

MAKING THE INVISIBLE VISIBLE:

Parents with Psychiatric Disabilities

"One nurse said to me that I should not think of having children with my mental illness. She said my children would probably be in the mental health system. I'd like to prove this lady wrong." — a mother with mental illness

The experience of the woman quoted above, who participated in a focus group on parents with mental illness funded by the Massachusetts Department of Mental Health, reflects the still-prevalent attitude that individuals with psychiatric disabilities seldom have children and that if they do become parents, the outcome is likely to be negative.

According to a 1999 survey of state mental health systems by the Center for Mental Health Services Research in the Department of Psychiatry at the University of Massachusetts Medical School (UMMS), relatively few mental health systems routinely ask whether adult consumers are parents or provide services targeted to parents and their families.¹ "We really don't know about the parenting status of our adult clients," notes Meredith Alden, M.D., Ph.D., Director of Utah's Division of Mental Health and an advocate of improved services for parents with psychiatric disabilities and their families. "We don't know what supports they have or, more importantly, what supports they don't have."

Despite the lack of data on the parental status of public mental health consumers,² there is evidence that the seemingly invisible population of men and women with psychiatric disabilities who are parents constitutes a growing proportion of persons receiving public mental health services.³ Current research indicates that adults with psychiatric disabilities have children at about the same rate as other adults.⁴ A 1993 survey conducted in Orange County, New York, found that 66 percent of adults receiving public mental health services in the county reported having a child under age 18. [*See Focus on the States.*]

Although parenthood is hardly a new phenomenon for individuals with psychiatric disabilities, numerous factors have combined to make it possible for a growing number of persons with serious mental illness to live fuller lives that often include having children. Among these factors are the long-term emphasis on deinstitutionalization and community-based services; improvements in services, supports and medications; and the burgeoning consumer recovery and empowerment movements.

CMHS Study

In recognition of these new realities, the federal Center for Mental Health Services (CMHS) has initiated a number of activities to focus attention on families in which a parent has a psychiatric disability. Through its groundbreaking study, "Parents with Psychiatric Disorders and Their Families," CMHS has provided funds to the UMMS Center for Mental Health Services Research to collect information on the current state of knowledge and practice in providing services to parents with psychiatric disabilities and their families and to describe promising strategies for improving services.

To date UMMS Center staff have conducted a survey of state mental health agencies and interviewed a wide range of researchers, providers, policymakers, consumers, family members, attorneys and others to identify critical issues both within the mental health system and in related fields. The Center has performed a nationwide search to identify promising programs that address the needs of parents with psychiatric disabilities and their families, five of which have been selected for site visits and indepth assessment. The Center will issue several reports. "Out of this descriptive foundation, we hope to develop a range of possibilities for effective services and programs," explains Joanne Nicholson, Ph.D., Associate Director of the UMMS Center for Mental Health Services Research and the study's project director.

Dr. Nicholson points out that new information and perspectives are challenging long-held assumptions and stigma surrounding parents with psychiatric disabilities. She emphasizes that a variety of factors contribute to the impact of parental mental illness on children—including the individual characteristics of children and their parents, the strength of family bonds, the way family members interact, the level of support from extended family and friends and access to effective mental health services and supports. "The good news is that there are a multiplicity of factors and interventions that affect outcomes," Dr. Nicholson emphasizes. "There are many things that can be done to create conditions where parents with psychiatric disabilities and their families do better."

Family-Centered Services

In seeking ways to provide services to families in which a parent has a psychiatric disability, many mental health experts point to the family-centered model that has become a key element of children's mental health programs. "Historically, people who work with children with serious emotional difficulties have also considered the needs of parents and siblings," Dr. Nicholson notes. "We should use this same family-centered approach when a parent has a psychiatric disability."

One of the strengths of the family-centered approach is that it prompts mental health and other human and social services agencies to minimize restrictive eligibility requirements and categorical funding streams that create barriers to services for the

entire family, explains Barbara J. Friesen, Ph.D., Director of the CMHS-funded Research and Training Center on Family Support and Children's Mental Health at Portland State University in Oregon. Currently, if a parent is the primary consumer in the adult mental health system, it may be difficult to obtain services and supports for his or her children because of such barriers.

Judith Katz-Leavy, M.Ed., Senior Policy Analyst for children's mental health policy development at CMHS, adds, "Providing family-centered care to parents with mental illness is critical because it recognizes the fact that these individuals do not live in a vacuum but rather in a community context with roles and responsibilities similar to those we all carry. One of the most important of those roles is that of 'parent,' and it is important not only for the healthy development of the child but for the parent as well. It is an integral piece of his or her self image and can play a significant role in recovery."

The family-centered perspective also helps to illuminate common challenges faced by families in which a parent has a serious illnesses, whether psychiatric or physical."Parents are often in and out of the hospital, they have emergencies, they become physically debilitated, sometimes they are unable to actively parent," Dr. Nicholson points out. In an effort to obtain cross-illness perspectives on how to support families with a seriously ill parent, CMHS and the National Cancer Institute co-sponsored a 1998 meeting to discuss these issues. *[See article on page 1.]*

Custody and Parental Rights

Perhaps no issues are more problematic for parents with psychiatric disabilities than child custody and parental rights. Dr. Nicholson reports that a high proportion of parents with psychiatric disabilities lose custody of their children.⁵ Many states have laws that cite mental illness as a condition that can lead to loss of custody or parental rights. Thus parents with psychiatric disabilities often avoid seeking mental health services for fear of losing custody of their children, explains Gina Yarbrough, an attorney with Massachusetts' Mental Health Legal Advisors Committee, a state agency charged with protecting the rights of persons with psychiatric disabilities. Ms. Yarbrough stresses the importance of providing information about mental illness to judges, lawyers and other persons involved in the legal system, noting that they may be unaware of advances in the areas of rehabilitation and recovery or that effective services are available for parents with psychiatric disabilities. She notes that the National Association for Public Interest Law and the Massachusetts Bar Foundation have provided funds to the Committee for an attorney to represent members of psychosocial rehabilitation clubhouses in eastern and central Massachusetts concerning their parental rights in domestic relations and state intervention cases.

Mental health advocates note that with the right types of services and supports, many parents with psychiatric disabilities and their families can remain together and thrive. They emphasize that state and local mental health agencies have an enormous opportunity to recognize this issue and commit to serving parents with psychiatric disabilities. For agencies that have not provided such services in the past, the first step may be to obtain data on the prevalence of consumers who are parents within their systems.

"Rearing children while managing a mental illness means that, at times, parents may require additional supports, but the same is true for parents with any serious illness," notes Lucinda Sloan Mallen, Executive Director of the Mental Health Association in Orange County, New York, and founder of a program that serves parents with psychiatric disabilities and their families. "The basic truth of the issue is that parents with mental illness, like any other parent, simply want to be the best parents they can be. Our system of care should support this goal, not create barriers."

NTAC wishes to acknowledge Joanne Nicholson, Ph.D., Associate Director, and Kate Biebel, M.S., of the Center for Mental Health Services Research, Department of Psychiatry, University of Massachusetts Medical School, for their invaluable contributions to the development of this article.

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²Nicholson, J., Geller, J.L., Fisher, W.H., and Dion, G. L. (1993). "State Policies and Programs that Address the Needs of Mentally Ill Mothers in the Public Sector," *Hospital and Community Psychiatry* 44(5) 484-489.

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"Motherhood for Women with Seriuos Mental Illness: Pregnancy, Childbirth, and the Postpartum Period," *American Orthopsychiatric Association* 65(1) 21-38.

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Learning from Each Other...Coping with Parental Illness

by Gina Tesauro, M.S.W.

At age 10, I watched as my mother was carried out of the house on a stretcher and into an ambulance. I recall people towering over me in white coats, yelling, moving quickly, bumping into furniture and knocking over my family's picture frames and knick-knacks. That was the day my mother was diagnosed with a brain tumor and my family's world was literally and figuratively turned upside down.

As with many people experiencing serious illness, be it physical or psychological, my mother's cancer led to numerous hospitalizations, symptom exacerbation, treatments that caused debilitating side effects, expense, stigma and loss. Because of this experience, my childhood sense of security and stability was disrupted, replaced by loneliness and fear. I felt isolated from my peers, believing that mine was the only family affected by such a serious illness. As I grew older, however, I learned that many people came from families in which one or both parents were seriously ill. Regardless of the type of illness, we all experienced parental loss—whether in our parent's time, energy, hair, sight, mobility, support, communication skills, hope or even life itself.

During the past decade, a growing body of research has increased our understanding of the profound impact that a parent's serious physical or mental illness can have on a child. The mental health field has been a leader in examining both the psychosocial and genetic influences that may affect a child whose parent has a mental illness, particularly related to schizophrenia and affective disorders. Researchers have documented increased risk of affective disorders in children of parents who themselves have this condition.^{1,2} Increased risks for depression and other psychological problems have also been identified in children of parents with serious physical illnesses.³ However, research has also shed light on individual and familial attributes that lead to resilience in children—enabling them to thrive despite serious parental illness.⁴

Facing Common Challenges

In recognition of the common challenges faced by families in which a parent has a serious illness, the federal Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration, and the National Cancer Institute (NCI), National Institutes of Health, co-sponsored a meeting in 1998 to facilitate knowledge exchange among researchers, service providers, policymakers, children and parents concerning strategies for helping families cope with parental illness, from the perspectives of mental health, cancer, multiple sclerosis and HIV/AIDS.⁵ Participants emphasized their desire to learn from one another about effective strategies for helping families cope with parental illness. Among the key points that emerged from the meeting were that serious parental illness, whether physical or mental, can strain even the strongest family unit; parental illness affects

every aspect of family life; education and other supports are essential for assisting families to cope with parental illness; and families—and individual family members—often demonstrate impressive resilience in confronting serious parental illness. There was agreement that additional research is needed to gain a greater understanding of this phenomenon.

Following this meeting both CMHS and NCI initiated efforts to focus on serious parental illness: CMHS funded a project to assess current knowledge about parents with psychiatric disabilities and their families and to identify gaps in knowledge and services. NCI promoted a mechanism for researchers to study the impact of cancer on families, including the impact of parental cancer on children, by awarding 10 administrative supplements totaling \$1 million to NCI-funded Clinical and Comprehensive Cancer Centers. Meeting participants described a number of national and local programs that address parental illnesses:

Wraparound Milwaukee. Children whose mothers have breast cancer receive a variety of mental health services and supports through this CMHS-funded program, which utilizes the “wraparound” concept pioneered in the mental health arena to provide services to meet the needs of each family member.

National Multiple Sclerosis Society. The National Multiple Sclerosis Society (NMSS) has established a nationwide program to support and educate families affected by multiple sclerosis. The Society developed a series of brochures on the illness for youth at each age level. Families can order the publications at no cost from the Society. The NMSS website (www.nmss.org) emphasizes the importance of addressing the needs of the entire family.

Kids Konnected. Kids Konnected (www.KidsKonnected.org), a nationwide support program for children whose parents have cancer, was the inspiration of an 11-year-old boy whose mother was diagnosed with breast cancer.

Despite the emergence of innovative programs that focus on serious parental illness, advocates note that several hurdles must be overcome before such programs can be established nationwide. One of these hurdles is the lack of funding for rigorous evaluations needed to identify effective practices and incorporate them into comprehensive service systems. Another is the need for additional research on the long-term impact of parental illness on children.

In speaking to groups of people, I am often asked how I coped with my mother’s illness. I usually respond with this comment from a woman whose mother was diagnosed with depression: "Resilience is not the absence of ill health in the face of parental illness, but rather the capability to return to health after having experienced

adversity." By learning from one another, we increase our understanding of parental illness and find better ways to help children and families endure, and thrive, in the face of adversity.

Gina Tesauro, M.S.W., served as a Presidential Intern at the Center for Mental Health Services and the National Cancer Institute.

¹Weissman, M. (1997). "Offspring of Depressed Parents," *Archives of General Psychiatry* 54:932-940.

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³Compas, B.E., Worsham, N.L., Ey, S., and Howell, D.C. (1996). "When Mom or Dad Has Cancer: II. Coping, Cognitive Appraisals and Psychological distress in Children of Patients," *Health Psychology* 15(3): 167-175.

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⁵Tannen, M.S. (January 2000). *The Impact of Parental Illness on the Child and Family: Implications for System Change*. Washington, DC: The National Technical Assistance Center for Children's Mental Health at the Georgetown University Child Development Center.

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networks is supported under a Cooperative Agreement between the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, and the National Association of State Mental Health Program Directors. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CMHS/SAMHSA. For more information, visit NTAC's web site at: <http://www.nasmhpd.org/ntac>

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Message from NTAC's Director

It was the best of times, it was the worst of times. That famous line from Charles Dickens' *Tale of Two Cities* comes to mind when I think about the topic of the current issue of *networks*—parents with psychiatric disabilities and their families. This is a propitious moment for the mental health community: the U.S. Surgeon General's report has focused national attention and concern on mental illness, advances in mental health services and supports as well as improved medications are opening up greater opportunities for persons with psychiatric disabilities, and finally there is a growing understanding that people can and do recover from mental illness.

Yet in the face of these positive developments, it is humbling to realize that, as this issue's lead article points out, many parents still lose custody of their children simply because the parent has a psychiatric disability. At a time when persons with psychiatric disabilities have unprecedented opportunities to lead full lives, including experiencing parenthood, outdated assumptions and practices continue to create barriers to needed mental health services and supports.

As NASMHPD's Deputy Executive Director, I am honored to add the role of Acting Director of NTAC to my responsibilities. Bruce D. Emery, M.S.W., NTAC's Director since its inception in 1996, has left to pursue new opportunities. On behalf of NASMHPD, I want to express our gratitude to Bruce for his many valuable contributions to NTAC and its mission of providing high-quality technical assistance to NTAC's core constituents. We wish him well.

I am happy to report that NTAC has embarked on the new millennium with many exciting goals. We plan to expand our on-site technical assistance activities during the coming year in our ongoing efforts to help state and local mental health systems address the challenges that lie ahead, with special emphasis on promoting recovery, coalition-building technologies and access to effective services and supports.

In closing, I wish to thank our colleagues at CMHS, Judith Katz-Leavy, M.Ed., and Joyce T. Berry, J.D., Ph.D., and all of the other individuals who contributed to this issue of networks. If the topic of parents with psychiatric disabilities is finally emerging as an important concern, it is due in large part to the efforts of persons such as these who have devoted their energy and commitment to this issue.

— Gail P. Hutchings, M.P.A.

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Suggested Reading

American Psychiatric Association. (1998). Special Issue on Women and Chronic Mental Illness. *Psychiatric Services* 47.

Blanch, A., Nicholson, J., and Purcell, J. (1994). "Parents with Severe Mental Illness and their Children: The Need for Human Services Integration," *Journal of Mental Health Administration* 21(4): 388- 396.

Fox, L. (1999). "Missing Out on Motherhood," *Psychiatric Services* 50(2): 193-194.

Gopfert, J., Webster, J., and Seeman, M. (Eds.) (1996). *Parental Psychiatric Disorders: Distressed Parents and Their Families*. Cambridge, England: Cambridge University Press. (Cost: \$44.95; call 800-872-7423).

Mental Illness Education Project Videos. (1999). *I Love You Like Crazy—Being a Parent with Mental Illness: Balancing the Challenges of Mental Illness with the Needs of a Child*. (videotape). Hohokus, NJ. (Cost: \$39.95; call 800-343-5540).

Miller, L. (1996). "Sexuality, Pregnancy, and Child Rearing Among Women with Schizophrenia-Spectrum Disorders," *Psychiatric Services* 47: 502-505.

McLennon, J., and Ganguli, R. (1999). "Family Planning and Parenthood Needs of Women with Severe Mental Illness: Clinicians' Perspective," *Community Mental Health Journal* 35(4): 369-380.

Nicholson, J., Geller, J., and Fisher, W. (1996). "Sylvia Frumkin Has a Baby: A Case Study for Policymakers," *Psychiatric Services* 47(5): 497-501.

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Tannen, N. (2000). *The Impact of Parental Illness on the Child and Family: Implications for System Change*. Washington, DC: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration/National Technical Assistance Center for Children's Mental Health at the Georgetown University Child Development Center. (Cost: \$6.00; call 202-687-8803).

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www.parental.illness

American Academy of Child and Adolescent Psychiatry: Offers a wide selection of resources for families living with mental illness. Within "Facts for Families," see fact sheet on children of parents with mental illness. www.aacap.org

Beacon of Hope: Directed toward men and women who are partners of someone with a serious mental illness. Provides information about mental illness and specific links to sites for both partners and children. www.lightship.org

Mental Health Net—Parenting Resources: Provides a comprehensive list of on-line parenting information and self-help resources. Sample topics include fatherhood, non-custodial parenting, effective parenting strategies, single motherhood and pregnancy. mentalhelp.net/guide/parents.htm

National Mental Health Association (NMHA): Provides on-line forums for consumers and providers to share information. Presents updates on topical legislation and news relevant to persons in the mental health community. www.nmha.org

National Women's Health Information Center (NWHIC): Serves as a gateway for information about women's health issues. Parenting, reproductive health, abuse, access to health care, financial assistance, and services and supports are discussed as they relate to women with disabilities. www.4women.gov

Parenting Options Project (POP), University of Massachusetts Medical School: A 3-year, National Institute of Disability and Rehabilitation Research-sponsored project to develop education and skills training materials for parents with mental illness.

Offers a parent manual, self-assessment tool and a quarterly newsletter, PARENT LINK. www.umassmed.edu/POP

Through the Looking Glass (TLG): A community-based, non-profit organization that provides services, referrals and information to families in which one or more members (parents or children) have a disability or medical condition. TLG supports interventions that are empowering to consumers. www.lookingglass.org

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CALENDAR OF EVENTS

April 27-29: Health Care for the Homeless Information Resource Center. **2000 Health Care for the Homeless Conference: Compassion, Collaboration and Change.** Denver, CO. Call (888) 439-3300.

May 4-5: Rural Policy Research Institute (RUPRI), University of Missouri. **Rural Dimensions of Welfare Reform: A Research Conference on Poverty, Welfare and Food Assistance.** Washington, DC. Call (314) 882-0316.

May 7-10: National Council of Juvenile and Family Court Judges. **Mental Health Issues in Juvenile Justice.** San Diego, CA. Call (775) 784-6012.

May 14-18: Florida Mental Health Institute. **Ethics in Research: An Intensive Training Course Focusing on Behavioral Health Services.** St. Petersburg Beach, FL. Call (813) 974-4602.

May 22-26: International Association of Psychosocial Rehabilitation Services (IAPSRs). **Annual Conference.** Washington, DC. Call (410) 730-7190.

May 30-June 2: Center for Mental Health Services and the Mental Health Statistics Improvement Program. **9th National Conference on Mental Health Statistics: Back to the Future-Out of the Past.** Washington, DC. Call (301) 443-3343.

June 6: National Mental Health Consumers' Self-Help Clearinghouse. **Summit 2000: The Second National Summit of Mental Health Consumers and Survivors.** Washington, DC. Call (800) 553-4539, ext. 297.

June 7-10: National Mental Health Association. **50th Annual Clifford W. Beers National Mental Health Conference.** Washington, DC. Call (703) 838-7504.

June 9-13: National Technical Assistance Center for Children's Mental Health. **Developing Local Systems of Care for Children and Adolescents with Emotional Disturbances and Their Families: Improving Policy and Practice.** New Orleans, LA. Call (202) 687-5000.

August 4-6: National Association for Rural Mental Health. **Bridging Space and Time: Rural Mental Health in a New Age.** Portland, OR. Contact Cathy Britain at (541) 962-3430 or LuAnn Rice at (320) 202-1820.

August 11-13: National Depressive and Manic-Depressive Association. **Annual Conference: Partnerships for Success.** Cambridge, MA. Call (800) 826-3632.

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Focus on the States

New York Program Pioneers Services to Parents with Mental Illness

Lucinda Sloan Mallen, Executive Director of the Mental Health Association (MHA) of Orange County, New York, often reflects on the time a decade ago when she came face to face with an issue that she had thought about for much of her life. As the daughter of a mother who suffers from bipolar disorder and depression, Ms. Mallen understood the challenges of growing up in a family with a parent who has a serious mental illness. Yet in her numerous interactions with individuals who participated in MHA programs throughout the county, as well as with public mental health providers, the issue of parenthood had seldom surfaced.

That day as she made her rounds of program sites, however, something was different. She was about to have a child herself. "I wasn't just the administrator of an organization, I was a woman having a baby," Ms. Mallen recalls. "I started hearing stories from women about their children. I became painfully aware of how many of them had lost their children. I saw the sadness and animation in their faces as they talked about their kids."

This experience confirmed Ms. Mallen's conviction that something needed to be done to support families in which a parent has a mental illness. Yet in seeking to identify mental health services and supports for parents with psychiatric disabilities and their "invisible children," she said it became "apparent that existing policies and funding streams created barriers to providing mental health services for parents with mental illness and their families."

Although there were adult services and children's services, there were no services to help parents meet the challenges of child-rearing while coping with their disability. Children were not allowed to visit parents in public inpatient psychiatric facilities. Community-based mental health programs made no provision for child care. Public mental health care providers seldom asked consumers whether they had children. The perception, Ms. Mallen said, was this was a "non-issue."

Ms. Mallen was determined to challenge that perception. In partnership with the Orange County Mental Health Department and the Middletown (NY) Psychiatric Center, she embarked on a study to assess the prevalence of parenthood among adults who received public mental health services in the county. They found that 66 percent of this group reported having a child under 18. They also discovered high incidences of poverty, homelessness and children being removed from their homes. Many parents said they were reluctant to seek mental health services for fear of losing custody of their children.

With this data, Ms. Mallen began to make her case for providing services to families in which a parent has a psychiatric disability. She initiated alliances with several statewide and local organizations. With backing from the New York State Office of Mental Health (OMH), the coalition hosted a statewide conference on this issue. This led to other OMH initiatives including establishment of a state task force on parents with mental illness, convening of four regional meetings and publication of a report. OMH also provided grants to raise awareness, promote education and training, and support initiatives by community-based organizations.

Ms. Mallen notes three factors that helped her succeed—being able to marshal data and facts to back up her contentions, demonstrating "assertive and persuasive leadership" and collaborating with other organizations.

With funding from state and private sources, Ms. Mallen and the Orange County MHA launched the "Invisible Children's Program" in 1993. The program provides a range of services for families that includes respite and child care, supported work and education, case management, supportive housing, crisis intervention and a 24-hour help-line.

James L. Stone, M.S.W., Commissioner of the New York State Office of Mental Health, praised Ms. Mallen's advocacy and persistence. The state "recognizes that parenting is an important life role for adults with serious mental illness and that the

parents' illness will have an impact on the entire family," Commissioner Stone says. "We are proud to be a leader on this important issue."

Ms. Mallen notes three factors that helped her succeed—being able to marshal data and facts to back up her contentions, demonstrating "assertive and persuasive leadership" and collaborating with other organizations.

For more information, call Lucinda Sloan Mallen, Executive Director, Orange County (NY) Mental Health Association, at (914) 294-7411.

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Employment Tool Kit Earns Praise

"This is quite a remarkable compilation of resource information." — reader comment

Experts in the fields of mental health and employment have responded enthusiastically to *A Technical Assistance Tool Kit on Employment for People with Psychiatric Disabilities* developed by NTAC, NASMHPD and Matrix Research Institute with funding from the Center for Mental Health Services. Building on the successful Senior Executive Training Institute on Employment for People with Psychiatric Disabilities held in Alexandria, Va., March 11-12, 1999, the Tool Kit examines key employment-related issues, provides information on innovative state and local programs and presents numerous other resource materials. A broad audience of clinicians, consumers, family members, employment specialists, advocates and technical assistance providers report that they find the Tool Kit useful in promoting employment for persons with psychiatric disabilities. To obtain a copy of the Tool Kit, please send a check for \$20.00 made payable to NTAC to:

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66 Canal Center Plaza, Suite 302
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networks is published by the National Technical Assistance Center for State Mental Health Planning (NTAC) and is supported under a Cooperative Agreement between the Center for Mental Health Services, Substance Abuse and Mental Health Services

Administration (CMHS/SAMHSA), and the National Association of State Mental Health Program Directors (NASMHPD). Cited reproductions, comments and suggestions are encouraged.

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