Is it all bad?
Rewards and challenges of mothering children with hidden disabilities

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Abstract: *Little is known about mothering children with hidden disabilities affecting behaviour, so social workers can underestimate their impact. As research emphasizes negative outcomes, this study examined mothering rewards and challenges, along with influence of caregiving, family, work, demographic factors, perceived demands and supports. Survey participants were 197 employed Canadian mothers of children with ADHD and related disabilities. Rewards came from children's special qualities, progress despite disability and mothers' personal growth. Half the challenges arose from children's behaviour, others from school, organizational and family conflict problems. Higher rewards were predicted by mothers' education, fewer children, support (overall, school professionals). Nearly half the variance in challenges was explained by 4 predictors: combined ADHD subtype, perceived family demands, overall and health professional support. Social workers can point out rewards, recognize difficulties, reframe perceived demands, advocate for increased formal support and acceptance. Further research is needed on family impact of disability.*

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Introduction

Disability issues are attracting greater interest from social work researchers, practitioners and educators. While policy progress is not always reflected in improved practice or services, publications and research are helping professionals prepare to work in this field. However, numerous gaps in the literature make it difficult for social workers to help families of children with disabilities. Research deals mainly with affected individuals, even though families face stigmatizing attitudes, inadequate services, social exclusion and inequalities in work, leisure, finances and quality of family life (Dowling & Dolan, 2001; Seligman & Darling, 1997). Studies emphasize parent impact on child outcome, while services target children's needs. As parents' perspectives are rarely sought or used to inform service decisions, their feelings can go unrecognized and their needs unmet (Russell, 2003). Though parents should be supported with their own issues before having to assume roles that exceed usual expectations (Smith, Oliver & Innocenti, 2001), knowledge that might guide professionals in this regard is scarce. Research focuses on negative parental outcomes rather than their learning or agency, examining personal or family dynamics with little attention to social, economic or cultural context (Ryan & Runswick-Cole, 2008). The term 'parent' usually means mother, without recognizing their heavier care-giving load or its immense impact on their lives and options (Home, 2002; Shearn & Todd, 2000).

Much of this work treats parents as a homogeneous group, though having a child with physical disabilities can be quite different from raising one with Autism Spectrum Disorder (Ryan & Runswick-Cole, 2008). Research focuses on physical or intellectual impairments, yet less visible neurological disabilities such as Attention Deficit Hyperactivity Disorder (ADHD), Autism and Fetal Alcohol Spectrum Disorders bring unpredictable social and behaviour problems that pose particular parenting challenges. Wide variation in severity and presentation delay accurate assessment, while parents struggle to manage a difficult child, obtain scarce services and resist community blame. Public misunderstanding of less obvious disorders, fuelled by media misrepresentation of some as not 'real' disabilities, reduces social support and increases an already heavy burden (Hammerman, 2000). Some professionals still hold mothers responsible for behaviour related to conditions such as ADHD now known to be neurobiological in origin (Johnson et al, 2000). Social workers can underestimate the impact of these disorders in families with multiple, complex problems, yet biologically-at-risk children may face double jeopardy if living in difficult circumstances (Brooks-Gunn, 1995, Whalen & Henker, 1999), especially if adversity factors accumulate (Biederman et al, 1995). If the contribution of disability-related behaviour to couple difficulties or child abuse is overlooked, referrals may not be made to services that could reduce stress and improve quality of family life.

This paper discusses Canadian research[1] that attempted to fill some of these gaps. Based on Barnett's (1994) finding that parent role quality (balance of rewards and

concerns) is important in predicting mental health, this research examined how mothers, as primary care-givers, perceive both positive and negative aspects of raising children with hidden disabilities. It also investigated a range of factors, including those external to the disability, which may influence their experience. The focus was on mothers of children with ADHD, a mainly genetic disorder affecting 4 to 8% of the population worldwide across all IQ and income groups (Remschmidt, 2005) and nearly 22% of adoptive and foster children (Simmel, Brooks, Barth & Hinshaw, 2001). It brings developmentally inappropriate degrees of hyperactive-impulsive behaviour or inattention, resulting in cross-situational impairments in social functioning and learning (Segal, 2001). It rarely occurs alone, as nearly two-thirds also have learning disabilities such as dyslexia[3] or psychiatric conditions, which increase its impact on families (Barkley, Edwards, Haneil, Fletcher & Metevia, 2001).

To enhance responsiveness to community need, this 3-year project was carried out in close collaboration with the self-help association CHADD Canada[2], through ongoing involvement of an advisory committee representing its national and professional boards. This committee participated in all key decisions, co-presented a research poster and helped construct research measures, as well as facilitating recruitment and dissemination. The collaborative plan also featured regional feedback sessions, which allowed participants, professionals and consumer organizations to respond to early results. The overall research used a mixed-method approach to balance control and depth (Morgan, 1998). This paper, however, focuses on survey findings regarding the rewards and challenges of mothering, along with factors related to them. The context, background literature and methods are discussed first, followed by key findings, discussion and implications for social work.

Context and background literature

This section reviews literature on parenting children with disabilities and factors that may influence it. As little is known about perceptions of parents whose children have ADHD (Bull & Whelan, 2006), other child disability research is included. That literature focuses on negative impacts (distress, burden) on parents' relationship, health and options. The limited research on benefits reports two main types. The first, children's special qualities, includes resilience or courage in the face of physical impairment, along with pride in their small accomplishments or progress (Audet & Home, 2003; Segal, 2001). The second concerns how mothers change. They learn skills such as advocacy or notice new ability to savour good times, be more sensitive or tolerant (Segal, 2001; Bass, 1990). Being 'stretched through parenting' (Audet & Home, 2003, pp.7-8) can also bring personal growth or reveal inner strengths (Ellison 2006). Mothers 'start as worriers and become warriors' (Ryan & Runswick-Cole, 2008,204), expanding advocacy into the wider community (Traustadottir,

1991), though these intrinsic rewards have no economic or status value (Ryan & Runswick-Cole, 2008).

Several challenges emerge consistently across research on parenting of children with disabilities, with some variation for those which are less visible. The combination of higher child needs with lower autonomy/flexibility brings intense, complex parenting which affects family and couple relationships, as well as their physical and mental health. Parenting requires more time, energy and resources while constraining work options, especially for mothers who routinely carry a much heavier care-giving load (Read, 2000; Shearn & Todd, 2000; Rolf, 2003). Despite added costs, many mothers reduce or curtail employment because of lack of adapted child care, insufficient workplace flexibility or societal demands that they mobilize their maternal role at any time (Shearn & Todd, Roeher Institute, 2000; Kagan et al, 1999). They must be available to seek services, attend appointments, and intervene in schools or the community (Segal, 2001; Curle, Bradford, Thompson & Cawthorn, 2005). Hidden disabilities usually require constant vigilance, responding to frequent, unpredictable crises (Segal, 2001), implementing complex behavioural interventions and coping with a demanding child who is rarely satisfied (Hammerman, 2000). This difficult parenting takes place in a context of negative community reactions and insufficient services. As children with disabilities cannot progress predictably to autonomy as expected (Green, 2007), parents face judgment, exclusion and stigma when normal appearing children fail to meet social expectations (Marshak, Seligman & Prezant, 1999). Though excluded from regular resources, many of these children are not considered disabled enough for adapted services (Fewell, 1998). Even if available, the latter are often strictly rationed, inaccessible due to cost or linguistically and culturally inappropriate (Kendall, Perrin & Hatton, 2005).

Research on factors influencing parents' experience focuses on child impairments. Those that are chronic or severe take a cumulative toll (Repetti & Wood 1997; Canning, Harris & Kelleher, 1996), while aggressive or defiant behaviour increases care-giver distress (Floyd & Gallagher, 1997; McDonald, Poertner & Pierpont, 1999). As there are three ADHD subtypes (hyperactive-impulsive, inattentive, combined), difficulties in executive functioning (planning, organizing, judgment) and behaviour vary widely. Furthermore, severity is only one factor that increases parenting stress. When it is controlled, oppositional and aggressive child behaviour has an immense impact especially if frequent or severe (Podolski & Niggs, 2001; Harrison & Sofronoff, 2002). Such behaviour also alienates teachers and peers (Avery, 2000).

Emerging research suggests external factors may have considerable impact. Income influences parenting stress and well-being when children have ADHD (Avery, 2000; Baldwin, Brown & Milan, 1995; Smith et al, 2001) and families dealing with disability face more hardship with each affected child (Meyers, Lukemeyer & Smeeding, 1998). Single parent, low-income families may be more vulnerable (Sloper et al, 1999; Boyce et al, 1995) due to lower income plus high costs. These conditions also occur when mothers in two-parent households stay home (Dowling

& Dolan, 2001) yet being employed increases objective load (Green, 2007). Once such stressors are controlled, perceived caring burden contributes to care-giver distress (Canning, Harris & Kelleher, 1996), reducing perceived benefits (Green, 2007). While informal and formal support can increase well-being in these parents (Krahn, 1993), they report little informal support except in emergencies (Roeher Institute, 2000). Limited workplace and community supports designed for typical families cannot begin to meet their increased needs (Greenspan, 1998). Support can be elusive when children's difficult behaviour wears out family and neighbours (Avery, 2000) or leads to expulsion from community resources (Podolski & Niggs, 2001). Mothers find professionals insensitive to their emotional concerns (Bower & Hayes, 1998). Professionals are seen as unhelpful when mothers must fight for resources (Russell, 2003) or are blamed for their children's behaviour by professionals who see the disorder as related to poor parenting (Johnson et al, 2000).

The conceptual framework of the overall research examined mothers' multiple role and parenting experiences, along with factors that this literature suggests may influence them. These include actual demands from care-giving, family and work situations, perceived intensity of those demands, socio-demographic factors, as well as perceived support from diverse informal and formal sources. This paper, however, deals only with maternal role quality (mothering rewards and challenges) and factors related to it.

Method

This project focused on women who combine employment (10+ hours weekly) with mothering children aged 6-17, diagnosed at least 3 months previously with ADHD. These criteria targeted families involved with the school system, while excluding those likely to be dealing with transitional assessment issues. Children had to be living at home or with the mother half the time if custody was shared. The mail survey was selected to minimize intrusion, while letting busy mothers choose the most convenient time to participate. Following university ethics approval, recruitment was carried out mainly through self-help networks, as schools and hospitals added internal ethics procedures. Ads were placed in newsletters or on websites of associations for parents of children with ADHD, other hidden disabilities (Foetal Alcohol & Autism Spectrum Disorders, Learning Disabilities) as well as those for adoptive parents. In the National Capital Region and Montreal, wider recruitment included some French-language media and distribution of bilingual pamphlets to community centres, social agencies, libraries, clinics and some professionals' offices. Publicity described research goals, eligibility, procedures, and participant rights, with a toll-free number for further information or a questionnaire kit. The latter included the researcher's letter, with a form (kept separately) to return for a $10 cinema gift certificate and summary of findings. Finally, CHADD

Canada mailed questionnaire kits to all female members (families, professionals), with a letter explaining the Board's involvement. Eligible respondents were invited to return completed questionnaires to the research team, thereby protecting anonymity and the right to refuse participation. A reminder card, mailed three weeks later, indicated where to call for further information or a replacement kit.

The self-administered questionnaire included a few open questions as well as those with fixed response categories. After a pretest established face validity, the questionnaire was translated by a French team member, checked by the bilingual English researcher, revised by a translator and pre-tested in French. As ADHD is largely genetic, the questionnaire was printed on coloured paper to help any affected mothers avoid feeling overwhelmed or skipping parts. The *dependent* variables were measured in two ways. Two open questions, from a study of special needs adoptive parents (Audet & Home 2003), asked respondents to describe main rewards and challenges of this mothering. They then ranked overall balance on a 1 (very rewarding) to 4 (very challenging) scale. The second measure was adapted from Barnett's (1994) Parent Role Quality Scales, which ask typical families to what extent specific rewards and concerns[4] apply, from 1 (not at all) to 4 (extremely). The scales' names, appearance and structure were preserved but some items were modified or developed from interview data to better reflect parenting children with disabilities, such as financial strain, which became 'the extra financial strain (medication, tutors etc)'. The new scales were rated by a panel of four professionals with relevant practice or research expertise, two having experienced ADHD parenting. The reward (11 items) and concern (19) scales, approved by all judges prior to pre-testing, had high Cronbach's Alphas (rewards .8637, concerns .8710). Given strong internal consistency between open question responses and scale scores, the latter were used as sole measures in statistical analysis. Open responses were coded by theme for content and frequency analysis, with illustrative quotes added to enrich findings.

Independent variables included characteristics of mothers' situations (care-giving, family, work, demographic) as well as perceived demands and supports. Care-giving and family variables were age and number of children, family disabilities, family type (biological, adoptive), parenting or custody arrangements. Work variables were mother's job type, workplace, weekly hours, unpaid commitments, job situation changes (when, types, reasons). Demographic variables included mother's age, education, family income, residence, language, minority and citizenship status. Perceived demands covered both employee and family domains. The Job Demands Scale (9 items, Cronbach's Alpha = .762) combined the reverse-scored brief workplace flexibility scale (Berry & Meyer Rao, 1997) with 4 items from the Job-Time Demands scale (Johnson, 1982). The Family Demands Scale (Cronbach's Alpha = .876) added a 7th item (unexpected family crisis) to Home's (1997) measure, which asks how often (1 never to 5 almost always) specific caregiver demands occur. Availability of 25 informal (family, friends, neighbours, spouse) and formal supports was examined, along with perceived usefulness (1 low to 5 high) of those used. Derived from two

studies (Home, 1997; Kramer & Houston, 1998), formal sources included groups, community associations, professionals (health, school), medication, respite, child care, mothers' learning activities, workplace benefits, policies, practices, options. Average support usefulness was calculated across all sources each respondent used (25 items, Cronbach's Alpha = .939)[5].

Preliminary analysis identified general trends as well as relationships between rewards or concerns and all independent variables[6]. To capture significant differences, independent variables with 3 or more categories were recoded dichotomously, for example, ADHD subtype became presence/absence of combined ADHD. Potential predictors so identified were submitted to hierarchical stepwise multiple regression analysis to learn how they together account for variance in rewards or concerns. Hierarchical analysis was chosen to recognize theoretical and temporal order of two variable blocks, while stepwise selection was used within each one[7]. Care-giving, family, demographic and work variables were submitted as the first block, perceived demands and supports as the second. Criteria were $p < .05$ for entry and $p > .10$ for removal.

Findings

Respondent characteristics and general trends

The 197 respondents, aged mostly 35 to 44, resided mainly in Ontario (60%) or western Canada (25%). Fifteen percent were French-speaking, 10% were from minority groups, 16% lived in blended families and 9% had adopted children. The majority had a postsecondary diploma (college 33%, university 48%). Thirty-six percent had family incomes of CAN$50,000-$99,999, the rest being equally divided between higher and lower categories. These strong income levels probably reflect 75% working over 30 hours weekly, 46% being in professional or managerial jobs and most families having two incomes (18% single parents). Nearly 40% had made major job situation changes in the past 3 years, mainly by reducing hours or responsibilities and changing jobs/locations. Most were mothers of two, one-third had at least two children with ADHD and 15% of families included affected adults. One-third of children with ADHD had combined subtype and nearly two thirds had an additional disability (23% a learning disability, 42% a psychiatric disorder, sometimes with LD). Most frequent psychiatric diagnoses were oppositional, mood or anxiety disorders, Tourette's or Asperger's syndromes, Conduct and Fetal Alcohol Spectrum Disorders. These difficult situations, typical of families with ADHD, may explain why nearly two thirds rated their parent role quality as mostly or very (20%) challenging. Most reported low support from extended family (70%), community (78%), schools (54%) and the workplace (65%). Access to formal supports was limited, with 30% unable to obtain respite, 22% without adapted child care and 28% with no family leave or part-time work options.

Are there any rewards or is it all challenges?

There were indeed rewards, as shown in Table 1. Half those mentioned referred to unusual qualities of these children, who are entertaining, funny, notice tiny details, have a 'unique way of looking at things' and 'far-sighted views' (R 115). Some mothers loved watching this unfold, though 'the highs are soaring but the lows are low' (R 119) and 'I feed off their energy, even as it exhausts me'(R 128). Over 30% of rewards came from 'successes that most parents take for granted' (R142), when a child 'beams with pride over his grade' (R185) or teens 'develop into young adults despite their shortcomings – realizing that all the hard work was worth it' (R33). A smaller number of respondents reported learning to celebrate small victories ('he hasn't been thrown out of Boy Scouts yet', R 52), laugh at absurd situations, enjoy rare happy moments and 'not take everything so seriously, live more in the moment' (R163). Having to advocate or be resourceful made several others aware of their strengths or increased their tolerance of people with life difficulties. A few found this parenting brought the family closer.

Table 1: Rewards mentioned most frequently (*N* = 173)

Reward Theme	*n*	%
Child's interesting qualities -intelligent, entertaining, creative, imaginative, perceptive, humourous, energetic, enthusiastic, caring, talented	87	50.3
Child's progress or success despite ADHD - 'catching on' to something s/he has struggled with - making gains that seem trivial to others	54	31.2
Mother's personal growth or new perspective - appreciating small things - seeing world differently - new flexibility, qualities or skills	20	11.6
Other - stronger family bonds, times child is positive	12	6.9
Totals	173	100.0

Mothers also faced many challenges. As shown on Table 2, dealing with difficult behaviour was mentioned twice as often as any other category. These children were described as making 'unrelenting demands' (R 75), are constantly 'in your face' (R 40) and argue over everything. Their volatility means 'today could be fantastic or a crisis requiring police intervention' (R 46), as 'triggers can be pushed very quickly and an otherwise wonderful day destroyed abruptly by a seemingly minor situation' (R 28). To avert crises, mothers 'always have to stay one step ahead' (R18) can neither let down their guard nor leave children unsupervised (R68). Unpredictable behaviour contributes to school problems, which included nearly 20% of challenges. Mothers

'never know when a meltdown will happen, when we'll have to drop everything and go' (R72) and must spend endless hours supervising homework, assigned by 'beleaguered school systems' (R 27) which lack adequate resources to make needed adaptations. Insufficient training means teachers and administrators rarely understand the root cause of problems: 'If my son had a physical disability, they would sit up and take notice. However, he has ADHD so they treat him like a bad child or a pain in the neck' (R178). Organizational problems in managing time, space, paper or tasks formed the third category. These difficulties are often misinterpreted as laziness or lack of motivation that 'should' be solved at home, with little recognition of the huge amount of time mothers invest to keep these children on track and avoid school failure (R22). These stresses cause 'constant emotional turmoil in the family' (R55), 'disrupting and taking energy from everyone' (R74), bringing tension between parents, among siblings and with relatives. The constant drain takes its toll: 'A family doesn't realize how much they are in crisis when in the middle of one – you are sometimes too paralysed or just too tired to cope '(R50). Lack of understanding in schools is paralleled by negative attitudes in the community, which rarely acknowledges the personal impact of this family stress, leaving mothers on their own to deal with feelings of blame, guilt and incompetence.

Table 2: Challenges mentioned most frequently (n = 191)

Challenge Theme	n	%
Child's impulsive, hyperactive behaviour - unrelenting demands, lack of compliance - unpredictable, volatile, crisis-prone - needs constant vigilance, preventive planning	73	38.2
Problems with school - academic, behavioural - school lacks understanding, resources, adaptations - time required to manage crises, supervise homework	37	19.4
Distractibility, organizational problems - constantly having to remind or 'nag' to keep on track - child can't follow through, maintain routines or structure	29	15.2
Family conflict - emotional turmoil damages everyone - tension in couple, with siblings, relatives	*26*	*13.6*
Other - negative attitudes to child, family - mother's difficult feelings, lack of time/options	26	13.6
Totals	191	100.0

What factors influence mothers' rewards and challenges?

As levels of rewards and challenges varied, further analysis looked for factors that might be associated with each. As shown on table 3, more factors were related to concerns than to rewards and generally, at a higher level of significance. Number of children and mother's education were associated with rewards, while the number with ADHD and presence of combined subtype or a psychiatric disorder was very strongly related to concerns. Perceived demands were strongly related to the latter, family demands especially (p <.001). Average usefulness of supports used, along with that of teachers and school administrators, was associated with both rewards and concerns. Support from health professionals or family was related only to the latter, while that from professionally-led groups or school-based professionals was strongly related to rewards.

Table 3: Relationships between Rewards & Concerns and Predictors (Pearson's *r*)

Types of Predictors	Rewards	Concerns
Situation (care giving, family, job, demographic)		
Co-existing psychiatric disorder		.252***
Children with ADHD		.213**
Combined ADHD subtype		.181*
Extent of job situation changes		.220**
Number of children	-.140*	
Mother's education	.168*	
Perceived Demands		
Family demands		.656***
Job demands		.186**
Perceived Supports		
Average (across all sources)	.224**	-.276***
Family		-.200**
Health professionals		-.145*
Teachers/school administrators	.180**	-.145*
School-based professionals	.181**	
Professionally-led groups	.179**	

Note: Analysis sample size is 191 for rewards, 192 for concerns.
* *p* < .05, ** *p* < .01, *** *p* < .001.

Multiple regression analysis examined how potential predictors might together account for either rewards or concerns (challenges). Results distinguished clearly between the two. The four predictors that entered into the final model for rewards accounted for less than 13% of variance, indicating that factors others than those examined have the major role. In order of entry, significant predictors of rewards

included mothers' education, number of children, average support and that from non-teaching school professionals.

Table 4: Hierarchical Stepwise Multiple Regression of Concerns on Situational Characteristics, Demand and Support Predictors (analysis sample *N* = 192)

Predictor Variables	Step	R2	Final Model	
			b[1]	β[2]
Characteristics of mother's situation				
-Coexisting psychiatric disorder	1	.064	.67	.59
-Extent of job situation changes	2	.104	.027	.042
-Combined ADHD	3	.134	.188*	.113
Perceived Demands and Supports				
- Family demands	4	.443	.551***	
- Support of health professionals	5	.474	-.051**	
- Average support usefulness	6	.487	-.104*	-.120
Constant			1.410	

1 Unstandardized regression coefficient.

2 Standardized regression coefficient.

* *p* < .05, ** *p* < .01, *** *p* < .001.

For concerns, 6 of the 10 potential predictors entered the final model, as shown in Table 4. ADHD subtype was the only first block variable to remain significant to the end, though co-existing psychiatric disorders and extent of job changes had entered earlier. When perceived family demand was added, explained variance jumped from 13.4% to 44%, such that those two predictors no longer made a unique contribution. Two other second block predictors entered the final model. Average support was significant, as was that of health professionals. The final model was quite powerful, explaining nearly half (48.6%) the variance of concerns.

Discussion and implications

This section will first discuss rewards and challenges separately then trace overall implications for social work. While all three reward types have been reported by other researchers, children's special qualities and progress despite disabilities encompassed 80% of rewards in the present study. The former was especially important (50% of mentions) and its content somewhat unusual. As noted by Segal (2001), children with ADHD are often very creative, highly intelligent individuals, who are keen observers and interesting to be with, when their impairments are well managed. However, the latter may mask the positive aspects, which may explain why a number of respondents mentioned no rewards. In the qualitative study, several mothers'

only rewards were 'good' days or stages, while others thought of benefits only after discussing their many challenges. It is striking that these identical rewards emerged in the same order from both the survey data and the earlier interviews with 40 mothers (Home, Kanisberg & Trepanier 2003).

Findings on factors related to rewards are intriguing. No disability-related factors were significant but having fewer children was. The qualities or progress of a child with ADHD may be more obvious when mothers have more time/energy to spend with him/her. Community college (versus university) education predicted higher rewards, possibly bringing more realistic expectations, increasing satisfaction with children's progress. Similar findings have been reported in adoption studies. More support overall and from school professionals such as social workers or psychologists predicted higher rewards, but that from teachers and groups led by professionals showed only associations. Professionals in schools may be more accessible for emotional support and referrals than those in agencies. While groups can be useful, finding the right one can be complicated, as many focus on teaching strategies (Seligman & Darling, 1993), which limits time for sharing or support.

The findings on challenges indicated that difficult behaviour was central because of children's constant arguing, relentless demands and unpredictable explosive or impulsive actions. Vigilance was obligatory, keeping mothers 'always on guard', unable to 'trust what she's going to do next' according to mothers interviewed earlier (Home, Kanigsberg & Trepanier, 2003). Helping distracted children stay on task or work on homework also required constant monitoring, as reported by Segal's (2001) study. Difficult behaviour made for a tense, conflict-laden climate at home and obliged mothers to intervene at school, when 'uncontrollable' children were unable to comply with instructions or cope with unstructured social situations. As in other hidden disabilities, problem behaviour brought relentless challenges 'shading all activities and functions of the family' (Fox, Vaughn, Wynette & Dunlap, 2002, p.445), while restricting mothers' time, energy and options. This type of challenge was mentioned less, perhaps due to women's hesitation to discuss personal impact, as society still fails to take such issues seriously if they affect 'only' the mother (Traustadottir 1991). Negative community attitudes were mentioned mainly indirectly, via school and other challenges.

Factors influencing challenges shed light on these findings. Concerns were related to several aspects of mothers' situations, including recent job changes and perceived job demand, though neither remained significant in the final analysis. Open question responses suggest job changes may reflect an effort to gain needed time and flexibility in difficult care-giving situations, three of which were associated with higher challenges. Children with combined subtype or co-existing psychiatric disorders have complex behaviour, social and academic difficulties, while caring for more than one child with ADHD can increase chaos, perhaps without 'easy' children to help mothers feel successful. It is known that psychiatric disorders are related to greater parent-child disruption and parent distress (Johnston, Chen & Ohan, 2006), but these disorders may act primarily by making family demand

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feel unreasonable. Once this key predictor is controlled, combined subtype is the only care-giving characteristic making a unique contribution. Children with both hyperactive-impulsive and inattentive impairments need help with behavioural as well as organizational/learning difficulties. Neither set of impairments is easy to manage yet few people realize they are disability-related, so it appears mothers continue to be judged for failing to control either one or the other.

Fortunately, some supports seem to help. Family support was related to concerns without predicting them and most respondents (70%) had reported little support from this source. Family help being available only for crises may cut cross child disabilities (Roeher Institute, 2000), but some studies suggest this pattern is more common when children have behaviour difficulties. Cronin (2004) found mothers of children with a physical impairment had much more family support then those dealing with ADHD. Very few participants in the qualitative study found encouragement or family child care available, as most relatives wanted nothing to do with this 'difficult' child (Home & Pearce, 2003). Further analysis of survey findings found higher family support reduced perceived family demand (Home & Webster, 2006), suggesting further research should examine obstacles to family support and factors that enhance it.

Certain professionals can provide useful support. Teacher support was associated with both rewards and concerns without predicting either, perhaps because only 'rare gems' understand and adapt, given lack of time and resources (Home & Pearce, 2003). In contrast, average support was a significant predictor for both. Challenges may feel more manageable if mothers are supported overall, as support can lessen stress in parents of children with other disabilities (Krahn, 1993). Support from health professionals lowered concerns in this study, perhaps partly because Canadian physicians can diagnose ADHD through publicly funded health insurance. An accurate, timely diagnosis can relieve worry, reduce self-blame (Singh, 2004) and open the door to services. However, qualitative results indicated that doctors are useful mainly if they are knowledgeable about hidden disabilities and take the time to make a careful diagnosis, discuss it with the family and provide solid follow-up (Home & Pearce, 2003). This cannot be taken for granted within the severe time constraints experienced by Canadian general practitioners. Doctors can also prescribe medication, which can reduce symptoms for 70% (Barkley et al, 2001). The fact that medication is not available free of charge in most parts of Canada may help explain why it did not emerge as important in this study, despite intense media attention to this issue. Mothers did want others (teachers, relatives) to stop giving unsolicited advice about medication, as such interference does not occur when children have better understood conditions such as epilepsy or diabetes

Contextual factors such as family structure, income or ethnic/cultural background were not significant predictors in this study, but this does not necessarily mean they lack importance, given sample characteristics. Perceived family demands increased when mothers' first language was not English (Home & Webster, 2006) but only a quarter of participants were from linguistic or cultural/racial minorities. Single

mothers were underrepresented as were others from lower income or educational categories. Recruiting mainly via self-help organizations may have masked the impact of contextual factors, as these associations tend to attract mainstream culture, middle-class members (Farris Kurtz, 2004). Targeting employed mothers was critical to this survey, but those who had left the work force need further study, as do women managing this caring role on very limited government assistance. Ensuring these mothers and those who are culturally different can participate in future studies will be difficult, given research ethics restrictions, but it is essential their needs and views be represented. Other methodological limitations (use of self-report measures, diverse recruitment strategies, cross-sectional design), along with international differences in policies and contexts restrict generalization of findings.

Nevertheless, these results provide food for thought for social workers. This study has drawn attention to rewards that may flow from this difficult care-giving experience, as well as highlighting the central role played by perceived intensity of family demands. Findings suggest mothers may not 'see' any rewards due to the overwhelming nature of some challenges. Social workers can point out how well these women are doing in very difficult situations, highlight their agency and help them identify what they have learned. The use of humour can help, such as when professionals began a group for mothers of children with ADHD asking members to share their funniest experience. This identified common ground, lightened the climate and highlighted a special quality of these children that others rarely notice (Home & Biggs, 2005). However, helping mothers reframe will not change their very difficult situation. While these mothers need to know that it is legitimate to feel stressed and prioritising self-care is essential, social workers should also work to improve service access, change community attitudes and increase support. Only when the objective situation of these mothers improves will they be able to live more normal lives, despite their child's disabilities.

Further research is needed to examine and pursue some findings of this study. Such work could examine rewards and challenges of both mothers and fathers of these children, perhaps in comparison to those of parents dealing with other hidden disabilities, such as Autism Spectrum Disorder. Further study of factors exterior to the child and family is important, as results of the present research suggest both ecological and social models of disability may be applicable. It will be essential to involve user groups and providers as collaborators in any future studies, to include varied perspectives and find ways to reach diverse families who rarely participate in either research or consumer groups. Finally, social work education needs to provide more opportunities for students to study about disability and family, carry out relevant field placements and practice-research. These measures are needed to ensure the next generation of practitioners can better support families of children with disabilities.

Notes

1. The author wishes to thank Social Sciences and Humanities Research Council of Canada for their financial support.
2. Children and Adults with Attention Deficit Disorders, Canada, especially Greg Trepanier and Joel Kanisberg, made an invaluable contribution to this research.
3. Learning disabilities should not be confused with intellectual disabilities. In Canada, the former term refers to 'disorders which affect the retention, acquisition, understanding or use of verbal or nonverbal information ... in individuals who otherwise demonstrate at least average abilities essential for thinking and/or reasoning' (National Definition of Learning Disabilities, LDAC, 2002)
4. Barnett's term 'concerns' was conserved in this scale, which is used to measure challenges. The author wishes to thank Rosalind Barnett for permission to adapt her scales for this study.
5. Support items were converted to a 6 point scale ('0' if unavailable or not used). Because the average was based only on support each respondent used, it was necessary to substitute all the values indicating 'not used' or 'not available' with average usefulness of support, to obtain Cronbach's Alpha across all 25 items.
6. Bivariate relationships are presented using Pearson's r, which is inherent to multiple regression analysis designed to capture relationship between rewards, concerns and predictors.
7. Significance of R^2 in the final model of each multiple regression analysis was tested using Wilkinson's (1997) method, to take into account inflation of R^2 resulting from use of stepwise selection.

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