

Appendix 1
Suggested Reading for
Chapter 1: Introduction

FORGING NEW PARTNERSHIPS WITH WOMEN: EXECUTIVE SUMMARY*

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In 1998, the Substance Abuse and Mental Health Services Administration (SAMHSA) funded fourteen sites nationally for a two-year period to study and improve services for women with co-occurring mental health and substance use problems and histories of physical or sexual abuse. A key assumption that formed the backdrop for this national collaborative study is that women with these co-occurring problems, many of whom have children, are receiving fragmented and inadequate care in the specialty alcohol, drug, and mental health (ADM) treatment systems, even though they are among its heaviest users of services. Thus, the charge to the fourteen study sites was to work at the local level to develop an integrated and trauma-informed service system that might more effectively meet the needs of this group of women. In addition, sites were charged with the task of addressing the special service needs of women who are mothers of young children.

The Women and Mental Health Study Site of Dane County, one of the fourteen sites that were a part of this national collaborative study, undertook the charge with a special focus on economically disadvantaged women in Dane County, Wisconsin, specifically women who are dependent on publicly funded alcohol, drug, and mental health (ADM) services for their care. Employing a collaborative team of consumers, consumer advocates, Dane County system administrators and providers, and clinical and research faculty from Social Work, Nursing, Pharmacy, and Medicine at the University of Wisconsin-Madison, we designed an "action research" project that guided our system change efforts. In this report, we summarize findings from an important part of our research activities, namely interviews with 204 women who received two or more episodes of care in the ADM services system in Dane County in 1998. These interviews, which represent the first phase of our needs assessment, were designed to address three broad questions.

First, we wanted to determine *the scope of the problem*. That is, how many women receiving services in the public ADM system have histories of physical or sexual abuse and co-occurring mental health and substance use problems? Second, we wished to determine how these women, whom we subsequently refer to as women who meet target group criteria, *view the quality of their care* in comparison to other women receiving services in similar settings. In short, what evidence is there that women who meet target group criteria are falling through the cracks of our existing

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service delivery system versus getting high quality care? Finally, given our commitment to learning from women who are consumers of publicly funded services in Dane County, and to developing an integrated services model that is tied to women's perceptions of what they need to improve the quality of their lives, we wished to determine *what women who meet target group criteria define as their own recovery goals and needs*. That is, what do women view as important areas of their lives they want to change, how do they conceptualize their own recovery, and what services or resources do they feel they need to help them on the path to recovery? In the discussion that follows, we summarize findings related to these questions and discuss their implications for ongoing system change and service development efforts.

The Scope of the Problem

Our findings show that the number of women who meet target group criteria is substantial. Forty-seven percent of the women interviewed were positive for a co-occurring mental health and substance related problem and a history of abuse. This included 61.9% of respondents who had had services from both a mental health and substance abuse service provider in 1998, 56.6% of respondents who had had services from a substance abuse service provider only, and 11.1% of respondents who had had services from a mental health service provider only. If we project these numbers to each of the three populations of women from which our samples were drawn, we conclude that almost a third of the women (30.3%) seen in the ADM system in 1998, or 648 women, would meet these criteria. Although the majority of women with co-occurring mental health and substance use problems and histories of abuse are seen in some segment of the substance use services system, significant numbers have treatment episodes in both systems.

Given the larger absolute number of women with two or more treatment episodes in the mental health services system in 1998 (1546) compared to the substance abuse services system (865), we estimate that approximately 337 women, or 1 out of every 5 women seen by a mental health service provider, would meet target group criteria. Another 465, or 1 out of every 2 women seen by a substance use service provider, would also meet target group criteria. These treatment episodes occurred in virtually every agency the county funds to provide services to women experiencing poverty in Dane County.

Assessing Quality of Care

To assess women's perceptions of the quality of their care, we employed measures developed by the Consumer Outcomes Workgroup of Wisconsin, which were designed to assess three dimensions of quality care: (1) women's access to integrated, trauma-informed services; (2) women's perceptions of the quality of, and satisfaction with, those services, and (3) women's perceptions of the impact of services on important life outcomes. We also employed a number of other measures of women's functioning across an array of life domains. Since many of these measures are new and have no benchmarks, we compared women who meet target group criteria with other women who do not meet these criteria but who received services during the

same period.

Findings show that significant numbers of women are very positive about the care they have received in the public ADM system in Dane County. This is particularly true with respect to women's perceptions of the caregiving climate and their relationship with their primary caregiver(s). For example, the vast majority of women interviewed--from 88% to 94% of the women, depending on the questions asked--perceived their caregivers as respectful and sensitive people who "are genuinely interested in me" and "care about my feelings." Moreover, close to 90% of the women feel that the place where they received care is "clean, inviting, and comfortable," as well as a place where they feel safe.

A majority of the women, in the aggregate, also view their services as well-coordinated, their caregivers as competent, and the caregiving relationship as "consumer oriented" in that women were actively involved in the development of their service plans, were given thorough assessments of their strengths as well as their problem areas, and received "recovery oriented" care that was focused on outcomes that mattered to them. Indeed, our summary measure of satisfaction with services shows that significant numbers of women--from three quarters to 87%, depending on the questions asked--are quite satisfied with the care they have received from providers and agencies that comprise the public ADM system in Dane County.

Moreover, contrary to the notion that women who meet target group criteria are more likely than other women to be receiving poor quality care, we find that the former group is significantly more positive than other women about their care along each of these dimensions. In fact, in all comparisons of the two groups along dimensions that the Wisconsin Governor's Blue Ribbon Commission on Mental Health (1997) has defined as benchmarks for high quality consumer-oriented care, women who meet target group criteria do not fare significantly worse than other women receiving services in the public ADM system. Thus, these findings afford some good news about the quality of care women are receiving in the public ADM system in Dane County.

However, other findings suggest that the news is not all good. A key and troubling finding is that women who meet target group criteria are significantly worse off than other women on virtually every outcome measure that Wisconsin has identified as critical for systems of care. They suffer from lower self-esteem, rate themselves significantly lower in daily functioning across a range of behaviors, are less satisfied with the quality of their daily lives, are more symptomatic across an array of measures, are more likely to be struggling with a substance use problem and its sequelae, and view their emotional problems as having a significantly greater adverse affect on their capacity to function in their daily lives, work, and social relationships compared to other women.

Moreover, although many women who meet target group criteria feel their services have helped them cope more effectively with their daily lives, particularly

with the traumas in their lives and with their substance use problems, significant numbers do not feel their services have had much impact on other important aspects of their well-being and daily functioning. Notably, 40% of the women do not feel their symptoms have decreased as a result of services they have received, 37% are not doing any better in social situations, 36% are not doing better in their jobs or studies, and 28% do not feel their services have helped them feel more hopeful about the future. In short, even though many women who meet target group criteria like the services they have received in the publicly funded ADM services system, and are heavy users of services, those same services do not appear to be fueling a sense of hope for many woman, or helping them improve areas of life functioning that are important to them.

Although the cross-sectional nature of our data precludes estimating change in important life arenas over time, or linking such changes to the quality of care women have received in the public funded ADM system, three findings support the conclusion that many women, including disproportionate numbers of women who meet target group criteria, are indeed "falling through the cracks."

- 1) Women who meet target group criteria are not getting access to services needed to address their co-occurring problems.
- 2) Services that women are receiving do not consistently measure up to the standards for recovery-oriented care outlined in the Governor's Blue Ribbon Commission on Mental Health.
- 3) Women's own recovery goals call for a reconceptualization of public ADM services, as well as services that go beyond ADM treatment.

We discuss each of these findings and their implications for improving services below.

Insufficient Access to Integrated, Trauma-informed Services

A major impetus behind the national collaborative study is the belief that women with histories of abuse and co-occurring mental health and substance use problems are not getting the kind of integrated and trauma-informed services needed to help move them toward recovery. Four critical services identified as part of the SAMHSA initiative are: (1) trauma-specific services; (2) mental health services; (3) substance abuse services, and (4) services related to the special needs of women who are mothers. Our findings show that many women are not getting access to these services despite considerable need. Moreover, integration of such services is lacking for some women.

(1) Among women who have experienced physical or sexual abuse (100% of the women who meet target group criteria and 83.3% of other women):

- 75% and 59.6%, respectively reported that it is moderately, considerably, or extremely important to "get help with these experiences now"

- Of these women, 39% of the former and 55% of the latter have not had any treatment for these experiences in the prior six months and are not currently in treatment
- 25% of women who meet target group criteria and 58% of other women have never had treatment that addressed the abuse experiences in their lives.

(2) Among women who report a current mental health problem, which includes 96% of women who meet target group criteria and 60% of other women:

- 31.5% of the former and 29.2% of the latter are not currently receiving mental health services
- Among those not receiving treatment, 79% of the former and 53% of the latter report that it is moderately, considerably, or extremely important to "get help with [their] mental health problems now"

(3) Among women who report a current substance use problem, which includes 43% of women who meet target group criteria and 4% of other women:

- 51% of the former and 50% of the latter are not currently receiving substance use services
- Among those not receiving treatment, 53% of the former and none of the latter report that it is moderately, considerably, or extremely important to "get help with [their substance use problems now]"

(4) Among women who have had children, which includes 60% of women who meet target group criteria and 72% of other women:

- 38% of the former group and 47% of the latter have dependent children
- Among women who have dependent children, 36% of women who meet target group criteria and 32% of other women do not have those dependent children living with them
- Sixty-nine percent of the mothers who meet target group criteria have lost a child against their will compared to 40.3% of mothers who do not meet such criteria--an event ranked highest of all aversive events in terms of its continuing impact on women's lives
- Although the majority of women feel good about their parenting, a quarter to a third, depending on the question, neither feel good nor are confident about their parenting abilities
- Women who meet target group criteria are less confident about their parenting abilities than are other women
- 37% of women who meet target group criteria who have dependent children and 35% of other women who have dependent children feel they get little or no support from their mental health or substance use service providers with regard to their parenting roles and responsibilities

In sum, many women are not currently receiving services for major traumas in their lives, for their mental health and/or substance use problems, or for their problems related to children and parenting. Importantly, these are women who were very heavy users of services in the public ADM system in 1998, yet many continue to have major life problems with which they need help.

To better understand why many women with high need are not currently receiving care, we asked women a number of questions about their awareness of ADM services in the community, their perceived accessibility and convenience, as well as the sensitivity of providers to women's cultural and ethnic backgrounds. We also asked about specific barriers that may have deterred women from using services in the prior six months. Most women are aware of services and find them offered in a timely, convenient, and culturally competent manner. Moreover, women who meet target group criteria are somewhat more likely than other women to see services as accessible. Paradoxically, with few exceptions, women who meet target group criteria are also more likely than other women to report a number of barriers to receiving needed care:

- 46% (39% of other women) reported that they did not have the money to pay for needed services
- 31% (23% of other women) did not have adequate transportation to get to needed services.
- 30% (14% of other women) were deterred from seeking help because of a dislike of being labeled as "mentally ill"
- 19% (9% of other women) were deterred from seeking help because of a dislike of being labeled as an "alcoholic" or "drug abuser"
- 40% (35% of other women) agreed with the statement "I prefer to handle my problems on my own, rather than seek the help of professionals."

Women's reticence about seeking care is surprising, given that the majority of women who meet target group criteria view themselves as having major problems with which they need help. One explanation for this finding is that some women anticipate or fear adverse consequences from seeking help. For example, almost a quarter of the mothers who meet target group criteria and 11% of other mothers reported that they were reluctant to seek services because of a fear that their children will be taken away. In response to an open-ended query, other fears about unwanted treatment emerged including a fear of being sent back to prison, being hospitalized, or being forced to take medications, as well as the anticipation that desired services would simply not be available.

These findings suggest that significant numbers of women are "falling through the cracks," in the sense of not getting access to needed services. Support for this conclusion was further affirmed by women's response to the question: "If you were able to change one thing about the mental health and substance abuse services in

Dane County, what is the first thing you would do?" The most frequent response, endorsed by 50% of women who meet target group criteria and 42.6% of other women, was to recommend an increase in the availability and accessibility of affordable services. A second, and related theme is the need to reduce barriers that preclude a woman's ability to get the services she feels she needs. In some instances, these are limitations of insurance coverage; in others, ADM system-level or agency level policies that are often experienced as punitive and unreasonable. All, however, speak to women's economic adversity and the challenges of navigating a complex service delivery system with few material resources.

Inconsistent Provision of Recovery-Oriented Care

Although many woman are satisfied with the care they have received in the publicly funded ADM system, and 10% state that they would not change anything with the existing mental health and substance abuse services in Dane County, a significant minority do not share these feelings. For example, almost a quarter of women, if given the choice, would choose to go elsewhere for their services, rather than continue with their current provider. Moreover, depending on the area of inquiry, we concluded that the quality of women's care is falling short of standards set by the Governor's Blue Ribbon Commission on Mental Health, as well as the Substance Abuse and Mental Health Services Administration. It is also falling short of many women's expectations. In response to the query: "If you were able to change one thing about the mental health or substance abuse services in Dane County, what is the first thing you would do?" almost a third of women proposed changes in the ADM system that were directed at "improving the quality of care." In the discussion that follows, we identify four themes that emerge from these findings.

(1) Women want to have a greater voice in and control over services they receive, including medications.

The issue of having more voice in and control over one's services emerged repeatedly over the course of interviews with women. Thirty-six percent of women who meet target group criteria reported being "denied services I feel I need," and almost as many (33%) received services that they did not want. A critical area where women feel their voice is not heard and their choice compromised is in the area of medications. Three quarters of the women who meet target group criteria (74.1%) and over half of other women (56.1%) report they are currently taking a prescription medication for a mental health problem; 16.7% of the former and 1.9% of the latter also report taking medications for a substance use problem. When we asked women whether they had any choice in "picking medications that are right for me," 46% stated that they did not. Other queries about medication management suggest that significant numbers of women are not happy about this aspect of their treatment. Fully 30% of the women disagreed with the statement: "The medications I received were right for me." Further, almost 20% of the women felt their complaints about medication side effects were not taken seriously, and similar numbers reported that they had not been told what side effects to watch out for. Thus, one of the major areas of needed improvement in services is a system that is more responsive to