

Challenging Hidden Oppression: Mothers Caring for Children with Disabilities

By Alice Home, MSW, PhD

Many years ago, our Toronto ADHD community assisted Alice Home with gathering feedback on mothers of children with ADHD for a study she was doing at the time. She has graciously agreed for us to include this recent article of hers in our CADDAC newsletter.

Alice Home teaches group work and research methods. Previous teaching areas include family and disability, as well as intercultural practice. Her current research focuses on peer and professionally-led groups for parents whose children have an invisible disability, either on the autism or fetal alcohol spectrums or ADHD. Her previous research, supported by Social Sciences and Humanities Research Council, dealt with mothers who combine employment with caring for a child with ADHD (2002-25) or university studies.

Abstract

There is growing recognition that people with disabilities face oppression in a society which marginalizes those who are different; however, there is evidence that families living with disability also face exclusion, inadequate services and stigmatizing attitudes. Existing research uses gender-neutral terms, which obscure women's primary role in care giving and hide the high costs they bear. This paper examines the hidden, gender-based oppression experienced by mothers caring for children with disabilities. Relevant literature is reviewed critically to analyse difficulties these women encounter and supports they use. Examples are drawn from three exploratory studies of role quality and supports, reported by mothers caring for children with disabilities.

Challenging Hidden Oppression

There is growing recognition that people with disabilities face oppression in a society which marginalizes and devalues those who are different. Disabled people, who make up 16% of the Canadian population, have higher levels of unemployment and lower levels of education, often leading to poverty and social exclusion (Hanes, 2001). Those who are members of other marginalised groups face complex, interacting oppressions. While disability research centres and optional courses attest to increasing social work interest, surprisingly few courses focus on disability in contrast to the number dealing with other oppressions related to gender, race or culture and aging (Stanton & Swift, 1996).

A major impetus for treating disability as oppression has come from the consumer-led Disability Rights Movement. Progress has been made in legal protection; however, considerable ambivalence persists regarding the acceptance of people with disabilities, who continue to be stigmatised and stereotyped (Hanes, 2001). That ambivalence persists is evident in the continuing presence of a medical model, which treats disability as a personal tragedy, requiring professional assistance focussed on the individual. In contrast, the emerging social oppression model views disability as resulting not only from functional impairment, but also from social, political and economic inequality (Hanes, 2001, Thompson, 1997). As in feminist theory and practice, the latter model attempts to focus on social barriers, such as stigmatising attitudes and inadequate support, without denying the personal experience of oppression experienced by people with disabilities (Sheldon, 1999; Sloper, 1999). While this increasing scholarly interest is welcome, its primary focus on disabled individuals obscures the reality that families also live with disability. There is considerable evidence that families with a disabled child also face stigmatising attitudes and inadequate services, as well as exclusion from informal social networks (Seligman & Darling, 1997, Gartner, Lipsky & Turnbull, 1991). Those studies that do examine family impact focus more on child or family characteristics than on community attitudes and supports. In addition, this literature often uses gender-neutral terms, which hide women's primary role in caring for family members with disabilities (Baines, Evans & Neysmith, 1991).

This paper examines the hidden oppression experienced by mothers caring for children with disabilities. In this article, oppression refers to denial of a group's right to full participation in society, through undervaluing the group and limiting its access to power and resources. Relevant literature will be examined critically, to highlight the changing context and hidden costs of women's caring. Feminist

and ecological frameworks will be used to analyse both the gendered nature of caring and the impact of social factors on mothers' experience. The focus will be on the rewards and challenges of mothering (maternal role quality), and on factors which can influence them. Illustrative quotes and examples will be drawn from two exploratory studies of mothers who care for children with disabilities, along with preliminary observations from a study in progress. Similarities and differences in mothers' experiences will be discussed in the light of existing literature, with a view to drawing implications for anti-oppressive theory, practice and research.

The Changing Context of Women's Caring

Traditionally, women have been attributed primary responsibility for family work in most societies. In spite of massive economic and social changes which have profoundly affected women's roles in western countries, women continue to be ascribed the primary caring role and still carry the bulk of family work (Vanier Institute, 1998, Napholz, 1995). Women's massive entry into the work force, combined with diversification of families, means less than 15% of (US) households comprise a breadwinning husband and homemaking wife (Gerson, 1998). However, economic, work and community arrangements are still based on assumptions of the "traditional" family and the separation of work and family spheres (Cancian & Oliker, 1998). This has meant that women's unpaid family work remains undervalued and invisible, while the high economic, social and psychological costs borne by women go unrecognized.

Not only has women's work increased because of their double workday, but women's caring burden has expanded in recent years. Public responsibility for vulnerable and disabled individuals has been largely replaced by community and family care, the latter justified by "natural" explanations of women's caring (Baines, Evans & Neysmith 1991; Gerson 1998). This increased work has not been matched by marked changes in community policies and resources (Cancian & Oliker, 1998). Family and community care has translated into more unpaid work for women, who are increasingly called upon to take on added responsibility for ill and disabled family members. The intensity and complexity of women's caring has grown as well, especially emotional and executive components, comprised of identifying family needs, planning, scheduling and following up, seeking appropriate resources and advocating when needs are not met (Lee, 1998, Devault, 1999).

One reason is that family division of labour has changed little. In families with average children, mothers usually assume ultimate responsibility for parenting and family management, while fathers “help out”, even when mothers are employed (Leslie, Anderson & Branson, 1991). When disabilities are present, research shows that mothers reduce workplace commitments, while fathers tend to withdraw from family work to invest more in their jobs (Martin, 1996), such that their direct and indirect child care involvement is lower than in families without disabilities, according to some researchers (Bristol, Gallagher & Schopler, 1988). Fathers’ withdrawal increases mothers’ burden (Harvey, 1998), yet the indirect costs to women (loss of earnings and reduced options) go unrecognised (Meyers, Lukemeyer & Smeeding, 1998).

Inequitable family division of labour, however, is only one reason these women (along with single mothers) have the most difficulty balancing family and outside commitments (Descarries & Corbeil, 1998). Community provisions, designed for traditional families, do not begin to meet the flexibility needs of these mothers (Greenspan, 1998). The prolific literature on women’s multiple roles has focused on women caring for elders or non-disabled children (Stephens & Townsend, 1994). While this body of research has identified obstacles to work-family balance, (Duxbury, Higgins & Lee 1994, Home 1997a) it has virtually ignored mothers in atypical family situations, who are “mothering at the margins” (Garcia Coll, Surrey & Weingarten, 1998).

The few studies of mothers caring for children with disabilities found these women make considerable personal sacrifices in response to the intense family demands they face. Given the need for frequent workday involvement, coupled with lack of adapted child care, many women give in to societal pressure and return to a traditional homemaking role (Willoughby & Glidden, 1995; Marcenko & Meyers, 1985). Recent expanded opportunities for women in the public arena are fragile, as society’s tolerance of women’s involvement in employment decreases once demands for mothers’ family work intensify. (Trausadottir, 1991). Recent studies suggest that some women give up leisure time instead of cutting back on work (Jenkins, 1997), while others find ways to fit work commitments around their heavy caring burden, by reducing their hours, working altered schedules, passing up promotions or working part-time (Roehrer Institute 2000; Shearn & Todd 2000, Trute, 1995). These women may feel obligated to help cover the vastly increased costs of providing for a special needs child, but they encounter “disabling barriers to effective and fulfilling management of both roles” (Kagan et al, 1999).

These obstacles include lack of adapted child care, often needed for longer than in most families, lack of workplace understanding of their intense family needs, inadequate flexibility for dealing with crises and societal ambivalence regarding these mothers' right to work. Underlying this ambivalence is implicit expectation that these women's maternal roles can be mobilized at any time, which is at odds with norms in a production-oriented society that the job must come first (Kagan et al, 1999; Roeher Institute, 2000; Shearn & Todd, 2000). Thus, these mothers are facing oppression as women in a male-dominated society as well as that which accompanies family disability in an ableist world. Many women respond by making whatever individual adaptations they can while bearing the costs in silence.

Maternal Role Quality: Rewards, Challenges and Supports

An important line of multiple role research has explored women's subjective experience (role quality) in their work and family roles. Studies of parental role quality (rewards and challenges of parenting) are of particular interest, as women whose parental concerns outweigh their rewards have high distress (Barnett et al, 1994). However, the extensive work done by Barnett (1994) and her colleagues is based on research in families facing average parental demands, often with adequate resources. This means that instruments used to measure perceived rewards and concerns do not reflect the experiences of mothers whose children have disabilities. Furthermore, this research tends to ignore social and environmental factors, such as income and community supports, which can play a critical role in these mothers' experience.

The family disability literature is helpful, as it makes these families' needs more visible. It points out that families with special needs carry a heavy burden due to unpredictable, persistent demands which increase family work while decreasing leisure and employment options (Greenspan 1998, Repetti & Wood, 1997, Seligman & Darling, 1997). This situation is exacerbated by stigmatising attitudes, which lead to social exclusion of both children and their families from community activities and mainstream resources (Gartner et al, 1991). When lack of informal community support is combined with inadequate services, isolation often results. It is precisely this lack of societal acceptance and absence of adapted resources that can transform impairment into disability, according to the social model (Thompson, 1997).

However, this literature has several weaknesses. It usually uses terms such as parent, family and caregiver, which hide the role of gender in these women's oppression. Furthermore, the dominant influence of medical models is evident in its emphasis on negative aspects of caring for children with disabilities, with little consideration of any rewards or learning. Finally, this body of research focuses on the impact of child and family characteristics, giving short shrift to environmental factors such as income, resources and supports, so important in social work.

Most studies of family impact focus on child factors, such as severity of impairment and type of disability. Although severity can increase family work and influence mothers' decisions to reduce workplace involvement (Canning, Harris & Kelleher, 1996, McDonald, Poertner & Pierpont, 1998), environmental factors, such as type of employment and availability of appropriate childcare, can affect women's decisions (Jenkins, 1997). In addition, severity of impairment per se appears to have less impact on mother's experience than does the presence of aggressive, defiant or destructive behaviour (Floyd & Gallagher, 1998). Furthermore, children with unpredictable, periodic behaviour problems at times appear "normal", as their disabilities are invisible. These children with their families have an ambiguous status, which impedes their acceptance in both the mainstream and disabled communities (Fewell, 1990). When behaviour problems do occur, both mother and child are blamed, due to public misunderstanding about these disabilities.

Attention Deficit Hyperactivity Disorder (ADHD) is a case in point, as it usually involves behaviour and social problems which can alienate teachers and peers (Harvey 1998, Dane 1990), yet it is poorly understood by both the public and many professionals. Misleading media representations of ADHD has led to the public to question whether it really is a disability, despite clear evidence of its biological origin and its enormous impact on children and their families (Bernier & Siegel, 1994). This public debate has even penetrated some scholarly circles (see Lloyd & Norris, 1999), displacing emphasis away from consumer priorities such as community and professional support. This obliges mothers to educate scholars, professionals and a doubting public, in addition to coping with a difficult child, fighting for needed resources and resisting the personal impact of constant community blame (Sloman & Konstantareas, 1990).

While relatively few studies examine family or environmental factors, (Boyce et al, 1995), there is evidence that stress increases when adverse conditions accumulate (Meyers, Lukemeyers & Smeeding,

1998). All families whose children have disabilities face vastly increased costs, as many needed services (such as assessment, treatment, equipment) are either not covered or strictly rationed under public health policies (Sloper, 1999). Inadequate income is a major source of anxiety (Sloper, 1999; Canning et al, 1996), as it restricts access to scarce resources, especially for increasing numbers of mothers in precarious employment situations, which offer no extra health benefits (Krauskopf & Akabas, 1998). Families with more than one exceptional child face increased material hardship and housing instability (Meyers et al, 1998). The higher stress reported by single mothers disappears once age, education and income are controlled, suggesting that their added difficulties are primarily due to economic inequality (Boyce et al, 1995). Risk of mental health problems increase in families living with ADHD, however, when low income is combined with other adverse conditions such as large family size (Biedermen et al, 1995).

Even when resources are available and accessible, they are rarely adequate to meet the child's and mother's needs. Unsatisfactory relationships with schools and professionals are a major source of stress, especially when children have behaviour or emotional problems (McDonald, Couchonnal & Early, 1996, Bernier et al, 1994). For example, parents of children with ADHD perceive clinical social workers as blaming rather than helping them (Johnson et al, 2000). This may reflect societal expectations that mothers should be able to cope with impossible family situations and offered services only when they fail (Davies and Krane, 1996) .It is small wonder many mothers turn to peer-led self-help groups, especially when trying to cope with the community rejection that behaviour problems bring (Floyd & Gallagher, 1997). One study found parents of children with ADHD perceived these groups as very helpful (Viola, 1997), perhaps because they empower members, by increasing their sense of parenting competence, self-efficacy, knowledge and systems advocacy (Singh et al, 1997). A sense of parenting being rewarding can also help (Yau & Li-Tsang, 1999), but many mothers are too overwhelmed by their intense responsibilities and the low community acceptance to feel much satisfaction.

Mothers Speak Out: Some Examples from Research

Given the lack of research on role quality and support, several exploratory studies were undertaken. The two completed studies include a survey of 25 parents who have adopted special needs children (Audet & Home, in press), and a small study of Franco-Ontarian mothers of developmentally delayed

adolescents, recruited through the schools (Fauteux, 2001). The latter used semi-structured interviews to collect data on rewards and challenges of mothering these children, as well as on helpful and needed supports. The data on adoptive parents is derived from two open-ended questions that were included in a survey, distributed to members of the Adoption Council of Canada (Audet & Home, in press). It is interesting to note that while 23 adoptive mothers responded, only 11 fathers participated in this section on rewards and challenges, designed to be completed by both parents. A third study, still in progress, uses semi-structured interviews to explore the same questions as in Fauteux's (2001) research, but with 39 employed mothers of children with ADHD.

Contrary to the medical model of disability, mothers in these studies did reap some rewards from parenting these special children, though these rewards differed from those found in average families. Mothers of children with physical and intellectual disabilities admired special qualities in their children, such as courage, resilience, polite and honest behaviour, which set them apart from many average children (Audet and Home, in press, Fauteux, 2001). Regardless of type of disability, however, rewards were less obvious to mothers when behaviour problems were present. Personal growth was a major reward, though it came from hard work. Mothers described being "stretched through parenting" (Audet & Home, in press), which involved learning new skills, such as advocacy, out of necessity. As one mother said, "I had to learn many things, such as how to push to get my child's needs met", while another was forced to go to the Human Rights Commission to obtain adapted transportation services that had been denied to her child (Fauteux, 2001). As in Traustadottir's (1991) study, these women found strengths they didn't know they had. However, these were rewards that came only after their persistent struggle to protect their children from injustice.

Taking pride in small accomplishments that "normal" children do easily was an important but difficult part of finding those rewards, as neighbours and extended family did not see "how far the kids have come – they focus on how far they have to go" (Audet & Home, in press). The community inability to see these children's "able" side meant many mothers had to work hard to keep their children's problems in perspective, to keep focussed on the positives and to maintain their parental self-esteem (Audet & Home, in press). Keeping a positive self-image is doubly challenging when children are defiant, immature or exhibit inappropriate or antisocial behaviour. Not only did some mothers have "a great deal of trouble liking him most of the time", but they also felt inadequate because the usual

child-raising methods just didn't work. However, they were reluctant to seek help, due to "fear they (family, professionals) will not understand. There is also this desire to 'manage on one's own'" (Audet & Home, in press). Their concerns are justified, as social workers can interpret admission of coping difficulties as a sign of inadequate mothering (Davies & Krane, 1996).

Participating mothers confirmed that their children's disabilities required patience with the slow pace of change, along with huge investments of time. Mothers gave up personal time, were too exhausted to pursue leisure or social activities and found all their decisions were based first and foremost on their children's special needs. Several mothers of developmentally delayed teens reduced their work hours, as they could not conciliate numerous medical appointments with rigid work hours, nor could they obtain adapted after school or holiday care (Fauteux, 2001). Societal expectations regarding age-appropriate autonomy have impeded provision of appropriate service for teens with disabilities, who continue to need some supervision and structure. While these mothers felt disadvantaged, they saw no alternative, given workplace inflexibility and inadequate community services (Krauskopf & Akabus, 1998).

Mothers in these studies indicated that dealing with the disability per se was not the greatest problem. Consistent with the social model of disability, it was lack of support from family, community and professionals that was most challenging for many women (Audet & Home, in press). For example, mothers of children with ADHD indicated that their burden was eased when extended family accepted the child, offering emotional and tangible help. However, informal support was rarely available either to these mothers or to those caring for developmentally delayed teens (Fauteux, 2001). While this was sometimes due to geographical distance, it often reflected discomfort with these different children. Both mothers and children were excluded from informal get togethers and organised community activities, perhaps because society does not want to "see" families with a disabled child (Greenspan, 1998). Some mothers turned to others in the same situation for understanding and support, but this can result in a ghetto mentality, unless other social networks are accessible.

Public reactions to these mothers and children were usually negative, while varying with type and visibility of the disability. One mother of a developmentally delayed teen said she was stared at and felt judged, because her child wasn't "100% like the others" and his difference was interpreted as deficiency. Adoptive mothers of special needs children wanted to be treated as just as parent, rather

than as saints or martyrs (Audet & Home, in press). Mothers of children with ADHD received unsolicited advice from strangers, who thought the inappropriate public behaviour of these normal-appearing children reflected inadequate mothering. Finally, neighbourhood children were often uncaring or cruel, refusing to be friends with these children or with those who were developmentally delayed. Seeing their children excluded was the most painful part for some women, such as two mothers whose ADHD children waited in vain for “friends” who never showed up for their birthday parties.

The dearth of informal help made formal support even more important for mothers who participated in these studies. They found that existing services were not always affordable, accessible and appropriate to the particular needs of their children. Special classes were greatly appreciated by mothers who had adolescents with developmental delays or whose children with ADHD had access to them. However, recent cuts to special education meant schools had little time for the ongoing communication or monitoring needed to ensure identified individual educational needs were met. Mothers of children with ADHD were often told their child’s disability was not severe enough to merit special help, yet many schools often misinterpreted the behaviour and academic problems this disorder brings as signs of poor parenting, bad character or laziness. Needing to maintain vigilance, while advocating constantly and “educating” teachers added to the burden these mothers bore (Anthony & Foster, 1999).

Some services were available only to those in extreme need, perhaps because these supports were deemed unnecessary in a society ambivalent about inclusiveness. For example, 75% of the adoptive mothers were unable to obtain needed respite and adapted child care (Audet & Home, in press). Access to financial support was restricted and the amounts were inadequate to cover real costs. Some supports were available only for certain types of disabilities. Adapted transport was denied to developmentally delayed adolescents, without consideration of the difficulty they would have in negotiating their way around a complex public transit system (Fauteux, 2001). Finally, mothers of children with ADHD spoke of the ambiguous status of families living with invisible disabilities. Consistent with Fewell’s (1990) observations, some of these mothers had to cope with rejection from both the “normal and disabled communities. One mother, whose child’s severe ADHD required a special class placement, sought his admission to a programme for disabled skiers. The initial response

was “we can’t just open the floodgate to anyone who THINKS he’s disabled”. When the mother approached the mainstream ski school, she was told it might not be appropriate. It took the intervention of an instructor for the disabled, who had given the boy a private lesson and who was himself the father of a visually disabled child, to gain admittance to the adapted programme. As found in Anthony & Foster’s (2001) focus group study of parents of children with ADHD, the burden was eased when someone understood how difficult this family’s life was and made an effort to collaborate with the parents.

Conclusion and Implications

Findings from these recent exploratory studies illustrate some complexities of the oppression experienced by mothers of children with disabilities. As suggested in some writings, these mothers felt obliged to make personal, economic and career sacrifices in the face of societal rejection and lack of support. However, their gender-based oppression often seemed hidden even from themselves, perhaps because the impact of disability is minimised by families “if it only limits the mother” (Traustadottir, 1991, 223). In addition, professionals and the community may still be taking mothers’ constant availability for granted, while holding them responsible for conditions they cannot control. Helping these mothers feel competent and giving them real options will require profound changes in attitudes, policies and resources.

Community education is needed, to ensure inclusiveness policies are enforced consistently across all disabilities and to promote tolerance of difference. Examination of existing policies is another necessary step, to analyse their benefits for different disability groups and to identify the role conservative ideologies play in restricting access to needed resources. Professional education needs to include obligatory content on disability and its impact on families, taking into account the complex ways it interacts with other oppressions. Finally, further research needs to be done to make these mothers’ hidden oppression more visible, including action-research designed to promote social change. However, it is clear that this is a complex issue, because of public ambivalence and governmental priorities related to control of public spending. Social workers need to join mothers in their struggle to move this issue higher on the public agenda.

REFERENCES

Anasopoulos, A., Guevremont, D., Shelton, T. & DuPaul, G. (1992). Parenting stress among families of children with attention deficit hyperactivity disorder. *Journal of Abnormal Child Psychology*, 20(5), 503-520.

Audet, M. & Home, A. (2001, in press). Adopting special needs children: Parents= perception of their role quality and social support. In Kufeldt, K. & McKenzie, B. (Ed.), *Child welfare: Connecting research, policy and practice* . Waterloo, Wilfrid Laurier University Press.

Anthony & Fisher (2001) Lessons learned. *The ADDvocate* 17, 1-3.

Baines, C., Evans, P. & Neysmith, S. (1991) *Caring: Its impact on the lives of women*. In Baines, C., Evans, P. & Neysmith, S. (Eds) *Women=s Caring* (pp.11-35). Toronto: McClelland & Stewart.

Biederman, J, Milberger , S. Faragone, et al (1995)Family-environment risk factors for Attention-Deficit-Hyperactivity-Disorder. *Achives of General \psychiatry*. 52, 464-470.

Barnett, R.(1994). Home to work spillover revisited: A study of full-time employed women in dual earner couples. *Journal of Marriage and the Family*. 56,(3) 647-656.

Bernier, J. & Siegel, D. (1994). Attention-deficit hyperactivity disorder: A family and ecological systems perspective. *Families in Society*, 75(3), 142-151.

Bristol, M., Gallagher, J. & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and non-disabled boys: Adaptation and spousal support. *Developmental Psychology*. 24 (3), 441-451.

Boyce, G., Miller, B., White, K., Godfrey, M. (1995). Single parenting in families of children with disabilities. *Marriage and Family Review*, 20(3-4), 389-409.

Cancian, F. & Olikier, S. (2000). *Caring and gender*. New York: AltaMira Press.

Canning, R.D., Harris, E.S. & Kelleher, K.J. (1996). Factors predicting distress among caregivers to children with chronic medical conditions. *Journal of Pediatric Psychology*, 21 (5), 735-749.

Dane, E. (1990). *Painful passages: Working with children with learning disabilities* . Washington, DC. N.A.S.W.

Devault, M. (1999). Comfort and struggle: Emotion work in family life. *The Annals of the American Academy of Political and Social Science*, 561 , 52-63.

Fauteux, L. (2001). Les défis rencontrés et le soutien reçu par les mères Franco-Ontarian qui a un enfant à besoins spéciaux. *Mémoire de Maîtrise, inédit*. Ottawa. Université d'Ottawa.

Fewell, Rebecca R. (1990) Parenting moderately handicapped persons, in Seligman M. (Ed.) *The family with a handicapped child* , (pp. 203-236). Boston: Allyn and Bacon.

Floyd, F. & Gallagher, E. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family-Relations*, 46 (4), 359-371.

Gartner, A., Lipsky, D. & Turnbull, A. (1991). *Supporting families with a child with a disability* . Baltimore; Toronto: Brookes.

Gerson, K (1998). Gender and the future of the family: Implication for the postindustrial workplaces. In Vanney, D & Dubeck, P (Ed) *Challenges for work and family in the twenty first century* . New York: Aldine de Gruyter.

Hanes, R (2001) *Social work with persons with disabilities: The world of one in six*. In Hick, S (ed.) *Social Work in Canada: An introduction* Toronto : Thompson (217-233).

Harvey, E. (1998). Parental employment and conduct problems among children with attention deficit hyperactivity disorder: An examination of child care workload and parenting well-being as mediating variables. *Journal of Social and Clinical Psychology*, 17(4), 476-490.

Home, A. (1997a). Learning the hard way: Role strain, stress, role demands, and support in multiple-role women students. *Journal of Social Work Education*, 33, 2.

Jenkins, C (1997). Women, work and caregiving: How do these roles affect women`s well-being? *Journal of Women and Aging*, 9, (3), 27-45.

Kagan, C., Lewis, S., Heston, P., & Cranshaw, M. (1999). Enabled or disabled? Working parents of disabled children and the provision of child care. *Journal of Community and Applied Social Psychology*, 9, 369-381.

Krauskopf, M. S. & Akabas, S.H. (1988). Children with disabilities: a family/workplace partnership in problem resolution . Social Work Papers: University of Southern California, School of Social Work.

Lee, D. (1997) Having it all / having enough: New York: Amacom

Leslie, L., Anderson, E. & Branson, M. (1991) Responsibility for children: The role of gender and employment. Journal of Family Issues 12, (2), 197 - 210

Lloyd, G. & Norris, C. (1999). Including ADHD. Disability & Society. 14, (4), 505-517.

Marcenko, M. & Meyers, J. (1991). Mothers of children with developmental disabilities: Who shares the burden? Family Relations, 40, 186-190.

Martin, L. (1996). The influence of parent gender on division of work in families with disabilities. Unpublished PhD thesis, Iowa State University

McDonald, T, Poertner, J, & Pierpont, J. (1999). Predicting caregiver stress: An ecological perspective. American Journal of Orthopsychiatry, 69 (1), 100-109.

McDonald, T., Couchonnal, G. & Early, E. (1996). The impact of major events on the lives of family caregivers of children with disabilities. Family in Society, 77 (8), 502-514.

Meyers, M., Lukemeyers, A. & Smeeding, T. (1998). The cost of caring: childhood disability and poor families. Social Service Review, 72(2), 209-223.

Roeher Institute (2000), Beyond the limits: Mothers caring for children with disabilities . North York, Ont.: L=institut Roeher Institute.

Seligman, M. & Darling, R. (1997). Ordinary families, special children. 2nd Ed. New York: Guilford.

Shearn, J & Todd, S. (2000). Maternal employment and family responsibilities: The perspective of mothers of children with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 13, 109-131.

Sheldon, A. (1999) Personal and perplexing: Feminist disability politics evaluated. Disability and Society. 14(5), 643-657.

Singh, N., Curtis, W., Ellis, C., Wechsler, H., Best, A. & Cohen, R. (1997). Empowerment status of families whose children have serious emotional disturbance and attention-deficit/hyperactivity disorder. *Journal of Emotional and Behavioral Disorders*, 5 (4), 223-229.

Sloper, P. (1999). Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health & Development*, 25 (2), 85-99.

Stainton, T. & Swift, K. (1996). "Difference" and the social work curriculum. *Canadian Social Work Review* 13 (1), 75-87.

Stephens, M., Franks, M. & Townsend, A. (1994). Stress and rewards in women=s multiple roles: The case of women in the middle. *Psychology and Aging*, 9(1), 45-52.

Thompson, N. (1997). *Anti-discriminatory practice*. 2nd Ed. London: MacMillan.

Traustadottir, R. (1991). Mothers who care: Gender, disability, and family life. *Journal of Family Issues*, 12 (2), 211-228.

Vanier Institute of the Family (1998) *From the kitchen table to the boardroom table*. Ottawa. Vanier Institute.

Viola, S. (1997). Concerns and perceptions of parents of children and adolescents with Attention-deficit-hyperactivity-disorder . Unpublished PhD thesis. Indiana State University.

Willoughby, J. & Masters-Glidden, L. (1995). Fathers helping out: Shared child care and marital satisfaction of parents of children with disabilities. *American Journal on Mental Retardation*, 99(4), 399-406.

Yau, M. & Li-Tsang, C. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. *British Journal of Developmental Disabilities*, 45(88 Part 1), 38-51.