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Father Involvement Research Alliance

## Fathers of Children with Special Needs Cluster

### Fathers of Children with Special Needs Cluster Executive Summary Father Involvement Community Research Forum Spring 2006

*Ted McNeil*

#### EXAMINING FATHERS' EXPERIENCES OF CARING FOR A CHILD WITH A CHRONIC HEALTH CONDITION WITHIN THE CONTEXT OF THE COUPLE RELATIONSHIP: EXPLORING THE CO-CONSTRUCTION OF ROLES AND IDENTITIES

This research addresses a continuing gap in the literature by examining the experience of fathers of children with select chronic health conditions (i.e., cerebral palsy, spina bifida and juvenile rheumatoid arthritis) within the context of the couple relationship. Of particular importance is the exploration of the way that fathers and their partner co-construct their identities and roles. This unique perspective will contribute new knowledge relevant for clinical practice, policy and future research.

There has been growing interest in contextual variables within the family that shape a father's role, particularly factors related to the spouse. Efforts to understand fathers, without a simultaneous understanding of the mothers' or partner's role and their relationship together, are inherently limited.

Historically, systems theory has been important for identifying the relevance of family functioning and the relationship between partners. Systems concepts of viewing the family as a unit, understanding the importance of transactional patterns for shaping behaviour, and the phenomena of complementarity/symmetry are particularly germane. Complementing this systemic perspective, a social constructionist approach, with its emphasis on interpretive processes and meaning-making, is useful.

This study uses a grounded theory methodology which has included the following:

- (1) Couple interviews with fathers and mothers/co-parents together
- (2) Individual interviews with select fathers and partners

This study builds on a number of earlier studies that have examined the experiences of mothers and fathers respectively. Examination of couples together marks a significant development in knowledge development.

#### Preliminary Findings and Analysis

Data gathering is underway, and currently 16 interviews with couples and 4 interviews with individuals have been completed.

Earlier research has shown that mothers and fathers are profoundly affected by caring for a child with a chronic health condition. However, examination of individual mothers and fathers in isolation has been unable to provide an understanding of the ways that their experiences are intimately linked. Data analysis of interviews completed to date reveals that fathers' experiences are indeed closely linked to their partner's experiences. For example, in families with a chronically ill child, often one parent must reduce their work outside the home or leave it altogether to care for the child. In most cases, families decide that mothers will leave work and preserve the father's income. This may be experienced as a disappointment by mothers in terms of their career aspirations and puts added pressure on fathers to ensure success as a breadwinner. There appears to be some evidence that in lower paid jobs employers are less flexible in permitting time away from work to attend hospital clinic visits which, in turn, may frustrate a father's attempts to engage more in the care of his child and adds to the care responsibilities that the mother carries. Depending on the way that the couple feels about this arrangement, it may be interpreted as more or less workable and satisfying. A father's efforts to care for the child in the evening and on weekends in order to relieve his partner can leave little time for relaxation and down time. If a child has high needs, it is particularly challenging for the couple to have time together for entertainment together. Mothers appear more likely to seek support from a variety of sources such as friends and other parents whereas fathers may rely more on self support and are often reluctant to 'burden' their partner by sharing the extent of their own stresses which can leave them somewhat isolated. The deep love for their child and the meaningful relationship they have that both parents often express add a deeper dimension to the experience of parenting a child with a chronic health condition.

Interviews have explored a broad range of factors that influence parental choices and experiences, including the influence of culture, religion/spirituality, experiences in family of origin, nature of the child's health condition and the related care needs, parental skills and preferences, work considerations, available social supports, etc.

Generally, we are finding that influences that shape fathers' and their co-parents' experiences fall into five main categories. They involve:

- (i) child factors including the child's health condition,
- (ii) individual characteristics of the parents,
- (iii) developmental processes related to individual growth and changes in the health condition and status,
- (iv) relational factors in the child-parent relationship and couple functioning, and finally
- (v) broader social/structural factors such as work, friends and social support.

The particular way in which these influences come together to shape the couple relationship and experience is the primary object of the study. Fathers' and mothers'/co-parents' experiences are shaped by these various factors and the way that they make sense of them.

Emerging ideas have to do with ways of characterizing how the couple relationships are configured. It is evident that the ways that couples define their roles is complex. Therefore, any model that we develop must reflect this. To date, attributes of an emerging model include the following features:

- (1) Multifactorial and complex
- (2) Developmental i.e., evolving over time
- (3) Co-constructed by fathers and mothers/co-parent with an emphasis on meaning
- (4) Systemic i.e., relational, transactional and reciprocal
- (5) Combines both complementary and symmetrical characteristics (i.e., both shared and unique skills)
- (6) Adaptation is idiosyncratic, relative, practical and reflects “what works” for the couple
- (7) Current state reflects best choices perceived to be available

### Questions for Discussion

1. Are there other ideas that should be considered as we analyze the data and attempt to define a model for understanding couple relationships and experiences?
2. Do you have any suggestions about drawing conclusions from the individual and couple interviews when they are inconsistent i.e., there are many truths and how to decide what to privilege?
3. Given the methodology of this study, what question would you like us to answer that would be helpful in terms of your work or understanding?

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## FATHER INVOLVEMENT RESEARCH ALLIANCE\* CURA

### Immigrant Fathers Cluster

Focus: The challenges faced by immigrant men (Russian and Sudanese) as they parent in Canada including role reversals of parents and children due to children’s rapid acculturation; racism and its impact on immigrant fathering; family and neighbourhood isolation and the impact of un/under-employment on fathering. Based in Calgary with links to Toronto and Montreal, and led by Dr. David Este, University of Calgary.

### Gay Fathers Cluster

Focus: The effects of homophobia on gay fathering; social, legal, and cultural barriers to fathering for gay men; access to services for gay fathers and what can be learned about parenting from men operating outside of traditional gender dynamics. Based in Toronto and led by Rachel Epstein, coordinator LGBT Parenting Network/David Kelly Services, Family Service Association of Toronto (FSAT).

### Separated and Divorced Fathers Cluster

Focus: The salient legal, emotional, and financial issues faced by separated and divorced fathers; the strengths they bring to their family relationships; identification of patterns that sustain and interfere with positive father involvement; identification of needs and evidence based solutions. Based in Vancouver and Vancouver Island, and led by Dr. Edward Kruk, School of Social Work and Family Studies, University of British Columbia.

### New Fathers Cluster

Focus: The support services provided to fathers through the first eighteen months of the child’s life, including pre-natal period; the impact of becoming a dad on the father’s physical and mental health and on the father’s personal development; and examination of the degree of support afforded to fathers by the health care system. Based in London, York Region, and Toronto, and led by Ed Bader, Co-Chair FIRA (Community): Catholic Community Services of York Region.

### Young Fathers Cluster

Focus: The multiple dimensions for young fathers that need support (work, school, housing, relationships); challenging the negative perceptions of young fathers as expressed through social services and the courts; identification of programming needs for young fathers. Based in the Ottawa/Hull Region and led by Dr. Annie Devault, Université du Québec en Outaouais.

### Fathers of Children with Special Needs Cluster

Focus: The challenges of fathering a special needs child and determining the factors that limit or facilitate involvement; improving the practice of “family-centred” care with fathers of children who experience a chronic health condition and/or a physical disability. Based in Toronto and London, and led by Dr. Ted McNeill, Director of Social Work, The Hospital for Sick Children.

### Indigenous Fathers Cluster

Focus: The unique issues affecting Indigenous fathers’ caring for young children (0-6) enrolled in centre-based child care; improving community outreach to Indigenous fathers; creating meaningful roles for Indigenous fathers involved with their children in child care and development programs; and to alter program structures, program materials, and program activities in order to better serve fathers. Based in Victoria, Vancouver and northern British Columbia, and led by Dr. Jessica Ball, University of Victoria.

\* Social Sciences and Humanities Research Council (SSHRC), Community-University Research Alliance Program

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Father Involvement Research Alliance CURA  
Centre for Families, Work and Well-being  
17 University Ave. E.  
University of Guelph  
Guelph, ON  
N1G 2W1

519/824-4120, ext. 53829  
web site: <http://www.fira.uoguelph.ca/home>