

Building the Foundation for the *Family Options Project*

Adults with mental illness in the U.S. are as likely to be parents as those who are not living with mental health disorders. Over two-thirds of women and about three-quarters of men with serious and persistent mental illness (SPMI) living in the community are parents.⁸ Often, parents have mental illnesses that occur in combination with other mental illnesses, substance use disorders, or physical health conditions as well. In secondary analysis of data on biological parents of children with serious emotional disturbances receiving services in systems of care programs, 52% had a biological family member with a history of mental illness, 59% had a family member with a history of substance abuse, and 36.5 % had histories of both mental illness and substance abuse disorders.^{1,6} Family disruptions—parent-child separations and permanent loss of contact or custody—may also be common occurrences in families where parents have mental illnesses.⁹ Data from various



small-scale studies indicate that 25% to 75% of mothers with mental illness no longer have custody of their children.⁷

Overlapping Needs

The needs of families in which a parent, and sometimes a child as well, has a mental health condition are complex and intimately intertwined, requiring an array of services and supports. “Family-centered treatment” has evolved as a concept in the children’s mental health services world. The Comprehensive Mental Health Services for Children and Families Program has led to the development of intensive, community-based approaches such as systems of care and wraparound services, tailored to meet the needs of children with the most serious emotional and behavioral difficulties. However, the unique needs of their parents are not necessarily addressed through these programs.⁴ Thus, parents with mental illnesses are likely to be members of families that use multiple, uncoordinated services in both the child and adult service sectors, or who receive no appropriate services at all. While the former

comes at great cost to public and private payers, the latter potentially cost even more to society, as communities and family members themselves bear the costs of untreated mental illness.

The needs of adults as parents are not necessarily a focus of evidence-based practices in mental health. The Assertive Community Treatment (ACT) model, typically touted as the “state of the art” case management model for adults with serious mental illness, is embraced by many state mental health authorities as the model of choice. However, parenting is not routinely identified as a desired role for adults with mental illness, nor are treatment goals relevant to parenting typically set by ACT team members.² Previously-tested parenting interventions do not consider the characteristics and concerns of adults with mental illnesses.¹⁰ Parents with mental illness often find these models irrelevant, as they do not address the illness-specific issues parents identify. However, intervention strategies can be drawn from these models, combined with one another, and tested for effectiveness among parents with mental illnesses.

In a national review of existing programs for parents with mental illnesses and their families, which included program surveys and site visits, program participants, staff, and collaborating providers identified essential intervention characteristics and components.^{12,3} Regardless of theoretical orientation, providers and family members across programs attributed successful outcomes for parents and children to a family-centered, strengths-based approach to intervention. That is, the entire family, rather than an individual adult or child, is the “unit of service.” Parents and family members are engaged in a process that focuses on building on strengths, rather than emphasizing deficits or failures. Essential intervention components include: (a) availability of and access to formal services and natural community resources to meet basic needs; (b) coordination of multiple services and providers when their involvement is necessary, and the facilitation of communication among multiple providers; (c) emotional support in the context of trusting relationships with providers

and peers; (d) flexible funds to provide concrete assistance, and meet unique family and individual needs; (e) availability of staff, 24-hours a day, seven days a week; and (f) education for parents regarding child development, parent-child relationships, and parenting tasks.^{12,13} Potential outcomes include enhanced well-being and functioning; and supports and resources for adults, children, and families. These outcomes may be reflected in variables such as a decrease in emergency hospitalizations for parents, a decrease in out-of-home placements for children, increased employment for adults and improved school attendance for children, better access to medical and mental health care, greater parent competence, and enhanced child safety.

We have added trauma-informed interventions as an essential approach to working with these families.⁹ For families receiving services in systems of care, a family history of mental illness and/or substance abuse is associated with other child and family risk factors, including child physical or sexual abuse, child psychiatric hospitalizations, child history of substance abuse, and history of domestic violence within the family.⁵ Adults living with mental illnesses often have histories of violent victimization, or are currently at risk.^{9,15} Strategies for engaging and sustaining helping relationships in interventions with these families must be informed by the likely impact of trauma on the ability and willingness of those who have experienced violence to participate.

The Employment Options/ University of Massachusetts Partnership

The *Family Options* pilot program and research studies were born out of a long-standing partnership between Employment Options, Inc., a psychosocial rehabilitation agency in Marlborough, MA, and the University of Massachusetts Medical School’s (UMMS) Center for Mental Health Services Research. This partnership is unique in its duration and productivity. Lead personnel and staff have worked together for over a decade on behalf of individuals and families living with mental illnesses. Lead per-

sonnel from each organization serve on the advisory groups for the other organization, and work together to identify and bring new initiatives to fruition.

Highlights in a Program of Research

1995: UMMS conducted focus groups with mothers with serious mental illnesses and case managers from the Massachusetts Department of Mental Health to identify the challenges these parents face.^{13, 14}

1997: The National Institute on Disability and Rehabilitation Research (NIDRR) funded the four-year Parenting Options Project. This important project, which involved consumers in all aspects of design and implementation, resulted in the development and distribution of a series of newsletters and fact sheets for parents and providers, as well as numerous presentations and publications, including *Parenting Well When You’re Depressed: A Complete Resource for Maintaining a Healthy Family*.¹¹

1999–2002: UMMS received funding from the Substance Abuse and Mental Health Administration (SAMHSA) to conduct survey and site visit studies of interventions for families living with parental mental illness. This was the first step in an effort to begin developing an evidence base by identifying common and effective program components.^{12,13}

2002: Employment Options, Inc., with the technical assistance of the UMMS Center for Mental Health Services Research, was awarded a Community Action Grant from SAMHSA for the community consensus-building initiative, Strengthening Families’ Recovery from Mental Illness. Local stakeholders were engaged in the process of considering the feasibility of implementing an intervention for families living with parental mental illnesses. Through a consensus-building process, existing program models were reviewed, determination was made to pursue development and implementation of a similar intervention, a strategic plan was created, barriers to intervention implementation and participation were identified, and relevant modifications were recommended for the development of the

FAMILY OPTIONS RESEARCH STUDIES

In the Fall of 2005 UMMS received funding to study the *Family Options* program. UMMS is currently conducting parallel implementation and outcomes studies.

Program Evaluation Study

Principal Investigator: Joanne Nicholson, Ph.D.

Using a developmental evaluation model, the experiences of and outcomes for parents and their children are being studied. Findings will contribute to refinement of the program logic model.

- The intervention group is being compared with those receiving "services as usual" in a comparable community sample.
- Blended qualitative and quantitative methods are being used.

Program Implementation Study

Principal Investigator: Kathleen Biebel, Ph.D.

The implementation study documented the process of implementing *Family Options* within *Employment Options*, studying the agency's paradigm shift from serving individual adults to working together with families over almost two years.

- Community stakeholder agency interviews were conducted to collect information about services available to families and eligibility criteria for those services, so that information could be used to develop a resource guide for program staff and families.
- Focus groups with program and agency stakeholder groups were conducted to assess the organizational climate of Employment Options in regard to the acceptance of and readiness for the new *Family Options* program.
- Key informant interviews were conducted to identify and describe key domains critical to the implementation of the program.

Findings will contribute to the national scientific dialogue about the implementation of evidence-based practices, as well as facilitate the replication and further testing of the *Family Options* model by providing broader guidance and greater specificity regarding implementation challenges of and strategies for the standard operating procedures document.

For more information about *Employment Options* programs: <http://www.employmentoptions.org>

For more information about UMMS/CMHSR research on families living with mental illnesses:

<http://www.umassmed.edu/Content.aspx?id=38838> and www.parentingwell.org.

Family Options model.

2005: The *Family Options* project began.

Service Program Highlights

1995: The original Family Project was first implemented by Employment Options, Inc. The program provides supports to non-custodial parents, including parent education and peer support, liaison with other programs and agencies, and visitation with children. Funding has been provided over the years by the Massachusetts Department of Mental Health and the United Way.

1999: The Clubhouse Family Legal Project was established. The project is a collaborative effort of Employment Options, Inc. and the Mental Health Legal Advisors Committee in Boston. The program provides pro bono legal representation to low-income parents with mental illness. In addition to providing legal referrals and direct legal counsel in family law cases, the Clubhouse project leads advocacy efforts in the legal system on behalf of persons with mental illnesses. Funding for the program is provided by Massachusetts Bar Association and Massachusetts Department of Mental Health.

2005: Employment Options Inc. and the UMMS Center for Mental Health Services Research received funding for the development, pilot testing and refinement of *Family Options* for parents with mental illness and their families. (See box.)

References

1. Center for Mental Health Services (2004). *The Comprehensive Community Mental Health Services for Children and Their Families Program: Evaluation findings—Annual report to Congress, 2004*. Atlanta, GA: ORC Macro.
2. Gewurtz, R., Krupa, T., Eastabrook, S. & Horgan, S. (2004). Prevalence and characteristics of parenting among people served by assertive community treatment. *Psychiatric Rehabilitation Journal*, 28, 63-65.
3. Hinden, B. R., Biebel, K., Nichol-

son, J., Henry, A., & Katz-Leavy, J. (2006). A survey of programs for parents with mental illness and their families: Identifying common elements to build the evidence base. *Journal of Behavioral Health Services Research, 33*, 21-38

4. Hinden, B. R., Biebel, K., Nicholson, J., & Mehnert, L. (2005). The invisible children's project: Key ingredients of an interven-



tion for parents with mental illness. *Journal of Behavioral Health Services & Research, 32*, 393-408.

5. Hinden, B. R., Gershenson, B., Williams, V., & Nicholson, J. (2006). Families with overlapping needs. *Center for Mental Health Services Research University of Massachusetts Medical School Issue Brief, 3*(5), 1-2.
6. Hinden, B. R., Williams, V., Gershenson, B., Nicholson, J., Banks, S., Blau, G., et al. *Family mental illness and substance abuse in children's systems of care*. Manuscript submitted for publication.
7. Nicholson, J., Biebel, K., Hinden, B., Henry, A., & Stier, L. (2001). *Critical issues for parents with mental illness and their families*. Rockville, MD: U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration,

Center for Mental Health Services.

8. Nicholson, J., Biebel, K., Williams, V., & Katz-Leavy, J. (2004). Prevalence of parenthood in adults with mental illness: Implications for state and federal policy, programs, and providers. In R. W. Menderscheid & M. J. Henderson (Eds.), *Mental Health, United States, 2002*. (DHHS Pub. No. SMA 04-3938). Rockville, MD: U. S. Department of Health and Human Services, Substance Abuse and Mental Health Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.
9. Nicholson, J., Finkelstein, N., Williams, V., Thom, J., Noether, C., & DeVilbiss, M. (2006). A comparison of mothers with co-occurring disorders and histories of violence living with or separated from minor children. *Journal of Behavioral Health Services & Research, 33*, 225-243.
10. Nicholson, J., & Henry, A. D. (2003). Achieving the goal of evidence-based psychiatric rehabilitation practices for mothers with mental illness. *Psychiatric Rehabilitation Journal, 27*, 122-130.
11. Nicholson, J., Henry, A. D., Clayfield, J. C., & Phillips, S. M.

(2001). *Parenting well when you're depressed: A complete resource for maintaining a healthy family*. Oakland, CA: New Harbinger Publications.

12. Nicholson, J., Hinden, B. R., Biebel, K., Henry, A. D., & Katz-Leavy, J. (2007). A qualitative study of programs for parents with serious mental illness and their children: Building practice-based evidence. *Journal of Behavioral Health Services & Research, 34*, 395-413.
13. Nicholson, J., Sweeney, E. M., & Geller, J. L. (1998a). Mothers with mental illness: I. The competing demands of parenting and living with mental illness. *Psychiatric Services, 49*, 635-642.
14. Nicholson, J., Sweeney, E. M., & Geller, J. L. (1998b). Mothers with mental illness: II. Family relationships and the context of parenting. *Psychiatric Services, 49*, 643-649.
15. Swanson, J. W. (1994). Mental disorder, substance abuse, and community violence: An epidemiological approach. In J. Monahan & H. J. Steadman (Eds.), *Violence and mental disorder: Developments in risk assessment*. (pp. 101-136). Chicago: The University of Chicago Press.

Authors

Joanne Nicholson is Professor in the Department of Psychiatry at University of Massachusetts Medical School, Associate Director of the Center for Mental Health Services Research, and Principal Investigator of the *Family Options* research projects.

Kathleen Biebel is a research assistant professor and Co-Investigator of the *Family Options* projects.

Valerie Williams is a research instructor, and Co-Investigator and Statistical Analyst for the *Family Options* projects.

Karen Albert is Project Director for the *Family Options* projects.