

SPRING, 2008

# ON THE uptake



## HOT TOPIC: Caring for caregivers



Caregivers are instrumental in facilitating the growth and happiness of children and adolescents with various types of disabilities. Regardless of whether the caregiver is a biological or adoptive mother, father, grandparent, foster parent or other extended family member, children rely on them for their survival and well-being. Caregivers provide structure, nurturing, predictability, intimacy, and create opportunities for their child to achieve whatever potential they have. In Canada, 9% of caregivers have at least one child between the ages of 4 and 11 that has a neurodevelopmental condition (e.g., im-

pairment in speech, dexterity, mobility, and/or cognition). Raising a child who is diagnosed with cerebral palsy, global developmental delay, or autism is more complex as caregivers face additional responsibilities and challenges. A caregiver's experience of raising a child with a neurodevelopmental condition has both personal and social dimensions. The family's income, the caregiver's physical and psychological well-being, how the caregiver interacts with their child, the meaning that their child's disability has for them and for their family, the efforts that they make to manage what needs to be managed, and the amount of support they receive from their family and community, are some of the components of the personal dimension. Raising a child with a disability

also has a social dimension insofar as caregivers must interact with health, education and social service systems as well the general public and the physical environment. Although these systems are meant to be supportive, caregivers are faced with policies that fall short of addressing relevant issues, limited

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Presented by/présenté par:



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resources, and attitudes that create barriers to their child's full participation and social inclusion.

## Challenges of a Personal Kind

The experience of being a parent to a child with a neurodevelopmental condition is a personal journey and there is no correct or prescribed path to follow. As observers of and participants in their child's life, caregivers acquire an understanding of their child's strengths and limitations. Coming to terms with the level of care their child requires and managing what needs to get done on a day-to-day basis places an extraordinary emotional as well as physical demand on caregivers. Caregivers monitor their child's symptoms on a moment to moment basis and when a child's has aids or technical devices, these require technical knowledge and maintenance. Caregivers accommodate limitations in functioning by either teaching their child how to achieve a particular skill, or modify the task so that it can be achieved, and/or by doing it for them if that is not possible. Caregivers are also instrumental in creating opportunities for their child's social engagement and minimizing potentially stigmatizing reactions by others. Inviting peers to play, allowing their child to follow their instinctive drive for independence, teaching others about their child's impairment and what it does or does not mean, are ways in which caregivers advocate for their child's social inclusion.

Given the extra demands that are placed on caregivers, it is not surprising to learn that researchers have documented the extent to which their physical and psychological health is compromised when compared to caregivers of children who do not have these conditions. They have more back problems, migraine headaches, ulcers, arthritis and pain, are more likely to report having at least one chronic health condition and to be limited in at least one domain of activity (eg. motor, cognitive, speech). When caregivers have a child with a neurodevelopmental condition as well as behaviour problems, they are more

likely to report elevated symptoms of depression. No inferences can be made about how the child's disability led to these health problems. Furthermore, although the risk for depression among these caregivers is higher, it is not the majority of caregivers who have psychological health problems. In fact, in one study only 8.3% had symptoms that are considered in the clinical range. Therefore, although the risk is higher, it is not a majority who experience emotional distress.

In clinical practice, there is an implicit understanding that the type and quality of parenting plays a significant role in the emotional, behavioural, social and quality of life outcomes of children with disabilities. For example, when making parenting decisions, caregivers must decide how much to 'let go' and how much to 'protect' their child from potentially dangerous or stigmatizing situations. Difficult questions arise such as: When should I allow my child to walk to school on her own? Should I allow my child to attend that summer program? Will the respite worker be able to anticipate dangerous situations the way that I do? Will they care for my child the way that I do? These are tough questions, the answers to which are based on what parents believe is in the best interests of their child. Everyone has an opinion about these issues, but in the end, it is the caregiver who experiences the discomfort, worry and consequences of their decision. It is important for health care providers to be sensitive to the precarious nature of this tension and the pivotal role that it plays in family life.

As parents situate themselves along this continuum of restrictiveness and permissiveness, they are also managing the meaning of their child's disability for their own caregiving identity. For some, being a caregiver is who they are and their identity is closely tied to the functions that they perform in that role. At the other extreme are caregivers who experience the demands of caregiving as an imposition or burden. Along this continuum are caregivers who manage to acknowledge the challenging aspects of raising a child with a neurodevelopmental

condition but also acknowledge the ways in which their experience has been life-enhancing for them and for other family members. This counter-narrative is one that has not been documented as well as the narrative about disability as a tragedy or about disability as a precipitating factor for neglect or abuse. It certainly comes closer to depicting the complexity involved in raising a child with a neurodevelopmental condition.

## Challenges of a Social Kind

Canadians have recognized that support to caregivers is a national priority and policies have been developed at various levels of government to ensure that services are delivered through a family-centred lens, enabling parents to be full partners in their child's care. Federal and provincial programs exist to provide support to these caregivers, ranging from income supplementation to tax credits to access to programs that provide specific employment, health, educational and social service support.

There are two major social trends that make the consideration of caregiver well-being particularly relevant. First, there has been a decided shift toward community-based rehabilitation (CBR) of children with neurodevelopmental conditions. In addition to maximizing opportunities for social inclusion, CBR recognizes caregivers as partners in the provision of care. Second, the principles of family-centered care have been embedded in health policy and embraced by health and social service agencies providing services to children with disabilities and their families. Here, too, caregivers are instrumental partners who take an active role, influencing the nature and direction of the care their child receives. Although these trends place greater emphasis on caregiver voice and involvement, they also place more responsibility on parents to provide care.

The ideal of a 'partnership' becomes more challenging once one considers how literacy, and culture play a role.



Caregivers may not have a template or narrative for how to interact with health, education and social service systems if they cannot speak the dominant language or if their culture has a different way of treating children with a particular type of impairment. It is incumbent on health providers to anticipate these potential barriers, appreciate the significant role that they play, and put in place supports that will increase the likelihood that services are commensurate with cultural understandings without compromising the quality of care that the child receives.

Once caregivers are connected to health, social service and education, managing knowledge transfer is fundamental. The extent to which the child's school understands the connection between the child's cognitive limitations and the child's behaviour is instrumental in creating an academic environment that is supportive. For example, educators may not understand the nuances of a child's impairment that explain inattentive behaviour – that it is related to an inability to filter out competing auditory stimuli vs. malignant intentions. Management of the transfer of information between primary, secondary and tertiary level health care centres, ensuring that providers in the education and social service sector have an adequate understanding of the neurodevelopmental disorder, can make a tremendous difference to the quality of care that a child and their caregiver receive. Although these systems

strive to providing continuity of care, barriers such as waiting lists, inclusion/exclusion criteria regarding who does or does not have access to services, and limited resources imply that caregivers must meet these extraordinary demands.

## Resilience of Caregivers

Given the nature of what caregivers face, it is important to recognize the extraordinary resilience of caregivers. Facing inadequate resources, stigmatizing environments, and a culture that treats their child's impairment mostly as a tragedy, caregivers find ways of surpassing these challenges. They find positive meaning in who their child is and the contribution that their child makes to others. They appreciate the joy that their child brings to their life, the life of the child's siblings, and to their community. They applaud their child's successes even when those successes are not equally valued by others. They locate meaningful sources of support, acknowledge the stresses and challenges they face, and go about teaching significant others about the beauty of their child. This is not a narrative about tragedy, but rather a narrative about valuing life, challenging what is considered normal, and embracing success in a different kind of way. Those of us who work in the field know who these families are and our hats are off to them for teaching us about this important way of looking at and understanding

their identity as caregivers.

- Dr. Lucyana Lach

## KEY REFERENCES:

Lach, L.M., Kohen, D.E., Garner, R.E., Miller, A.R., Brehaut, J.C., & Klassen A.F. et al. (2008). Health and psychosocial functioning of caregivers of children with neurodevelopmental disorders: Results from the Canadian Longitudinal Study of Children and Youth. *Disability & Rehabilitation*, accepted January 23, 2008.

Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science Medicine*, 47(7), 865-875.

Skok, A., Harvey, D., & Reddihough, D. (2006). Perceived stress, perceived social support, and well-being among mothers of school-aged children with cerebral palsy. *Journal of Intellectual and Developmental Disability*, 31(1), 53-57.

## COMMENTARY



It is well documented that parents living with a child with a disability must cope with greater physical, emotional and social demands in comparison to those living with a healthy child. In a study

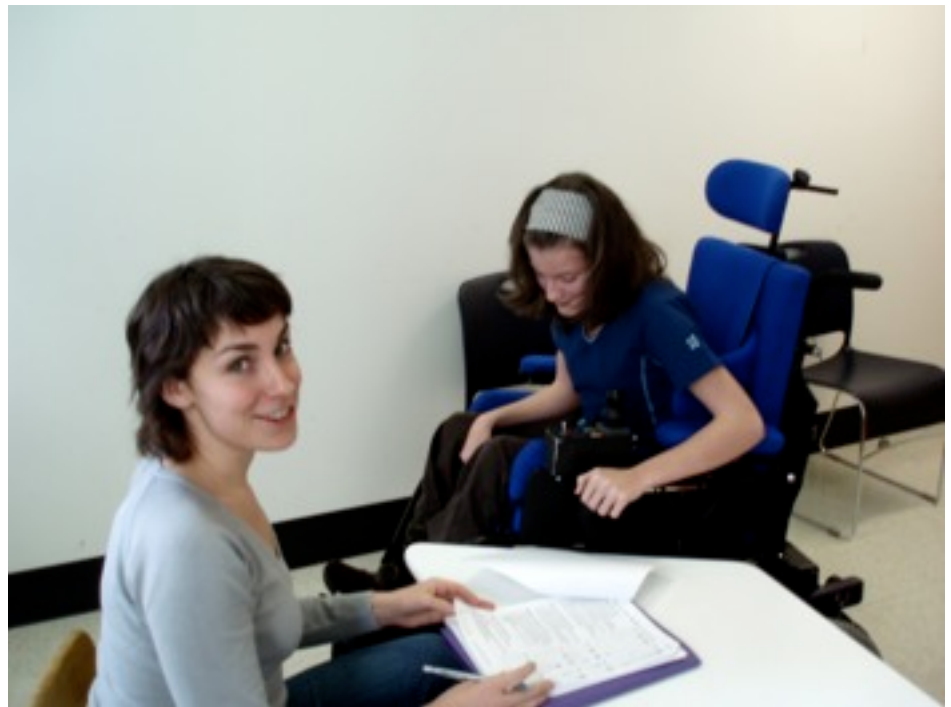
comparing parental coping in two groups of parents (mother or father) caring for a child with a chronic condition: one with 182 children with juvenile idiopathic arthritis (JIA) (mean age  $10.2 \pm 4.4$  years) and the other with 150 children with less medically involved physical disabilities (PD) (mean age  $3.4 \pm 1.3$  years) parents reported using family, social and healthcare related coping behaviours to varying degrees to help manage the demands of caring for their child. Results showed that parents found understanding the medical situation through communication with healthcare professionals and maintaining

social support by seeking out community based resources most helpful in coping with their family situation, respectfully for the JIA cohort and the PD group. Certain characteristics such as the nature of the condition, child's age, and the availability and frequency of the healthcare services received by children may influence parental coping and may account for the differences in preferences observed between diagnostic groups (JIA and physical disabilities). In both groups however, greater functional limitation (i.e. severity of child's dysfunction) was associated with parents seeking out information relating to their child's condition from healthcare professionals, possibly in an attempt to better their child's situation. These results underscore that healthcare professionals have an important role in helping parents cope with the demands of their child's care by providing valuable information about the condition, developmental progress, interventions (home programs, rehabilitation services) and available community social services (support groups, respite care). In the past decade, paediatric rehabilitation professionals, possibly due to the limited resources, have reshaped their approach to intervention by making it more family-centred. Parents are now recognised as key players in their child's treatment. Although parents do play a major role in advocating for their child, healthcare professionals must be aware of the potential stress that these new responsibilities can have on unprepared parents. Healthcare professionals can help ease parents into their new complex role by adopting effective communication techniques and ensuring accurate knowledge transfer to help parents cope with their child's health situation.

- Sabrina Cavallo M.Sc., OT

#### KEY REFERENCES:

Cavallo, S., Feldman, D., Swaine, B., Meshefedjian, G., Malleson, P.N., Duffy, C. (2007). The impact of child's functional severity on parental coping in two cohorts: children with juvenile idiopathic arthritis and children with physical disabilities. Dissertation, University of Montreal,



Montreal, Quebec, Canada.

## EMERGING EVIDENCE

### ...In Progress

**Title:** *Determinants of quality of life and participation in leisure activities in adolescents with cerebral palsy.*

**Description:** This study is describing quality of life and frequency and intensity of involvement in leisure activities at home and in the community in a sample of adolescents (12-18 years of age) with cerebral palsy. As part of this study, factors that are associated with greater life satisfaction and greater involvement and enjoyment of leisure activities are being identified. These factors not only include child attributes and environmental characteristics, but also aspects of family functioning.

**Investigators:** Majnemer, A., Law M., Shevell, M., Rosenbaum P., Poulin C.

**Funding:** CIHR. REPAR

**Recruitment details:** We are interested in recruiting any adolescents with cerebral palsy, so please contact us if interested.

**Contact for recruitment:** Annette.majnemer@mcgill.ca

**Title:** *The economic dynamics of families who care for a child with a disability in Canada.*

**Description:** Because most children with disabilities are cared for in the home, families are the most important source of care and assistance. However caring for a child with a disability often requires extra costs. Of concern is evidence that indicates that these families are bearing more than their fair share of the costs of caring for their children. "The economic dynamics of families who care for a child with a disability in Canada" is an economic study of the cost (consumption and time costs) of caring for a child with a physical disability (cerebral palsy or spina bifida). The study is funded by the Canadian Institutes for Health Research (CIHR). The study's main source of data consists of a telephone survey which will be carried out with 405 families looking after a child with CP and SB in three regions of Canada. In this survey, parents who care for a child with a disability are asked to provide information about their personal costs including consumption of good and services and time cost related to the child's condition. The project is currently recruiting families to participate in the study. Participants are invited to complete the telephone administered survey six times with one month intervals between com-

pletions. Three Canadian sites (135 subjects/site) are participating in this study: Quebec, Ontario, Alberta. "The economic dynamics of families who care for a child with a disability in Canada" aims at identifying the cost to families who care for a child with a disability. Once we have collected this data we will inform policy makers of the extra cost these families have to pay to meet their child's needs. By doing this we hope the governments will create policies that will help compensate for the extra costs to these families.

**Investigators:** Anderson, D., Dumont, S., Tétreault, S., Jacobs, P., Fassbender, K., Azzaria, L., & Fraser, A.

**Funding:** CIHR

**Recruitment Details:** We are currently recruiting families who care for a child with cerebral palsy or spina bifida from Quebec, Ontario and Alberta.

**Contact For Recruitment:**

(613) 952-9504 or  
donna\_anderson@hc-sc.gc.ca

## ...In Press

**Title:** *Determinants of life quality in school-age children with cerebral palsy.*

**Description:** The aim of this study is to characterize the quality of life of children with cerebral palsy. Ninety-five children were recruited and parents completed the Child Health Questionnaire and the Pediatric Quality of Life Inventory. When feasible, children also completed these questionnaires. Children were between 6-12 years of age, and half had mild motor impairment (47% level I GMFCS). Mean scores were below the normative mean. Results demonstrate that about half experience a good life quality, similar to typically developing children, however these children at risk. Motor impairments and other activity limitations are indicators of physical well-being but not psychosocial health. Family functioning (impact on the family, family stress), behavior problems and motivation were significantly associated with psychosocial health. Better understanding of the factors that influence quality of life may guide resource allocation and health promotion initiatives to optimize the health of the child and

family.

**Journal:** Journal of Pediatrics

**Investigators:** Majnemer, A., Shevell, M., Rosenbaum P, Law M, Poulin C.

**Funding:** United Cerebral Palsy Foundation

**Title:** *The personal cost of caring for a child with a disability: A review of the literature.*

**Description:** This article presents a review of the literature published from 1989 to 2005 for articles that examined the economic burden incurred by families as a result of caring for a child with disabilities. The review was performed according to a comprehensive economic conceptual model developed by the authors and to the guidelines set out by Canadian Coordinating Office for Health Technology Assessment. The analysis indicated that the burden incurred by these families can be substantial, especially among families who care for a child with a severe disability. However, the variability and the quality of methods is such that the return

on investment in knowledge of costs in this area is not as high as it could have been had methodological procedures been more standardized. A comprehensive and systematic approach is suggested for future research.

**Journal:** Public Health Reports.

**Investigators:** Anderson, D., Dumont, S., Philips. J., & Azzaria, L.

**Funding:** N/A

## HELPFUL WEBSITE LINKS FOR CAREGIVERS

1. Camp Massawipi:

[www.moncamp.com](http://www.moncamp.com)

2. Camp Papillon:

[www.enfantshandicapes.com](http://www.enfantshandicapes.com)

3. Camp Carawanis

[www.diabetes-children.ca](http://www.diabetes-children.ca)

4. Friendship Circle:

[www.friendshipcircle.ca](http://www.friendshipcircle.ca)

5. Viomax:

[www.viomax.org](http://www.viomax.org)

6. Emergo:

[www.montrealfamilies.ca/special.htm](http://www.montrealfamilies.ca/special.htm)

## PARENTING PERSPECTIVE

### Parenting a disabled or sick child

Myriads of books and articles have addressed parenting challenges, including those of parenting disabled children. Over and over, we come across words like grief, anger, disappointment, frustration, jealousy, burnout, stress, marital tensions, sibling challenges, family dysfunction, guilt, migraines, back pain, resentment and depression. Whether we speak of a developmental handicap that requires long-term therapy and slow improvements or acute and chronic diseases that hit hard and quickly, all disabilities and illnesses change lives and create stress.

When a diagnosis is confirmed, instantly or over time, families begin the grieving process of broken dreams and start rebuilding a new life under new conditions, restrictions

and expectations. We search for every service available, seek medical and professional advice in every corner to offer our child the best chance at health and happiness. The right therapies, the right schools, the right treatments, the right medication, the latest research - it is a dynamic process that never truly ends.

Eventually, we reach a cruising speed, put a plan in place and realize there is no such thing as complete acceptance but rather a way to deal with a new reality. In this world of disabled or sick children, there is usually very little consistency. What we experience are cycles of progression, regression, ups and downs in both the child's condition and the ways the family deals with it.

Ultimately, we all seek a sense of 'normalcy', for our child, their siblings, our partner and ourselves. We are told: "don't forget to take care of yourself, your relationship, your other children" and "don't let your child's condition take over your entire life, let it only be a part of your life" as well as "you are no good to anyone if you are not physically and mentally healthy yourself". While often easier said than done, these statements are nonetheless the truest of all. While the government offers tax deductions, and covers important expenses such as a certain number of babysitting hours, etc, what many families crave is more and longer respite -that is delegating the care of the child in order to reorient our focus towards finding and establishing serenity. Day camps, sleepaway camps, weekend retreats and any other opportunities that will allow a parent to distance him/herself from the day-to-day care and allow for replenishment of physical and emotional resources, are positive experiences. In order to benefit from respite programs, one needs to research them, prepare the child and the family for them and be able to afford them. Many families shy from the opportunity claiming: "my child can't leave me", "it's too much prep work, it's just not worth it", and "I don't trust the other caregivers". Such perceptual barriers hinder the positive development of both the child and his/her family. Respite programs are usually win-win situations - the child is usually thrilled and proud if his/her enhanced independence, and the parents awaken to a life outside the disability and are given a chance to explore life. From my experience, all come back refreshed and recharged.

If finances are a problem, there are financial assistance programs and community-based social workers who can help find the right respite program for you. We need to continue fundraising for such programs, lobby the government to offer longer and less expensive respite service and ask municipal leisure departments to lower staff-participant ratios for better integration. It is clear: a few hours, a few days, a few weeks, any time at all to replenish parenting resources is critical to the child who has a disability and to their family's function and development.

-Nicole Vien, mother of 3, one with physical and learning disability, one with a chronic disease

