STUDY UPDATE
NOVEMBER 2003

We would like to thank you again for participating in the "Caring About Caregivers" Study. The research team has been busy analyzing the information we collected during the study and we have some findings to share with you.

In this newsletter, we will update you about the four main issues the study tried to address:

1. A model which describes the relationships between many different factors that affect caregiver health.

2. A comparison of the health of caregivers in our study to the health of Canadian parents of children without Cerebral Palsy.

3. A description of challenges and facilitators (things which offer assistance) that caregivers in the study identified, along with a list of things caregivers would like health professionals working with their families to be aware of.

4. A description of respite use among caregivers of children with Cerebral Palsy in Ontario.

TESTING OUR IDEAS ABOUT CAREGIVER HEALTH

In both the mailed questionnaire and the interview, we asked you questions about your physical and emotional health, as well as questions about many things that might influence your health.

These questions were all related to a set of factors that previous research has shown might influence caregiver health. Our research team developed a way to try to explain how, when all of these factors are looked at together, they might relate to each other and impact on caregiver health. The factors we included in our model were:

Family Demographic Factors:
- Family Income
- Caregiver's Level of Education
- Caregiver's Occupational Status

Child Characteristics:
- Child's Functional Ability
- Child's Behavior

Caregiving Demands
Caregiver's Perception of Formal Care and Services
Family Functioning
Social Support
Stress Management
Caregiver's Self-Perception

The factors on this list had all been looked at individually in previous research. The model we are proposing is one of the first attempts to look at a group of factors at the same time, to determine which factors are most important to explain differences in caregiver health.

We took all of the information we collected from the study and used a procedure called Structural Equation Modeling (SEM) to see if the information we collected during the study fit with the model we developed.

Overall, there was a good fit between the information we collected in the study and the model we developed. A few of the main findings are outlined below:

- The following factors explain quite a lot of the variation in caregiver **psychological health** (that is how caregivers are different from each other with respect to their psychological health):
  - caregiving demand,
  - caregiver self-perception,
  - family functioning
  - child behavior
  - stress management

- All of the factors included in the model only explained a small amount of the variance in caregivers' **physical health** (that is how caregivers are different from each other with respect to physical health). This means that there must be other factors that weren't included in the model that impact on caregiver physical health.

The model of caregiver health and preliminary results from this study have been presented as a talk at both:
- The American Academy for Cerebral Palsy and Developmental Medicine
- The Department of Clinical Epidemiology and Biostatistics at McMaster University.

COMPARING THE HEALTH OF CAREGIVERS IN OUR STUDY TO THE HEALTH OF CANADIAN PARENTS OF CHILDREN WITHOUT DISABILITIES

In this part of the study, we are comparing information from some of the questions you answered to information from a sample of Canadian parents in two recent national surveys done by Statistics Canada:

- The National Population Health Survey (NPHS)
- The National Longitudinal Survey of Children and Youth (NLSCY)

One of the findings from this comparison is that the caregivers in our study reported lower household incomes than the parents in the national surveys. This finding has been reported in other research done with families who have children with Cerebral Palsy and is believed to be associated with the extra financial requirements of caring for a child with CP.

In general, people with higher educations are more likely to have higher incomes. Caregivers in our sample did not differ very much from parents in the national samples in terms of their education levels but were however, less likely to work full time and less likely to describe working as their main activity.

These findings about income, education and working suggest that caregivers of children with CP are reporting lower household incomes not because they are less educated than parents in the national surveys but rather because their caregiving competes with or sometimes replaces their time spent working.

The information we collected on social support, (that is, support from family and friends) indicates that caregivers of children with CP are more likely to have regular contact with family and friends than the parents in the national samples, which is good news as social support has been indirectly linked to better health outcomes in previous research.

Another area where we did some comparisons was to look at chronic physical conditions in parents. We found that caregivers of children with CP are more likely to report chronic physical conditions (i.e. allergies, asthma, arthritis, back problems, migraines, sinusitis, diabetes, heart disease, cancer, stomach ulcers). We don't know whether having more chronic conditions is a direct result of being a caregiver of a child with CP or, if they are a result of other factors associated with caregiving, such as having a lower income.

It is important to note that these data are correlational which means that they tell us about relations between things but not causes. This means we cannot say that being a caregiver causes more chronic physical conditions, but we can say that caregivers are more likely to have more chronic physical conditions.

CHALLENGES AND PERCEIVED FACILITATORS TO CAREGIVING

Challenges

Just over a third of the caregivers in our sample (34%) provided written comments that identified some of the challenges they encounter as caregivers of a child with CP. A number of different challenges were identified, and these were categorized into the following areas:

- The need for society to be more educated about CP (social stigma, teacher, friends)
- Constantly having to advocate and fight for their child
- Lack of information on resources/services
- Barriers to accessing and maintaining services (paperwork, inconsistent staffing, transportation)
- Lack of flexibility of services
- Lack of coordination of services
- Balancing work and caregiving
- Uncertainly/concern for their child's future
- Balancing time with other children in the family
- Personal health (stress of daily living, exhaustion)
- Financial issues
- Lack of support from others for the caregiver role (by family, friends and professionals)
- Preserving self (making time for self)

Perceived Facilitators

Caregivers made many suggestions about factors that would make their lives easier. These suggestions were categorized into the following Perceived Facilitators:

- Decrease/remove barriers to service (financial, paperwork, accessibility, transportation)
- Provide emotional and psychological support to both caregivers and children
- Provide opportunities for caregivers to connect with each other (peer support)

Things for Health Professionals to be Aware of:

Caregivers identified issues in the following areas that they would like health professionals to keep in mind when working with them and their child:

- Communication (respect, level of language)
- Aspects of child and family health in additional to physical issues
- Approach (focus on child's ability and potential rather than on disability)

The findings from the analysis of these Challenges and Perceived Facilitators have been presented as:

- A workshop at a conference for the Ontario Association of Children's Rehabilitation Services (a workshop for service providers and families)
- A poster at the American Academy for Cerebral Palsy and Developmental Medicine
- A poster at a research day for the Department of Clinical Epidemiology and Biostatistics at McMaster University

DESCRIBING FACTORS RELATED TO FORMAL RESPITE SERVICE USE IN ONTARIO AMONG CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

Based on an analysis of the information caregivers in our study told us about their experiences with respite services, we have prepared a report for the Integrated Services for Children Division of the Ministry of Health and Long Term Care. This report describes the factors related to formal respite service use in Ontario among caregivers of children with CP.

The report describes:

Respite Use

- 60% of caregivers had used formal respite services at some time
- 46% of caregivers had used formal respite services in the past year

Of those who had used respite services in the past year:

- 41% paid out of pocket for services
- 51% accessed more than one source of respite
- 52% had respite services provided in their home
- 52% had respite provided by a trained worker, 44% by a babysitter and 4% by Extend-a-Family
- 57% used respite services for less than a day

The top two reasons for using formal respite services were:

- A planned vacation or break
- Assistance with daily living

Caregivers' Perceptions of Respite Services

- Nearly all (96%) caregivers who used respite services in the past year felt that the services were beneficial for their families
- 46% felt they had adequate services for their family
- 37% reported that respite services were easy to obtain

Common Barriers To Respite Use

4 of the top 5 barriers were related to accessing appropriate respite services and information:

- Respite resources were limited
- Respite services were often difficult to arrange
- The service the family needed was difficult to find
- Caregivers were concerned about the quality of care their child would be receiving
- Information regarding respite services was difficult to find

Factors Associated with Respite Use

The three strongest factors that determined if a caregiver used respite services were:

- The child's gender (caregivers of male children were more likely than caregivers of female children to use respite services)
- The child's level of function (caregivers were more likely to use respite services if their child's level of function was low)
- The number of additional medical conditions the child had (caregivers were more likely to use respite services if their child had additional medical conditions)

NEXT STEPS….

We still have a lot of work to do!

Future steps include:

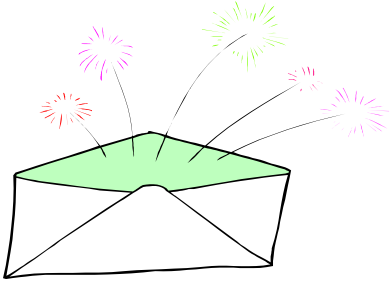
- Continuing analysis of the relationships among factors in the model based on the study findings
- Completing the analysis of the comparison of caregivers in our study to Canadian parents of children without disabilities
- Writing a final report for the research study
- Sharing the findings from the study with a number of different groups of people including:

  -> Other caregivers of children with developmental disabilities (through reports in parent newsletters and magazines)

  -> Health care professionals (through presentations and articles in professional journals)

  -> Policy-makers in the provincial and federal governments

HAVE YOU MOVED?



If you have moved, changed your phone number, or plan to move in the coming months, please contact us as soon as possible.

We'd like to make sure we have your current contact information so that we can continue to send you the findings from the study.

FOLLOW US ON THE WEB!

You can follow new information from the Caregiver Study as well as other research related to childhood developmental disabilities by visiting our website at: www.fhs.mcmaster.ca/canchild/

While visiting the website you can subscribe to the *CanChild* newsletter and receive regular email updates about all of our research.

If you have any questions related to the Caregiver Study please contact the Study Co-ordinator, Marilyn Swinton. You can reach her by phone at: 905-525-9140 ext. 22905 or by email: swinton@mcmaster.ca