

# The Work That Never Ends

## *Employed Mothers of Children with Disabilities*

The struggle for recognition of mothers' unpaid family work has been central in feminist circles. Scholars have addressed such themes as the undervaluing of mothers' time and expertise, the gulf between idealized perceptions of motherhood and everyday realities, as well as judgments as to what constitutes "good mothering" (Read, 2000). Giving mothers voice while making their daily work visible has exposed some myths surrounding the "labour of love." It is recognised that mothers' job description includes not only child care and domestic labour but also emotion work, aimed at improving interpersonal relationships and others' wellbeing (Strazdins, 2000). Furthermore, reduced public spending has made women increasingly responsible for the "executive" components of this work, such as identifying family needs, planning, scheduling and following up, seeking resources and advocating when needs are not met (Lee, 1997, Devault, 1999).

While demand for women's unpaid labour has increased, so too has their involvement in the paid workforce. However, they continue to be ascribed the primary caring role in society (Vanier Institute, 1998), while economic, work and community arrangements are still based on assumptions of their constant availability (Cancian and Oliker, 2000). Research indicates that family division has changed little in most families, as fathers mainly "help out" while employed mothers retain responsibility for family management (Leslie, Anderson and Branson, 1991). Inequitable division of family work is only part of the problem, however, in a society where many families are headed by the mother.

These issues have spawned a burgeoning research literature on women who combine employment with child care, which has drawn attention to the costs, benefits and workload involved, as well as to the obstacles to achieving job-family balance. Research on parental role quality has shown that women's

mental health is better when the rewards and challenges of mothering are in balance (Barnett, Brennan and Marshall, 1994). The literature on multiple roles also points out that existing family-work policies and practices are overwhelmingly based on average families' needs (Kagan, Lewis, Heaton and Cranshaw, 1999). Until recently, there was little research on combining mothering children with disabilities and employment, as many mothers gave in to societal pressure to leave the workplace (Marcenko and Meyers, 1991). Despite needing to help cover the increased costs disability brings, these women faced overwhelming tangible barriers to employment (lack of adapted child care, workplace rigidity), reflecting ambivalent public attitudes regarding their right to work (Kagan et al, 1999, Shearn and Todd, 2000). Recent research indicates some women are finding ways to fit employment around their unusual mothering responsibilities (Jenkins, 1997).

This paper addresses some gaps in the mothering and multiple role literature. It presents findings from a qualitative study<sup>1</sup> of 40 employed mothers of children with a prevalent invisible disability, Attention Deficit Hyperactivity Disorder (ADHD). The study deals with these women's maternal role quality and supports, as well as combining this caregiving role with paid work. Data on the benefits and costs of this combination were the main source for this paper.

This study draws on feminist work regarding women's caring as well as on family disability literature. The former stresses how the gendered distribution of caring work has been masked by depicting women as "natural caregivers." Coupled with descriptions of caring as "a labour of love," this has minimised the difficulty of the mother's work, while making it very difficult to feel justified anger that is supposedly against women's nature (Mullaly, 2002). Mothers' caring work goes unrecognised in the economy, while the substantial personal, economic and career costs they bear remain hidden (Baines, Evans and Neysmith, 1991). When caring occurs in difficult situations, women are often blamed for being "inadequate" without addressing the societal context of their mothering (Swift, 2000). For example, mothers are expected to cope with impossible family situations and offered services only when they fail to manage (Davis and Krane, 1996). Instead of seeing mothers as doing a competent job in difficult circumstances, mothers who deviate from societal stereotypes of the "good Mom" are marginalized (Garcia Coll, Surrey and Weingarten, 1998).

Mothers whose children have disabilities are one such marginalized group. Not only is their caring workload vastly greater than that of most mothers, but they also receive little support. Those in couples often receive less help than in families without disabilities (Bristol, Gallagher and Schopler, 1988), as fathers tend to withdraw to their jobs (Martin, 1996), or focus on providing economic, financial and decision making support to the mother in "her" caring role (Traustadottir, 1991). Limited workplace provisions, already inadequate for average families, do not begin to meet the flexibility needs of these families (Greenspan, 1998). When the family situation is complicated by several disabilities, severe impairment or behaviour problems, the mother's caring role

can be mobilised at any time, yet she is expected to avoid disrupting work commitments (Shearn and Todd, 2000).

This situation is especially complex when disabilities are invisible and misunderstood, as with ADHD. This neurological disability leads to behavioural, social and learning problems, which can alienate teachers, peers and the community (Harvey 1998, Dane, 1990). Two-thirds of children with ADHD have a co-existing psychiatric or learning disability, yet the complexity of this disorder and its immense family impact are unrecognised (Anasopoulos, Guevremont, Shelton, and DuPaul, 1992). Despite scientific evidence of the biological origin of ADHD, media misrepresentation has led many to question whether it is a real disability (Barkley, 1997). This obliges mothers to educate professionals and the community, while coping with a difficult child and fighting for scarce resources (Sloman and Konstantareas, 1990).

### **Methodology and sample characteristics**

Semi-structured interviews were the method of choice for eliciting in-depth data, while ensuring full coverage of key themes by these mothers, some of whom had attentional issues caused by this inherited disorder. The pre-tested interview guide covered work and family situations, rewards and challenges of mothering children with ADHD, supports used and combining this family work with employment. The transcribed interview data were coded into categories developed and cross-checked by two researchers, then thematic content analysis was carried out using data display tables (Miles and Huberman, 1984). A purposive, contrast sampling strategy (Patton, 1990) was used to reach a diversity of Ottawa area mothers of children aged 6-17, who were diagnosed with ADHD. Forty mothers, all employed at least ten hours weekly, were recruited via publicity (pamphlets) in social agencies and the community (libraries, recreation centres), as well as through three self-help groups. One-hour interviews were carried out in summer 2002 by two researchers, both mothers of children with ADHD.

The sample includes participants in various family situations, including nearly 40 percent in blended or one-parent families and several adoptive mothers. Children in the 6-12 age group and adolescents are both well represented. There is some cultural diversity, with 30 percent French-speaking and two First Nations women. Many participants describe difficult situations typical of families living with ADHD (Barkley, 1997). Over a third have several children with this disorder, half of whom also have an additional learning or psychiatric disability, such as a mood, anxiety or oppositional disorder.

These women occupy various paid work situations but are concentrated in the public, health and education sectors. Seventy percent work full-time, often for financial reasons or because suitable part-time work is lacking. Many choosing part-time work seek more availability or wish to “not have to divide myself up so much.” Over 60 percent hold professional or managerial positions, a quarter are in administrative support or paraprofessional jobs and 13 percent

are self-employed, some in artistic or communications fields. A few have additional part-time jobs, heavy volunteer commitments or post-secondary studies. Not surprisingly, it is “go-go-go all day long” on the job.

It should be noted that while every effort was made to reach a diverse population, some mothers in the private sector and service industry may have lacked time to be interviewed. Some mothers may not have heard of the study, as recruitment was prohibited in schools and hospitals without additional internal ethics procedures. For these reasons, the findings are considered to portray accurately the experiences of these 40 women, but not necessarily those of all Canadian mothers in their situation.

## **Findings**

Before presenting the findings on combining this unpaid family work with employment, it is important to examine briefly how mothering a child with ADHD is experienced. Results on role quality indicate that the balance of rewards and challenges varies amongst mothers and can shift rapidly with children’s age and changing school situation. Rewards can come from the child’s interesting qualities (humour, creativity) or progress despite the disability, from mothers’ new skills or personal growth. However, challenges predominate, arising mainly from the child’s difficult behaviour (defiance, irritability) or a tense family climate (conflict, arguing). Behavioural and organizational problems oblige mothers to be “always on guard” for crises, while “constantly running the ship.” Other challenges include the high cost of medication and professionals not covered by public health insurance, as well as mothers’ lack of time, energy and options. While some mothers get support from extended family, friends and professionals, many encounter negative attitudes, as “no-one understands my challenges” or are blamed for their children’s behaviour. These mothers assume the additional burden of educating family, community and those professionals who are “quick to judge and slow to act,” as well as having to find and access rationed services (Home, Kanigsberg and Trepanier, 2003).

## **Advantages and disadvantages of employment**

Mothers’ reflections on the benefits of combining this challenging family work with a job are summarized in Table 1, while the costs are found in Table 2. Pros or cons are expressed as a percentage of total responses for each table and listed in order of frequency of mention. As shown in table 1, being employed brings four main *benefits* according to these mothers.

Most important (one-third of responses) is the protective effect jobs can have on maternal mental health, given the intense emotional demands of these children. Seven women report that their sanity would be endangered if they were to stay home all the time. One mother explains: “I can’t imagine spending 24/7 with these kids. I’d go mad,” while another adds “It’s not that I don’t love my son dearly. It’s just that I cannot imagine *not* working, having a child whose

behaviour is as emotionally challenging as his. At work, there's just not the same emotional drain." A job offers a break from constant vigilance and incessant demands, while providing something else to think about, rather than being "totally focused on my son." Otherwise, as one mother put it, "I would be at home worrying ... and wondering what more I could possibly do."

Another benefit, feeling more competent and confident, helps explain the first. Like many employed mothers, these women derive enjoyment, intellectual and social stimulation from autonomous outside involvement, which provides societal recognition of their work. However, these mothers need even more positive feedback to counterbalance feeling like "a terrible mother," getting so few parenting rewards and sensing so little accomplishment in their family role. The enhanced confidence from working also helps some mothers advocate more effectively for their children.

**Table 1:  
Benefits of Employment for Mothers of Children with  
ADHD**

Categories of benefits	% of responses
Protects sanity, provides an emotional break	33%
Provides access to support and resources	28%
Enhances confidence and feelings of competence	21%
Positive job - family spillover	18%

Work can provide increased access to support, such as emotional help and understanding of colleagues in similar situations or who have counselling skills. Tangible support (salary, benefits) allows some mothers to purchase specialized resources such as tutors or special camps and obtain coverage of insured services. Getting information about resources, services or professionals through "accidental advice and connections" is also helpful.

Less obvious are benefits that flow from positive spillover, either from job to home or vice versa. Respondents working with families realise they are doing a good job mothering and some mental health professionals use their knowledge or techniques at home. Conversely, difficult mothering can enrich job performance, such as when teachers who understand what these parents go through are more able to modify their classroom expectations. Seeing their mother employed also helps some children understand that all family members have responsibilities: "you have to go to school, you gotta get a job."

**Table 2:**  
**Costs of Employment for ADHD Mothers**

Categories of costs	% of responses
Endless family work, low support = triple, quadruple workday	33%
Intense job-family role conflict, due to frequent daytime appointments and sudden school crises.	20%
Role contagion, as office work is late, both job and family work are emotionally demanding.	15%
Role overload from “the constant never having a break.”	10%
Sacrifices at work (refuse promotions, quit, work part-time) or in personal life (physical and emotional health, guilt, burnout)	25%

However, these mothers pay a heavy price for these benefits. Participants suggest these *costs* go beyond those borne by most multiple role mothers, because of the increased quantity and intensity of their family work. “Having to organize myself, my workday and my other child is already a lot ... but my ADHD child is twice as much work definitely.” Another woman explains “there are more demands, emotional, physical, and time-wise with a kid like mine ... more appointments, discussion with teachers, help with homework, more of everything.” This added work includes arranging for and following up on extra academic and professional help, seeking accommodations and advocating with reluctant school and community authorities. However, it is the emotional intensity that mothers find most draining, because “when you have an ADHD child, you work hard every time you’re with him.”

There is little extra support to ease the load. Spouses work late or travel on business, extended families live elsewhere or provide only emergency care, after school programmes cannot manage these children, and direly needed respite care is rarely available. Workplace family leave policies require advance notice, part-time work with benefits is scarce and rigid job schedules still abound. Some women manage by working out of their homes, but their ADHD children respect neither their work time nor space, and “with constant interruptions, I might as well give up.” This combination of limited support and

intense family demands leaves many mothers feeling “alone to raise my difficult child.”

Along with their heavy workloads, these women report having to contend with particularly disruptive job-family conflict and negative spillover. When frequent day-time appointments disturb work commitments such as important meetings, criticism and career consequences can ensue. Given these children’s unpredictable behaviour problems, an emotionally wrenching form of role conflict occurs when school crises strike. A typical scenario is: “You get a call saying ‘L is suspended for some horrible deed and he’s arriving home immediately.’ Everyone assumes you can just drop everything and run.” One woman even keeps her child home when she senses a crisis brewing, but most are like the mother who sees no solution to this frequently occurring situation: “I have been called at work by the school so many times that I don’t think it will ever stop. I think ‘What did he do now?’ Then having to leave in the middle of the day to go to the school and bail him out of whatever, suspensions...”

Never knowing when this might happen leaves many mothers with negative spillover, as they are “constantly worrying about him...thinking ‘please don’t let him hurt somebody today.’” As “he’s always in my head” and office work never gets done on time, eleven mothers report they never feel “fully present” and sense they are not doing a good job anywhere. Feeling guilty about “Robbing Peter to pay Paul” is another common problem. An intense form of role contagion is experienced by mothers in the helping professions whose clients have psychiatric or learning disabilities. In this situation, the lines between paid and unpaid caregiving can blur, as “I have to think a lot before I say anything, I have to structure them and it’s very similar to home.” On days when clients have crises, “you go home and you’re ‘still on’, you can never relax. There’s too many emotions...and not enough energy for my child, my husband, my clients...those are the days I think I might as well quit.”

Many employed mothers experience overload that is manifested in constant rush and double workdays. ADHD mothering, however, means “energy is sucked out of you,” there is never “calm time” for unfinished work or rest until after 10:00pm. As a result, there is “no time to take care of my work...or myself” and several mothers have physical stress symptoms or regular sleep disturbances. To avoid burnout (“trying to do it all just about killed me”), many women make career sacrifices. They cut back on hours or effort, “let promotions go elsewhere,” change to a more flexible or part-time position or leave the workplace temporarily, such as when a child was “throwing such fits everywhere that they wouldn’t want to keep him.” While some mothers do not question the need to make these changes, a few wonder “why is it always up to me to make the concessions” or lament “mothers with ‘garden variety’ kids move ahead with their careers without having to slow down or constantly apologize.”

## **Discussion**

These interview findings suggest that while combining mothering with

paid work has some common features, others are different when children have disabilities and some are specific to those with behavioural manifestations. Several studies have found employment brings mental health benefits to employed women (Home, 1997), such as feeling better about themselves and gaining access to stimulation, information, social network or resources. For mothers whose caring role is both demanding and devalued and who lack adequate support, however, these benefits have more survival value. Mothers' salary and benefits are necessary for single parents and other families lacking job security or benefits, even if there are no disabilities. When the latter are present, high costs coupled with the need to escape from "the emotional pressure cooker" make employment almost essential for the mother.

Employment brings a double workday to many mothers, along with overload, periodic role conflict and negative spillover (Home, 1997). When disabilities are present, however, mothers' family workload is much higher due to increased direct care along with having to coordinate contact with the "outside world." Regardless of disability type, research has shown that it is the mother who must anticipate needs, absorb new tasks and patch up any situations that fall apart (Read, 2000), which requires skills in advocacy, nursing, education, case management and service coordination. These "job requirements" go well beyond what is usually expected of mothers (Roehrer Institute, 2000), yet the fact these women are doing "exceptional mothering" goes unrecognized (Greenspan, 1998). The findings from this study suggest that in many ways, the heavy invisible workload borne by mothers of children with ADHD is similar to that of mothers whose children have other disabilities.

However, there are some aspects of "ADHD mothering" that are specific to situations where children's disabilities include behaviour problems. With ADHD, mothers report that their family work is criticized as well as unappreciated. This increases their risks of depression and burnout, problems which can then be seen as contributing to their children's difficulties. Yet as Greenspan (1998) points out, if mothers feel responsible for doing a job no single person is capable of doing, it is not surprising that they end up feeling inadequate, exhausted and depressed. In addition, while the rewards of mothering usually outweigh the challenges even when children have certain special needs (Audet and Home, 2003), caring for children with ADHD offers few rewards. The emotion work is intense, as mothers engage mainly in "regulation" activities to stop children's disruptive behaviour or "help" activities to alleviate others' negative emotions. These activities are intrinsically less rewarding than those used to create positive emotions, more commonly employed in other families (Strazdins, 2000). When the difficulties of mothering children with ADHD are recognised, the burden feels lighter (Anthony and Foster, 2001), but continuing public and professional misunderstanding of ADHD mean that this understanding is often lacking.

It is clear from the findings that these mothers end up making sacrifices in



their health and well-being, their careers or in both domains. Previous research shows some mothers of disabled children feel comfortable not being “on the fast track,” given their unusual caring work (Landsman, 2000). However, other studies question why the costs of caring are not counted when it affects only the mother (Traustadottir, 1991), while suggesting that society’s tolerance of mothers’ employment decreases when a child’s disability brings extra family work. The present study indicates that mothers of children with ADHD may choose to be employed, as long as the job does not interfere with their constant availability to deal with family crises (Kagan et al., 1999). These mothers are expected to make the necessary career adjustments or else to devote all their time and energy to their combined workload.

While societal expectations of all mothers are unrealistic, what is asked of these mothers is close to impossible. It is hoped that making their voices heard through this study will make their needs more apparent. As two participants put it, it seems unfair that they are always “the last one that gets anything” because of “the work never ends.”

<sup>1</sup>This research is supported by a grant from Social Sciences and Humanities Research Council (SSHRC) and carried out in collaboration with CHADD, Canada (Children and Adults with Attention Deficit Disorder).

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