EXPERIENCES OF PARENTS WITH MENTAL ILLNESSES AND THEIR SERVICE NEEDS

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The needs of parents with serious mental disorders and their families are frequently overlooked by service providers and planners. As a result, these families are at risk on multiple levels and caregiving responsibilities often fall on mentally ill parents' spouses or partners and extended family members, particularly the children's grandparents (especially grandmothers), siblings (often sisters), and other relatives. This article presents principles underpinning a comprehensive system of care for these families and describes the services needed to implement these principles. Wherever possible, examples are provided from U.S. and Canadian programs that serve consumer parents and their children.

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Key Service Delivery Principles for Working with Mentally Ill Parents and Their Children

Ongoing availability of services is a central feature of working with families in which a parent has mental illness. Assistance cannot be time limited or age limited, as in programs which exclude teenage parents or those in which service delivery ceases upon the child's entry into primary or (in rare cases) junior or senior high school. Services also should not be context-dependent, as with programs that cease serving parents who are in hospital or undergoing substance abuse treatment or are incarcerated. Second, the *family must be the focus* of service delivery, not solely the child or adult service recipients. "Child providers" and "adult providers" must coordinate their efforts so that services "wrap around" the entire family unit. The fact that many of these families are headed by single parents means that grandmothers and other extended family are involved and experience their own stresses and strains. A third principle involves a *service-mix of treatment, rehabilitation, and support*. The idea is to not focus solely on clinical treatment while ignoring efforts to promote recovery and the development of natural supports. Without rehabilitation and supportive environments, services cannot be preventive or proactive. A fourth principle calls for *sensitivity to stigma* associated with mental illness and especially prejudices faced by mentally ill parents and their offspring. Surveys show that large segments of society hold very prejudicial attitudes toward procreation and child rearing among persons with brain diseases. Children of consumer parents also experience this rejection and discrimination, from both peers and from other parents, making disclosure an issue for the *entire* family. Related to this stigma is a fifth principle that acknowledges the paramount *importance of custody concerns* in the decision to seek and accept assistance. Enactment of this principle demands a focus on prevention of custody loss through advanced directives, respite care, and supports specifically designed to preserve the custodial relationship. A sixth and poorly understood principle involves recognition of child rearing as a central role in which *parenting serves as the foundation for a parent's recovery* from mental illness and not an obstacle. Studies of mentally ill mothers and also those with drug addiction indicate that parenthood plays an organizing role in their lives, a role around which they seek to plan and achieve concrete goals. Seventh, *interagency collaboration* is called for among numerous service delivery systems, including health, public health, mental health, child welfare, education, psychosocial rehabilitation, housing providers, nursing professionals, and others. At the center of this coordination must be the family itself, since collaborative activities must be driven by consumer and family involvement.

Comprehensive Services for Parents with Mental Illnesses

Presented below are brief descriptions of a comprehensive set of needed services for parents with mental illnesses. Examples from programs offering these also are provided.

Assessment of Parenting Strengths and Needs. Assessment needs to involve the entire family and to be conducted, as much as possible, in the home and larger community. The assessment must focus as much on strengths as on weaknesses. The Parenting Options Project in Massachusetts developed one such assessment, a tool specifically designed (and pilot tested) with the input of parents with severe mental

illness to aid in consumer-centered service planning and identification of parenting needs.

Case Management. Case management is critical; it must be available to the entire family and use models emphasizing follow-through to make sure service linkage occurs. Many programs provide 24 hour per day seven days per week case management availability, enabling them to resolve emergency or crisis situations. These programs include Peanut Butter and Jelly Family Services in Albuquerque, New Mexico; Ashbury House in San Francisco, California; and the Parent Infant Program in New York City.

Peer Support, Self-Help and Parent Mentoring. Research indicates that opportunities to be mentored by other parents are important ingredients in client support programs for parents with mental illnesses. An example of this type of support is the Parenting Options Project in Worcester, Massachusetts, which involves parents with mental illness working together to develop a parent training manual and workbook for other consumer parents. Another example is at Iowa City's Family Support Services Program, which holds monthly mothers' support groups and potlucks for entire families. The same advantages result when children of consumer parents can support each other and find role models for dealing with parental mental illness. For example, a set of interactive storybooks about being the child of a parent with mental illness involves the child reader in a "dialogue" with the story's protagonists, an 11 and nine year old brother and sister who share *their* experiences with their mentally ill parent and invite the reader to do the same. Support groups for children of parents with mental illness are another mechanism for peer support, as in Kids in Control run by the British Columbia Schizophrenia Society.

Medication Management. An honest and open relationship between patient and prescribing psychiatrist is essential throughout the parenting years, but especially so for mothers during pregnancy and the menopausal years. These are times when important psychopharmacological issues often arise due to hormonal changes.

Housing and Supports for Independent Living. Availability of high quality housing is a major motivator for parents to participate in programs. A powerful combination of peer support and housing is now being realized by the Mental Patients Association in Vancouver, Canada, who have opened a community residence for consumer mothers and their children. Ashbury House in San Francisco and Atlantic House in Quincy, Masssachusetts are other examples of supported housing and residential programming specially designed for consumer parents.

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Child Development and Parenting Skills Training. This is one of the most commonly offered types of service in parent-child programs, given ample evidence that parenting skills can be learned and improved, especially through role modeling. One of the goals of the Invisible Children's Project (ICP) in Goshen, New York, is to empower the parent to be a role model for her child. In cases where that is not possible, ICP's case managers step in to mentor the child as a role model for the parent. In many programs, parenting skills are taught in therapeutic nursery settings, which incorporate structured dyad activities and facilitate the child's cognitive and emotional development. Some programs which provide a therapeutic nursery include Thresholds Mothers' Project in Chicago, Illinois, Peanut Butter and Jelly Family Services in Albuquerque, New Mexico and the L.A.M.B. (Loving Attachments for Mothers and Babies) Program in Detroit, Michigan. Other family caretakers should be involved in these activities as well, to reinforce new skills and offer supportive feedback.

Vocational Rehabilitation. Research shows that parents are highly motivated to pursue employment goals, especially to support their immediate families. For children, studies show that having working parents is associated with young people's attachment to the labor force in their later lives. A few examples of programs that provide services such as career counseling, occupational training, community job placements, and employment support include Providence Center in Providence, Rhode Island, Ashbury House in San Francisco, and Thresholds Mothers' Project in Chicago. Arranging affordable, reliable child care is an important issue for working parents.

Custody/Relinquishment Counseling and Support. Study after study finds that custody loss is a common experience for mentally ill parents. As a result, their fear of termination or limitation of parental rights prevents many from seeking needed assistance. Development of best practices in this area could enhance the field's competency in creating a safe custody environment for service recipients and their children. One example is the Clubhouse Parents Legal Support Project in Marlborough, Massachusetts, a legal cooperative providing representation for parents with mental illness who are at risk for losing custody or contact with their children. Assistance with the grieving process also is important if parents lose custody.

Supported Education/Training. Education is necessary to help parents pursue their career goals, enhance self esteem, and upgrade learning skills. Many mothers are motivated to enhance their educations in order to better assist their children in learning fundamentals.

Birth Control Counseling, Pregnancy Decision-Making and Support. Research suggests that women may become pregnant in order to replace children lost through custody termination, and this points to the essential nature of counseling around pregnancy decision making. Issues of loss and grief often need to be dealt with sensitively.

Crisis and Respite Care. Parenting for many involves a series of crises, and mentally ill parents are particularly vulnerable to crises. Availability of short term care and in home supports is an often-needed option, especially during periods of remission. Respite care must be available to other family caretakers as well.

Foster Care Support and Linkage. If children enter protective custody or foster care, parents often need assistance negotiating the complex child welfare system. Too many parents feel unsupported in dealing with child protective services agencies and need help protecting their parental rights and maintaining contact with their children.

Trauma and Abuse Counseling. The rates of physical and sexual abuse among both women and men with mental illness are very high and evidence suggests that parenting often re-awakens issues regarding trauma, especially childhood trauma. This requires individual and sometimes group therapy and ongoing support.

Substance Abuse Treatment. Co-occurring mental illness and substance abuse is fairly common, and parents are no exception. As with other groups, the best approach for parents involves integrating mental health and substance abuse staff in delivering simultaneous treatment. The Center for Mental Health in Washington DC, for example, integrates addiction, mental health, child development and support services in their program for dually-diagnosed parents and their children.

Marital and Family Counseling. The dual strains of child rearing and dealing with emotional difficulties place stressors on couples' relationships that could benefit from marriage and family counseling. Family support and self help should be available to parents and members of their natural support network (families, children, partners).

Assistance with School Issues. Educators typically are absent from case planning for students who are impacted by a parent's mental illness. Disclosure typically occurs only after a problematic situation has arisen in the classroom. Teachers should be involved in care coordination, and attending school meetings with parents is one way for case managers to educate teachers and advocate for the family while supporting the parent.

Advance Directive Planning and Support. A major feature of parenting with a mental illness is interruption, and this influences parental bonding and attachment which is so dependent on continuity. Maintaining the parent-child bond during periods of hospitalization or incarceration is a critical service, often involving advocacy and working with multiple systems to ensure minimal disruption.

Benefits and Public Entitlement Counseling. Lower socio-economic status occasioned by poverty level benefits and entitlements, such as Transitional Assistance for Needy Families (TANF) and Supplemental Security Income (SSI), creates financial strains and outright impoverishment for many families. Parents need information about government programs (WIC, food stamps, etc.) aimed at low income parents. The Family Support Services Program in Iowa City lends support and assistance to clients when applying for such entitlements. Clients also need help with financial planning on limited incomes and in dealing with Welfare-to-Work expectations that they work or participate in work training programs in order to continue TANF eligibility.

Building an Effective System of Care

Many would ask: How can we assemble a system that provides such an extensive array of services to parents, their children, and the extended families who care for them? Is brokered or comprehensive case management the better approach? If the former, how can we transform attitudes and behaviors of unresponsive service systems? If the latter, how can we fund such diverse programming? The programs cited above testify to an existing service need (many have lengthy waiting lists) and are providing multiple services, either directly or through brokering and assertive follow-up. A multisite study now underway at the National Research and Training Center on Psychiatric Disability of the University of Illinois at Chicago is examining outcomes of four of the programs mentioned above over a one year time period and, hopefully, will answer questions about what correlates with success. Until then, this underserved population should be the focus of considerable research and service design attention including: 1) increased and permanent funding for these programs and services; 2) provider training and skill building in this area, especially cross training; 3) explicit and binding interagency agreements spelling out who will provide which services and who will pay for them; 4) service delivery by comprehensive, interdisciplinary teams rather then single case managers, whenever possible; 5) effective communication mechanisms and information sharing that allow all parts of the team and each system to know what is going on with a family at any particular point in time; 6) central involvement of peer support and self help organizations as well as family-to-family support for caregivers (e.g., NAMI, Federation for Families); and 7) blended funding and co-location of staff to encourage interagency collaboration and truly mutual investment in a family's outcomes. But most importantly, there must be the willingness to innovate, to "think outside the box" by applying the "WIT" factor (whatever it takes). This area needs new paradigms — ones that make sense for diverse communities of parents with severe mental disorders and that take account of new ways of organizing and financing systems of care for these vulnerable families. ■