker to be most effective, several other pieces need to be in place:

- ❖ A system that would ensure that at-risk girls and women retain Mass Health eligibility without the need to reapply.
- ❖ The assignment of a female PCP who will commit to at least a three year relationship with the woman.
- ❖ The assignment of a medical home base (a clinic, hospital, agency).
- ❖ A system of providing transportation to and from the medical home base.
- ❖ A system of storing all of their medical records in a computer-based system so as to decrease dependence upon their holding onto paperwork.

Stable and Secure Housing

In light of our finding that homelessness is the strongest correlate for seriously poor health, any broad plan needs to address the lack of secure housing among the women. For many of the interviewees, insecure housing situations began in childhood when they left (or were taken from) home because of sexual abuse or substance use. Only a small number of our interviewees knew where they would live once their limited stay at the Boston Rescue Mission would end. All of our interviews described shuffling between a variety of punitive and treatment programs, being thrown out of their homes or out of treatment facilities, or of having no choice other than to live in a dangerous situation. Permanent housing can:

- ❖ Help women address the chaos of their lives
- ❖ Facilitate their keeping track of records, medications, and appointments
- ❖ Decrease their dependency upon violent and abusive men

- ❖ Help women stay away from drugs and prostitution (and thus facilitate better health)

“Housing first is an alternative to the current system of emergency shelter/transitional housing, which tends to prolong the length of time that families remain homeless. The methodology is premised on the belief that vulnerable and at-risk homeless families are more responsive to interventions and social services support after they are in their own housing, rather than while living in temporary/transitional facilities or housing programs. With permanent housing, these families can begin to regain the self-confidence and control over their lives they lost when they became homeless. The housing first approach provides a link between the emergency shelter/transitional housing systems that serve homeless families and the mainstream resources and services that can help them rebuild their lives in permanent housing, as members of a neighborhood and a community. In addition to assisting homeless families back into housing, the approach can offer an individualized and structured plan of action for alienated, dysfunctional and troubled families, while providing a responsive and caring support system.”
See www.housingfirst.net

Supportive Housing programs developed in several other cities (New York City, New Haven) are models of integrated solutions for individuals who need long-term or permanent support because of physical, mental or other disabilities.

Victims of Violence Program

One of the striking findings of the present study is that while the majority of the women have been diagnosed with mental illness, relatively few have accessed either psychotherapy or detox / treatment programs that have been helpful. In fact, this is not surprising. Conventional therapies have poor success rates in helping women who have been victims of sexual and physical abuse. Thus there is a need for efforts to identify new approaches and programs that can help the women process, come to terms with, and move beyond the emotional, physical and sexual violence that has characterized their lives.

The Cambridge Health Alliance’s Victims of Violence (VOV) Program uses a multi-faceted approach to provide a range of individual and group services to victims of violence. A uniquely successful aspect of the VOV Program is its emphasis on helping victims of violence reestablish a sense of meaning in their lives.

Specific Recommendations Throughout the Life Course

CHILDHOOD

- ❖ Increase training for emergency room staff, family doctors and school counselors to help identify and respond to childhood sexual and physical abuse.
- ❖ Increase training in juvenile detention facilities and other settings to focus on the possibility / probability of girls’ histories of sexual and physical abuse.
- ❖ Adopt the Cambridge Health Alliance’s Victims of Violence model into juvenile detention and other relevant facilities.
- ❖ Develop and maintain programs that provide long-term psychotherapy for at-risk girls.
- ❖ Screen at-risk girls for learning disabilities.

ADULTHOOD

- ❖ Continue to fund needle replacement programs. Only 26.9% of the respondents report having shared needles and none of the respondents report being HIV positive.
- ❖ Expand access to dental care.
- ❖ Simplify the Mass Health enrollment system for at-risk and re-entry women.
- ❖ Increase awareness regarding the short-term and long-term health implications of sexual and physical abuse among emergency room staff and providers at detoxification and other facilities.

INCARCERATION

- ❖ Increase medical staffing in prison so that incarceration can serve as an opportunity for women to take care of the backlog of medical problems that developed while they were on the street.
- ❖ Develop and maintain a medical advocacy program.
- ❖ Develop and maintain a program in which each incarcerated woman has a prison PCP.
- ❖ Reduce waiting time for medical care.
- ❖ Expand prison mental health services.
- ❖ Adopt the Cambridge Health Alliance's Victims of Violence model into women's prisons.
- ❖ Screen for learning disabilities.
- ❖ Support programs that facilitate maintenance of relationships with children (including babies), sisters and mothers.
- ❖ Improve screening for and management of MRSA.

RE-ENTRY

- ❖ Ensure that women leave prison with their first post-release doctor's appointment in place.
- ❖ Ensure that women leave prison with Mass Health enrollment activated.
- ❖ Ensure that women leave prison with an adequate supply of medication.
- ❖ Assign a medical case worker to arrange continued medical care post-incarceration.
- ❖ Support programs that facilitate maintenance of relationships with children (including babies), sisters and mothers.
- ❖ Adopt the Cambridge Health Alliance's Victims of Violence model into re-entry programs.
- ❖ Ensure that policy is discussed regarding transfer of medication and medical records from incarceration to community supervision agencies.

Future Research

The present study, a small-scale, time-limited research effort, points to the need for further research in a number of areas. Future studies would (1) track longitudinally the health status of women who have been involved with the criminal justice system, (2) would expand the sample size to allow analysis of differences among the women, and (3) would evaluate programs that address the health needs of at-risk, incarcerated and re-entry women.

Longitudinal research recognizes that the women in the criminal justice system have experienced illness and trauma throughout their life course. Potential future research projects include:

- ❖ Retrospective and longitudinal study of the health and well-being of women who were last incarcerated ten or fifteen years ago. Where are they now? How many are alive? What, if any, factors or programs helped them exit the world of substance abuse and involvement with the criminal justice system?
- ❖ A study of resilience and the health maintenance strategies of women involved with the criminal justice system.

A larger sample would allow researchers to identify which groups of women are at high risk for severe health problems, and which health problems are most closely linked to risk of incarceration and recidivism.

- ❖ Exploration of possible relationships between learning disabilities and involvement with the criminal justice system for women. This study could be carried out most efficiently among a currently incarcerated prison population.
- ❖ Comparative analysis of health and health care issues among white, African-American, and Hispanic women.
- ❖ Analysis of health and health care issues among women of various age groups.

Studies assessing specific programs could track the outcome of existing re-entry programs at the Boston Rescue Mission and elsewhere, as well as track the outcome of pilot projects as described in the Recommendations section of this report. For example:

- ❖ A study tracking the outcome of a pilot project that assigns incarcerated women a PCP to coordinate their care while in prison.
- ❖ A study tracking the outcome of a pilot project that assigns women a medical caseworker who begins working in prison to set up and coordinate post-release care and continues to coordinate care post-release.

Finally, in the wake of health care reform legislation in Massachusetts, it is crucial to track how the new individual mandate to have health insurance, together with reductions in the free care pool, are affecting women who are or have been involved with the criminal justice system.

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