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Measuring the Impact of Integrated, Trauma-Informed Services

Editorial Staff

The Women, Co-Occurring Disorders and Violence Study (WCDVS) is generating important knowledge on how to improve services and service delivery systems to better meet the needs of women who have substance abuse and mental health disorders and histories of violence and their children. One vehicle for this learning is the Study's on-going evaluation activities.

The Study is utilizing a number of strategies to document and assess various interventions being implemented and operated in nine communities across the country. These include:

- cross-site process and outcome evaluations of the women's intervention
- cross-site process and outcome evaluations of the children's intervention
- cross-site cost-finding and cost effectiveness analyses
- individual site-level process and outcome evaluations

The development of this comprehensive evaluation plan has included administrators, clinicians, researchers, and consumer/survivor/recovering (C/S/R) women from local project sites, the Federal Project Officers, and members of the Coordinating Center. These individuals have worked hard over the last

three years to create hypotheses, protocols, instruments, and outcome measures. This collaborative process has resulted in an evaluation approach that will allow us to capture learnings that will help move the field forward and ultimately result in meaningful changes for women and their children.

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This issue of *The Tapestry* describes the various components of the WCDVS's evaluation efforts. Included are articles on both the women and children's cross-site process and outcome evaluations, which provide general overviews and describe both accomplishments and challenges encountered to date. An article on the Cost Study summarizes the key components and implementation strategies being used. The piece written by Suzanne Garverich of the WELL Project highlights the importance of including C/S/R women in all evaluation related activities.

The "News From The Sites" column provides an update on sites' local evaluation efforts.

Let us hear from you. You can email us at dawn.moses@familyhomelessness.org or send a fax or letter to Dawn Jahn Moses, The National Center on Family Homelessness, 181 Wells Avenue, Newton Centre, MA 02459; fax number 617-244-1758. ■

Key Issues and Challenges in Evaluating Integrated Services for Women with Substance Abuse and Mental Health Disorders and Histories of Violence

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The Women, Co-Occurring Disorders and Violence Study (WCDVS) is evaluating for whom, and under what circumstances, comprehensive, integrated, trauma-informed services positively impact the lives of women with substance abuse and mental health disorders and histories of violence. To accurately document and assess the effects of the services being developed, the WCDVS is conducting a cross-site process and outcome evaluation. The Women and Violence Coordinating Center is facilitating these efforts.

The study has been implemented in two phases. Phase I focused on capacity development at each site, evaluation design, and instrumentation. An evaluation subcommittee was formed during Phase I to direct these efforts. This committee consisted of Coordinating Center representatives, Federal Project Officers, consumer/survivor/recovering (C/S/R) women, evaluators from each site and expert consultants in the fields of substance abuse, mental health and trauma. The group was responsible for guiding the evaluation design and played a major role in instrument development for both the process and outcome evaluations.

Phase II focused on the recruitment and enrollment of women, service provision, and periodic process and outcome assessments. At the start of Phase II, an analysis subcommittee replaced the evaluation subcommittee with a new goal of directing these components of the evaluation.

Cross-Site Process Evaluation

The process evaluation is:

- documenting the process of project implementation;
- providing feedback to sites for developing their projects; and
- systematically describing each site's intervention so that meaningful comparisons can be made among study sites and between treatment and comparison groups at each site.

The process evaluation is assessing the degree to which sites are implementing the required eight core service components: outreach and engagement, screening and assessment, ongoing treatment activities, parenting, resources coordination and advocacy, trauma-specific services, crisis intervention and peer-run services. In addition, it is assessing each site's efforts to achieve service systems integration, clinical service integration and C/S/R integration. At the service systems level, the evaluation is measuring the level of communication and coordinated activity among organizations across the broader service system. At the clinical level, the evaluation is documenting the degree of coordinated activity occurring for the purposes of serving women's individual needs. Also being measured is the extent to which C/S/R women are integrated into all aspects of the local projects.

The cross-site process evaluation effort is centered around four data collection strategies:

- **Logic Models**

During the developmental phase of the project, each site created a logic model that graphically depicts the context, philosophy and elements of each site's intervention and their relation to expected outcomes.

- **Administrative Reporting Form (ARF)**

Sites complete the ARF annually. This form documents characteristics of the projects such as staffing and governance, services being provided and collaborating organizations.

- **Site Visits**

Annual visits gather qualitative information from project administrators, service providers, C/S/R women and community stakeholders. These meetings help clarify aspects of project design and provide information on the implementation status of various project components.



- **Implementation Status Rating Form (ISRF)**

Upon completion of each site visit, site visit team members use the ISRF to record the extent to which integration strategies and services at each site are implemented.

The cross-site process evaluation has faced a number of challenges that arise primarily from the scope, complexity and innovative nature of this broad, multi-site study. The process evaluation has been challenged by the variation among funded study sites and by the complexity and differences among the interventions that the sites are fielding. Furthermore, an extremely broad array of individuals take part in the WCDVS in many roles, both at the site and cross-site levels. This diversity is one of the study's major strengths and challenges us as process evaluators to capture the rich texture of attitudes and approaches these participants bring. In approaching this variation of strategies and voices several things have been learned:

- Process evaluation data must be gathered from multiple informants. On project site visits, it is valuable to meet with junior and senior project staff, C/S/R women, staff of collaborating agencies and other stakeholders.
- It takes time and effort for multiple stakeholders to come together and reach a common understanding of the project. Taking time early on to develop a shared understanding of key project terms and concepts is critical, and can help later collaborative work progress smoothly. The WCDVS's two-phased design was helpful in this regard.

Difficulties of measurement constitute another challenge the process evaluation has faced. The program level characteristics being looked at have few existing instruments available. Key constructs such as "trauma-informed services", "consumer involvement", or even "service integration" are somewhat vague and difficult to capture and document reliably. Primary learnings from this include:

- Both quantitative and qualitative approaches should be used to measure program level characteristics. Simple quantitative scales along with rich, textual description have provided the best overall picture of the interventions and their development.
- Having site visit team members complete assessments of sites individually and then come together for a group consensus rating provides the most complete picture of the sites. The process of forming individual opinions and then having a group discussion serves to clarify the information gathered and resolve discrepancies among team members, and ultimately leads to more thoughtful and reliable ratings.

Cross-Site Outcome Evaluation

The cross-site outcome evaluation is assessing whether women receiving comprehensive, integrated, trauma-informed services fare better than those receiving existing services. A common interview protocol is assessing demographics, service use and outcomes and has the following sections:

- Personal history
- Trauma symptoms
- Substance abuse status
- Mental health status
- Services used
- Perceptions of services

The protocol is capturing and tracking trauma and mental health symptoms, feelings of safety, substance use, abstinence and relapse, living situation, education and employment, children (including number of children, custody status, etc), legal system involvement, physical health, services used and perceptions of services used over a one-year period. The interview is administered at baseline, six and twelve months. To ensure accuracy and reliability of the service use data, information about the services a woman has used is also obtained at three and nine-month follow-up points.

The twelve-month baseline accrual period began in January 2001. Recently, a decision was made to extend the accrual period through mid-February 2002. Analysis of baseline data is slated to begin early in 2002. This will be followed by six-month and twelve-month outcome analyses beginning in late 2002.

The cross-site outcome evaluation has faced a number of challenges during the first portion of Phase II. Many of these challenges are rooted in the study's commitment and sensitivity to the women being served; ethnically and culturally diverse women who have experienced trauma and ADM disorders in their lives. The sheer nature of the life circumstances of these women has influenced the work of the outcome evaluation by prompting additional supports and protections for all study participants. This work has included the development of an accurate Spanish version of the interview protocols, a comprehensive human research participant protections protocol, and a strategic plan for recruiting and retaining women. In addition to the obstacles faced during these tasks, developing a comprehensive and appropriate analysis plan for the study has also been a key issue. The important learnings gained from these challenges make the discussion of them worthwhile.

Obtaining an adequate Spanish translation of the baseline protocol was an eight-month endeavor, including two pilot tests and multiple versions and revisions. Due to the predominantly clinical nature of the language in the interview, primarily around trauma and ADM disorders, a literal translation of the English version was inappropriate and did not represent the true meaning of many of the questions. Compounding the challenge was the fact that the Spanish-speaking women in the study come from various countries. These geographic differences often result in different meanings of words and phrases. As a result, project participants and consultants who were both bilingual and bicultural and who carried with them a clinical perspective were

used to translate the baseline instrument, the eligibility screen and all of the follow-up instruments. Two key learnings that came out of this work were:

- A commitment to study ethnically and culturally diverse populations necessitates the diversification of the research investigators themselves. If the ethnic and cultural background of the research team is not representative of the population being studied, it is recommended that the research investigators collaborate with professionals, consumers and/or consultants that do represent the cultural mix of the study population.
- Developing a culturally sensitive and appropriate protocol takes much time and collaboration, both of which should be considered in the timeline and budget process.

When conducting research involving human beings, there are a number of Federal, state and local laws that have been established to protect privacy and confidentiality, and to ensure appropriate conduct among researchers. Each of the nine participating projects was required to meet a variety of regulatory procedures prior to data collection. This is often a time consuming and complex process. Due to a backlog at the Federal level, this process took much longer than originally anticipated. Additionally, since the beginning of data collection several of the women enrolled in the study have become incarcerated. This new development added another challenge since there are additional requirements that must be met before conducting research with prisoners. From this we have learned:

- Lead time must be allowed for the human participant protections process.
- Any events that may change the status of the study population to a more vulnerable population, as defined by the Federal regulations, should be anticipated and addressed beforehand.

Recruiting and retaining women into the study has been another ongoing challenge. Methods to minimize the number of participants who drop out of the study before it is complete should be addressed at both the cross-site and individual site levels. There are characteristics of the study group as a whole (e.g. women, dual-addiction, parenting), as well as site-specific characteristics (e.g., urban vs. rural, residential vs. outpatient) that should be factored into the strategic plan for minimizing drop-out. The challenge for both the Coordinating Center and the local projects has been to develop creative strategies for recruiting and retaining women.

To date, these strategies include post-interview safety plans, using peer advocates, engagement techniques and locating techniques. Another tool developed to monitor data collection and subject recruitment is a subject tracking system. This system helps determine eligibility, monitor and track enrolled women

and keep track of pending follow-up interviews. Two key learnings around retention and minimizing the drop-out rate among this population of women are:

- Due to their histories and life circumstances, the supports needed for women to be fully engaged should be budgeted for and implemented throughout the data collection process. A few of these include: child care, transportation, and financial compensation. It also is important that research practices are culturally sensitive and flexible.
- Recruitment and retention strategic plans should include both cross-site and site-specific strategies, taking into account factors such as geographic location and program characteristics.

A final key issue for the outcome evaluation in Phase II has been the development of a comprehensive and appropriate analysis plan. The WCDVS is designed as a quasi-experiment with two naturally occurring groups—an intervention group that receives comprehensive, integrated, trauma-informed services and a comparison group that receives usual care. Although the project sites share a common intervention framework and set of eligibility criteria, the intervention is not standardized. Considerable leeway was allowed in the content and duration of intervention services, in the auspices and location of services, and in the background characteristics of the women enrolled.

As a result of this variability, the usual statistical procedures employed in clinical trials were not appropriate. Rather than constituting a single multi-site experiment, the WCDVS sites are best thought of as multiple, individual studies that are testing the same theories. The statistical method most compatible with this data structure is called prospective meta-analysis (Banks et al., 2001). A key learning in developing the analysis plan for the WCDVS is that in multi-site studies, it is critical to invest the time in developing an analytic framework that is best suited for this type of research. ■

For more information on the Women, Co-Occurring Disorders and Violence cross-site process evaluation, please contact: Nick Huntington, The National Center on Family Homelessness, 181 Wells Avenue, Newton Centre, MA 02459; (617) 964-3834; nick.huntington@familyhomelessness.org

For more information on the Women, Co-Occurring Disorders and Violence cross-site outcome evaluation, please contact: Wendy Vogel, Policy Research Associates, 345 Delaware Avenue, Delmar, NY 12054; (518) 439-7415; wvogel@prainc.com

REFERENCE:

Banks S., McHugo G., Williams V., Drake R., and Shinn M. (2001). *A Prospective Meta-Analytic Approach to Analyzing Multi-Site Data*. Worcester, MA: University of Massachusetts Medical Center (Unpublished).

Exploring New Directions in Working with Children Exposed to Trauma: An Overview of the WCDVS Children's Subset Study

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The WCDVS Children's Subset Study is an exploratory, longitudinal study designed to examine outcomes for children who are enrolled in trauma-informed, age-specific interventions as compared to children's services "as usual." To be eligible for the Children's Subset Study, women must be currently enrolled in the WCDV Study, and must have at least one child, aged 5-10, for whom she is a caretaker and has at least weekly contact. As part of the study, the children of these women participate in a three-part intervention that includes integrated case management services, a comprehensive assessment and a standardized group intervention. The study is currently in its second year during which the four study sites are fully implementing the children's service model.

Goals of the Study

The primary goals of the WCDVS Children's Subset study are to:

- 1) generate empirical knowledge about the effectiveness of trauma-informed, culturally relevant, and age-specific intervention service models for this population of children;
- 2) determine whether trauma-informed, age-specific interventions for children, including concurrent services for mother and child, and as compared to services as usual, lead to increases in safety, self-care, healthy relationships, and self-identity (including increases in self-awareness and self-worth)
- 3) identify models of care for the field that will prevent (or reduce) intergenerational perpetuation of violence, substance abuse and mental health problems.

Study Intervention

The design of the core intervention is a one-year multi-model service intervention. As part of this core intervention, each program must offer a common assessment, service coordination and advocacy, a safety plan, self-care strategies, and a skills-building group covering issues such as abuse, anger, violence, assertiveness, and protection planning.

The standardized group intervention component of the program has been adapted from Einat Peled and Diane Davis' (1995) *Groupwork with Children of Battered Women: A Practitioner's Manual*, to include a broader range of topics specific to the characteristics of the children enrolled in the study and to be more applicable to children who may have witnessed violence and/or a parent's substance abuse or mental illness.

The nine-session skills-building group intervention covers issues such as abuse, anger, violence, assertiveness, and protection planning. A safety plan was also developed for use during the session on protection planning. This adapted version of the groupwork intervention was manualized and clinicians from each of the study sites received training and a copy of the completed manual at the beginning of the study. Additionally, a common assessment protocol was developed and has been implemented by study clinicians at each of the program sites.

Process Evaluation

The process evaluation is documenting the process by which trauma informed services for children of mothers with substance abuse and mental health disorders and histories of violence are implemented. This is being accomplished primarily through annual site visits that gather qualitative data from project administrators, service providers, consumers and community stakeholders. The information collected is used to clarify and document various aspects of project design and to provide an update of where sites are in implementing the three intervention components. Process evaluation activities will occur during each of the study's three years.

Outcome Evaluation

The purpose of the outcome evaluation is to assess the effectiveness of service delivery for women and their children. The outcome evaluation is primarily quantitative and is designed to complement the qualitative process evaluation. Outcome evaluation activities will continue throughout all three years of the project.

Hopefully, what has been learned, coupled with what will be learned, will inform the field of new intervention techniques that result in better outcomes for children and their caregivers.

First, a common data collection protocol for use in the cross-site study was developed and refined. Interviewers were trained in the use of the common protocol, and a number of strategies to address participant recruitment were developed. Outcome evaluation efforts are currently focusing on collecting baseline and follow-up data using the common interview protocols and will then turn to analysis of baseline and follow-up data, and reporting findings.

Like any research study, the outcome evaluation has encountered a number of issues and challenges thus far. The first was developing the survey instrument to be used to collect data. A group of researchers, clinicians, consumer/survivor/recovering (C/S/R) women and various experts in the field came together to undertake this task. Given the diverse group, creating a survey that was reasonable in length, yet encompassed all of the domains that were important to the study, and was sensitive to everyone's perspective, was not an easy task. Over time, as the group became accustomed to working with one another, a certain level of trust and cohesion was achieved. This greatly facilitated the process and though still challenging, the process itself became a unifying factor. After much labor, the process resulted in the data collection instrument currently being used.

As with any study requiring a significant time commitment from participants, especially from a group of people encountering as many changes and life transitions as the women and children enrolled in the study, one of the major obstacles that has arisen has been "losing" women and children from the study along the way. Given the myriad circumstances under which most of the women come into the study and the many changes in their life circumstances that occur throughout the study period, maintaining contact with both the mothers/caregivers and their children, has proved to be a very challenging, yet important, task.

Though each of the study sites has a group of women who in many ways are very similar, each woman has her own set of unique characteristics, stressors, strengths, challenges and needs. The challenge faced by the study sites has been how to best address such a broad range of needs, as well as choosing the best way to tailor such strategies to individual women. Sites have found that in order to maintain relationships with women and their children, issues ranging from more concrete needs such as transportation and/or child care to more intangible needs/issues such as a woman's readiness for treatment and need for trust, all must be addressed.

Throughout the study thus far, many lessons have been learned. Along with these challenges have also come some great successes. Though there is still quite some time before the study concludes, much insight has been gained into the needs and challenges of women and their children who have experienced trauma, as well as mental health and substance use issues. Hopefully, what has been learned, coupled with what will be learned, will inform the field of new intervention techniques that result in better outcomes for children and their caregivers. ■

For more information on the Children's Subset Study, please contact: Chan Noether, Policy Research Associates, 345 Delaware Avenue, Delmar, NY 12054; (518) 439-7415; cnoether@prainc.com

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Determining the Cost of Integrated Care

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Many communities around the country are interested in developing a service capacity to respond to the needs of women with substance abuse and mental health disorders who have histories of trauma. In doing so, one of the primary questions that arises is the cost involved in providing comprehensive trauma-informed services for this group of women. The Women, Co-Occurring Disorders and Violence Study (WCDVS) is conducting a Cost Study to gain a better understanding of the resources needed to implement integrated substance abuse, mental health and trauma programs. By exploring the estimated costs associated with developing and operating such service programs, the study hopes to generate useful information for other communities interested in creating similar service capacities.

The WCDVS Cost Study includes two components: a cost-finding analysis and a cost-effectiveness analysis. The study will run during the three-year period of Phase II and is being directed by the Cecil G. Sheps Center for Health Services Research at the University of North Carolina-Chapel Hill, as part of the WCDVS Coordinating Center.

Cost-Finding Analysis

The first year of the cost-finding analysis was dedicated to measuring program start-up activities, which were defined as anything needed to get program capacity up to the point where it could begin to provide the chosen intervention services.

These activities could include planning, recruiting, training and developing or expanding physical facilities that were necessary to deliver the intervention service, or to establish or expand any of the eight required treatment services.

Five study sites were asked to participate in this effort: Prototypes, Culver City, California; New Directions for Families, Thornton, Colorado; DC Trauma Collaboration Study, Washington, DC; Triad Women's Project, Avon Park, Florida; and Franklin County Women's Research Project, Greenfield, Massachusetts. Sites were selected based on their diversity across three dimensions: geography (urban, suburban, rural), program setting (residential, outpatient, mixed) and organizational complexity (number of involved agencies).

Data collection in the first year centered around 2-day visits to each site. The visits consisted primarily of meetings with project directors, financial officers, and other staff members directly involved with the project. Sites were asked to identify

employment dates and compensation for all staff who were involved in the project for at least 5% of their total time during Years 1 and 2. Site visit team members then calculated what percentage of staff time was allocated to start-up activities. To gain a sense of non-personnel costs involved with start-up, the team reviewed budget abstracts, revenue and expenditure reports.

In its second year, the scope of the cost-finding analysis has shifted from start-up to operating costs. Data from all nine sites will be included in the operating cost study. During this phase of the research, the primary goal is to learn what it costs per person to serve women in comprehensive, trauma-informed, consumer-involved service programs. Several tasks are planned to determine the answer.

First, a person-level and project-level dataset will be assembled from the outcome study's self-reported service utilization data. The cost finding will be conducted by identifying the costs associated with each unit of service a woman receives. A standardized cost for each type/unit of service will be derived using Medicaid or other insurance-based reimbursement rates as well as estimates based on State block grant reimbursements to capture costs for uninsured persons. Utilization data will then be weighted by its associated unit cost and analysis will be performed at the person level and then aggregated to determine project-level costs.

Cost-Effectiveness Analysis

The cost-finding analysis will lay the foundation for a cost-effectiveness analysis in the final year of the project. The cost-effectiveness analysis will link outcome data (e.g. decreased symptoms or substance abuse) to cost data to answer the question: "How much does it cost to achieve a unit change (improvement) in the outcome for participants?" Project-level costs will be compared to provide information about the relative cost-effectiveness of the different program models represented in the women's study. Data from all nine sites will be included in the cost-effectiveness analysis.

The results of the Cost Study will provide estimates of what it costs to launch and operate comprehensive, integrated services for women with co-occurring disorders and histories of violence. This information will be useful to the local project sites, and

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Consumers in Research

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I currently am the Project Manager for the Cambridge site of the SAMSHA funded Women with Co-Occurring Disorders and Violence Study. I am responsible for supervising all the interviewers, I manage the data base for the project, and I am part of the research team that constantly does problem solving.

Our research team spends a considerable amount of time talking about the women we are researching in terms of how they are affected by the research study, how to reach and retain the women, how to deal with crisis situations that the women are having, confidentiality of the women, and many other aspects, all which pertain to the women involved in the study. So I ask, how can we as a research team responsibly and effectively answer any of these questions without having at least one person in the room who is representative of the people we are trying to answer these questions for? As researchers, we need to make sure we have all perspectives accounted for before we can make informed, responsible decisions.

Having a consumer present can only give the research team and study a much needed different perspective and insight. A consumer can also correct any misinformation that is being “passed around” about the population. At one time some of our interviewers became frustrated about women not receiving the services that were offered to them. These researchers voiced their concern and belief that if women began receiving services, they should naturally be receiving even more services down the line. They didn’t understand why women were not open to getting the help that was being offered to them.

It was very interesting to me that the interviewers assumed the recovery path is only forward and they were getting frustrated with the women in the study. From my experience, I knew that recovery is anything but linear, and I had assumed everyone knew that. Consequently, my supervisor and I thought it would be extremely beneficial to talk to them about the process of recovery.

We decided the best way to do this, with my agreement, was to tell the interviewers my story of recovery from mental illness, substance abuse and trauma. I explained to them the constant relapses in my life. I also talked a lot about how the process of recovery is not strictly a forward process, but one that ebbs and flows, and sometimes even takes steps backwards. I really believe without sharing my experience

with the interviewers they would not have been able to grasp what mental illness, substance abuse and trauma do to the women they are interviewing.

They now have a better understanding of the women in the study’s perspective. Having a better understanding, they now become less frustrated, which leads them to have more compassion for the women and simply to have less standing in the way of getting their job done.

When people do not understand something, they sometimes become judgmental. I believe that part of my job is to focus in and expose that judgment and one of the

most effective ways to do that is through education. Having mental illness, substance abuse and trauma in my life, like the women we are researching, enabled me to bring to our research team another perspective, one that was extremely informative and helped other people at the table gain insight into the population they are working with.

Another benefit of having a consumer involved in research is the wealth of knowledge she/he can bring to staff training. When my supervisor and I were preparing the training of study interviewers, we took into consideration what the interviewers needed to know about not only the interview process and protocol, but also the women they were going to be interviewing.

We decided that I, a woman from this population, would do the training piece of who these women are, what it means to have mental illness, substance abuse and trauma, how a woman’s life might be affected by this and, in general, how these three things affect every aspects of a person’s life. Someone else not from this population may have been

able to talk hypothetically and statistically about the women in the study, but no one except a woman with these particular experiences could talk experientially and specifically on the topics covered in our training. The interviewers got a complete and authentic picture of the women they were going to encounter. They were also able to have many of their concerns and questions addressed by someone directly from the population and not by hearsay.

When we talk about consumers in research it is not as simple as we would like it to be. It has not always been easy to be the identified consumer. There have been times when decisions have been made that I did not support, there have been times when I have been upset about people not being

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News From the Sites

For this issue of *The Tapestry*, sites were asked to provide a brief update on their local evaluation activities. Please contact the individuals listed if you would like additional information on the material listed below. The column that follows includes the eight sites that responded to this request.

PROTOTYPES

Culver City, California

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A major focus of PROTOTYPES is that both service and systems integration work is occurring. At PROTOTYPES, the integrated model is distinguished by the fact that service integration is achieved by providing all services on-site. PROTOTYPES also adopted a leadership position with respect to systems integration, beginning with one service area in the county. Here PROTOTYPES is bringing together key leadership from mental health, substance abuse, domestic violence, child and family services, etc., to affect coordination of service delivery at an administrative level.

The comparison sites include several facilities affiliated with two respected substance abuse agencies in other service areas (most sites are for women only; some include an emphasis on domestic violence). Our local evaluation uses qualitative approaches to assess systems integration, e.g., participant observation at the systems integration meetings. In addition, we have included three local measures for women in the study:

- (a) **Stages of Change:** This measure assesses a participant's readiness to make changes in her life. We will look at whether this measure predicts which women are more successful in treatment, across different sites.
- (b) **Coping Skills:** This measure evaluates the kinds of cognitive behavioral skills taught in Seeking Safety. We will look at whether participants in Seeking Safety show change on these skills.
- (c) **Parenting Inventory:** This measure taps parenting skills, where we expect greater change among those in the Nurturing Parenting groups.

Allies: An Integrated Services System of Care/Women's Health Study Stockton, California

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In parallel to the cross-site evaluation, the Allies/WHS includes both outcome and process evaluation components. Local outcome and process data collection has been ongoing since March 2001 in both the experimental and comparison communities.

Data for the local outcome study, as with the cross-site study, are collected via client interviews at five time-points. Baseline, 6- and 12-month interviews are conducted in person, with interviewers having the option of completing the shorter 3- and 9-month interviews over the phone. The baseline interview schedule asks questions pertaining to education, homelessness history, spiritual coping strategies, child custody and caregiving responsibilities, parenting, and social networks and support; this instrument was modified slightly for the 6- and 12-month interviews. At 3- and 9-months, women are asked to respond only to questions relating to their social networks and support over the prior three months.

The local process evaluation is designed, primarily, to assist in the interpretation of the outcome evaluation results. Key components include data collected via focus groups with clients and drug counselors from the primary treatment/referring sites and individual interviews with program directors, senior administrators, and Allies staff members. In January 2002, client case study interviews began with eight women participating in the outcome study. During a series of 5-6 interviews, these women will be encouraged to tell their stories. These studies will help to elucidate individual women's perceptions of: the relationship between mental health, substance abuse, and trauma in their lives; their treatment experiences over time; their experiences as parents (or non-parents); the role of spirituality in their lives; and the successes and challenges experienced in recovery.

While these studies are expected to provide insights into women's views of the inter-relationships between mental health and substance abuse disorders and trauma, and the road to recovery, it is also hoped that through this work these women's goals and dreams will be heard and their gifts known.

**New Directions for Families
Thornton, Colorado**

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New Directions for Families has added a few other measures to the baseline, six-month, and twelve-month evaluation points. Arapahoe House is administering the Child Abuse Potential (Milner, 1986) which screens for potential child abuse. We have also assembled a questionnaire that contains some relevant subscales from the following instruments: Personal Resource Questionnaire (Weinert, 2000) to measure social support, the Adult Adolescent Parenting Inventory (Bavolek & Keene, 1999) to assess reversal of parent/child roles, and the Resiliency Attitudes Scale (Biscoe & Harris, 1994).

In addition, we are conducting a qualitative interview with a sample of the women in the experimental group as they exit the treatment center. This interview contains questions about the woman's experiences in treatment, her opinion on co-occurring disorders, employment, and cultural and ethnic sensitivity. The results are used to better understand our study population and to improve the quality of care provided at our treatment center.

**District of Columbia Trauma Collaboration Study
Washington, District of Columbia**

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The D.C. Trauma Collaboration Study site-specific evaluation is focusing on project engagement, TREM outcomes, model fidelity, and general outcomes. We want to know what services women use and what leads to project engagement. We track group attendance and clinician and peer contacts, and we assess which project features are most engaging. We also want to know how women are doing in the 11 skill areas targeted by TREM. Clinicians use the Trauma Recovery and Empowerment Profile to rate current skills and to identify several for one-on-one work. The Trauma Recovery and Empowerment Scale provides a self-assessment of TREM skills and is part of the site-specific interview. We also want to know how well the TREM groups and the Integrated Trauma Services Teams are implemented, and thus we assess model fidelity repeatedly. Finally, we want to know how well women are functioning and what role religion and spirituality play in their recovery. We included standardized instruments in these areas in the site-specific interview. These activities will enable us to describe the intervention and to evaluate its impact on both specific and general outcomes.

**Triad Women's Project
Avon Park, Florida**

Principal Investigator: Margo Fleischer-Bond
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The Triad Research Team has been working hard to achieve our ambitious study objectives. Due to a later than expected start-up time we were unable to achieve our original targets for subject enrollment. However, as this fourth year of the study begins, we are close to achieving the final enrollment goal of 180 women in our intervention site and are focusing our efforts on minimizing attrition and obtaining the needed enrollment in our comparison site. Research efforts have included continuous quality assurance, inspecting data and double entry of site-specific measures and information to ensure data integrity. We have begun preliminary qualitative and quantitative data analysis. Review of baseline Triad data shows intervention and comparison groups to be similar in their demographics and other characteristics. Tests of the Global Symptom Index (GSI) means and trauma related symptoms show no differences between groups. Not surprisingly, our data indicate a high incidence of stressful life events and experiences. More than 80% of the population reported a past experience of rape and 64.5% of women reported being separated from their children against their will.

**Women Embracing Life and Living (WELL) Project
Cambridge, Massachusetts**

Principal Investigator: Norma Finkelstein
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The WELL Project site-specific study includes both process evaluation, currently focused on monitoring the environment at the sites, and outcomes evaluation, concentrating on issues of particular interest to us such as relapse skills. Beginning this year, we will do in-depth interviews with a subsample of women after they have completed the 12-month follow-up. Next year, we will repeat the Interorganizational Network (IO) Analysis study we did in Phase I to assess the impact of the WELL Project's systems integration efforts.

For this update, we would like to highlight an important and ongoing issue in implementation. The initial training for the Research Interviewers included information on substance abuse, mental illness, trauma, and the trajectory of recovery, as well as on the role of the researcher. When the Research Interviewers began follow-up interviews, they discovered that some women were having trouble in their recovery and that some were not getting all the services that they needed. Many women they interviewed, especially at the integrated sites, were doing well and getting needed services, yet the Research Interviewers were disturbed by what they heard from women

who were not doing as well. They were frustrated by what they perceived to be inadequacies of the service system and of their role as researchers.

The Project Research Director and the Project Research Manager, herself a consumer, decided to revisit topics covered in the initial training. At her suggestion, the Project Research Manager told her “story”, giving the Research Interviewers a first-hand account that the trajectory of recovery is neither simple nor straight. It involves engagement with services and retreat from services, acceptance of help and rejection of help, steps forward and steps back. At our request, WELL Project clinicians spoke about their work, including stories about women participating in the WELL Project who are making progress in their recovery. Lastly, the Project Research Director, Project Research Manager, and Project Assistant reviewed the differences between the role of a clinician or even a friend who can help directly and of a researcher whose job does not help any given woman being interviewed but, hopefully, helps many women in the future through the knowledge gained. As follow-ups continue and Interviewers go on with their rewarding but challenging jobs, the WELL Project research team is finding it helpful to revisit regularly the issues of recovery; the role of the researcher; and, always, the maintenance of boundaries and self-care.

Franklin County Women’s Research Project Greenfield, Massachusetts

Principal Investigator: Rene Andersen
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The Franklin County Women and Violence Project is approaching the end of its enrollment period. We are conducting 3-month, 6-month and 9-month follow-ups in both sites and 12-month follow-ups began at the end of December in the experimental site. We are very pleased that attrition has not been a problem in either site. The control site has a 100 percent retention rate for 3-month follow-ups to date while the experimental site has a retention rate of 95 percent.

In addition to the cross-site instrument, we have added site-specific questions at 3-, 6- and 12-months asking women about their social roles and how they change over time. The questions ask women to identify the words or roles their providers would use to describe them and how women would describe themselves. They are also asked how much they and others value those roles. Finally, we ask women whether they have assumed or dropped roles since the last interview and what events or thinking led up to that change. We believe this information will be critical in understanding women’s trajectories toward healing.

Finally, we are now analyzing our ethnographic interviews. One of the preliminary findings from this study suggests that women value service providers who are willing to “cross the line,” sharing their own experiences when appropriate to help women deal with situations as opposed to being told what to do or having strictly “professional” interactions.

Portal Project

New York, New York

Principal Investigator: Sharon Cadiz
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The evaluation team for the Portal Project in NYC is based at Hunter College School of Social Work, City University of New York. Our study is enrolling women from three Project Return Inc. residential programs. We have supplemented the cross-site study with qualitative interviews to deepen our understanding of the lives of the women in the study; additional site specific measures; and an extensive review of case records to explore the match of worker and client perceptions of services. Nearly 250 women are in our study. More than fifty women have had narrative interviews and will be interviewed again as they reach the nine-month point in their treatment career.

We are very interested in women’s social support networks and their impact on treatment outcome so we are asking questions on social supports developed in collaboration with Allies. Because the Adoption and Safe Families Act was identified as a critical issue by our Project’s Policy Action Committee, we are documenting our participants’ experiences with child visitation, child welfare services, court and change of parental rights. We are also collaborating with the WELL Project in using the Abstinence Self-Efficacy Scale. We expect that the women who participated in the study will work with us in the analysis and interpretation of the data through our Consumer Advisory Committee for the Evaluation. ■

The Women, Co-Occurring Disorders and Violence Study is generating knowledge on the development of integrated services approaches for women with co-occurring substance abuse and mental health disorders who also have histories of physical and/or sexual abuse.

The Tapestry is a product of the Women, Co-Occurring Disorders and Violence Coordinating Center which is operated by Policy Research Associates, in partnership with The National Center on Family Homelessness and the Cecil G. Sheps Center for Health Services Research. The Coordinating Center provides technical assistance to program sites, conducts cross-site process and outcome evaluations, and develops a range of application products from the study sites. This publication was developed by The National Center on Family Homelessness.

The Women, Co-Occurring Disorders and Violence Study is funded by the Substance Abuse and Mental Health Services Administration's three centers – The Center for Substance Abuse Treatment, The Center for Mental Health Services, and The Center for Substance Abuse Prevention.

For more information on this Initiative, please contact Policy Research Associates, 345 Delaware Avenue Delmar, NY, 12054 518-439-7415 e-mail: wcc.prainc.com web: www.prainc.com/wcdvs

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Consumers in Research... (continued from page 8)

able to understand why some of the study participants are behaving in certain ways, and there have been times when I just didn't want to divulge my personal experience to anyone.

The things that have gotten me through these times are key to successfully having consumers part of a research team. My supervision has been outstanding. My supervisor not only treats me like everyone else, she also understands that my job is somewhat different and demanding in ways that other people's jobs are not. Having those two things understood enables me to do my job, be a worker among workers, but also have my experience be with me at the same time.

The other extremely important factor of me being able to stay in this identified consumer researcher role is that everyone on my research team views my experience as being knowledge, needed knowledge. People see me as an expert, and they treat my experience as knowledge they want and need. This has helped me to stay in the room and share my experiences.

Another issue that sometimes comes up for me, being the only identified consumer in our research team, is that I find myself speaking for hundreds of women, and making decisions for all of them. I can only input my experience when we are discussing a issue or trying to make a decision. Every decision that is made feels very heavy and that if the wrong decision is made, I will be letting people down, that it would be my fault.

The more identified consumers on a research team the more the study, the participants, and the staff will benefit. The more experiential knowledge in a room, the better. The pressure will also be taken off the person who was carrying the weight of a hundred participants.

The barriers we face having identified consumers on research teams are ones that are manageable and we learn and gain from any barriers that we are able to overcome. It is extremely irresponsible for a research study not to get the perspective of the population they are studying. It is not only irresponsible, but it is trying to research a population without having all the necessary information available. How can we make decisions about the population concerned without someone representing that population? Research organizations and researchers must begin to look at experiential knowledge as being beneficial, and knowledge that a study cannot do without. ■

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Determining the Cost... (continued from page 7)

other organizations interested in developing a similar service capacity. Locally, the results can be used to secure funding from state/county legislatures to continue this service initiative and introduce others like it. At the broader level, agencies contemplating adopting the interventions used in the WCDVS or programs of a similar nature may use the cost study findings to budget for program start-up, operation or expansion. For the research community, the results will provide a foundation for conducting future cost finding and effectiveness studies of interventions that offer integrated services for substance abuse, mental illness and trauma.

A report summarizing the findings from Year 1 of the Cost Study is available through The Women Co-Occurring Disorders and Violence Coordinating Center, 345 Delaware Avenue, Delmar, NY 12054; 518-439-7415 (phone); 518-439-7612 (fax); wvcc@prainc.com. ■

For more information about the Cost Study, please contact: Terri Nadlicki, University of North Carolina, Chapel Hill, 101 Conner Drive, Suite 302, CB# 3386, Chapel Hill, NC 27599; (919) 966-0914; terri_nadlicki@unc.edu