JoDD
Journal on Developmental Disabilities
Le journal sur les handicaps du développement
Volume 17, Number 2, 2011

Authors

Karen Auyeung,[1]
Julie Burbidge,[2]
Patricia Minnes[2]

[1] Psychology Department, University of British Columbia, Vancouver, BC

[2] Psychology Department, Queen's University, Kingston, ON

Correspondence

kauyeung@psych.ubc.ca

Keywords

intellectual disabilities,
disability type,
parents,
stress

Perceived Parental Stress: The Relative Contributions of Child and Parent Characteristics

Abstract

Normative demands often associated with raising a child can be intensified for parents of children with intellectual disabilities (ID). The purpose of this study was to explore the experiences of stress reported by parents of individuals with ID in two age groups: high school students and adults. We also investigated this issue with respect to the type of disability experienced (i.e., Down syndrome or ID due to an unknown cause). One hundred and five parents completed the Family Stress and Coping Interview (FSCI) which provides a profile of stressful issues related to caring for a person with ID. Significant differences were found in individual issues reported by parents across age groups and type of disability. Implications and directions for future research are discussed.

Over the lifespan, families face many challenges associated with raising children. However, normative demands related to maintaining family health, participating in leisure activities, and pursuing education and careers are intensified for parents of children with intellectual disabilities (ID) (Grant & Whittell, 2000).

Previous research has produced mixed results about the nature of parental stress and challenges of caring for a family member with ID over the lifespan. Some studies have put forward a "wear-and-tear" hypothesis, whereby stressors accumulate and resources are depleted as caregivers and their children age (Johnson & Catalano, 1983; Webster, Majnemer, Platt, & Shevell, 2008). Other studies suggest an "adaptational" hypothesis in which caregivers demonstrate better adjustment over time (Townsend, Noelker, Deimling, & Bass, 1989), whereas an additional group of studies has described periods of intermittent stress often related to transitions (Minnes, 1988; Minnes & Woodford, 2004; Schneider, Wedgewood, Llewellyn, & McConnell, 2006; Wikler, 1986). Given such contradictory views based on the results of studies of families to date, some researchers are considering the influence of various child and caregiver factors that might differentially influence how well a family can cope with stressful events (Haveman, van Berkum, Reijnders, & Heller, 1997), and service use (Hayden & Heller, 1997).

The purpose of our study was to focus on two of these factors: age of child (i.e., high school students and adults) and type of disability. Given the need for more in depth research into the different needs, characteristics, and perceptions of parents of aging individuals with ID in order to inform services and policies geared to this population (Blacher, 2005; Davys & Haigh, 2007), this study investigated differences in stress in parents of high school students and adults.

The differential impact of disability on family stress is also of interest. For example, family stress varies across diagnosis based on availability of information concerning the disability, its course, and related behaviours (Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004). Studies to date have examined the differences in family and maternal stress across disability types in children and adolescents. Most studies have found elevated behavioural difficulties in children with autism and higher maternal or family stress, particularly in comparison to children with Down syndrome (Eisenhower, Baker, & Blacher, 2005; Griffith, Hasting, Nash, & Hill, 2010; Seltzer, Krauss, & Tsunematsu, 1993). Families of individuals with Down syndrome show more positive adjustment compared to families of individuals with ID of different etiologies (e.g., Blacher & McIntyre, 2006; Eisenhower et al., 2005; Seltzer et al., 1993). Several explanations for this phenomenon have been put forward, including that it may result from the personality stereotype associated with individuals with Down syndrome as being more cheerful and easygoing (Dykens, 1999), or that they generally have fewer behaviour problems (e.g., Eisenhower et al., 2005; Poehlmann, Clements, Abbeduto, & Farsad, 2005). Recently however, this so-called "Down syndrome advantage" was contested as a possible artefact of confounding factors such as maternal age (Corrice & Glidden, 2009). The likelihood of having a child with Down syndrome or other developmental disabilities generally increases with age, and similarly, older parents are more likely to be more established in their jobs and have higher incomes, which could account for lower levels of stress. Similarly, some authors have criticized the common comparison between individuals with Down syndrome and autism, citing the results as evidence of possible "autism disadvantage" rather than a "Down syndrome advantage" (Hodapp, Ricci, Ly, & Fidler, 2003; Stoneman, 2007). More research is required to shed light on the differences between individuals with Down syndrome and other disabilities that take child and parent age into account. Finally, many previous studies have focussed on the experience of individuals with known diagnoses, however less is known about the experiences of families and individuals with ID due to an unknown cause (Stoneman, 2007). Families of these individuals may have more difficulty accessing information, resources, and support groups in comparison to individuals with known etiologies. This study investigated differences in stress in parents of children and adults with Down syndrome and ID due to unknown cause, as well as whether identified differences were due to parent and child age.

Objectives

This study had two objectives: 1) to explore differences in perceived stress of parents of individuals with ID in two age groups (high school students and adults) and with different types of ID, and 2) to identify stressful life issues of greatest concern for parents of individuals in different age groups and with different types of disabilities.

Method

Participants

The sample consisted of 74 parents of individuals with ID who were divided into two age groups. One group included 45 parents (43 women, 2 men) of high school students with ID. These parents ranged in age from 34 to 62 years (*M* = 48.16, *SD* = 6.44) and their children (28 young men, 17 young women) ranged in age from 14 to 22 years (*M* = 17.67, *SD* = 1.75). The other group included 29 parents (27 women, 2 men) of adults with ID. These parents ranged in age from 58 to 88 years (*M* = 70.28, *SD* = 7.76) and their children (12 men, 17 women) ranged in age from 29 to 59 years (*M* = 41.10, *SD* = 8.93). Table 1 includes information about parents' marital status and education level and the children's disability type.

Procedure

Parents of adults with ID were recruited through Associations for Community Living in 10 communities in Eastern and Central Ontario. Parents of high school students with ID were recruited through various agencies and school boards. Archival data from these two separate samples were used for comparison purposes. Ethics approval for this study was granted by Queen's University.

Table 1. High School and Adult Groups' Child and Parent Demographic Information

	High School n (%)		Adult n (%)	
Child Disability Etiology				
Down syndrome	10	(50.0)	10	(50.0)
ID due to unknown cause	35	(64.8)	19	(35.2)
Parent marital status	15	(33.3)	14	(48.3)
Single/divorced/widowed	30	(66.7)	15	(51.7)
Married/common law partner				
Parent Education Level				
Partial high school	8	(17.8)	13	(41.5)
High school diploma	14	(31.1)	9	(31.0)
Some college	4	(8.9)	2	(6.9)
College or university degree	19	(42.2)	5	(17.2)

In both groups, information was obtained through structured telephone interviews with parents that ranged from approximately 1.5–3 hours in length. Questions were selected from a battery of questionnaires used previously. In a few instances, interviews were held over multiple sessions to accommodate participant needs.

Measures

Parent Demographic Questionnaire

Parents provided their age, gender, marital status, highest level of education attained, and occupation. They also provided information about their son or daughter with ID, including date of birth, gender, and type of ID.

Checklist of Supports for Individuals with Developmental Disabilities (Woodford, 1998)

This questionnaire was developed in consultation with parents and service providers to measure service use in families of children and adults with ID. The questionnaire lists seven services (e.g., physical therapy) and asks whether the individual with ID is using the service, how satisfied parents are with services being used, and reasons for not using specific services (e.g., not aware of the service). Each service was scored as either a 1 if the service was being used or a 0 if the service was not used. Scores were then summed to create a total score ranging from 0 to 7. Information regarding satisfaction with services and reasons for not using services was not included in this study.

Family Stress and Coping Interview (FSCI; Nachshen, Woodford, & Minnes, 2003)

The FSCI is a quantitative and qualitative measure of stress and coping in families of individuals with ID; data from the qualitative section were not collected for this study. The FSCI focuses on 24 caregiving issues (e.g., explaining the disability to others, dealing with health professionals). Level of stress related to each issue is rated on a 4-point scale ranging from 0 (*not stressful*) to 3 (*extremely stressful*). The sum of these ratings was used as an overall perceived caregiving stress score. Only 23 issues were used to calculate stress scores, which ranged from 0 to 69. Issue 22 ("Arranging time apart from child") was not included in the analyses due to missing data. The FSCI has high internal consistency ($\alpha = .89$), good test-retest reliability ($r = .80$), and good face validity (Nachshen et al., 2003); it also had good internal consistency for this sample ($\alpha = .89$).

Results

Services and Supports

Participants' children were using approximately three of the seven services on average. There were no significant differences between the high school students ($M = 2.62$, $SD = 1.83$) and adults ($M = 2.50$, $SD = 1.23$) for number of services used, $t(71) = 0.31$, $p = .76$. Only two participants had children who were using the maximum of seven services (2.7%), and six participants (8.1%) had children who were not using any services. The most commonly used services were social and recreational services (51.1%; e.g., Special Olympics, music lessons) among high school students and respite care (58.6%) among adults. There were no significant differences between individuals with Down syndrome ($M = 3.00$, $SD = 1.93$) and individuals with ID due to unknown cause ($M = 2.43$, $SD = 1.47$) for the number of services used, $t(71) = 1.34$, $p = .19$.

Demographic Characteristics

A 2×2 chi-square test of independence was conducted between families of high school students and adults to investigate whether differences existed in parents' *marital status*. There were no significant difference between groups based on age group, $\chi^2(1, n = 74) = 1.65$, $p = .20$, nor based on the child's type of ID, $\chi^2(1, n = 74) = 1.34$, $p = .25$.

A 2×4 chi-square test of independence was conducted to investigate whether patterns of *level of education* differed. The overall test was significant for age groups, $\chi^2(3, n = 74) = 8.03$, $p = .045$, but not for the child's type of ID, $\chi^2(3, n = 74) = 1.71$, $p = .63$. Follow-up 2×2 chi-square tests showed that only partial completion of high school and having a college or university degree were significant, $\chi^2(1, n = 74) = 7.87$, $p = .005$. More parents in the adult group had partial high school, and more parents of high school students had college or university degrees ($n = 19$, compared to $n = 5$ among parents of adults).

The *t* test for differences in age between disability groups was also significant, $t(72) = 2.77$, $p = .007$, indicating that parents of individuals with Down syndrome ($M = 63.35$, $SD = 13.22$) were significantly older than parents of individuals with ID due to an unknown cause, ($M = 54.41$, $SD = 12.02$).

Models of Family Stress

Hierarchical regression analysis was used to investigate the relative contributions of age group, disability type, parental age, and service use on family stress after controlling for parental level of education (see Table 2). Parental level of education was entered in step 1 of the model and age group, disability type, and parental age were entered in step 2. Model 1 did not account for a significant amount of the variability in reported family stress, $R^2 < .001$, $F(1, 71) = 0.01$, $p = .920$, indicating that parental level of education was not a significant predictor of family stress. The regression equation for model 2, however, was significant, $R^2 = .25$, $F(4, 67) = 4.41$, $p = .002$, indicating that approximately 25% of the variance in family stress in the sample could be accounted for by the linear combination of age group, disability type, and parental age. At this step, families using more services reported significantly more stress. Also, though older parents reported significantly less stress, there was no difference between the stress levels of parents of high school students and adults. None of the other variables were significantly related to reported levels of family stress.

Specific Stressors and Children's Age Group

A two-group multivariate analysis of variance (MANOVA) was conducted to determine whether the two age groups differed in

Table 2. Predictors of Family Stress Entered into the Hierarchical Regression Models

Variables Entered	*B*	*SE B*	β	*p*
Step 1				
Level of education	0.13	1.25	.01	.92
Step 2				
Level of education	-0.95	1.21	-.09	.44
Age group	-10.26	5.37	-.39	.06
Disability type	3.76	3.36	.13	.27
Parental age	-0.67	0.22	-.65	.003
Services	2.44	0.86	.31	.006

reported stress on the individual FSCI items. Significant differences were found, Hotelling's $T^2 = 3.81$, $F(23, 41) = 6.79$, $p < .001$, indicating that there were differences in the FSCI items between the two parent samples (high school students and adults).

Multiple independent samples *t* tests were conducted on the individual items of the FSCI as follow-up tests to the MANOVA (see Figure 1). A Bonferroni correction was used to control for Type I Error such that a *p*-value less than .002 (.05/23 items) was required for significance. Parents of high school students rated the issue of "long term planning for residential accommodation" as most stressful ($M = 1.71$, $SD = 1.10$), whereas parents of adults rated the issue of "planning for wills, trusts, and guardianships" as most stressful ($M = 2.45$, $SD = 0.95$).

Significant differences between the two age groups were found for several issues on the FSCI (see Table 3). Parents of individuals in high school reported significantly higher levels

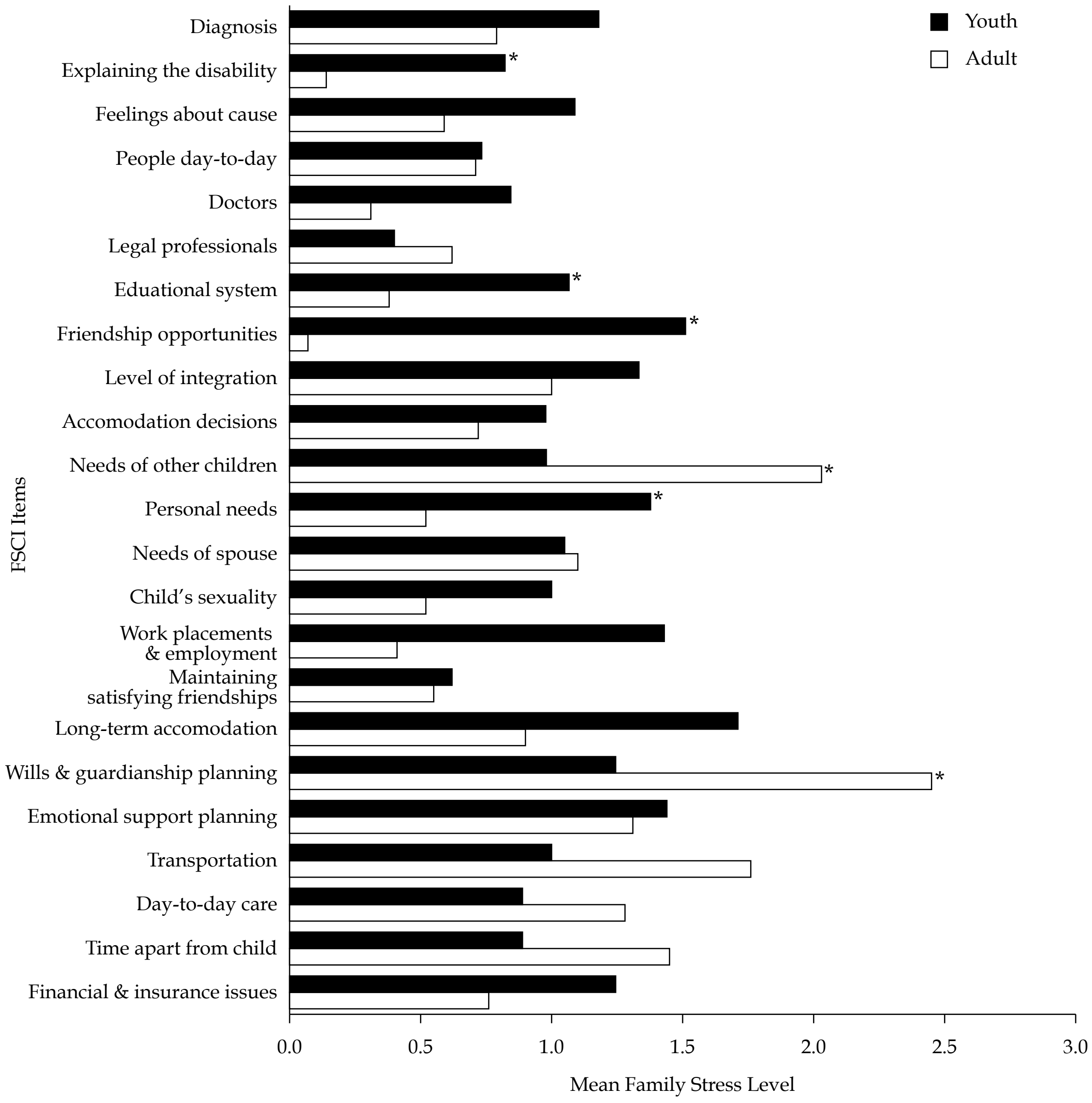

Figure 1. Mean levels of stress reported by parents of high school students and adults arranged by FSCI item.

$^* p < .002$

of stress related to explaining their child's disability, finding opportunities for their child to form friendships, dealing with the education system, meeting their own personal needs, finding work placements and employment for their child, whereas parents of adults reported significantly higher levels of stress for issues related to meeting the needs of their other children and planning for wills, trusts, and guardianships.

Specific Stressors and Children's Type of Disability

A two-group MANOVA was conducted to determine whether parents of the two disability groups differed in their reported stress on the individual FSCI items. There was no significant difference, Hotelling's $T^2 = 0.73$, $F(23, 41) = 1.29$, $p = .23$. The issue of "planning for wills, trusts, and guardianships" ($M = 2.54$, $SD = 0.84$) was rated as most stressful by both parents of individuals with Down syndrome ($M = 2.05$, $SD = 1.15$) and parents of individuals with ID due to an unknown cause ($M = 1.59$, $SD = 1.22$).

Discussion

Differences in Parental Stress by Age Group

Parental age emerged as a significant predictor of family stress, with older parents generally reporting lower levels of stress. These results would appear to support an adaptational theory of stress over the lifespan, though caution must be taken in interpreting these results due to the cross-sectional nature of the data. Previous studies have found that older parents use adaptive coping strategies (e.g., acceptance, positive reinterpretation and growth, and turning to religion) more often than maladaptive strategies (Krauss & Seltzer, 1993). Other studies have found that older parents report less perceived stress due to having lowered expectations of the service system. For example, one study found that caregivers aged 55 and older reported less burden and fewer perceived unmet needs than younger caregivers (Hayden & Heller, 1997). Services were not as readily available in the past, and thus, older parents did not perceive their needs as being unmet by the system (Haveman et al., 1997).

Table 3. Descriptive Statistics for FSCI Issues With Significant Differences Between Age Groups

Issues	*High School* *M (SD)*	*Adult* *M (SD)*	T-*Test* *Results*
Explaining to others about the disability*	0.82 (1.03)	0.14 (0.58)	$t(71) = 3.65$, $p < .001$
Creating and/or finding opportunities for child to find friendship and participate in activities*	1.51 (1.12)	0.07 (0.26)	$t(51) = 8.30$, $p < .001$
Dealing with the education system	1.07 (0.86)	0.38 (0.94)	$t(72) = 3.23$, $p < .001$
Meeting the needs of your other children	0.98 (1.10)	2.03 (1.18)	$t(68) = 3.98$, $p < .001$
Meeting your personal needs	1.38 (1.01)	0.52 (0.95)	$t(72) = 3.67$, $p < .001$
Work placements and employment	1.43 (0.97)	0.41 (0.91)	$t(71) = 4.49$, $p < .001$
Planning for wills, trusts, and guardianships*	1.24 (1.13)	2.45 (0.95)	$t(67) = 4.94$, $p < .001$

Notes: (1) p-value less than .002 (.05/23 items) required for significance;
*(2) Welch's formula values are reported where Levene's test of homogeneity was violated (items denoted by *).*

The number of services used emerged as a significant predictor of reported family stress, indicating that families using more services reported higher levels of stress. Previous findings concerning stress and service use have been mixed. Some studies report that families that are more stressed are more likely to seek out and utilize formal support services (Floyd & Gallagher, 1997), whereas others have found that many parents are not receiving required services and therefore experience higher stress (Nachshen & Minnes, 2005), and still other studies have found no relationship between stress and service use (Minnes, Woodford, & Passey, 2007). Inadequate service provision or difficulty finding and maintaining services can also lead to added stress (Rapanaro, Bartu, & Lee, 2007). The results suggest that services might not be helping families as effectively as possible; however, given its correlational nature, a causal relationship cannot be established.

Neither parental level of education nor marital status emerged as significant predictors of family stress, though there were significant differences between the age groups (i.e., more parents of adults having completed partial high school, and less with college or university degrees). This finding is consistent with previous research and may be explained by cohort differences.

Issues of Particular Concern by Age Group

Although the parents in the two age groups did not differ in overall amount of reported stress, they did differ in the particular issues perceived to be most stressful. Parents of high school students reported higher stress concerning issues related to explaining their child's disability to others, finding opportunities for their child to develop friendships, dealing with the education system, meeting their own personal needs, and finding work placements and employment for their child. Parents may want their children to participate in the same types of social and work experiences as their peers, however actually finding suitable or available placements can be very stressful (Blacher, Kraemer, & Howell, 2010; Kraemer & Blacher, 2001). An Ontario study found that even when youth are still enrolled in high school, very low numbers of individuals with ID are involved in work placements or employment activities in comparison to typically developing adolescents (Burbidge, Minnes, Buell, & Ouellette-Kuntz, 2008). Some parents have reported that this loss or lack of social participation often extends to their own personal activities and outings, due to difficulties associated with organizing trips out or feeling confident that they can leave their child alone (Rapanaro et al., 2008).

Parents of adults with ID reported higher stress related to planning for wills, trusts, and guardianships and meeting the needs of their other children. This pattern is consistent with previous literature that cites issues of "anticipatory care" as major concerns for this age group (Grant, 2007). Older parents may not be able to easily remove themselves from their caregiving role, which may limit their ability to participate in activities considered "typical" for others in their cohort (e.g., retirement, travel, or addressing their own health concerns; Minnes, Woodford, & Passey, 2007). Given that the parents of adults were considerably older than the parents of high school students, issues associated with planning for the long-term care of their child may have been more pressing (Blacher, 2005).

There were several issues where no significant differences were found between the age groups. In particular, issues related to parents maintaining satisfying relationships, dealing with people on a daily basis, making accommodation decisions, and meeting the needs of their spouse were rated as similarly stressful across both groups. This finding highlights the ongoing nature of such needs as children transition into adulthood and beyond.

Differences in Parental Stress by Type of Disability

While differences across types of ID have been previously reported for availability of information concerning the disability, its course, and related behaviours (Seltzer et al., 2004), fewer studies have examined how the type of disability can impact family stress. Our study examined whether the adolescent or adult child's disability type predicted parents' reports of family stress in parents of individuals with Down syndrome and ID due to unknown cause. Disability type did not emerge as a significant predictor of family stress, which may have resulted from low power due to small sample sizes. It was hypothesized that the families of individuals with ID due to unknown cause may have elevated stress levels due to difficulties finding and gaining access to services in comparison to individuals with known etiologies. In this sample, families of individuals with ID due to unknown cause were using fewer services; however, this difference was not significant. More research is required to investigate the experiences and perceptions of families with unknown etiologies.

Conversely, the lack of difference in stress between parents of individuals with Down syndrome and parents of individuals with ID due to an unknown cause may add to the literature that questions the existence of the Down syndrome advantage (Corrice & Glidden, 2009; Glidden & Cahill, 1998; Stoneman, 2007). Similar to these studies, no difference, or a greatly reduced magnitude of difference, was found between groups after controlling for maternal age. As previously mentioned, older parents may have accumulated better coping strategies to deal with stress as they have raised their children. Similarly, some studies have found that older parents reported less perceived burden and may have lower expectations about the number of services they received (Hayden & Heller, 1997). In addition, the lack of differences may be related to the use of individuals with ID due to unknown cause as a comparison group. The Down syndrome advantage is most evident when compared to children with autism (e.g., Abbeduto et al., 2004; Blacher & McIntyre, 2006). As previously mentioned, parents of individuals with Down syndrome often report less maladaptive behaviour and more positive interpersonal behaviours, in contrast to parents of children with autism who usually show deficits in social behaviours (Eisenhower et al., 2005).

Limitations and Future Directions

The data in this study were cross-sectional in nature, and thus, we are unable to make causal inferences about changing relationships between age and other variables over time. Longitudinal research designs are needed to track changes in parental stress over the lifespan, and to fully test the "wear-and-tear" hypothesis. The findings have limited generalizability, as parents were self-selected and primarily consisted of highly educated, married mothers with enough time to participate in the research. Some fathers and other family members were included in the sample; however, further research is needed to obtain a broader understanding of the perceptions and experiences of fathers and siblings, as well as other relevant individuals, such as teachers or extended family members (Turnbull, Summers, Lee, & Kyzar, 2007). Other variables that were not examined (e.g., parental cognitions and appraisals) also may explain differences in parental stress (Hassall, Rose, & McDonald, 2005; Minnes et al., 2007). Similarly, differences in socioeconomic status (Stoneman, 2007) as well as the differences in both maladaptive and adaptive behaviours of the children (Blacher & McIntyre, 2006; Minnes & Woodford, 2004; Stoneman, 2007) are factors that should be taken into account in future studies.

The overall sample size was acceptable; however some groups were small when used for individual analyses or comparisons. Although information concerning etiology was available, information concerning the severity of disability, levels of adaptive behaviour, and cognitive, communication, or behavioural deficits was not available. Further research is needed to investigate the impact of limited resources on parents of individuals with ID due to an unknown cause (e.g., unavailable support groups, limited information on behavioural phenotypes, and community resources that may be more readily available to individuals with known etiologies). In addition, research is needed to investigate whether the relationships between individuals with Down syndrome and their parents differ from those of parents of individuals with other diagnoses, and the impact of such differences on parental stress.

In this paper, only quantitative data from the FSCI were collected. Recent research has moved towards emphasizing the positive experiences of families of individuals with ID (Ylven et al., 2006), including resilience, adaptation, and empowerment (Nachshen & Minnes, 2005), as well as understanding how different coping strategies, knowledge, and attitudes interact with other family characteristics (Blacher, Neece, & Paczkowski, 2005). Further research is needed to take into account both the positive and negative experiences of families to understand how they might interact or buffer each other. Finally, further research is needed to evaluate the strategies, decisions, and arrangements parents make related to various services including long-term accommodation, maintenance of services, social and emotional support, and daily caregiving tasks, in order to provide families with ongoing assistance.

Key Messages from This Article

People with disabilities: Parents of children with intellectual disability often worry about different things. We found that what parents worried about depended on the age of their child, but not on their type of disability. More research is needed to find out how stress levels of parents and families change over time.

Professionals: Helping people with disabilities requires more in-depth understanding of the individual situations and concerns of parents and ensuring that individuals with disabilities due to unknown cause are provided with more support.

Policy makers: More research is needed to better understand the different needs and concerns of parents of various age groups and to ensure that service provision is effectively addressing issues important to families of individuals with intellectual disabilities at different life stages.

References

Abbeduto, L., Seltzer, M., Shattuck, P., Krauss, M., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on mental Retardation, 109*(3), 237–254.

Blacher, J. (2005). Widening the lens on intellectual disabilities: An emerging focus on genetics, the lifespan, and evidence-based practice. *Current Opinion in Psychiatry, 18*, 467–468.

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research, 50*, 184–198.

Blacher, J., Kraemer, B. R., & Howell, E. J. (2010). Family expectations and transition experiences for young adults with severe disabilities: Does syndrome matter? *Advances in Mental Health and Learning Disabilities, 4*(1), 3–16.

Blacher, J., Neece, C. L., & Paczkowski, E. (2005). Families and intellectual disability. *Current Opinion in Psychiatry, 18*, 507–513.

Burbidge, J., Minnes, P., Buell, K., & Ouellette-Kuntz, H. (2008). Preparing to leave school: Involvement of students with intellectual disabilities in productive activities. *Journal on Developmental Disabilities, 14*(1), 19–26.

Corrice, A. M., & Glidden, L. M. (2009). The Down syndrome advantage: Fact or fiction? *American Association on Intellectual and Developmental Disabilities, 114*, 254–269.

Davys, D., & Haigh, C. (2007). Older parents of people who have a learning disability: Perceptions of future accommodation needs. *British Journal of Learning Disabilities, 36*, 66–72.

Dykens, E. M. (1999). Direct effects of genetic mental retardation syndromes: Maladaptive behaviour and psychopathology. In L. M. Glidden (Ed.), *International review of research in mental retardation*, *22*, 1–26. San Diego, CA: Academic Press.

Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research, 49*, 657–671.

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

Glidden, L. M., & Cahill, B. M. (1998). Successful adoption of children with Down syndrome and other developmental disabilities. *Adoption Quarterly, 1*, 27–43.

Grant, G. (2007). Invisible contributions in families with children and adults with intellectual disabilities. *Canadian Journal on Aging, 26*(1), 15–26.

Grant, G., & Whittell, B. (2000). Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the life span. *Journal of Applied Research in Intellectual Disabilities, 13*, 256–275.

Griffith, G. M., Hastings, R. P., Nash, S., & Hill, C. (2010). Using matched groups to explore child behaviour problems and maternal well-being in children with Down syndrome and autism. *Journal of Autism and Developmental Disorders, 40,* 610–619.

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*, 405–418.

Haveman, M., van Berkum, G., Reijnders, R., & Heller, T. (1997). Differences in service needs, time demands, and caregiving burden among parents of persons with mental retardation across the life cycle. *Family Caregiving for Persons with Disabilities, 46*, 417–425.

Hayden, M. F., & Heller, T. (1997). Support, problem-solving/coping ability, and personal burden of younger and older caregivers of adults with mental retardation. *Mental Retardation, 35*(5), 354–372.

Hodapp, R. M., Ricci, L. A., Ly, T. M., & Fidler, D. J. (2003). The effects of the child with Down syndrome on maternal stress. *British Journal of Developmental Psychology, 21*, 137–151.

Johnson, C. L., & Catalano, D. J. (1983). A longitudinal study of family supports to impaired elderly. *The Gerontologist, 23*, 612–618.

Kraemer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation, school preparation, parent expectations, and family involvement. *Mental Retardation, 39*(6), 423–435.

Krauss, M. W., & Seltzer, M. M. (1993). Current well-being and future plans of older caregiving mothers. *Irish Journal of Psychology, 14*, 48–63.

Minnes, P. M. (1988). Family resources and stress associated with having a mentally retarded child. *American Journal on Mental Retardation, 93,* 184–192.

Minnes, P., & Woodford, L. (2004). Well-being in aging parents caring for an adult with a developmental disability. *Journal of Developmental Disabilities, 11*(1), 47–66.

Minnes, P., Woodford, L., & Passey, J. (2007). Mediators of well-being in ageing family carers of adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 20*, 539–552.

Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research, 49*(12), 889–904.

Nachshen, J. S., Woodford, L., & Minnes, P. (2003). The Family Stress and Coping Interview for families of individuals with developmental disabilities: A lifespan perspective on family adjustment. *Journal of Intellectual Disability Research, 47*(4/5), 285–290.

Poehlmann, J., Clements, M., Abbeduto, L., & Farsad, V. (2005) Family Experiences associated with a child's diagnosis of fragile X or Down syndrome: Evidence for disruption and resilience. *Mental Retardation, 43*(4), 255–267.

Rapanaro, C., Bartu, A., & Lee, A. H. (2008). Perceived benefits and negative impact of challenges encountered in caring for young adults with intellectual disabilities in the transition to adulthood. *Journal of Applied Research in Intellectual Disabilities, 21*, 34–47.

Schneider, J., Wedgewood, N., Llewellyn, G., & McConnell, D. (2006). Families challenged by and accommodating to the adolescent years. *Journal of Intellectual Disability Research, 50*(12), 925–936.

Seltzer, M., Krauss, M. W., & Tsunematsu, N. (1993). Adults with Down syndrome and their aging mothers: Diagnostic group differences. *American Journal on Mental Retardation, 97*, 496–508.

Seltzer, M., Abbeduto, L., Krauss, M., Greenberg, J., & Swe, A. (2004). Comparison groups in autism family research: Down syndrome, fragile X syndrome, and schizophrenia. *Journal of Autism and Developmental Disorders, 34*(1), 41–48.

Stoneman, Z. (2007). Examining the Down syndrome advantage: Mothers and fathers of young children with disabilities. *Journal of Intellectual Disability Research, 51*(12), 1006–1016.

Townsend, A. L., Noelker, L., Deimling, G. & Bass, D. (1989). Longitudinal impact of interhousehold caregiving on adult children's mental health. *Psychology and Aging, 4*, 393–401.

Turnbull, A. P., Summers, J. A., Lee, S.-H., & Kyzar, K. (2007). Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 346–356.

Webster, R. I., Majnemer, A., Platt, R. W., & Shevell, M. I. (2008). Child health and parental stress in school-age children with a preschool diagnosis of developmental delay. *Journal of Child Neurology, 23*(1), 32–38.

Wikler, L. M. (1986). Periodic stresses of families of older mentally retarded children: An exploratory study. *American Journal of Mental Deficiency, 90,* 703–706.

Woodford, L. (1998). *Well-being in parents of adults with developmental disabilities*. Unpublished M.A. thesis. Department of Psychology, Queen's University, Kingston Ontario Canada.