

Chapter 10

The Prevalence of Parenthood in Adults with Mental Illness: Implications for State and Federal Policymakers, Programs, and Providers

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Introduction

Parents with mental illness describe the challenge of living with mental illness and its impact on their parenting experiences and ability (Nicholson, et al., 1998). We know less about the effects of parenting on mental illness for adults, though motherhood is described as a source of enhanced personal worth and feelings of accomplishment (Mowbray, et al., 2001) and can provide motivation for treatment and recovery (Mowbray et al., 2001; Nicholson et al., 1998). Parental mental illness conveys risk to children (Beardslee et al., 1996; Biederman et al., 2001; Goodman and Gotlib, 1999; Oyserman, et al., 2000), although recent studies focus on the resilience of children and the strengths that emerge in what could be construed as difficult family situations (Goodman and Gotlib, 1999). Data on the prevalence of parenthood in adults with mental illness are key to establishing the significance of the issue, the value in meeting the needs of parents and family members, and the potential for tragedy in missed opportunities for intervention and support.

The needs of parents with mental illness and their families often are overlooked. In a survey of State Mental Health Authorities (SMHAs) conducted in the early 1990s, adults receiving public sector mental health services were routinely asked about their status as parents in only 16 States (Nicholson, et al., 1993). This oversight is pervasive in treatment settings as well, reflected in the fact that agency or hospital records do not contain information about the children of adult clients (DeChillo, et al., 1994; DeChillo, et al., 1987; Rudolph, et al., 1990). Mothers with serious mental illness indicate that, although they perceive the need for such services as parenting skill training or support, almost half receive few or no services related to parenting (Mowbray et al., 2001). Understanding the prevalence of parenthood in adult clients is essential to policymakers, administrators, and providers, who set policies and regulations, craft service contracts, and provide treatment and rehabilitation to individuals in greatest need, potentially multiplying the likelihood of positive effects for all family members.

Researchers are beginning to explore the relationships between Federal policies and programs

and families living with parental mental illness. For example, Lennon and colleagues (2001) describe the implications of the high risk of depression in low-income women and women on welfare for Temporary Assistance for Needy Families (TANF) and Welfare-to-Work policies and programs. While parental mental illness may be a barrier to successful Federal policy and program outcomes (e.g., depression as a barrier to employment) (Lennon et al., 2001), it may be equally likely that Federal policies and programs affect outcomes for parents with mental illness and their families in both negative and positive directions. Federal policies and programs may afford innovative opportunities to support families when the prevalence of parental mental illness is understood and the unique characteristics and circumstances of these families are considered.

Until now, information on the prevalence of parenthood in adults with mental illness could only be derived from agency databases or from relatively small-scale studies of participants recruited in clinic or inpatient settings. Efforts to extrapolate prevalence rates from existing data sets or clinical sites are limited by the types of information routinely obtained and the characteristics of adults receiving services. For example, the Research and Training Center (RTC) National Survey of Parents with Disabilities, funded by the National Institute on Disability and Rehabilitation Research (NIDRR), provides data from a convenience sample of more than 1,200 adults self-identified as having disabilities (Barker and Maralani, 1997). These data are supplemented by a secondary analysis of the 1993 U.S. Census Bureau Survey of Income and Program Participation (SIPP). In this study, one in seven parents identified a psychiatric disability as his or her primary disability. According to SIPP data, about seven million parents with children under the age of 18 have disabilities. Applying the NIDRR-RTC rate of one in seven to the SIPP data, it is possible to estimate that approximately 1 million parents of children under the age of 18 have psychiatric disabilities. However, this is a gross underestimate given the convenience sample of self-identified parents, a high percentage of whom were female, White, English-speaking, and highly educated. These data do not include information about parents whose children are adults or those with children living in alternative family situations.

Data from public sector management information systems sources indicate that a significant percentage of adult clients receiving public sector

mental health services are parents. New York State data from the Office of Mental Health indicate that 45 percent of women under the age of 35 receiving intensive case management services have children, and, of these, 20 percent are the custodial parent (Blanch, et al., 1994). Prevalence estimates based on public sector mental health systems sources are most likely underestimates as well, given that adult clients receiving SMHA services are individuals with mental illness who meet eligibility criteria regarding severity and duration of illness, functional impairment, and criteria such as multiple hospitalizations and homelessness. The circumstances and experiences of these individuals may differ greatly from those of adults less severely impaired, those receiving services in the private sector, or those whose psychiatric disorders are undiagnosed and untreated.

In Massachusetts, clinicians in three sites provided data on the parenting status of their clients. The sites were a Massachusetts Department of Mental Health case management site, an outpatient department in a community mental health center, and a site providing both case management and outpatient treatment services (Nicholson, 1994). Clinicians described 33 to 50 percent of the female clients as mothers by clinicians. Clinicians knew that 21 percent of the male clients were fathers (Nicholson, et al., 1999). These prevalence figures are most likely underestimates, because they are based on clinicians' knowledge of their clients' parenting status and because the clients themselves are diagnosed with severe and lengthy mental illnesses.

The purpose of this chapter is threefold. The first objective is to examine the prevalence of parenthood among adults meeting criteria for mental illness, and to compare the prevalence of parenthood and characteristics of parents in adults with and without psychiatric disorders using data from the National Comorbidity Survey (NCS) of the United States (e.g., Kessler, 1994). Second, we provide current information on the approach of the SMHAs to the parenting status and needs of adult clients in the public sector by analyzing data from a national survey conducted in 1999 by University of Massachusetts Medical School (UMMS) researchers. Last, we review their potential impact of current Federal policies and programs on parents with mental illness and their families, and suggest opportunities for these policies and programs to improve outcomes for all family members.

The Prevalence of Parenthood and Characteristics of Parents with Mental Illness

The National Comorbidity Survey

Analyses were carried out using data from the 5,877 respondents ages 15 to 54 in the Part II subsample of the NCS, a nationally representative cross-sectional mental health survey (e.g., Kessler, 1994). Conducted from 1990 to 1992, this survey was designed to assess the prevalence and correlates of *Diagnostic and Statistical Manual of Mental Disorders*, 3rd edition (DSM-III-R) disorders and was administered to a nationally representative household sample of noninstitutionalized civilians in the 48 contiguous States. Data were weighted to adjust for nonresponse, for variation in the probability of selection, and to approximate national population distributions on the basis of the 1989 National Health Interview Survey. With the exception of nonaffective psychosis, DSM-III-R diagnoses in the NCS were assigned on the basis of structured interviews using the University of Michigan Composite International Diagnostic Interview (UM-CIDI), a modification of the Composite International Diagnostic Interview (CIDI) (World Health Organization, 1990). Following a screen for psychotic symptoms, nonaffective psychosis diagnoses were determined in re-interviews by experienced clinicians, using an adapted version of the Structured Clinical Interview for DSM-III-R (Kessler, McGonagle, Zhao, et al., 1994).

The NCS data have been one of the main sources of estimates of treatment need in the United States (U.S. Department of Health and Human Services [DHHS], 2000), and the methods and procedures of the NCS have been described in detail elsewhere (Kessler, 1994; Kessler, Anthony, et al., 1997; Kessler, Foster, et al., 1995; Kessler, Little, et al., 1995; Kessler, McGonagle, et al., 1994). The NCS data have been used to address research questions regarding lifetime and 12-month prevalence of psychiatric disorders (e.g., Kessler, Anthony, et al., 1997; Kessler, Grum, et al., 1997; Kessler, McGonagle, et al., 1994; Kessler, Sonnega, et al., 1995), gender (e.g., Kessler, McGonagle, et al., 1994; Silverstein, 1999; Sheikh, et al., 2002), socioeconomic status (Bassuk, et al., 1998; Katz, et al., 1997; Mutaner, et al., 1998; Wells, et al., 2001), family forma-

tion and stability (Forthofer, et al., 1996; Kessler, et al., 1997; Kessler, et al., 1998), and interpersonal relationships (Zlotnick, et al., 2000), among others (e.g., Kessler and Frank, 1997, Kessler, et al., 2001; Molnar, et al., 2001).

For this chapter, respondents were considered parents if they reported having natural-born children. Respondents who reported having only adopted or step, foster, or other unrelated children living with them, or who had given birth to a child who subsequently died and had no other children, were classified as nonparents. Respondents who reported having both natural and step, foster, or other unrelated children were classified as parents.

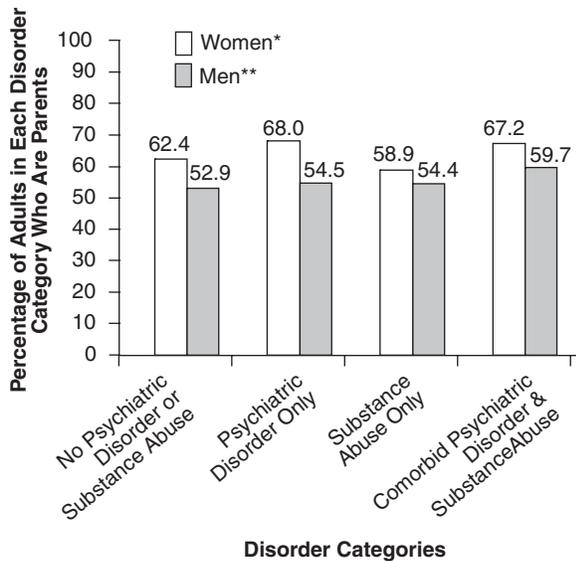
UM-CIDI/DSM-III-R diagnoses were used without exclusions for DSM hierarchy rules. All the estimates presented here have been weighted, and their associated standard errors have been generated using version 8.0 of the SUDAAN statistical package, which employs sampling design parameters and the jackknife replication method (default procedure of Delete-1 jackknife) for estimation (Research Triangle Institute, 2001). Comparisons between rates of different groups were made using *t*-tests performed by SUDAAN.

Severe and persistent mental illness (SPMI) in the previous 12 months was defined following the criteria described by Kessler et al. (1996): (1) 12-month prevalence of mania, bipolar disorder, or nonaffective psychosis (includes schizophrenia, schizoaffective disorder, and other psychotic disorders not accompanied by changes in mood); or (2) lifetime prevalence of mania or psychosis with treatment within the past year; or (3) 12-month prevalence of depression or panic disorder treated with medication or hospitalization.

Lifetime prevalence of mental illness, rather than 12-month prevalence, was chosen for most analyses in this chapter to reflect the notion that parenthood is a "longitudinal" rather than "cross-sectional" experience that occurs across years rather than in just a year. It is likely that having a parent with mental illness affects the lives of children at any age, although its impact is likely to differ by the age of the child when the parent becomes ill, as well by the severity and duration of the parent's illness (Oyserman et al., 2000; Wickramaratne and Weissman, 1998). In addition, many individuals with serious mental illness experience multiple disorders over time, most of which began early in life (Forthofer, et al., 1996; Kessler, et al., 1994).

What Is the Prevalence of Parenthood in Adults With Mental Illness?

Results of NCS data analyses regarding the lifetime prevalence of mental illness and parenting suggest that adults with psychiatric disorders or with co-occurring psychiatric disorders and substance abuse may be at least as likely, if not more likely, to be parents than those who do not meet criteria for a psychiatric disorder or substance abuse. Figure 1 presents the prevalence of parenthood among NCS respondents within four broad, exclusive, and exhaustive categories: (1) no psychiatric disorder or substance abuse, (2) psychiatric disorder only, (3) substance abuse only, and (4) comorbid psychiatric disorder and substance abuse. In only one case is the prevalence of parenthood in a disorder category less than the prevalence in the no disorder category, and that is the prevalence of motherhood in the “substance abuse only” category. The percentages of women and men who are parents in all other categories are greater than the percent age of parents in the “no psychiatric disorder or substance abuse” category. Of the female respondents with a lifetime prevalence of psychiatric disorder only, 68.0 percent are mothers. The difference between this proportion and the proportion of women with no psychiatric disorder or substance abuse who are mothers is statistically significant ($p = .04$). Among men in the NCS sample with a lifetime prevalence of psychiatric disorder, slightly more than half (54.5 percent) are fathers.



* All standard errors < 3.9.
 ** All standard errors < 3.0.

Figure 1. Lifetime Prevalence of Parenthood Among NCS Respondents.

Given that the NCS data are used to provide the rates of parenthood in adults with mental illness, our findings could be vulnerable to the type of criticism leveled at NCS methods and instrumentation in general. Critics of the prevalence rates of mental illness in the NCS data have suggested that NCS methods and instrumentation are oversensitive (i.e., reduced specificity due to false positive diagnoses) and therefore generate higher prevalence rates than actually exist or than are meaningful to policy development or service planning (Narrow, et al., 2002). Narrow and colleagues advocate generating revised prevalence estimates by applying a clinical significance criterion to each disorder. Wakefield and Spitzer (2002) argue, however, that addressing the issue of false positive diagnoses of disorder in psychiatric epidemiologic studies requires a more valid assessment of disorder status—one that takes into account the context in which the symptoms occur (Spitzer and Wakefield, 1999; Wakefield, 1997; Wakefield, et al., 2002).

As a further check of these prevalence rates, and to generate useful findings for State and Federal policymakers and planners, we analyzed data from adults in the NCS meeting criteria for SPMI. Our thinking was that the rate of parenthood in this group and, in particular, in the group meeting criteria in the limited period of the previous 12 months would provide more conservative estimates of parenthood prevalence. Often adults with SPMI, particularly men, are considered to be least likely to have children (Nicholson et al., 1999). In addition, public sector administrators and providers may consider the “psychiatric disorder only” category and the comorbid category as reflecting data on adults with less “serious” disorders, such as certain anxiety disorders, who are less likely to come to their attention.

Analyses of the NCS data indicate that equal or greater percentages of adults meeting criteria for SPMI in the previous 12 months are parents than are individuals without psychiatric disorders. A total of 67.2 percent of the women with SPMI are mothers, and 75.5 percent of the men with SPMI are fathers. In fact, men with SPMI are significantly more likely to be fathers than men with no psychiatric disorder or substance abuse ($p = .000$).

The NCS data were obtained in a community-based sample and do not represent individuals who were institutionalized at the time of the survey. It is possible to construe that these parenthood prevalence rates are somewhat inflated, because they reflect higher functioning individuals within the SPMI category who are living in the community and

are potentially more likely to form families. It is also important to remember that the NCS data include adults who meet criteria for psychiatric disorder and who are not in treatment. While these adults may not be precisely representative of individuals receiving SMHA services, they may well be representative of the larger population of individuals with SPMI, and may reflect even greater risk and unmet service need. It is quite possible that the experience of parenthood is different, and the impact of parental mental illness is greater, for those living with SPMI.

Results indicate that parents represent a significant proportion of the adults in all diagnostic categories. Table 1 shows the prevalence of parenthood among respondents within several diagnostic categories. For both men and women, the prevalence of

parenthood was highest (72.8 percent for women and 67.9 percent for men) among respondents who met criteria for diagnosis in the post-traumatic stress disorder category and lowest (61.8 percent for women and 55.2 percent for men) among those in the nonaffective psychosis category, which includes schizophrenia, schizoaffective disorder, and other psychotic disorders not accompanied by changes in mood. About two-thirds of the NCS women who met criteria for a diagnosis in the affective disorder category, which includes bipolar disorder type I, major depression, and dysthymia, or the anxiety disorder category, which includes agoraphobia, panic disorder, generalized anxiety disorder, simple phobias, and social phobia, were parents. A little more than half of the NCS men in these disorder categories were parents (58.0 and 56.4 percent, respectively).

Table 1. Lifetime prevalence of parenthood among NCS respondents meeting criteria for psychiatric disorders

| Disorders (UM-CIDI/DSM-III-R) | Women in Each Category Who Are Mothers (%) | | Men in Each Category Who Are Fathers (%) | |
|----------------------------------|---|------|---|------|
| | % | SE | % | SE |
| Affective Disorder | 66.8 | 2.0 | 58.0 | 2.6 |
| Anxiety Disorder | 68.2 | 1.6 | 56.4 | 2.3 |
| Posttraumatic Stress Disorder | 72.8 | 2.9 | 67.9 | 4.8 |
| Nonaffective Psychosis | 61.8 | 10.3 | 55.2 | 12.6 |

How Many Parents Have Mental Illness?

Among NCS respondents who are parents, almost half (46.8 percent) of the mothers and almost a third (29.5 percent) of the fathers have a lifetime prevalence of psychiatric disorders (see table 2). Approximately one-quarter (25.7 percent) of the mothers and 14.7 percent of fathers meet criteria for diagnosis in the affective disorder category. About one-third (32.4 percent) of mothers and 20.3 percent of fathers have a lifetime prevalence of anxiety disorders. Slightly over 11 percent of mothers and about 6 percent of fathers meet criteria for post-traumatic stress disorder, and fewer than 1 percent of parents (mothers 0.9 percent, fathers 0.6 percent) meet criteria for a nonaffective psychosis disorder diagnosis.

Parental Illness Characteristics

Illness characteristics are mediators in the relationship between parental mental illness and child outcomes. The relationship of specific parental diagnoses to child outcomes is unclear (Warner, et al., 1995). Illness characteristics such as severity of symptoms and duration of illness, however, are negatively related to outcomes for children (Sameroff and Seifer, 1983; Warner et al., 1995). Earlier parental age at onset of depression (prior to 30 years old) has also been found to be related to poor outcomes for children (Warner et al., 1995; Wickramaratne and Weissman, 1998). The relationship between children’s age at time of exposure to parental mental illness and child outcomes has been studied with mixed results. Inoff-Germain and colleagues (1997) found worse behavior problems among younger children whose parents were depressed.

The average age of illness onset for parents across diagnostic categories and the average age at birth of first child among NCS respondents who are

Table 2. Lifetime prevalence of psychiatric disorders, average age of illness onset, and average age at birth of first child among NCS respondents who are parents

| Disorders (UM-CIDI/ DSM-III-R) | Mothers (<i>n</i> = 1,899) | | | | | | Fathers (<i>n</i> = 1,599) | | | | | |
|--------------------------------------|-----------------------------|-----|---------------------------------------|-----|--|-----|-----------------------------|-----|---------------------------------------|-----|--|-----|
| | % of Mothers | SE | Average Age of Illness Onset | SE | Average Age at Birth of First Child | SE | % of Fathers | SE | Average Age of Illness Onset | SE | Average Age at Birth of First Child | SE |
| Affective Disorder | 25.7 | 1.3 | 25.7 | 0.5 | 21.9 | 0.2 | 14.7 | 1.1 | 27.0 | 0.7 | 24.5 | 0.3 |
| Anxiety Disorder | 32.4 | 1.4 | 15.7 | 0.5 | 21.9 | 0.2 | 20.3 | 1.3 | 16.6 | 0.6 | 24.4 | 0.4 |
| Posttraumatic Stress Disorder | 11.3 | 0.9 | 16.8 | 0.7 | 21.1 | 0.3 | 5.8 | 0.8 | 19.3 | 1.2 | 25.2 | 0.9 |
| Nonaffective Psychosis | 0.9 | 0.2 | 23.4 | 5.2 | 19.5 | 1.0 | 0.6 | 0.2 | 22.7 | 3.7 | 19.7 | 1.3 |
| Any Psychiatric Disorder* | 46.8 | 1.8 | 17.2 | 0.4 | 21.9 | 0.2 | 29.5 | 1.6 | 19.1 | 0.6 | 24.8 | 0.3 |
| No Psychiatric Disorder** | 53.2 | 1.8 | N/A | — | 22.8 | 0.3 | 70.5 | 1.6 | N/A | — | 25.3 | 0.3 |

* Includes comorbid psychiatric disorder and substance abuse, and excludes substance abuse only and antisocial personality disorder.

** Includes substance abuse only and antisocial personality disorder.

parents are presented in table 2. The sequence of average age of illness onset and average age at birth of first child varies by diagnostic category. The average age of onset for affective disorder is several years older than the average age at birth of first child for both NCS mothers and fathers. A similar sequence is apparent for individuals meeting criteria for nonaffective psychosis. The average age of onset for both anxiety and post-traumatic stress disorder among parents in the NCS sample is several years prior to the average age of birth of first child.

Mothers who met criteria for lifetime prevalence of psychiatric disorders tended to have their first children at slightly younger ages (mean = 21.9 years), than those without psychiatric disorders (mean = 22.8 years) ($p = .006$). A similar pattern is apparent among NCS fathers, though it is not statistically significant. Fathers who met criteria for lifetime prevalence of psychiatric disorder had their first children at slightly younger ages, on average (24.8 years), than did fathers without psychiatric disorders (mean = 25.3 years).

Characteristics of Parents With Mental Illness

Moderators that can enhance outcomes for children include the presence and availability of a supportive spouse or partner (Musick, et al., 1987). Environmental stressors such as minority status, single parenthood, low educational levels, and poverty increase the likelihood of negative outcomes for children whose parents have mental illness (Beidel and Turner, 1997; Hammen et al., 1987; Harnish, et al., 1995; Nicholson, et al., 2001).

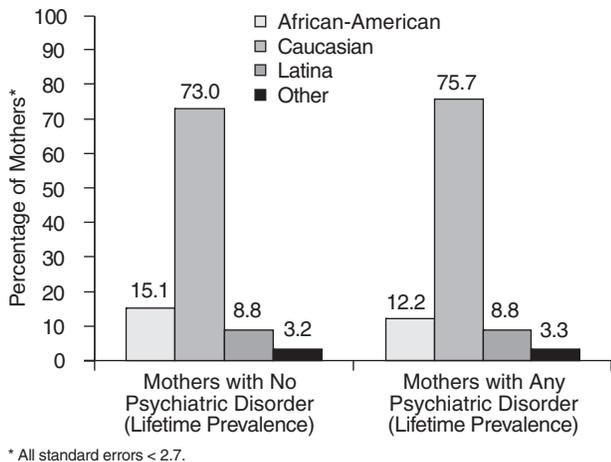


Figure 2. Race/ethnicity of NCS Women Who Are Mothers ($n = 1,899$).

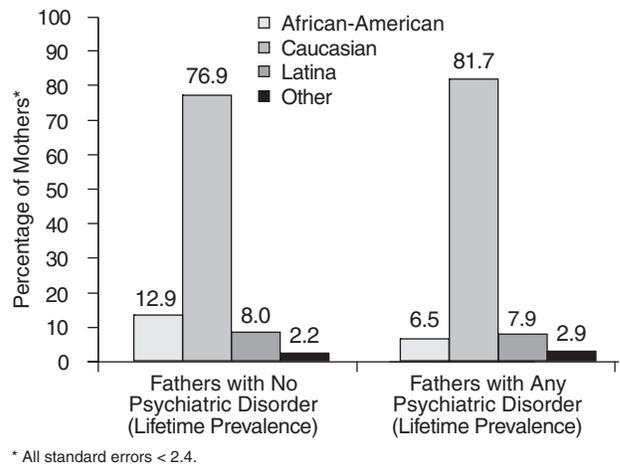


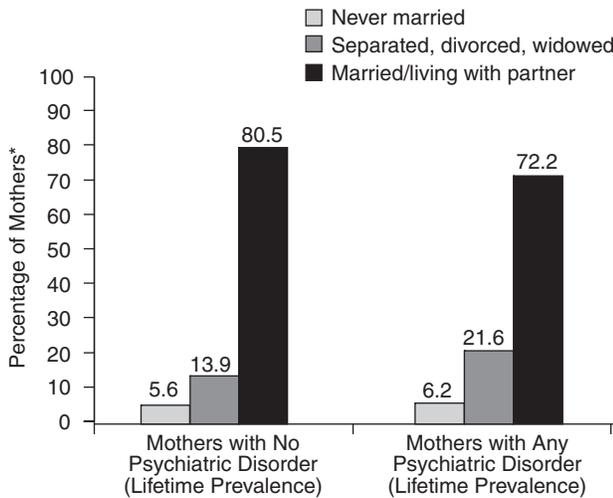
Figure 3. Race/ethnicity of NCS Men Who Are Fathers ($n = 1,599$).

It is important to note that the reference period for the demographic questions is the time of the survey. Thus, information on marital status, education, and income may not coincide with the experience of mental illness (see figures 4 and 5 and table 3).

Race/Ethnicity. In all groups, Caucasians represent about three-quarters or more of the total parents with no or any psychiatric disorder (see figures 2 and 3). No striking differences exist among NCS mothers between the race/ethnicity distributions of the “no psychiatric disorder” and “any psychiatric disorder” groups. Among NCS fathers, however, the differences in race/ethnicity between the two groups are statistically significant ($p = .002$). Caucasians represent a larger proportion of the fathers in the “any psychiatric disorder” group than in the “no psychiatric disorder” group (81.7 and 76.9 percent, respectively), and there are fewer African-Americans in the “any psychiatric disorder” group than the “no psychiatric disorder” group (6.5 and 12.9 percent, respectively).

Marital Status. Across the groups, about three-quarters or more of the NCS parents, both mothers and fathers, report being married or living with a partner in a steady, marriage-like relationship at the time of the survey (see figures 4 and 5). Among NCS mothers, the “no psychiatric disorder” and “any psychiatric disorder” groups differ significantly in terms of marital status ($p = .0001$). Women in the “married/living with partner” category make up a greater proportion of the mothers in the “no psychiatric disorder” group (80.5 and 72.2 percent, respectively), and more mothers in the “any psychiatric disorder” group.

Section III: Population Dynamics

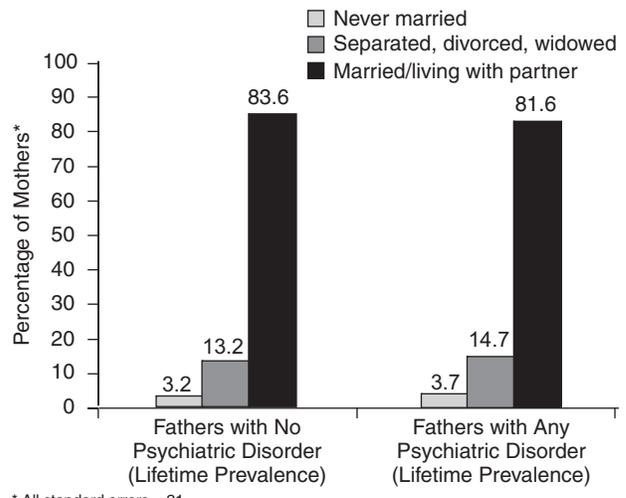


* All standard errors < 2.0.

Figure 4. Marital Status of NCS Women Who Are Mothers ($n = 1,899$).

der” group report being separated, divorced, or widowed than in the “no psychiatric disorder” group (21.6 and 13.9 percent, respectively). There are no striking differences in terms of marital status between the two groups of NCS fathers.

Age, Education, Proportion Below Poverty Level, and Number of Children. NCS mothers and fathers in all groups are similar in age and number of children, with the average number of children being



* All standard errors < 21.

Figure 5. Marital status of NCS Men Who Are Fathers ($n = 1,599$).

about 2.2 (see table 3). Fathers in the “any psychiatric disorder” group report significantly fewer years of education relative to the “no psychiatric disorder” group ($p = .04$). Significantly more of the mothers in the “any psychiatric disorder” group report household incomes falling below the poverty level than do those in the “no psychiatric disorder” group ($p = .006$). The same pattern is apparent among the NCS fathers, though it is not statistically significant.

Table 3. Selected characteristics of NCS respondents who are parents*

| Characteristic | Mothers | | | | Fathers | | | |
|--------------------------------|-------------------------|-----|--------------------------|-----|-------------------------|-----|--------------------------|-----|
| | No Psychiatric Disorder | | Any Psychiatric Disorder | | No Psychiatric Disorder | | Any Psychiatric Disorder | |
| | Mean/% | SE | Mean/% | SE | Mean/% | SE | Mean/% | SE |
| Mean Age | 37.1 | 0.5 | 36.9 | 0.4 | 38.4 | 0.4 | 38.4 | 0.4 |
| Mean Years of Education | 12.9 | 0.1 | 12.7 | 0.1 | 13.0 | 0.2 | 12.7† | 0.1 |
| Proportion Below Poverty Level | 10.8 | 1.5 | 16.3†† | 1.3 | 6.6 | 1.2 | 8.6 | 1.3 |
| Mean Number of Children | 2.2 | 0.1 | 2.3 | 0.1 | 2.2 | 0.1 | 2.3 | 0.1 |

* Categories represent lifetime prevalence.

† Significant difference compared with fathers in the “no psychiatric disorder” category ($p = .04$).

†† Significant difference compared with mothers in the “no psychiatric disorder” category ($p = .006$).

Implications of the Prevalence Data and Parental Characteristics

The majority of American adults who meet criteria for mental illness over the course of their lifetime are parents. This is true, as well, for those who meet criteria for SPMI who were living in the community at the time of the survey. Greater percentages of women and men in the affective, anxiety, and posttraumatic stress disorder categories are parents than are women and men without psychiatric disorders or substance abuse. While the numbers of women and men meeting criteria for nonaffective psychoses are small, the prevalence of parenthood is about the same for women in this category as for those without mental illness, and is slightly higher for men with nonaffective psychoses than for those without mental illness. Clearly, parenthood is a prevalent phenomenon among American adults with mental illness.

Although parenthood, *per se*, is common among these individuals, their experiences and those of their children may well vary by characteristics of their illnesses. These variations have implications for family interventions and support. For example, simply looking at the average age of illness onset and the average age at which first children are born shows variability across diagnostic categories. Adults living with affective disorders are likely to have their first child prior to illness onset, suggesting that for first children, at least, parents are well when the children are young. Parental depression, therefore, may be identified first by pediatric health care providers. The children may not come to the attention of professionals until they are school-age. On the other hand, the data indicate that illness onset precedes the birth of the first child for individuals in the anxiety disorder and posttraumatic stress disorder groups, suggesting the benefit of strategies targeted to earlier identification, intervention, and the support of resilience and coping for individuals with these disorders who are considering parenthood or becoming parents, as well as for their offspring.

Adults meeting criteria for nonaffective psychosis have their children, on average, at much younger ages than individuals in the other diagnostic groups, and prior to their reported average age of illness onset. The average ages of illness onset for parents in this group (mothers = 23.4 years; fathers = 22.7) are slightly lower than the average ages typically cited for the onset of schizophrenia in the literature (late 20s for women; mid-20s for men (DHHS, 2000)). Although schizophrenia is only one

of several diagnoses in this category, this comparison points to the need to explore further the undoubtedly complex relationships among mental illness, reproductive issues, childbearing, and child rearing.

Likewise, differences among groups of parents along the dimensions of race/ethnicity and marital status have implications for research, intervention, and support. Many of the studies in the past decade on the experiences of parents with mental illness have primarily involved mothers who are African-American or described as ethnically and racially “diverse” (Nicholson et al., 2001). The experiences of the largest group of mothers with mental illness in this study, Caucasian women, are largely unexplored, as are the experiences of Caucasian fathers. Patterns of care giving and social support have been found to vary among ethnic and racial groups of mothers with mental illness, with mothers of color more likely than Caucasian mothers to be primary caretakers of children (White, et al., 1995). Our analyses of the NCS data suggest that there are proportionately fewer African-American fathers in the “any psychiatric disorder” group than in the “no psychiatric disorder” group. These data may represent the characteristics and experiences of African-American men least well, particularly given the civilian, noninstitutionalized status of the households surveyed, because African-American men were more likely than Caucasians to be incarcerated at the time (Bonczar and Beck, 1997; U.S. Department of Justice, 1997). Our findings, combined with findings from previous research, suggest the importance of a broader consideration of racial/ethnic characteristics in future study, as well as the relevance of potentially distinct approaches to intervention and supportive services for families of diverse backgrounds.

The finding that greater percentages of mothers and fathers without psychiatric disorders are living in partnership with another adult than those with any psychiatric disorder is consistent with the literature suggesting that adults with mental illness have greater difficulty in intimate relationships and are more likely to experience family disruptions (Mowbray et al., 2000; DHHS, 2000). Far more parents in each group have ever been married than have not, a finding that also confirms earlier work (Mowbray et al., 2000; White et al., 1995) and suggests that marriage or partnership predisposes individuals with or without mental illness to parenthood. The higher percentage of mothers with mental illness living without partners (27.8 percent) compared with those with no mental illness

living with partners (19.5 percent) corroborates earlier studies and underscores the conclusion that mothers with mental illness may be more isolated and in need of social supports (Mowbray et al., 2000).

Even though the average age and education level of mothers without and with psychiatric disorders are virtually identical, a significantly higher percentage of mothers with psychiatric disorders are living below the poverty level, again suggesting that mothers with psychiatric disorders have fewer resources than their well counterparts. Fathers with psychiatric disorders are less well educated and more likely to report incomes below the poverty level than fathers without psychiatric disorders, although the proportion of fathers living below the poverty level is far smaller than the proportion of mothers. These gender differences may reflect tendencies for men to be working more hours and for higher wages than women, who may be more likely to be caring for children at home.

Given that the percentages of mothers and fathers with psychiatric disorders who have ever married (93.8 percent of mothers and 96.3 percent of fathers) are quite similar to the percents of mothers and fathers without psychiatric disorders who have ever married (94.4 percent of mothers and 96.8 percent of fathers), a significant proportion of families may include two parents, both of whom have a lifetime prevalence of psychiatric disorder. Under an assumption of independence (i.e., that the estimates of the two groups—mothers and fathers—are not related), about one-quarter of all families would fall into this category (the probability that both parents have mental illness = probability for mothers (.5) x probability for fathers (.5)). However, this assumption cannot be investigated, because the NCS was designed to sample individuals, not families. This estimate is especially conservative if an adult with mental illness is more likely to be in a relationship with another adult with mental illness. If this is the case, then we might expect up to 50 percent of families to include two parents with mental illness. That assumption has significant implications for the treatment of families because the participation of both parents would have greater benefit.

Our findings point to the complexities in the relationships between illness, individual characteristics, and parenting and only suggest potential impact on adults and children. The NCS data do not allow for complete understanding of these complexities. The data are not intergenerational (i.e., individuals are sampled, not families), limiting our use of family-related variables and our interpretation of

findings. While responses of adults are weighted to match national population distributions, information obtained about children has not similarly been statistically manipulated, limiting our ability to make inferences about the characteristics or experiences of the larger population of children living with parental mental illness. The most simple, and perhaps most powerful, conclusion that can safely be drawn from analyses of the NCS data is that parenthood is extremely prevalent among the millions of women and men with mental illness in the United States, and, therefore, many more millions of children are potentially affected by parental mental illness at some point in their lives.

Activities of the State Mental Health Authorities

The SMHA Survey

In 1999, UMMS researchers surveyed 51 SMHA commissioners and directors representing the 50 States and the District of Columbia regarding SMHA policies, programs, and practices for parents with mental illness and their families (Nicholson et al., 2001). The purpose of the survey was to understand whether and how public mental health systems respond to the parental role of adult clients. This survey was a followup to a study conducted at UMMS by Nicholson and colleagues in the early 1990s (Nicholson et al., 1993).

The person determined by the individual SMHA commissioner or director to have the most knowledge of adult services or the parenting issues of adult clients completed structured surveys. The respondent was most often the SMHA commissioner or director or the person responsible for adult mental health services. The participation rate was 100 percent. Surveys were returned between February 1999 and September 1999.

Survey respondents were asked the following questions: (1) Are adult clients formally identified as parents by the SMHA? (2) Does the SMHA have services or programs for adult clients who are parents? (3) Does the SMHA have specific written policies or practice guidelines regarding adult clients who are parents? Questions two and three, regarding specific services/programs and policies, were asked for each of 10 SMHA service categories: (1) inpatient services—acute; (2) inpatient services—continuing; (3) emergency mental health services; (4)

community residential services; (5) community rehabilitation services; (6) employment and vocational services; (7) clubhouses; (8) day treatment; (9) outpatient services; and (10) other.

Survey results indicate that the majority of SMHAs do not routinely address the parental role of adult clients. As indicated in figure 6, less than one-quarter of SMHAs ($n = 12$) formally identify adult clients as parents. Just over one-fourth of SMHAs ($n = 14$) have services or programs for adult clients who are parents (see figure 7), whereas only 8 percent of SMHAs ($n = 4$) have written policies or practice guidelines regarding adult SMHA clients who are parents (see figure 8). Services and programs for parents were evenly distributed across nine SMHA service categories (excluding “other”). No patterns of responses were seen for written policies or practice guidelines for adult SMHA clients who are parents. A total of 15 SMHAs (29 percent) address parental mental illness through one of two domains, either identifying clients as parents or providing services or programs.

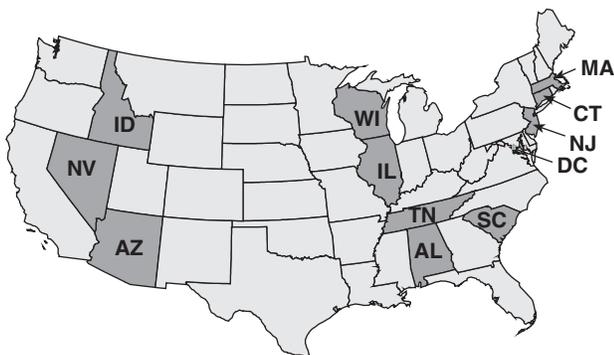


Figure 6. 1999 SMHA Results: Adult Clients Who Are Formally Identified as Parents by the SMHA.

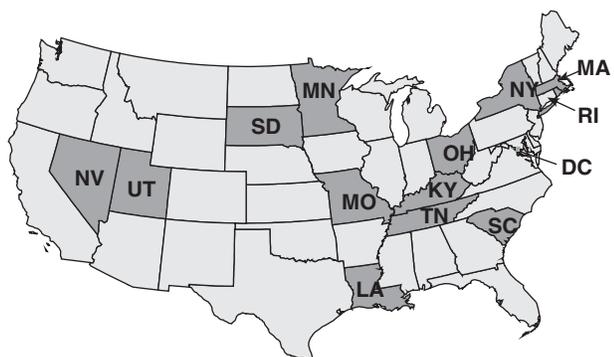


Figure 7. 1999 SMHA Results: Services/Programs for Adult Clients Who Are Parents.

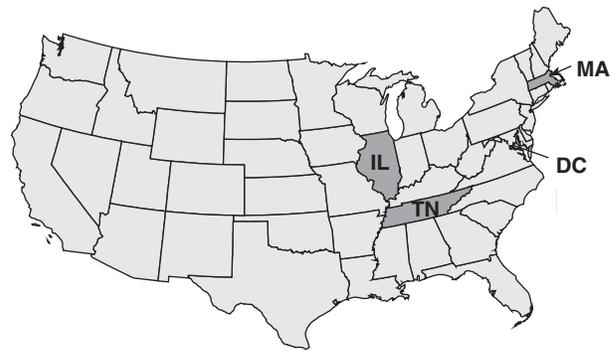


Figure 8. 1999 SMHA Survey Results: Specific Written Policies or Practice Guidelines Regarding Adult Clients Who Are Parents.

Understanding the Lack of Attention to the Parenting Role

The parental role of adult clients may not be addressed in public sector mental health services for a variety of reasons. SMHA administrators, staff, and providers may be genuinely unaware of the prevalence of parenthood among clients, especially given the reports of high rates of custody loss among adults with serious mental illness (Nicholson et al., 2001). Services typically are designed to meet the needs of individual adults with mental illness or children with serious emotional disturbance as “identified clients” and most often do not encompass the experiences and needs of adults as caregivers in the context of families. SMHAs may be overwhelmed by meeting the needs of existing special populations (e.g., individuals with dual diagnoses, with HIV/AIDS, or who are homeless) or a large number of clients, and may be limited in the ability to address additional special populations. Finally, parenting issues and services may be relegated to the child welfare agencies or viewed as the purview of the children’s mental health division of the SMHA.

Implications of SMHA Activities for Parents with Mental Illness and their Families

SMHA administrators, staff, and providers who are unaware of adult clients’ roles as parents are unable to meet their needs as parents and those of their families. Few SMHAs focus on the parental role of adult clients (Nicholson et al., 2001). The

lack of services, programs, and policies addressing parents with mental illness suggests that the parental role of adult clients generally has not been incorporated into SMHAs' systems of care nor attended to at a policymaking, administrative level.

Because most mental health program and policy decisions are made at the State level, SMHAs may miss opportunities to address issues important to clients. Missed opportunities may compromise parents' treatment and recovery, as well as opportunities for prevention and intervention with the at-risk children in these families. SMHAs' attention to the issues of parents with mental illness varies considerably among States.

Policy Consideration for State Mental Health Authorities

However, SMHA administrators and policymakers can affect change for parents with mental illness and their families. SMHAs need to "change the way they do business" and incorporate the needs of parents and their children into SMHAs' systems of care. Our recommendations include the following:

- **Prioritize Parenting and the Family:** SMHAs need to prioritize the issue of parenting and the needs of families. This requires embracing a philosophy of serving the family unit, rather than the more traditional models designed for identified individual "adult" and "child" clients. SMHA policymakers, providers, and agency directors could consider implementing family case management to provide supports and resources for an entire family rather than an "identified client." This would require developing flexible financing methods to support family case management through Federal and State funding streams.
- **Identify Adult Clients as Parents:** All SMHAs should identify the parenting status of their adult clients. Specific questions regarding parenting and children should be asked, including these: Do you have children? When were they born? Where are they living? With whom? If your children are under 18, do you have custody of them? If they are not with you, who provides their care? How often do you see them and under what circumstances? Adults may have children other than their biological offspring for whom they provide care, such as stepchildren or adopted children. Asking the "parenting" questions is a vital first step in beginning to consider parents with mental illness as members of families in which they have responsibilities as caregivers. These data should be collected by provider agencies and made available to the State through formal requirements.
- **Support Collaboration Between Adult and Children's Mental Health:** SMHA administrators and policymakers should encourage collaboration among adult and child mental health divisions, agencies, and providers in an effort to offer family-based services. Collaboration will encourage adult and child mental health providers to share expertise and will decrease the likelihood of duplicated or fragmented services and the frequently counterproductive activities that may occur when adults and children are served in separate sectors or systems of care. Efforts to collaborate must recognize the differing philosophies of the adult and child mental health divisions and providers. The adult mental health world often has ignored the parental role of clients, while the child mental health world has historically blamed parents for children's social and emotional problems. These patterns need to change. Research achievements over the past decade confirm the biological, chemical, and possibly genetic predisposition to many psychiatric disorders. Yet, there is no doubt that environmental factors (including family characteristics) also play a significant role.
- **Collaborate with Related Service Sectors:** SMHA administrators, staff, and providers should collaborate with other service sectors that likely serve many of the same families found in SMHAs. Like the public mental health system, substance abuse, homeless, criminal justice, and HIV/AIDS agencies and providers are also faced with the challenges of serving families. Just as parents and children are best served as members of families, support services are best delivered in an integrated and coordinated fashion that maximizes resources, decreases conflicts from disparate systems, and increases health and wellness for families. Memorandums of understanding may be required to spell out the mandates and roles of collaborating agencies and mechanisms for sharing information and resources.

The Relationship of Federal Programs and Policies to Parents with Mental Illness and their Families

No existing Federal programs or policies explicitly consider the circumstances of adults with mental illness as parents; however, many have the potential to affect the lives of adults and children living with parental mental illness. Parents with mental illness and their children are particularly vulnerable when policies disregard the influence of mental illness or the role of parenting on an individual's life functioning, recovery, and wellness. The consequences of these programs and policies are largely unstudied, and the understanding of their potential effect on families, both on the recovery trajectory of parents and the social, emotional, and cognitive development of their children is limited.

Medicaid and the Community Mental Health Services Block Grant are two Federal programs targeting health and mental health issues that offer opportunities to attend to the needs of parents with mental illness and their children. Other Federal policies, such as the Adoption and Safe Families Act (ASFA), the Americans with Disabilities Act (ADA), and the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA), meant for broader target populations, may have unintended consequences for families living with parental mental illness. Children's Health and Early Intervention programs have the potential to address parental mental illness through health and educational services for young children.

Medicaid

Medicaid is the primary funding source for State and local mental health services (Buck, 2001). States raise barriers for families and providers by focusing efforts on clinic and residential care while failing to support a full range of community-based services, including home-based supports, wrap-around approaches, and intensive case management (Bazelon Center for Mental Health Law, 2001). Most States have not taken advantage of the range of service options available, instead working with outdated Medicaid plans and rules that do not prioritize recovery and living in the community. Failure to use the various options available through Medicaid, specifically those within the Rehabilita-

tion Option, has left many adults with mental illness without access to effective services.

Opportunities. The Rehabilitation Option provides an array of services potentially useful to families. Rehabilitation services of particular interest to families in which a parent has a mental illness may include basic living skills training (maintaining a household, meal planning and preparation), social skills training (interpersonal skills for creating social networks, interacting with schools, self-advocacy), family education (educating family members about mental illness, support and training to deal with crises, crisis-respite services), and advance directives (determining care and temporary custody of children) (Bazelon Center for Mental Health Law, 2001).

The Early and Periodic Screening, Diagnosis, and Treatment program (EPSDT) is a Medicaid-funded program that pays for screening and physical and mental health services for children. States are required to provide Medicaid-eligible children any medically necessary health care services that fall within the federally defined scope of services, even if the service is not available under a particular State's Medicaid plan. Some providers have leveraged EPSDT dollars to provide services to parents by including these services as part of the treatment plan for the child. Services have included assessment of parent-infant attachment, identification of parental mental illness, referral for medication evaluations, and in-home visits by a mental health clinician.

Community Mental Health Services Block Grant

The Community Mental Health Services Block Grant program, a joint Federal-State partnership established in 1981, provides funding for creative and cost-effective community-based care for adults and children with serious mental illness. Each State develops and implements its own state mental health plan to address the need for services among special populations. Case management for the most seriously mentally ill and partnerships with primary health, dental, mental health, vocational, housing, and education services are encouraged. States must use the advice of State Mental Health Planning Councils, which require 51 percent consumer, family member, and nontreating professional citizen membership.

Opportunities. The Community Mental Health Services Block Grant provides opportunities for

States to support existing public services as well as develop new and innovative systems of community-based care. The flexibility of the funding allows community mental health providers, in consultation with State Mental Health Planning Councils, to determine the best use of the available dollars in relation to the needs of the State. Mental Health Block Grant funding has been used in a community mental health center in Iowa City, Iowa, to support a clinical case management program for families in which a parent has an SPMI and has minor children living in the home (Hinden, et al., 2002).

Adoption and Safe Families Act (ASFA)

The ASFA was designed to provide safety for neglected and abused children and ensure swift and permanent placements for children living in foster care. State child welfare agencies are required to make reasonable efforts to avoid unnecessary foster care placements and to facilitate children's reunification with their families.

ASFA regulations require permanency hearings to occur within the first 12 months a child is in foster care, which is 6 months sooner than the previous timeline set by the Child Welfare Act of 1980. In addition, termination of parental rights (TPR) proceedings must be initiated for all children in State care for 15 of the last 22 months (Rauber and Granik, 2000). TPR petitions may be circumvented if (a) a relative is caring for the child; (b) there is evidence that a TPR is not in the best interest of the child; or (c) the child welfare agency has not provided appropriate services to the family to ensure a safe return home for the child.

More restrictive time constraints will most likely disadvantage parents with mental illness and their children. There is concern that in an effort to meet the 12-month window to provide permanent placements for children, child welfare agencies may focus on out-of-home placements instead of coordinating efforts to support or reunify families. Child welfare agencies may be ill-equipped to work with the complex needs of parents with mental illness. These agencies have limited resources and referral sources to support these families, as few services and programs specifically address the needs of families experiencing parental mental illness (Nicholson et al., 2001).

Opportunities. The best interests of children and the needs of parents may be met through comprehensive, in-home services that support families staying together. The Invisible Children's Project of

Mental Health Association of Orange County, New York, collaborates with the local child welfare agency to provide flexible and complementary supports to meet the complex needs of families living with parental mental illness. Child welfare workers and the Invisible Children's Project providers share expertise and resources in an effort to strengthen families and support reunification. A recent evaluation of the Invisible Children's Project indicated that collaboration between mental health and child welfare providers was critical to successful family outcomes (Hinden, et al., 2002).

Americans with Disabilities Act

Title II of the ADA requires local and State governments to provide equal opportunity and access to the benefits of all programs, services, and activities for persons with disabilities. When opportunity and access do not exist, local and State governments are required to make reasonable accommodations. Thus far, the ADA has provided little direct benefit to parents with mental illness. The ADA has not been used successfully in State or Federal court to argue lack of reasonable accommodations for parents with mental illness (Kerr, 2000; Mosier, 1998). With the exception of a single lower court ruling in Texas, individual TPR challenges using the ADA have been ineffective, because courts have found that the rights of parents to services or accommodation in services are not considered part of the benefits, services, and programs detailed by Title II of the ADA (Stefan, 2000).

Opportunities. The ADA has the potential to be a valuable tool in protecting the parental rights of all adults with disabilities. Parents with developmental disabilities have used the ADA successfully to ensure State-mandated parental supports. Mental health and legal advocates can learn from other disability rights advocates who have successfully defended the rights of parents, and can incorporate these techniques into their advocacy efforts.

Personal Responsibility and Work Opportunity Reconciliation Act

The Federal PRWORA limits lifetime welfare assistance to five years and requires employment after two years of continuous support. The high prevalence of women on welfare experiencing depression (Ahluwalia, et al., 2001; Lennon et al., 2001) raises concern about the impact of PRWORA

on women and families. Mothers with mental illness face multiple challenges when entering or returning to work. Work for persons with mental illness is often low paying and in stressful environments, which may exacerbate symptoms of depression. Stigma about mental illness is powerful and may prevent employers from hiring persons with mental illness, regardless of their ability to perform the required tasks. Mothers may have difficulty securing safe and affordable childcare. New work requirements detailed in the TANF State block grant do not specifically identify mental illness as a barrier to employment.

Opportunities. The PRWORA and TANF regulations should recognize that women on welfare have higher rates of depression than the population as a whole and require special consideration as they return to the workforce. Opportunities exist to educate employers about the issues of work and mental illness, such as stigma about mental illness and identifying job tasks that do not exacerbate an employee's illness. Securing affordable and appropriate childcare and finding reliable transportation to and from work are all part of the concerns of returning to work, especially for mothers with multiple vulnerabilities. The Ticket to Work and Work Incentives Improvement Act of 1999 provides incentives for people with disabilities to return to work, including extended Medicare coverage for Social Security Disability Insurance (SSDI) beneficiaries and expanded Medicaid eligibility categories for Supplemental Security Insurance (SSI) recipients.

Children's Health and Early Intervention Programs

Select Federal programs designed to improve health and educational services for young children have the potential to address parental mental illness:

- **Healthy Start:** Healthy Start strives to reduce infant mortality in targeted high-risk communities by working with primary care providers, such as pediatricians. All programs are required to provide screenings for depression in pregnant and postpartum women. Improving Women's Health through Screening and Intervention for Depression During and Around the Time of Pregnancy is Healthy Start's latest initiative, designed to provide mental health services to pregnant women in a primary care setting. Young fami-

lies are provided a core set of services, including direct outreach and peer mentoring, case management, home visiting, and links to health and mental health care for mothers and their infants.

- **Starting Early Starting Smart:** Starting Early Starting Smart (SESS) was a child-centered, family-focused program designed to address the needs of children from birth to seven years of age at risk for developing mental health and substance abuse problems. Services useful to families in which a parent has a mental illness included home visitation, dyadic therapy, parent education, in-home support, and mental health services.
- **Head Start:** Head Start is a Federal preschool program with a focus on the social, emotional, and cognitive development of young children. With a goal of strengthening families, Head Start can provide services to strengthen parenting skills and promote attachment between mothers and children. Early Head Start is an extension of Head Start, addressing children under three years old.

Conclusion

Parenthood is extremely prevalent among adults with mental illness. Their unique characteristics and circumstances have implications for State and Federal policies and programs and for provider practices. The majority of SMHAs do not address the needs of parents with mental illness and their families in systematic ways. Opportunities to develop policies and programs and to influence State-reimbursed providers on behalf of families living with parental mental illness are missed. Although Federal policies and programs have not explicitly taken the issues of parents with mental illness into account, many opportunities exist for innovative application of Federal guidelines and resources to support positive outcomes for all family members.

Meeting the needs of families living with parental mental illness requires acknowledging the high prevalence of this phenomenon. The potentially positive impact of dealing with individuals in the context of their families, while considering their family roles, cannot be overstated. When whole families are not the unit of analysis or service, the needs of individuals as family members are not met or are

partially met, often in duplicated and fragmented ways, with costs to service systems as well as individuals. The impact of mental illness on families and, likewise, of family circumstances on an individual family member's rehabilitation and recovery must be embraced and understood. The opportunities for policy and programmatic innovation, and for prevention, treatment, and rehabilitation, are many.

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