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Supported Parenting to Meet the Needs and Concerns of Mothers with Severe Mental Illness

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Abstract

Women with serious mental illness often parent without adequate support from psychiatric and behavioral health providers. The lack of such services is significant, given that women with SMI have children at the same or higher rates as women without psychiatric disabilities. In this call to action, we argue that the need to develop supported parenting initiatives for women with SMI is necessary and long overdue. First, we describe numerous social and systemic barriers in the U.S. that have hindered the development of parenting supports for women with SMI over the last century. We next describe recent qualitative and quantitative findings regarding the parenting needs and strengths of these mothers. Finally, we conclude with suggestions for future research, program development, and systems-level policy changes to support mothers with SMI in parenting most effectively.

Keywords

mothers; supported parenting; severe mental illness; policy initiatives

Women diagnosed with illnesses including schizophrenia, schizoaffective disorder, bipolar disorder, and major affective disorders often parent without adequate support from psychiatric and behavioral health providers (Blanch, Nicholson, & Purcell, 1994; Mowbray, Oyserman, & Bybee, 2000; Nicholson & Henry, 2003; Nicholson, Sweeney, & Geller, 1998). A recent qualitative review revealed only 23 programs in the U.S. focused specifically on helping parents with severe mental illness (SMI) to parent effectively; an area in which there is a striking lack of data regarding program effectiveness and outcome (Nicholson, Hinden, Biebel, Henry, & Katz-Leavy, 2007). Surveys of state mental health agencies have likewise revealed a very low rate of data collection regarding the parenting status and skills of women with SMI (Nicholson & Blanch, 1994). Thus, while many programs have been developed to help family members, including children, cope with the impact of a loved one's SMI, there are very few programs available at this time that focus directly and specifically on meeting the parenting needs of mothers coping with these disorders.

The paucity of such services is significant, given that women with SMI have children at the same or higher rate as women without these disorders (Mowbray, Oyserman, & Bybee, 2000). While some data suggest that women with SMI are more likely to lose custody of their children than are women without psychiatric diagnoses (Miller & Finnerty, 1996),

other work indicates that the vast majority of women with SMI continue to play some role in raising their children (Ritsher, Coursey, & Farrell, 1997). This involvement persists despite a number of concurrent difficulties that disproportionately impact women with SMI, including high rates of poverty (Mowbray, Oyserman, & Bybee, 2000), low levels of social support (Mowbray, Oyserman, & Ross, 1995), substance abuse, trauma, and homelessness (Nicholson & Henry, 2003).

In this manuscript, we argue that the need to develop parenting supports for women with SMI is both necessary and long overdue. Analogous to supported employment, supported parenting initiatives should aim to provide mothers diagnosed with SMI with a range of instrumental, emotional, and social assistance so that they may fulfill their parenting responsibilities to their fullest potential (see also Nicholson, Albert, Gershenson, Williams, & Biebel, 2009). Unlike supported employment, in which the beneficial impact of employment falls primarily to the employed individual, though, supported parenting affects, at minimum, two people (and possibly more) because these interventions target a parent's ability to care for her dependent child (or children). Therefore, supported parenting interventions will be necessarily complex in their design, incorporating elements intended to foster the well-being of both mothers and children simultaneously. We believe that this complexity, along with stigma regarding the parenting rights and capacities of mothers with SMI, has contributed to delays in the development of initiatives that will provide parenting support in the US.

To build the case for developing supported parenting, we have divided this manuscript into three parts. First, we highlight numerous social and systemic barriers in the U.S. that have hindered the development and provision of parenting supports for women with SMI over the last century. We next describe recent findings regarding the parenting needs and strengths of these mothers and suggest how these findings may be used to develop effective parenting programs. We conclude with suggestions for future research, program development, and policy changes that are needed in order to develop effective, appropriate supports for women with SMI who are mothering their children.

Obstacles to Addressing the Parenting Concerns of Mothers with SMI

During the 20th century, there were myriad factors that made it difficult, if not impossible, to address the parenting concerns of women with SMI. In fact, mental health policy in the U.S. during most of the 20th century suggested, at best, an implicit lack of approval and support for the parenting identity and needs of women with SMI and, at worst, overt discrimination against these individuals. This state of affairs was due in part to stigma regarding mental illness, as well as ever-evolving alterations to the structure, function, and policies regulating the American mental health system.

The most notable example of the failure of the mental health system to recognize the mothering role of women with SMI comes from the 100 plus years of institutionalization. At the time, medical opinion held a priori that women with postpartum psychosis were to be immediately separated from their children and not reunited until stable remission was achieved (see Howard, 2000b, for a review). Further, a woman who had become a parent prior to becoming institutionalized could face long, often unwanted, separations from her children. In their review of inpatient records spanning 1905–1974 in Leicestershire, England, Dipple and colleagues (2002) found that over 57% of women hospitalized for severe psychiatric distress had become separated from their children against their will. Dipple and colleagues (2002) also note a dearth of information in these women's psychiatric charts concerning their identity and role as mothers. We have every reason to believe that women in U.S. institutions experienced a similar fate; most likely resulting in their feeling

bereft over extended separation from their children (see also Schen, 2005). Further, the numerous restrictions placed on interpersonal and sexual relationships in institutions (Howard, 2000a; Miller, 1997), along with the overall eugenic prejudice against disseminating mental illness throughout society (Whitaker, 2002), contributed to very low reproductive rates for individuals with SMI prior to the 1950s (Erlenmeyer-Kimling, Rainer, & Kallman, 1966, as cited in Canton, Cournos, & Dominguez, 1999).

The most pronounced illustration of restrictions on parenthood for individuals with SMI is found in the compulsory sterilization of patients living in asylums and mental hospitals, often without their consent. Citing the need to prevent the “manifestly unfit from continuing their kind,” the U.S. Supreme Court voted 8-1 in 1927 that compulsory sterilization of individuals held in asylums was constitutional (*Buck vs. Bell*, 1927, as cited in Whitaker, 2002, pg. 59). By 1945, over 21,300 individuals in mental hospitals had undergone such sterilization procedures, with another 4,000 sterilized in the 1950s (Whitaker, 2002). Such practices, which were sanctioned by the majority of the American public in the 1930s (Whitaker, 2002), made it physically impossible for women with SMI to have children.

With de-institutionalization, there has been a significant increase in the reproductive rates of women with SMI (Mowbray, Oyserman, & Bybee, 2000; Nicholson, Geller, & Fisher, 1996). Further, the growth of the consumer advocacy movement and organizations including the National Alliance on Mental Illness (NAMI) during the 1970s and 80s provided a forum for individuals with SMI and their supporters to speak out against stigma and prejudice (Miller, Ponce, & Thompson, in press). Researchers have also begun calling attention to the parenting realities and needs of mothers with SMI (see Apfel & Handel, 1993 and Nicholson & Deveney, 2009, for reviews). But while the Community Support Movement that began in the 1970s placed greater emphasis on supporting the desires of persons with SMI to occupy normative adult roles in the community, parenthood has rarely been considered or supported in public policy or program development.

With the more recent Recovery Movement, new opportunities exist to broaden the scope of the “life in the community” envisioned by the 2003 President’s New Freedom Commission on Mental Health (DHHS, 2003) to include additional aspects of adulthood that were not previously addressed, including parenting. What remains to be done is to translate emerging research regarding the parenting strengths and needs of mothers with SMI (see next section) into policy or advocacy initiatives. We believe that now is the optimal moment to draw on this empirical literature to develop recovery-oriented, supported parenting initiatives for mothers with SMI.

The Parenting Concerns of Mothers with SMI

To help women with SMI meet their potential as mothers, research about these women’s experiences and feelings about parenthood, as well as inquiry into how these experiences could inform parenting program development, is warranted. For the most part, studies reveal that motherhood can have enormous emotional importance for many women, including women with SMI (Cook & Steigman, 2000; Fox, 2009; Miller, 1997; Mowbray, Oyserman, & Bybee, 2000; Mowbray, Oyserman, & Ross, 1995). In a 1999 study of women hospitalized for SMI, Joseph and colleagues surveyed 27 women on their feelings regarding motherhood. Of the 14 mothers who had underage children, 13 reported that it was “very important to continue mothering” their children, with the remaining mother endorsing that this was “important” (Joseph, Joshi, Lewin, & Abrams, 1999; see also Savvidou, Bozikas, Hatzigeleki, & Karavatos, 2003, for similar findings among inpatients in Greece). Further, in a large sample of economically disadvantaged women living with SMI, Mowbray and colleagues (2001) found that women endorsed their role as a parent to be of primary

importance. These women also reported various positive consequences of motherhood including improved self-esteem, cessation of substance use, increased motivation for psychiatric treatment, and enhanced ability to deal with their psychiatric concerns. Despite the stressors that parenting can also sometimes entail (Mowbray, Oyserman, & Bybee, 2000), women coping with SMI consistently voice the central importance that children and motherhood have in their lives (Bassett, Lampe, & Lloyd, 1999; Mowbray, Oyserman, & Bybee, 2000).

Research also highlights these mothers' desire for increased recognition of and support for their role as parents. Seven mothers in the Joseph et al. (1999) study reported that they wanted help reuniting with their children, and an additional 4 mothers requested education regarding effective parenting practices. Studies with mothers who are not hospitalized similarly reveal the desire for greater acknowledgement from their mental health professionals of their parenting concerns and more support for these concerns (Bassett et al., 1999; Mowbray, Schwartz, Bybee, Sprang, Rueda-Riedle, & Oyserman, 2000), despite lingering doubts about whether mental health professionals may be open to providing such supports themselves.

At the same time that they want to fulfill their role as mothers, some women with SMI may benefit from psychologically-focused supports that may enable them to parent most effectively. Research suggests that children raised by parents with a mental illness may be at risk for increased emotional and psychological difficulties themselves (Nicholson, Biebel, Hinden, Henry, & Stier, 2001), and that some women with SMI may have difficulty relating sensitively to their children, including problems engaging in reciprocal parent-child interactions (see Brunette & Dean, 2002, and Miller, 1997, for reviews). At the same time, prolonged parent-child separation may have even more negative consequences for both children and mothers. Rather than conclude that maternal mental illness itself is an inevitable risk factor for child maladjustment, then, research that more concretely highlights the specific psychological strengths and needs of these women, and in turn lends itself to empirically-informed interventions, can help mothers with SMI to parent most effectively, thereby fostering better outcomes both for them and for their children.

Empirical findings that could inform effective parenting interventions and supports for these women are just beginning to emerge. In a sample of mothers with SMI who had previously lost their children due to maltreatment or neglect, those who had insight into their disorders showed greater sensitivity in their current interactions with their children compared to mothers without such insight (Mullick, Miller, & Jacobsen, 2001). Translational work exploring psychological and behavioral mechanisms by which mothers' increased insight into illness might affect parenting is required if we are to incorporate insight-enhancing training into supported parenting initiatives. Also needed is more information about the degree to which psychotropic medications may negatively impact women's emotional responsiveness to their children and in turn their capacity to parent optimally (Brunette & Dean, 2002; Miller, 1997; Nicholson & Blanch, 1994).

On a related note, controlled empirical studies suggest that some individuals diagnosed with psychotic disorders, including schizophrenia, evidence difficulty understanding the mental states, feelings, and intentions of others (Bora et al., 2008; Harrington et al., 2005; Liotti & Gumley, 2008; Sprong et al., 2007). Studies of women diagnosed with borderline personality disorder (Bateman & Fonagy, 2004), bipolar disorder (Bora et al., 2005), and substance abuse (Suchman et al., 2008), have suggested that some of these individuals may also have difficulty reflecting on the feelings, thoughts, and desires motivating another person's behavior. Given that maternal reflective attunement to children's emotions and motivations has been linked to more sensitive caregiving (Fonagy et al., 2002; Fonagy &

Target, 1997) and, in turn, to a range of positive psychosocial and emotional outcomes for children (Fonagy & Target, 2006; Greenberg, 1999; Sroufe et al, 1984; Vondra et al., 2001; see also Slade, 2006 for a review), it is not surprising that interventions that help mothers with behavioral health concerns to reflect more sensitively about their children have shown notable promise for improving parent and child outcomes (Slade, 2006; Suchman et al., 2006; Suchman et al, 2008). The field needs more in vivo research exploring whether and how these reflective functioning deficits may evidence within the mother-child relationship for mothers with psychotic disorders and therefore how effective reflectiveness-based parenting interventions may prove for this population.

A Look toward Supported Parenting Programs

The tasks, joys, and struggles of parenting constitute a key, normative activity that helps many adults feel productive and fulfilled (Erikson, 1964). As an endeavor, parenting involves attending to more than just the instrumental concerns of raising children, such as providing meals, buying clothes, and dealing with schools. Parenting also requires thinking about and striving to meet the physical, emotional, psychological, and developmental needs of another human being. The research reviewed above suggests that the majority of women with SMI find great meaning and purpose in their relationship with their children. When asked, these women often voice the desire to take optimal care of their children as well. As with all parents, however, women with SMI may become overwhelmed by the demands of motherhood. These women may in turn require additional, unique supports to reach their parenting potential, just as adults with SMI sometimes need the additional assistance of employment supports to reach their vocational potential. In order to offer such supports, practitioners and researchers are in need of empirical data that will identify and describe what the needs of parents with SMI are and how best those needs can be addressed.

At this point, there is little outcome data concerning the effectiveness of parenting interventions. Our review of the literature revealed only a handful of outcome studies, in which the range of supports provided by parenting interventions varied considerably. Further, the notion of supported parenting for women with SMI, as we have noted above, is relatively new. Supported parenting should involve a variety of related but distinct components, including the developments of supports that are consistent with and address mothers' stated emotional, practical, and psychological needs. Pilot analyses of a supported parenting initiative developed by Nicholson and colleagues (2009) suggests that mothers' mental health status, social support, and access to needed services improved after they received instrumental assistance connecting with resources. Also beneficial to mothers was modeling from Family Coaches on time management, conflict resolution, and advocacy skills (Nicholson et al., 2009). Future supported parenting initiatives may need to expand the scope of such interventions to include modeling and support for women in being attuned and responsive to their children's emotional and social cues.

Additional research

In order for supported parenting to be based on an adequate empirical foundation, researchers must continue to study the parenting strengths and needs of mothers diagnosed with SMI. We believe that because parenting is an emotional, physical, and psychological endeavor on the part of parents, research questions should run the gamut from the psychological (e.g., do mothers with SMI have difficulty understanding their children's states of mind?), to the practical and instrumental (e.g., do mothers SMI need help with back to school shopping?), to the translational (can given supports be implemented easily within existing community mental health centers or other settings?), while also considering the interaction of these various domains with one another. Because the gap between empirically-validated treatments and standard practice remains ubiquitous (Nicholson et al, 2007),

periodic and systematic review of existing parenting programs, with an eye toward assessing their empirical merits and translatability, is needed (see Hinden et al, 2002).

Also of key importance is the approach that investigators take toward these mothers. Data suggest that mothers with SMI may feel hesitant to disclose their parenting concerns to social service and mental health providers for fear of negative consequences, including losing custody of their children (Bassett et al., 1999; Hearle, Plant, Jenner, Barkla, & McGrath, 1999; Ramsay, Welch, & Youard, 2001). In addition, women who already have lost custody may have particular sensitivity around the issues of separation and reunion. Studies suggest that mothers with SMI have greater involvement with child protective services than women without SMI, including higher rates of separation from their children (Park, Solomon, & Mandell, 2006). Strong feelings of inadequacy, guilt, and grief may accompany these prolonged separations (Schen, 2005) and may make women more hesitant to speak openly about their parenting needs. Researchers should be sensitive to this complex aspect of women's parenting concerns, working to strike a balance between empathic inquiry and respectful regard for the ways that mothers may or may not choose to divulge this information.

In the end, however, it will be these first-person accounts of mothers with SMI that will help us to develop appropriate supports for these women. We suggest that research about the parenting needs and strengths of women with SMI be collaborative in nature and take place, at least initially, in community settings where these mothers already receive mental health, case management, or other services (see Nicholson et al., 2009). Clinicians and peer staff could be informed in advance of opportunities for female clients to participate in parenting studies and could be available to offer encouragement and support during and following study completion. Also, holding focus groups regarding parenting needs in mental health agencies, including clubhouses and supported housing programs, could help women give voice to their concerns in environments they already find familiar and comfortable (see Hinden et al., 2009). Participatory research approaches that work collaboratively with, and empower, mothers as they speak openly about their parenting needs and strengths will help normalize the claim that women with SMI have to parenthood, with all of its attendant joys and challenges. Further, the stigma and fear that have contributed to the systemic neglect of parenting concerns to this point may also lessen as women with SMI are encouraged to speak openly about the reality of their day-to-day lives as mothers.

Appropriate supports

Once more is known about the psychological and instrumental parenting needs of mothers with SMI, appropriate supports can be developed. If ongoing research reveals that some mothers with SMI do, in fact, have unique difficulties reflecting and responding sensitively to their children's mental and emotional states, then clinicians and researchers can design support groups and individual interventions to help these women hone their reflective functioning skills. Several pilot reflective functioning groups of this sort are currently underway at community-based programs in Connecticut. On the other hand, if mothers with SMI feel that they need help setting boundaries with their children, getting their children to school on time, or remembering their children's school bus schedule, then assistance can be developed to target these more instrumental domains (see Nicholson et al., 2009). Mothers with SMI may also need help with childcare so that they can return to productive work outside the home. Staff members who are trained to help women with SMI interface with their children's schools, child protective services, the mothers' workplace, or children's after school programs could provide both instrumental and emotional assistance.

Like all caregivers, mothers with SMI parent within the larger contexts of family and community. To be most effective, supported parenting programs should provide supports in

line with women's existent social networks and economic resources. For example, if other family members including fathers or grandparents are involved with childrearing, then programs may consider offering weekly family support groups for these individuals as well as mothers with SMI. Further, mothers with more economic resources may be able to hire private childcare help for their children, in contrast to mothers who may not have these means. Supported parenting programs in lower income areas may therefore be called upon to provide onsite childcare for mothers who wish to return to work. Finally, children's developmental stage may also influence the content of supported parenting programs. Mothers of babies may need help learning to read infant behavioral cues, whereas mothers of toddlers may need help setting and maintaining boundaries. Program administrators and developers should be continuously open to the diverse life situations of the mothers they serve.

We also advocate for including trained peer mentors (i.e., individuals with a history of SMI who may themselves be mothers and who have been trained to provide mothers with the kinds of supports described above) in supported parenting programs. Research suggests that peer-delivered supports for individuals with SMI can be as helpful as traditional approaches to care (Davidson, Chinman, Sells, & Rowe, 2006), and we speculate that mothers' sense of comfort and ease disclosing their concerns may increase in the presence of peers. In light of this, we call for parent-to-parent peer-based supports in both group and individual formats as well as those provided by non-peer professionals (for information on a pilot peer-based parenting intervention, see the "Context of Parenting" study at <http://recovery.rfmh.org/>).

Systems-level integration

Because supported parenting must simultaneously address the needs both of children and of their mothers, such initiatives cannot be delivered exclusively by mental health professionals (Nicholson, Geller, Fisher, & Dion, 1993). Rather, integration of various health, mental health, and social services to address the parenting concerns of mothers with SMI is as warranted as it is challenging (Apfel & Handel, 1993; Bassett et al., 1999). One example of such collaboration could involve introducing family planning and pregnancy supports at community mental health centers, so that women with SMI, who generally do not receive adequate gynecological care (Coverdale et al., 1992), may have easier access to these important resources (see also Weisman, 1997). The incorporation of family planning funding into Medicaid under the 2010 health insurance reform law could help finance these programs (Kaiser Family Foundation, 2010). In this way, women with SMI will have more equitable access to family planning services and can be in a position to make informed decisions regarding their sexuality and parenting desires. Women with SMI could also be offered legal counsel regarding their parenting rights or could access childcare as they participate in other activities, such as work and clubhouse membership (Apfel & Handel, 1993). As a first step, simply increasing how frequently mental health agencies ask about and record clients' reproductive and parenting histories, as well as an increase in training for staff regarding the reality that many of their clients are parents, could help reverse the systematic neglect of parenting concerns in mental health care (Apfel & Handel, 1993; Nicholson et al., 1993).

Collaboration among different providers, including staff at various service agencies involved with the mother, in tandem with the child's pediatrician (Apfel & Handel, 1993), teachers, and mental health professionals, could result in increasingly open dialogue about women's parenting needs and desires, as well as much-needed discussion of these concerns in the context of children's emotional and physical needs. Educational trainings regarding the parenting rights and concerns of mothers with SMI that draw together staff from child protective services, pediatrics, mental health agencies, and other social services could also help agencies network, coordinate their services, and dialogue more freely with one another

(see Clark & Smith, 2009, for an example of such collaboration in Australia; see also Apfel & Handel, 1993). Such interagency collaborations may also help rectify the marked fragmentation of women's physical, mental, and emotional health concerns among various providers (Barrow & Laborde, 2008; Lee & Sanders, 2003; Weisman, 1997), making it more tenable for mothers with SMI who receive various social services to integrate their own care with the care of their children.

On the national level, joint advocacy by agencies that promote health care parity for women and others that address the rights of individuals with SMI might prove fruitful. For example, collaboration among the National Women's Health Network, NAMI, and the National Women's Law Center regarding the legal rights, needs, and strengths of mothers with SMI might result in greater awareness of and collective support for the parenting rights of women with SMI. Awareness campaigns by practitioners who focus on other recovery-oriented initiatives, including supported employment, education, and housing, along with peer advocacy, could also draw much needed attention to the supported parenting cause.

The present moment brims with enormous change for the U.S. health care system. The expansion of Medicaid to include more low-income individuals may lead to an increase in the use of the mental health system by individuals with SMI, some of whom may be parents in need of support. Although not an emphasis of this paper, we note that there are even fewer parenting resources for fathers with psychiatric difficulties (Styron, Pruett, McMahon, & Davidson, 2002). Policy change to help mothers- and fathers- with SMI parent more effectively is long overdue and necessary. At this moment of enormous change, we hope that systems of care will step back and take time to identify and address the parenting needs and rights of women with SMI.

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