

THE STIGMA OF SUBSTANCE USE: A REVIEW OF THE LITERATURE

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Introduction

Among the burdens carried by people who are marginalized in our society is the weight of stigma. How that stigma is defined and its effects on the stigmatized have been the subject of numerous academic works. The value in exploring this body of literature lies in the clues it may provide as to how to respond to stigma in way that will counter it. A review of the literature on stigma will be presented with particular reference to stigma in selected groups of the substance using population. This paper will first outline key theoretical concepts from the labelling perspective which help to explain the process of stigmatization. Specific topics to be covered related to substance use include; 1] the stigma of drug use among women, pregnant women and mothers in general, 2] the stigma faced by methadone users 3] the influence on stigma of methadone treatment staff attitudes with respect to abstinence , and 4] the courtesy stigma experienced by families. The paper will conclude with a discussion of strategies for destigmatization.

Conceptual Framework: The Stigmatization Process

The kind of behaviours which are considered deviant and therefore stigmatized varies considerably between cultures and over time [Schur, 1971]. The assignment of stigma to individuals and groups who engage in deviant behaviour is a decidedly social process involving negotiation, bargaining, power and, at times, resistance [Schur, 1971; Ben-Yehuda, 1990]. Hence, an examination of the literature on stigma within the drug using population can best be anchored in sociological theories such as the labelling perspective which explains stigma in terms of these processes.

Goffman [1963] used the term stigma to “refer to an attribute that is deeply discrediting” [page 3]. Inherent to this definition is the idea that this attribute is something which deviates from what society has deemed ‘normal’ [Schur, 1971]. This attribute can be a physical marking or a behaviour [Goffman 1963]. Because of its deviation from what is considered normal, society responds to this attribute with “...interpersonal or collective reactions that serve to ‘isolate’ ‘treat’, ‘correct,’ or ‘punish’ individuals engaged in such behaviour” [Schur, 1971, page 24]. As such, the response to stigma is social control [Ibid; Lemert, 1972].

Central to any discussion of stigma is the powerful influence it exerts on a person’s identity. Lemert [1951] distinguished between “primary” and “secondary” deviance [page 75]. Primary deviance is the initial act or behaviour which goes against the dominant norms of society. It may or may not result in the individual receiving an official stigmatizing label. When it does, however, the process of secondary deviation begins. As Lemert [1951] explained secondary deviance involves the assumption of certain “roles” which then become the central way through which the labelled person and society views and judges him or her [Ibid.]. The labelling perspective further argues that the stigmatized person becomes, by virtue of the label, isolated from non-stigmatized groups in society [Clinard and Meier, 1992]. This can severely limit the individual’s ability to fully participate in the everyday life of society, such as holding a job, having a home, getting access to any needed services and enjoying mutually supportive relationships with family and friends [Ibid]. In effect, the stigmatized individual who is denied legitimate

social roles adopts “a deviant social role”[Ibid, page 107]. This has profound implications for an individual’s view of his or her self. As Schur [1971] described, the deviant role causes an “engulfment” which changes a person’s identity [page 69].

One major consequence of the processes through which deviant identity is imputed is the tendency of the deviator to become ‘caught up in’ a deviant role, to find that it has become highly salient in his overall personal identity {or concept of self}, that his behavior is increasingly organized ‘around’ the role, and the cultural expectations attached to the role have come to take precedence, or increased salience relative to other expectations, in the organization of his activities and general way of life. [Ibid].

Having an identity as a deviant is extremely difficult to change as the stigmatized label is “sticky”[Goode, 1984, page 35]. As Goode [1984] noted, there are many symbolic ceremonies involved in the labelling process such as receiving a diagnosis, being arrested or being admitted to a treatment centre or jail. Yet, there are no equally powerful ceremonies which destigmatize and reintegrate the person who chooses to relinquish the deviant behaviour. In Goode’s [1984] words, “Nothing has happened to cancel out the stigmas that society has imposed” [Ibid].

Stigma can be seen as a multi-layered structure where several deviant statuses can be held at one time as in the case of a person who is poor and who uses substances. Membership in a low socioeconomic class makes a unique contribution to the stigmatization of substance use. As Schur [1971] outlined, people or groups who have few resources are less likely to be able to “resist” a stigmatizing label or to challenge the organizational body that is applying the label [page 150]. Thus, the use of substances by people who are poor or substance use which is “associated with socially marginal persons

is more likely to be considered deviant than the drug use among the well-to-do” [Clinard and Meier, 1992, page 186]. The act of labelling someone a ‘deviant’ is therefore a political one [Ben-Yehuda, 1990]. Only those groups with power are able to “impose” rules about morality against other less powerful groups [Ben Yehuda, 1990, page 65; Schur 1971; Jones et. al., 1984]. As Jones et. al. [1984] outline;

Potentially stigmatizing marks have a vastly different fate, depending on whether they are associated with high or low social status--with wealth, prestige, and ‘winners’, or with poverty, ignorance, and ‘losers’. Certain ‘deviant’ behaviors are inherently expensive, and may take on cachet because of that. The use of cocaine seems almost restricted to the wealthy, and users are, by and large, less stigmatized than heroin addicts. One reason for this may be the association of heroin with squalid surroundings and ‘buys’ financed by muggings and larceny. The popular image of cocaine does not include such discordant notes [pages 303-4].

Some scholars have developed frameworks to more closely examine stigma. Jones et. al. [1984] proposed that stigma has six “dimensions” which include; 1] the degree to which the stigmatizing attribute/behaviour can be concealed, 2] the expected long term result associated with the attribute/behaviour, 3] the degree to which activities of everyday life is impeded, 4] the physical appearance of the person who has the stigmatizing attribute, 5] the degree to which the person is responsible for the attribute/behaviour, and 6] the degree to which the attribute/behaviour is dangerous to others [page 24]. All of these dimensions could be argued to be part of the stigma that is related to substance use. The issue of responsibility is key when looking at the stigma of addictions. Jones et. al. [1984] noted that when an individual is held responsible for his or her stigmatizing condition he or she is apt “to be treated negatively and to be viewed

unfavourably” [page 58].

A significant part of the negative treatment substance users experience occurs because of stereotyping or what Kallen [1989] refers to as “contagion” [page 52]. This is defined as the spreading of negative characteristics which are attributed to a person who is a member of a stigmatized group such as a substance user [Ibid]. Hence the stereotype of the drug user as an immoral criminal who poses a dangerous risk to society. As Kallen [1989] explains, “It is this grotesque caricature of the stigmatized population that provides the legitimating grounds for categorical discrimination...” [page 52].

And what is the effect of this stigmatization and stereotyping on users? In a longitudinal study of men [N=84] who had a dual diagnosis of mental illness and substance abuse, Link et. al. [1997] investigated the stigmatization process and its effects. These authors conceptualized the process as involving three cognitive and behavioural components [Ibid].

- {1} culturally induced expectations of rejection,
- {2} experiences of rejection, and
- {3} efforts at coping with stigma [page 179].

The first component relates to the fact that in our culture we are socialized through interactions with family and friends to hold certain beliefs about people who are mentally ill and/or who use drugs. This writer would argue that media images of drug abuse may also play a role in the beliefs we acquire. As Link et. al. [1997] explained, these beliefs would relate to notions about the ability of a substance users to find work, to be a useful member of the community, to be involved in relationships with family and others and so

on. When a person receives a “drug-abuser” label, the beliefs that the person has with respect to drug users now “...become{s} personally relevant” [Ibid., page 179]. The substance user then becomes fearful of rejection. This belief that family, friends, employers and society will no longer value the person who uses substances and the expectations of rejection experienced by the user creates a host of problems for him or her. Link et. al. [1997] noted that “...labelling triggers powerful expectations of rejection that in turn erode confidence, disrupt social interaction, and impair social and occupational functioning” [page 179].

Unfortunately, the expectations of rejection are often reinforced through the experience of rejection. Within their sample of 84 men, Link et. al. [1997] found that, because of their substance use history, 24% had received lower wages at work, 16% found landlords unwilling to rent them an apartment and 6% had been refused health care [page 183].

Because of the expectations and experiences of rejection, people who are stigmatized due to mental illness and/or drug use develop specific coping strategies. Link et. al [1997], hypothesized that “secrecy” and “withdrawal” would be particularly relevant strategies for people who are mentally ill and/or use drugs [page 180]. These researchers found that 52% of the sample believed that a history of drug use should be kept a secret and 76% believed that a drug use history should be kept secret from employers [page 183]. Furthermore, 57% of the sample stated that they would not try to get a job with an employer who felt negatively toward people with drug abuse problems [Ibid., page 184].

One can see how these two coping strategies could isolate users in their relationships with potential employers, co-workers, family and friends. In effect, these two strategies rely on the user being deceptive in or avoidant of interactions with others.

Given the fact that addiction is a condition which falls under a “disease model” [Acker, 1993, page 202] one might assume that medicalization offers protection against stigmatization. It has not always done so. As Acker [1993] outlined in her historical review of disease models, the psychiatric model of addiction which was popular between the 1940's-1970's attributed the individual's addiction to personality “flaws” [page 202]. Acker [1993] argued that an emphasis on the behavioural aspects of addiction have, in the last three decades, created a change in how addiction is viewed in society, resulting in less stigmatization of the substance user [page 203]. However, the author noted that whether or not an individual would be ‘treated’ as a blameless or blameful addict depends upon that individual's socioeconomic status and other factors such as the type of drug involved [Ibid]. This discrepancy in who is stigmatized for their drug use can best be illustrated in an examination of specific groups.

Stigma and Women: The Experience of Women Who Use Substances

Women users may experience what Copeland [1997] described as “double deviance” which refers to the extremely negative stereotype that women users are, in addition to being addicted, sexually promiscuous because of their drug or alcohol use [page 186]. This double deviance relates to notions about the traditional ‘place’ which women have occupied in society. In her book which explores society's response to the

female alcoholic, Ridlon [1988] argued that women have been seen “...as the preservers of morality, charged to uphold the moral and spiritual values of society” [page 25]. A stereotype exists that alcohol use in women will result in a loosening of sexual mores [Ibid, page 27]. Consequently, when women drink alcohol to excess they are likely to be stigmatized as sexually indiscriminate and ‘available’. As Ridlon [1988] explained, there is no such stereotypical pairing of drinking alcohol with sexual promiscuity in men who drink to excess. Hence, there is a “double standard” which increases stigmatization for women alcoholics [Ibid.]. Ridlon [1988] identified that because of this double standard, women may be discouraged from heavy drinking and are thus somewhat protected from the risk of alcoholism [pages 29-30]. However, because the stigma for women alcoholics is so great, a woman’s excessive drinking may become actively “hidden” by family and friends [Ibid., page 30]. This represents an effort to avoid a stigmatizing label. Fear of being stigmatized also acts as a “barrier” for women to get treatment for alcoholism or other drug use [Copeland, 1997, page 183]. As Ridlon [1988] explained:

The moral condemnation that has prevented many women from ever turning to drink keeps them from ever recovering once they develop a drinking problem. The woman is stuck with her drinking problem or condemned as a tramp, unfit mother, or worse if she does seek help. Alcoholic women, and frequently the people with whom they come in contact, end up doing all they can to keep from identifying the problem [page 37].

Other authors have argued that the stigma for women who use any licit or illicit drug is more severe than for men. Again this relates to women’s ‘place’ in society notably as the people who bear and rear children and who, historically, have had less power and status

than men [Schur, 1983]. As Schur [1983] noted, in the area of motherhood “...women’s behavior is subject to considerable normative regulation” [page 81]. This can most clearly be seen in the social response to women who use illicit substances during pregnancy. One response popular in many of the U.S. states is the criminalization of women who use drugs during pregnancy [Mahan, 1996, pages 38-40]. As Mahan [1996] reported, stigmatization and criminal sanctions have been rigorously applied to pregnant women in the U.S.A. who use crack. She further noted that this criminalizing response has not been levelled against pregnant women who abuse alcohol or cigarettes [Ibid]. While, in many U.S. states pregnant women can be incarcerated for endangering their fetus, Canada’s current laws differ. In 1997 Canada’s Supreme Court ruled that “...the courts cannot force pregnant women into drug treatment for the purpose of protecting the unborn child” [Boyd, 1999, page 24].

The late 1980's was witness to a “moral panic” over “crack babies” [Goode and Ben-Yehuda, 1994, page 216]. As was outlined by Goode and Ben-Yehuda [1994], the studies which supported the existence of a “crack-baby syndrome” were based on faulty research designs which did not control for important variables such as use of other substances, the mother’s overall health and living situation and the mother’s access to and compliance with prenatal medical care [pages 217-218]. These authors cited research which suggested that the crack-baby syndrome may have been due to the effects of the mothers’ chaotic and impoverished lives and their use of many other drugs [Ibid., page 218].

Another factor may be at play in the panic over maternal use of crack and that is the

overlay of stigmas seen in prejudicial attitudes attached to class and race. Humphries' [1999] book which focused on the media presentation of crack and cocaine use among pregnant women in the United States, identified that in the mid 1980's a stereotype emerged of the pregnant crack user as African American, poor and on welfare [pages 8-15]. Humphries [1999] argued that the media frenzy around women who used crack served a political agenda which focused on social welfare cuts. As she noted; "Fiscal conservatism fuelled by racist and sexist images of poor women of color justified cutbacks in social services in the 1980's" [Humphries, 1999, page 18]. Other research also identifies this complex nature of stigma and its influence on public policy.

A recent Canadian study conducted by Boyd [1999] explored the social effects of drug use among mothers. In this qualitative research, Boyd [1999] carried out in-depth interviews with mothers [N=28] about their experiences with health and social services as well as the criminal justice system. All of the women in her study had a history of illicit drug use involving either or both cocaine and narcotics [Boyd, 1999, page 42]. The women in her study recounted their stigma experiences during their prenatal and antenatal health care visits. For example, some women identified difficulty in accessing accurate information about the risks associated with continuing use of specific drugs including methadone on the fetus [pages 65-66]. Some of the women in Boyd's [1999] research also reported that they were treated disrespectfully by physicians and other health care staff during prenatal visits and childbirth [page 66]. In addition, the women who were receiving welfare described that once they were labelled as illicit drug users they were

“denied services and treated with less respect”[page 120]. Fears that their children would be apprehended by children’s aid agencies was one of the greatest concerns of the women in Boyd’s [1999] study [pages 124-129]. Boyd [1999] noted that;

The women interviewed stated that social workers were ill-informed about illicit drug use, and their misconceptions coloured their decisions. Mothers were often denied custody of their children because of their history as illicit drug users. There was little room for negotiation, and mothers stated that there was no way to ‘prove’ that they were capable of caring for their children once they had been labelled as illicit drug users [pages 128-129].

Boyd [1999] challenged the assumptions which guide policy vis a vis maternal drug use. Using a feminist analysis Boyd [1999] argued that policy makers assume that the only legitimate family type is two parent, “white and middle class” [page 211]. As well the assumption is made that drugs like alcohol and tobacco are less harmful than illegal substances [Ibid]. And, the assumption is further made that mothers who use illicit drugs are immoral criminals [Ibid]. Boyd [1999] presents an argument for the legalization of drugs as a way to counter the stigma associated with women’s illicit drug use. In her conclusion, Boyd [1999] stated;

The combination of our fear of illicit drugs, moralism, the regulation of reproduction, the suspected breakdown of the family and of traditional gender roles, racism, sexism and classism has contributed to the social construction of mothers who use illicit drugs as scapegoats who embody all that is feared and considered evil in Western society [Page 212].

Many of the findings outlined in Boyd’s [1999] study have also been noted in other studies of mothers who use illicit drugs [Murphy and Rosenbaum, 1999]. Moreover, recent research suggests that treatment resources for pregnant users are woefully

inadequate due, in large part, to the male-centred nature of many drug treatment programs [Murphy and Rosenbaum, 1999, pages 150-151]. Murphy and Rosenbaum [1999] reported, in their study of pregnant women [N=120], a need for treatment programs to be designed that are sensitive to the needs of women who may be sole support parents. These researchers also found that users in their sample attempted to reduce harm to the fetus by decreasing the dose of substances or switching to a substance that was perceived to be less harmful [pages 83-85]. While Boyd [1999] called for the legalization of illicit drugs as a strategy for ending the stigmatization of users, Murphy and Rosenbaum [1999] argued for a harm reduction approach; empowering women through information, access to respectful and supportive prenatal care and efforts to address the structural barriers to ceasing or decreasing drug use, notably poverty.

Stigma And Methadone Users: The Contribution Of Policy And Staff Attitudes

The stigma of methadone use is the stigma of heroin addiction, despite the fact that methadone users are, by definition, in treatment to stop using heroin. In their review of three qualitative studies conducted in the 1980's, Murphy and Irwin [1992] described methadone patients as having a “marginal identity” where they saw themselves and were viewed by society as deviant, despite their efforts to end their addiction [page 258]. While people enter methadone treatment to stop using heroin and to normalize their lives, the stigma attached to being in treatment for a heroin addiction interferes with this process. As was discussed by Link et. al. [1997], there is a pressing need experienced by patients to maintain secrecy about their addiction. This can pose problems in relationships with

loved ones as secrecy about important issues can create emotional distance within close relationships or feelings of betrayal and rejection if the secret is 'discovered' [Murphy and Irwin, 1992]. As Murphy and Irwin [1992] described, people attending methadone clinics spend considerable time and effort in "concealing" their status as methadone patients from the people in their lives outside of the clinic [page 261]. Thus, layered over the patients' efforts in substance abuse treatment were the stresses associated with compartmentalizing their social networks into those who were 'in' on the secret and those who were not [Ibid]. Moreover, the coping strategies which patients used were perceived negatively by those people in their social networks who did know that they were in methadone treatment [page 262]. As Murphy and Irwin [1992] explained:

...the methadone patient might be seen as a chronically late person by his employer because he or she has to go to the clinic prior to arriving at work. A methadone patient who was not properly adjusted to the prescribed dose might be perceived as inattentive or without energy in the late afternoon in the classroom [Ibid].

In other words, the fear of being stigmatized leads to secrecy about methadone treatment. The side effects and protocols of this treatment can lead to problematic behaviour on the part of patients {i.e. being late, being sleepy} which are then interpreted in a manner which results in stigmatization of the patient for the problematic behaviour. As Murphy and Irwin [1992] aptly stated, "at this juncture the methadone patients were in a double bind" [Ibid]. Not surprisingly, patients in these studies struggled around the decision to tell new friends and others in their social networks about their status as methadone patients [Ibid].

Why does methadone treatment have, inherent to it, such stigma? Ben-Yehuda [1990] suggested that methadone treatment is surrounded by a “moral debate” where the philosophies of abstinence and “maintenance” clash [page 159]. These two philosophies operate with different value sets. The abstinence ideology of heroin treatment which is characteristic of “Therapeutic Communities” argued against supplying heroin addicts with another addicting substance on the grounds that doing so does not effect change in the substance user’s values, beliefs or lifestyle [Ibid., page 160]. The maintenance ideology argued that methadone treatment helped heroin users to normalize their daily lives and also assisted in decreasing patients illegal activities [Ibid]. And this latter treatment ideology has been supported in empirical research [Nadelmann et. al., 1997]. Essentially, the conflict between these two treatment philosophies represents the conflict between prohibition and harm reduction. Indeed, it is possible that the source of the stigma which is associated with methadone treatment may be located at the level of policy makers and in the attitudes of some methadone treatment providers. As Nadelmann [1997] explained:

There is widespread ignorance of the proper use of this treatment and often hostility toward methadone among many of those working in MMT {methadone maintenance treatment} programs. Problems include administration of inadequate doses....and a misguided orientation toward abstinence not just from illegal drugs but also from methadone itself, as a treatment goal [page 25].

Nadelmann’s [1997] argument is echoed in the work of Boyd [1999]. In her description of the methadone treatment programs in British Columbia, Boyd [1999] noted that government policy has set a maximum daily dose of 80mg of methadone that can be

prescribed to any patient in treatment, irrespective of whether a patient might need a higher dose [page 146]. This is clearly an example where public policy has not been guided by science. For example a joint publication by the Addiction Research Foundation and the regulatory colleges for physicians and pharmacists [1996] acknowledges that treatment compliance and outcomes are improved when the methadone dose is 60 mg or more [page 4].

Two studies investigated the effects on patients of treatment staff's attitudes with respect to abstinence from methadone as the ultimate treatment goal. Caplehorn et. al. [1996] conducted their research in Australia on physicians [N=10] most of whom were psychiatrists [N=8] in private practice [page 665]. These doctors were surveyed twice over three years with regard to their attitudes about abstinence [Ibid]. Patients [N=280] receiving methadone treatment under the care of these physicians were also interviewed [pages 665-7]. The hypotheses of this study were twofold:

...that greater commitment to abstinence-oriented policies is associated with decreased retention of patients and that strong commitment to abstinence-oriented policies tended to overcome the improved retention usually associated with higher doses of methadone [page 664].

From the physician attitudes surveys the researchers were able to determine that four physicians did not endorse abstinence as the ultimate treatment goal and, in effect, "offered indefinite maintenance" [page 670]. The remaining six physicians did endorse abstinence as the treatment goal [Ibid]. There were differences in the methadone dosages that were given to patients, with patients in the indefinite maintenance category generally

receiving higher maintenance doses than patients treated by pro-abstinence physicians [Ibid]. Patients in the indefinite maintenance category also stayed in treatment significantly longer than those in the abstinence category [Ibid]. So then it can be argued that those patients in indefinite maintenance likely received greater benefit from their treatment experience. In citing previous research Capelhorn et. al. [1996] noted that “the strength of methadone staff’s commitment to abstinence-oriented policies is primarily associated with their support for the punishment of illicit drug users” [page 673]. A more recent study by Capelhorn et. al. [1998] which surveyed staff in six large methadone clinics also found that patients in those programs which were pro-abstinence tended to leave treatment early [pages 58-60-60].

Capelhorn et. al. [1996 and 1998] were not looking at staff attitudes and patients’ gender in terms of patients’ experience of stigma. Boyd [1999], however, did. Some of the women in Boyd’s [1999] study perceived that they were stigmatized by treatment staff “as ‘bad’ women” because of their drug use history and any history of prostitution [Ibid]. Routine practices such as “supervised” urine tests and other intrusive measures were experienced negatively by patients [page 147]. As well, some interactions with treatment staff were reported to be dehumanizing:

The women interviewed described the sexist attitude of many of the doctors who prescribed methadone. One woman noted how she was continually ignored by doctors during her twenty years on methadone. Instead of speaking to her directly, the doctor always addressed her husband [pages 149-150].

As mentioned at the outset of this paper stigma has a multi-layered structure and that

structure seems most apparent when examining groups which have multiple stigmas such as women methadone patients. Of course, another layer in the stigma structure affects families of substance users.

Courtesy Stigma and Families of Substance Users

It would be naive to assume that the families of substance users are untouched by stigma. Concern and worry for a family member with substance use problem is likely going to create struggles within the family and between the family and the outside world [O'Farrell and Cowles, 1989; Birenbaum, 1970]. Goffman [1963] used the term "courtesy stigma" to describe the stigma attached to the families of persons who are stigmatized [page 30]. The literature on courtesy stigma among families of substance abusers is scant. However, this writer would argue that the social dynamics of this type of stigma, which has been researched in other groups that have been stigmatized, can be generalized to families of substance users.

A person with a courtesy stigma essentially occupies two social realities at once. On one hand, he/she does not engage in the behaviour which resulted in the labelling of their family member. Or if he/she does engage in the same behaviour it has not been officially labelled. As such, the family member is part of the 'normal' social world of the non-stigmatized [Ibid]. Yet, on the other hand, the family member shares the stigma of his/her loved one and also has membership in the social world of the stigmatized [Ibid]. As Birenbaum [1970] noted, families of stigmatized people are seen as "... 'normal' yet 'different'" [page 196]. Goffman [1963] outlined that families may respond to this

courtesy stigma in one of two ways; by accepting their loved one in the hopes of showing the world how to treat their loved one with compassion or the family member may distance from their loved one in order to shield themselves against stigma [pages 30-31]. Birenbaum [1970] conceptualized courtesy stigma as dynamic in that this type of stigmatized identity constantly goes through a process of “construction” and “avoidance” depending upon the social context in which the family member is present [page 197]. To apply Birenbaum’s [1970] concept to substance use the family member may, around people who are unaware of their loved one’s substance use problem, avoid talking about him or her or provide only superficial non-stigmatizing information. While this avoidance certainly protects the family member’s loved one from censure, it also protects the family member from being perceived negatively. Even around people who do have knowledge of the stigmatizing condition, the family member and his/her social audience may join in a dance of “tactful inattention, strictly contrived to appear as if the objective fact of the courtesy stigma is of no major subjective importance” [Ibid, page 197].

In his research on the courtesy stigma experienced by mothers [N=103] with a developmentally delayed child, Birenbaum [1970] discussed the changes in social relationships that families made in order to maintain the appearance of being ‘normal’ families to themselves and to the outside world. He noted that, like the stigmatized person, families go through “...cycles of affiliation and dissociation from the community” [page 206]. Friendships were maintained or distanced based upon whether or not the mother’s interactions with friends increased or decreased her perception that she or her

child were being stigmatized [pages 197-200]. Relationships with support groups were experienced by the mothers as helpful but close social connections were generally not made. As Birenbaum [1970] reported;

...too strong an involvement in this world would threaten such a life style by accentuating the mother's identity as the mother of a retarded child at the expense of her identity in the conventional social order [page 202].

From Birenbaum's [1970] study one gets the sense of the delicate 'foot work' families of people who are stigmatized needed to employ in order to maintain an identity as 'normal'.

MacRae [1999] conducted a study of stigma in people who had a family member with Alzheimer's disease. In her qualitative research, MacRae [1999] explored a variety of stigma issues with family members [N=47] including; 1] families' experience of shame related to their loved one's symptoms or behaviour, 2] patterns of avoidance of social situations or locations where interactions with other members of the community were likely to occur, 3] families' efforts to shield information from their social networks about someone in the family having Alzheimer's disease, and 4] the ways in which families concealed information [pages 57-58].

MacRae's [1999] results were interesting. Just over one-half of family members who were in primary care giving roles experienced shame over their loved one's behaviour and just over one-third of the family members who did not assume care giving roles experienced shame [page 59]. Those family members who did feel embarrassed typically avoided accompanying their loved one to public places such as the local shopping mall [pages 59-60]. Among those family members who did not experience stigma, several

coping strategies were used when dealing with social contacts outside of the family. The first involved framing the “misbehaviour” of the loved one with Alzheimer’s as being the symptoms of an illness over which the loved one has no control [page 63]. The second involved actively hiding any information about the symptoms or presence of an illness from social networks [page 60]. Providing clear information about Alzheimer’s disease was used as a third strategy by some family members as a way of educating people in friendship networks [page 64]. Finally, rejection of those social contacts who were judgmental and stigmatizing was a means to avoid stigma [pages 65-66].

Of what relevance can MacRea’s [1999] research have to families of substance users? It is possible that what has been described in the literature as “enabling” or “co-dependent” [Miller, 1989, page 68] behaviours among family members represents the family’s attempt to protect itself from stigmatization. Covering up a family member’s substance use may have little to do with a family’s denial and everything to do with the family’s *awareness* of the negative way the community may respond to the family. If that assumption is made then what has been called co-dependent may simply be a valiant attempt to maintain the integrity of their identity as a ‘normal family’. What shifts when these assumptions are made is the locus of intervention from the family unit to the community and the relationship between the two.

The work of Barton [1991] highlights the problems in the interactions between the community and families of substance users. Barton [1991] conducted a qualitative study of parents [N=40] of adolescents who abused drugs [page 40]. These parents were in the

middle to upper middle class [page 41], employed, one third headed nuclear families and two thirds were either sole support parents or parents in reconstituted families [page 40]. The parents were involved in a weekly support group at a substance use treatment clinic [Ibid]. Ten of these parents volunteered to respond in writing to questions related to; 1] their experiences as parents of substance using teenagers, 2] the effect of their child's substance use on their perception of themselves as parents and, 3] the effect on their social and professional helping network [Ibid]. Barton's [1991] data included "field notes" from researchers who observed the groups, the ten parent volunteer's "journal recordings" and face to face interviews with three parent couples [Ibid].

Barton's [1991] results described the process parents' go through in coming to terms with their child's drug use. This involved initial "denial" of the severity of their child's substance use, "evaluation" of their parenting styles and feelings of "fear", "anger" and "grief" [page 41]. As Barton [1991] reported, most of the parents blamed their parenting styles for their child's substance use [Ibid]. Over the course of the support group self blame on the part of parents gave way to a belief that they needed assume "a new role" in their management of their child [page 42].

Of particular relevance to the issues of stigma were parents' experiences with social and helping networks. The majority of the parents reported that close friends, colleagues at work and their bosses were supportive of them and were helpful in concrete ways such as giving them time off work as needed [Ibid]. Problems were encountered in dealing with neighbours and casual friends. For example, many parents reported that

neighbourhood children were instructed to stay away from their family and this resulted in isolation for the child and feelings of “shame” for the parents [Ibid]. Parents experienced the most stigma when dealing with professional networks including the schools, police and the justice system [Ibid]. They felt ignored, blamed and de-valued when dealing with people in these agencies [page 43]. Furthermore, parents described having difficulty getting these agencies to respond appropriately to their child’s drug abuse. As Barton [1991] noted;

The parents wanted these supposedly impersonal bureaucratic organizations to enforce the rules and laws, to charge the child with wrongdoing so that the child could be socialized about the consequences of drug abuse. Instead, the bureaucrats appeared to be reacting personally against the parents. The message parents received was that it was their responsibility to control the child, with minimal support from community institutions [Ibid].

Further research is needed in the area of stigma experienced by families of people who abuse substances. Barton’s [1991] study was the only one this writer could find which directly examined stigma in families of substance users.

Ending The Stigmatization Of Substance Users

Thus far, this paper has explored the processes involved in stigmatization and the impact of stigma on selected populations of substance users, those related to substance users, and methadone treatment providers. It seems clear that on a macro level, stigma, as a social phenomenon, has a strong influence on the policies which govern criminalization and, with respect to methadone, the kind of treatment that can be offered. At the level of the community, stigma may effect the manner in which a wide range of community

agencies respond to substance users and their families. At the individual level, stigma creates profound changes in the identity of the stigmatized person and it changes the way they are perceived by others. Stigma is a powerful and dynamic social force. How then can the harms associated with the stigma of substance use be stopped?

Various groups of people who have suffered from the effects of social stigma have managed to end or minimize that stigma by creating widespread change in social attitudes [Jones et. al., 1984]. Examples of groups, as outlined by Jones et. al [1984], which were previously seen as ‘deviant’ include gay and lesbian persons, divorced persons, disabled persons, African American persons and the list can go on [Ibid]. Among the “destigmatization” strategies successfully used within the Gay movement and among other stigmatized groups were, “...legal protection, equal access to housing and employment, and the avoidance of public labels that imply derision” [Ibid., page 306]. In other words, some of the successful destigmatization strategies shifted the discourse *from* deviance and stigma *to* human rights [Kallen,1989]. This would involve, in the case of substance users, an emphasis on their human rights to health care, pre-natal care, drug treatment, housing, welfare, employment and the same respectful treatment by social agencies which non-stigmatized citizens expect.

Trying to unravel a stigma and create a new social definition which does not harm is a daunting and complex process. As Ben-Yehuda [1990] noted, by necessity, it must involve a renegotiation of morality, efforts by stigmatized groups themselves to garner widespread agreement for this new social definition and the political will among those

who hold power to assist in this process. As he stated:

In principle, the only way to neutralize the deviant stigma is to create a counter-movement that would attempt to use, or generate, power and to redefine morality and create a new symbolic-moral universe. Thus, the collective search for identity is not monopolized by deviant-producing groups. It also involves deviants who may try to organize themselves and successfully generate enough power and public support for their version of morality and for their collective attempts to destigmatize themselves. Since deviantization processes have a moral-political base {although often obscure}, the only means of reversal is a change in, or challenge to, that moral-political base [Ben-Yehuda, 1990, pages 66-67].

If one attempts to apply Ben-Yehuda's [1990] analysis of the destigmatization process to substance users then it becomes essential to ask questions that, first, identify key resources and, second, work to change attitudes at the edges of morality and politics. For example, in the case of pregnant substance users the following questions might be asked:

- Given that good pre-natal care is a important factor for maternal and baby health, what specific obstacles to pre-natal care for substance users exist in this community?
- Who are the main providers of pre-natal care in this community? What is their understanding of the obstacles to good care which pregnant users may experience? What policies or procedures have they enacted to assist pregnant users to access both pre-natal care and accurate information with respect to drug use in pregnancy?
- Do pregnant users have any formal opportunity to meet with other pregnant users so as to discuss mutual concerns and possible solutions to finding respectful and helpful pre-natal care?
- Are there any institutional barriers to drug treatment for pregnant users? Are these drug treatment programs sensitive to the special needs of pregnant clients? Are there enough drug treatment services for pregnant users in this community? If not, why not?
- What established lobby groups for women may be willing and able to amplify the voices of pregnant users?
- Are there any policies at the government level which impede pregnant users in their search for good pre-natal and ante-natal care? How are pregnant users portrayed in these policies? What assumptions underpin these policies? Are those assumptions accurate and consistent with empirical findings about the needs of

pregnant users? If there are inaccuracies, which groups or institutions are best able to challenge those assumptions?

- What are the specific negative stereotypes of pregnant users? How are these stereotypes propagated? Is there an overlay of negative stereotypes related to race and social class which affects pregnant users in this community? Is there a role for public education to counter these stereotypes? What public education campaigns have worked in the past to shift social attitudes about similar stereotyped groups?
- Are there any remedies in current law to dispel stereotypes of pregnant users?

These questions are only a beginning and may simply be one step in a critical examination of the possible actions and resources that may be required to counter the effects of stigma associated with substance users. Established policy orientations such as harm reduction, may also have much to offer in any effort to end the harms created by stigma.

Conclusion

This paper provided a review of the literature on stigma with specific reference to stigma in substance using populations. By no means is this review inclusive of all literature or all substance using populations. However the selected literature and topic areas provided a snapshot of current theory and its applications to stigma. There is a need for more research on stigma that is focused on substance use. There is a paucity of research available which examines stigma in families of substance users. Qualitative studies seem to dominate the field in research on pregnant substance users. It may be that qualitative methodology is best suited for study of this group. But, it can be argued that quantitative research which examines outcomes for substance using mothers who receive service under non-stigmatizing pre-natal care conditions, might provide the ‘numbers’

that can make a powerful argument for service changes.

Countering stigma and its associated harms to the physical, social and mental health of substance users seems so consistent with a harm reduction orientation. Given this, it may be useful for research to study the effects of the stigma of substance use from that perspective.

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