

THE JOURNEY TO COMPASSIONATE CARE

by Susan Boyd

In 1991, I helped create one of the first woman-centred, harm-reduction programs for women from the Downtown Eastside of Vancouver.¹ The grassroots program was named Drug and Alcohol Meeting Support for Women (DAMS) by women who met weekly. DAMS emerged as a response to concerns about harms associated with drug use, poverty, isolation, HIV/AIDS, and parenting. DAMS was committed to working with those women who were deemed difficult to reach, “non-compliant,” or “failures” by drug treatment workers and other professionals. DAMS was a non-discriminatory group whose members met to offer support to one another: our door was open to all women, especially pregnant women and mothers. Outreach, healing circles, one-to-one counselling, drop-in and educational workshops, day care, yearly retreats, and meals were eventually provided. The format was an alternative to twelve-step programs offered by Narcotics Anonymous and Alcoholics Anonymous. DAMS was dedicated to harm reduction, stabilization, and self-empowerment. Reunification of the family was also a central component of the program, because most of the women who participated in DAMS had at least one child apprehended by the state.

DAMS sought to meet the needs of women and their dependents: needs were defined as whatever a woman prioritized (i.e., housing, social, and economic support, medical care, prenatal services, reducing drug consumption — for example, smoking marijuana rather than crack-cocaine — methadone maintenance, detox, drug treatment, regaining or maintaining custody of children, getting one’s high school diploma, returning to college or university, etc.). Abstinence from drugs was not required: rather, support was diverse and women who used illegal and legal drugs were as welcome as those who sought to abstain. Our group was made up primarily of mothers, the majority of them First Nations women.

Because success was not based on abstinence, funding was quite difficult to obtain. In fact, in the beginning, everyone, including our coordinator, worked voluntarily. Harm reduction had not yet become a household phrase in Vancouver. In the early 1990s, pregnant women and mothers who used illegal drugs had few supports to turn to that were not abstinence-based, and most programs were punitive when they failed to, or could not, comply. Pregnant women and mothers who used illegal drugs were

often depicted by health, social service, and criminal justice professionals as manipulative liars, immoral criminals, threats to both themselves and their infants, and more deviant than their male counterparts. Consequently, women suspected of illegal drug use were regulated by overlapping and sometimes competing professionals who sought to identify, manage, and discipline them. It was believed they were incapable of parenting; drug use equaled poor parenting. Permanent child apprehension was the norm rather than the exception for poor women suspected of illegal drug use in Vancouver. Thus, DAMS offered not only support but also advocated on women's behalf. A handful of individual social workers, doctors, and drug treatment and outreach professionals worked with DAMS, providing services and a non-judgmental approach. DAMS was intent on changing the attitudes of medical, social service, and drug treatment professionals so that women and their children would have direct access to essential services, including culturally relevant, woman-centred, harm-reduction services.

However, in the early 1990s, there were no harm-reduction, prenatal, or maternity programs for women in British Columbia hospitals. Those infants thought to be prenatally exposed to drugs were often separated from their mothers and sent to Sunny Hill Hospital for Children in Vancouver — which developed a neonatal abstinence syndrome program in 1983 — or to smaller centres throughout the province. More often than not, these infants were apprehended by the state. Most of their mothers were poor, on social assistance, and First Nations, even though First Nations women's narcotic use rates were no higher than those of non-Aboriginal women (Sunny Hill Hospital Tertiary Task Force 1993).

At that time, the model of best practice for medical and nursing care at Sunny Hill Hospital for Children, and at other facilities, was based on the work of its founding director and Loretta Finnegan, an American pediatrician. It included measurement of the acuity of withdrawal symptoms, pharmacological management, separation of mother and baby with observation in a neonatal intensive care unit or nursery, sensory deprivation, minimal handling of the infant, and immediate referral to child welfare services (Boyd 1999; Lauridsen-Hoegh 1991). At that time (and still today), health-care professionals were taught little about addictions in their education programs.

DAMS sought to advocate for and provide harm-reduction services for women and their children. We were familiar with harm-reduction programs in the United Kingdom and the Netherlands. In the early 1990s, a number of our board members,² the coordinator of the DAMS program, and myself visited Dr. Mary Hepburn's Women's Reproductive Health Services clinic in Glasgow on different occasions to see first-hand how harm reduction was

applied to services for women. Dr. Mary Hepburn later visited our group and others in Vancouver, and we learned a lot from her, especially about the importance of providing ongoing education about harm reduction with a focus on pragmatic rather than moralistic interventions. Harm-reduction advocates note that drugs are one factor among many that shape pregnancy and, although drug use is a risk, it is a manageable one. In the early 1990s, we saw Dr. Mary Hepburn as the leading proponent of woman-centred, harm-reduction reproductive care, even though she never cast herself in that role. We were encouraged by the success of her program, and over the years we saw a number of harm-reduction services emerge in London, Liverpool, Manchester, and other places. These challenged conventional practices in relation to pregnancy, birth, and parenting for women who used illegal drugs. We came to recognize that when pregnant women and mothers are provided with comprehensive continuity of care that is supportive, sympathetic, woman-centred, and non-judgmental, maternal outcomes improve and mothers have more positive birth experiences (Hepburn 1993, 2002; Higgins et al. 1989; Latchem 1994; Lazarus 1988; Siney 1994, 1995).

Dr. Mary Hepburn traveled to British Columbia a number of times. In 1999 she outlined her philosophy at a provincial conference sponsored by the British Columbia Reproductive Care Program. Her visit coincided with the release of new provincial perinatal guidelines for health-care professionals working with women who use drugs and alcohol during pregnancy (British Columbia Reproductive Care Program 1999). These guidelines introduced the concept of harm reduction to many physicians and nurses for the first time. Dr. Ron Abrahams was instrumental in challenging existing practices and encouraging a move toward harm-reduction based maternity practices. Conference participants eagerly took this information back to their communities and began to examine their current practices from a woman-centred, harm-reduction perspective.

Rather than providing crisis intervention, successful maternity programs strive to normalize pregnancy and birth, providing multidisciplinary services, including midwifery care and early social worker involvement. Women are encouraged to freely disclose their drug use without fear of punishment. Stabilization rather than abstinence is the goal, so women can either stabilize on methadone or discontinue drug use during pregnancy. The consequences of drug use are mediated by a woman's social environment, as is her pregnancy. Consequently, woman-centred, harm-reduction programs seek to provide women and their children with medical, social, and economic support that is welcoming and appropriate to their needs (Hepburn 2002; Macrory 2002; Siney 1999).

Today, there is much more acceptance of harm-reduction philosophy and practice in Canada than there was in the early 1990s. We have seen the slow emergence of more diverse programs, including harm-reduction services for pregnant women and mothers. But we still have a long way to go, as was evidenced by the discussion of forty or so women and men who attended a two-day workshop hosted by Fir Square in the fall of 2004. Nurses, social workers, doctors, and outreach workers from around the province of British Columbia — including myself and Lenora Marcellus, the co-editor of this book — attended that workshop. Fir Square opened its doors in Vancouver in 2003; it is the first combined care maternity unit in Canada for substance-using pregnant women, and it takes a woman-centred, harm reduction approach to care. It was obvious from the moment the workshop began that the participants were hungry for information about applying a harm-reduction model to maternity and family services for substance-using mothers and their children. At the workshop, we learned about how Fir Square came about and how it is run. We also heard about the struggles participants experienced finding information about harm-reduction and maternity and family services. While there are now a number of diverse harm-reduction programs in Vancouver, they are not as numerous outside the city, especially in relation to pregnancy and family services. Many of the workshop participants lived and worked in rural British Columbia, far away from city centres, while others lived in smaller cities across the province. Participants wanted to know how they could move ahead to create harm-reduction, woman-centred services. They wanted to educate themselves and co-workers. They also wanted information that they could apply in a Canadian context.

This book brings together a number of Canadian authors who are working and writing about harm-reduction, woman-centred services. All the contributors are directly involved in providing and managing services. We highlight several Canadian services and outline critical theoretical perspectives on prenatal substance use, reproductive autonomy, and harm-reduction practice. The authors draw on Canadian and international writers who have paved the way to provide compassionate care to pregnant women, mothers, and their children. One of the strengths of this book is that it draws from critical sociological, health, and feminist perspectives. Its contributors are interested in bridging the gap between practice and theory. This book examines how women's lives, drug use, and maternal outcomes are shaped by interpersonal history and social and cultural environments, as well as by medical and social-service practices and by drug law and policies. These perspectives allow us to explore how women's personal problems are shaped by social factors (Mills 1975). Here, we introduce readers

to the concept of harm-reduction philosophy and practice, because without a conceptual framework it is difficult to conceive, implement, and maintain alternative services for women and their children.

Harm Reduction

Over the past twenty years, gender questions have changed the face of harm-reduction theory and practice, especially in relation to maternal drug use and the development of services for drug-dependent mothers and their infants. Stemming from challenges related to women's health in the 1970s and 1980s, activists, practitioners, and researchers sought to remodel services and drug-treatment programs to better serve women. At the forefront of these shifts was recognition of the social factors that shape women's lives and the acknowledgment that women's drug use differs from men's. A wide array of feminist research emerged about women who use both illegal and legal drugs, demonstrating that women's experience of drug use is shaped by gender, class, race/ethnicity, sexuality, and culture. Because drug use is mediated by these factors, the consequences of drug use are not the same for all women: poor women, aboriginal women, and women of colour are the most vulnerable to arrest, child apprehension, and poor health outcomes. We have come to recognize that double standards of morality, reproduction, and mothering, as well as legal and social inequality, shape women's experience. Because women have the capacity to become pregnant, they have been judged and regulated differently than men.

Alongside these shifts came questions about the central tenets of the disease model of addiction. Drawing from his earlier work, drug researcher Norman Zinberg (1984) clearly outlined his "set and setting model" in the 1980s. He illuminated how "set," people's attitudes and their expectations about a specific drug can be just as important, or more important, in shaping long-term relationships with the drug than the specific drug's pharmacology. "Setting" refers to the social, cultural, and physical environment where the drug is consumed. Drug use is shaped by set and setting. Thus, interacting variables — sociological, cultural, psychological, and biological — shape drug use (Reinarman 2005). Early on, Zinberg and a number of other researchers contributed to our understanding of how social and cultural factors shape drug use and cessation (Zinberg 1984; Becker 1963). Yet, the disease model of addiction remained the primary model of care even when social factors such as gender inequality were acknowledged. North American drug treatment remained abstinence-based, and those clients who failed to achieve sobriety or remain abstinent were individually blamed.

In response to the failure of the state and conventional drug-treat-

ment services to respond to the needs of drug users and the HIV/AIDS epidemic, harm-reduction philosophy and practice emerged in Britain and the Netherlands in the 1980s. It was not adopted in Canada until the early 1990s, although a number of programs such as methadone maintenance and needle exchange have been up and running for more than thirty years. Harm reduction offers practical, non-judgmental services that seek to minimize drug-related harm to both the individual and society. One of the most important philosophical differences between the disease model of addiction and the harm-reduction model is that abstinence is not the goal in the latter, although it is viewed as one option among many. Harm reduction recognizes that humans have historically used drugs to change consciousness. And so “zero tolerance” is both impossible and unrealistic, given that drugs can be health enhancing, used for spiritual purposes, and foster community cohesion (Coomber and South 2004). Most people who use drugs — both legal and criminalized drugs — do so without fear of escalated use or negative addiction. People use drugs for a wide variety of reasons: for fun, therapeutically (to heal or sustain health), for religious and spiritual purposes, to enhance work, school, or athletic performance, to alleviate hunger, to reduce physical and emotional pain, and as a strategy to cope with political and social factors such as violence, colonization, dislocation, and war (Alexander 2006; Boyd 2004; Gruskin, Plafker, and Smith-Estelle 2001).

Harm reduction offers pragmatic interventions that make legal and illegal drug use safer. It recognizes that drug use is not static: rather, it is diverse and ranges from positive to negative experiences over a continuum. Therefore, it is the patterns of use and one’s relationship — good or bad — with drugs that interest harm-reduction practitioners. In addition, harm-reduction advocates recognize that the line separating illegal and legal drugs is political and has little to do with how dangerous a drug is or how likely it is to cause harm. In terms of health and financial costs, tobacco and alcohol are our most costly drugs (Single et al. 1999; MacPherson et al. 2005).

Alcohol is the most widely used drug in Canada. The 2004 National Canadian Addiction Survey notes that in the year prior to the survey, 79.3 percent of Canadians reported drinking alcohol. In contrast, only 1.9 percent of Canadians reported using cocaine. However, legal drugs — alcohol and tobacco, and prescribed drugs like Prozac and Valium — are often ignored when we talk about drug use. We hear instead about the harm associated with illegal drugs. Only a small percentage of Canadians report being “drug free”: only 7.9 percent of female respondents and 5.6 percent of men surveyed reported being lifetime abstainers from alcohol and illegal drugs (Adlaf, Begin, and Sawka 2005). However, there may be even fewer

lifetime abstainers, because the 2004 survey did not include over-the-counter and prescription drugs, nor did it include tobacco, although data for tobacco consumption is available. Overall, Canadians are drug consumers, whether they consume over-the-counter or prescribed drugs, tobacco, alcohol, or illegal drugs. Harm-reduction services seek to minimize the harm related to both legal and illegal drug use for both individuals and society.

The harm-reduction movement challenged conventional drug treatment by offering pragmatic programs such as needle exchange, peer-to-peer outreach, controlled drinking programs, and, later, supervised injection facilities and heroin maintenance programs. Key questions were raised. What do women need in order to feel safe in these programs? Are these and other programs effective for all women? What cultural and economic barriers keep women from accessing services? What do women say they need for themselves and their children? What cultural, social, political, and economic factors shape the transmission of disease and infection (i.e., HIV and Hepatitis C)? In response to these questions, woman-centred programs were established to address the needs of women who use legal and illegal drugs. Yet, questions related to pregnancy and birth seemed more difficult to address, as policy and practice remained quite punitive, especially in Canada and United States.

Since the criminalization of some drugs such as opium, heroin, cocaine, and marijuana in the early twentieth century, women who are suspected of using them have been demonized, marginalized, and punished when they have sought care and support during pregnancy and parenting. Traumatic birth experiences at hospital, separation of infants from mothers at birth, child apprehension by the state, and stigmatization accompany pregnant women and mothers who use illegal drugs. Stigmatization is compounded by assumptions that drug use equals poor parenting and that substance-using mothers are unable to care for their infants due to their special needs if diagnosed with neonatal abstinence syndrome. Thus, social workers have been active in removing children from their mother's care when maternal drug use is suspected (Boyd 1999, 2004; Roberts 2002; Buchanan and Young 2002).

Early on, practitioners and outreach workers in Canada looked to the United Kingdom and the Netherlands for guidance, because those countries are seen as offering public-health and harm-reduction initiatives rather than just crime control. Since the mid-1980s, maternal drug services have emerged in the United Kingdom that challenge conventional practice. Rather than advocating punitive policies, in the mid-1980s Dr. Hepburn established a Glasgow clinic to provide reproductive care to women who were unable or reluctant to attend, and whose needs were not being met,

by “standard services.” Dr. Hepburn’s Women’s Reproductive Services program was the first to provide comprehensive woman-centred, harm-reduction care to pregnant women in hospital and in a clinical setting.

The program grew through self-referral, and it is now based at the Princess Royal Maternity Hospital in Glasgow. It offers outpatient care and city-wide community services to pregnant women, including both drug users and non-users. Maternal drug use is considered one risk — and a manageable one — among a myriad of other social problems. Stabilization is a key component of the multidisciplinary service, and methadone maintenance is available. Midwives are central to the services provided, and social workers are brought in early on to provide further support. Of 200 infants born to drug-using mothers at the clinic, only 7 percent exhibited withdrawal symptoms and required treatment (Hepburn 1993). Today, 95 percent of babies go home with their mothers following delivery (Hepburn 1999, 2002). Hepburn notes that poor women who use illegal drugs have higher rates of pre-term deliveries, low birth weight, sudden infant death syndrome, and perinatal death. However, these are non-specific effects, and the same incidence is found for women who are poor and do not consume illegal drugs and for those who smoke cigarettes (Hepburn 1999). When illegal drugs are eliminated, the birth outcome may remain the same. Consequently, providing comprehensive woman-centred, harm-reduction services, including social, economic, prenatal, and antenatal care are imperative. Poverty, rather than illegal drugs, has the most negative impact on fetal health and birth outcomes.

Research findings by Dr. Mary Hepburn served to spark interest in Canada and elsewhere (Hepburn 1993, 2002). Her work challenged studies in which researchers claimed that 60 to 90 percent of infants exposed to drugs experienced withdrawal symptoms. It also critiqued the usual state practice of child apprehension in these cases. Inspired by the success of the services in Glasgow, other services were set up elsewhere in the United Kingdom, including a drug liaison post at Liverpool Women’s Hospital in 1990 and, in Manchester, the establishment of a drug liaison midwife position in 1995 and a consultant midwife position in 2001 (Boyd 2004).

Although it is an ongoing challenge, Canada has adopted harm reduction as a national drug strategy, although this has not been realized in practice, partially due to resistance by national law enforcement groups. Nevertheless, Canada has implemented a number of harm-reduction programs, including needle exchange, a supervised injection facility, a North American Opiate Medication Initiative, and the Fir Square Combined Care Unit, which opened its doors in Vancouver in 2003. Fir Square is the first program in Canada to provide woman-centred, harm-reduction

care for pregnant substance-using mothers and their infants in a hospital setting.

Harm-reduction programs also exist in the United States, but American federal authorities and some states continue to reject harm reduction, instead supporting punitive approaches to women suspected of maternal drug use. In fact, since the mid-1980s, the regulation of mothers and challenges to women's reproductive autonomy has increased, even though maternal drug researchers note that punitive American policies only serve to deter pregnant women from accessing services, thus making them more vulnerable to health problems and poor maternal outcomes (Goldberg, Abrahamson, and Waldman 1999).

Chapter Outline

Drawing on feminist and critical sociological writing, in Chapter One, I examine a number of drug scares and moral panics about drugs, women's consumption of them, fetal harm, and parenting. Chapter One makes clear how contemporary women's reproductive rights and the "war on drugs" intersect. In addition, it provides a template to understand how punitive policy deters women from accessing health and social services.

In Chapter Two, Lenora Marcellus highlights the difficulty policy makers face in attempting to balance the rights and reproductive autonomy of pregnant women with society's interest in positive maternal outcomes. Using a feminist ethic to inform practice, she provides insight into systems of care that are non-punitive, holistic, contextual, and long-term.

In Chapter Three, Lenora Marcellus and Kimberly Kerns review the literature on prenatal substance use. Early reports of dire health outcomes are questioned in light of later studies that examined social, economic, and environmental factors that shape pregnancy outcomes. They discuss research findings on the long-term health and social outcomes for children with prenatal substance exposure. In addition, they outline a social and historical determinants of health approach.

In Chapter Four, Sarah Payne describes the development of and day-to-day running of Fir Square, the first combined care maternity unit in Canada for pregnant women with addictions and their infants. Fir Square has adopted a multi-disciplinary, woman-centred, harm-reduction approach since its inception, and it partners with Sheway Maternal Clinic, a community agency in the Downtown Eastside of Vancouver.

In Chapter Five, Alice Forsyth, Dawn Pomponio, and Laurie Robinson discuss how they provided woman-centred, harm-reduction services to one pregnant woman in a small community setting, while in Chapter Six, Sydney Weaver draws on findings from research she conducted, includ-

ing two surveys from worker training for the British Columbia Ministry of Children and Family Development and qualitative interviews with substance-using mothers and social workers to introduce readers to strengths-based discourse and practice.

In Chapter Seven, Margaret Leslie, Gina DeMarchi, and Mary Motz discuss their work in Toronto. In 1995 a Breaking the Cycle program, part of Early Intervention Programs at Mothercraft, was created. Recognizing that social and interpersonal factors shape women's drug use, Chapter Seven examines the experiences of three substance-using women across their lifespans from infancy to motherhood. The authors propose a pathway to understand the transmission of substance use across generations as well as a mechanism to understand change through the development of "relational capacity." They also highlight key principles, features, and practices that contribute to effectiveness in providing support for substance-using women and their children.

In Chapter Eight, Carolyn Schellenberg examines fetal alcohol syndrome (FAS). She asks important questions about FAS "knowledge," research, and practice. Finally, Chapter Nine discusses considerations for future woman-centred, harm-reduction research and practice, and the social, legal, and political obstacles to change.

Notes

1. The women who came to DAMS, Margaret Michaud, the coordinator, and Olive Phillips and I (counsellors and outreach workers) were the founders of this unique program. DAMS still exists, though the program has changed and the founding members no longer work there.
2. Including Dr. Ron Abrahams, one of the founding physicians of the Fir Square Combined Care Unit at the British Columbia Women's Hospital.