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Why Focus on Father-Inclusive Practice?

Focaliser sur la pratique d'inclusion paternelle : Pourquoi?

UN RÉSUMÉ EXÉCUTIF EN FRANÇAIS EST DISPONIBLE À LA FIN DU DOCUMENT

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INTRODUCTION

The contributions of caregiving fathers to their child's development, health and wellbeing are largely unrecognized in clinical settings and in research on parents of children with neurodisabilities. Fathers' invisibility from pediatric health and rehabilitation centres that provide services to families of children with neurodisabilities may obscure their contributions, leaving the impression that they are not interested in their child's health plan or developmental needs. Fathers' invisibility may also reinforce the idea that they do not have information or support needs. As a result, education and information about the child's care needs may be provided to the caregiver who is present at appointments, most typically the child's mother, relegating caregiving fathers to the role of supporter and placing an inordinate amount of responsibility on mothers. This picture is inconsistent with the changing and varied roles of actively involved caregiving fathers. Healthcare, social services and educational services that are mother-focused or mother and child focused can reinforce and even increase women's caregiving responsibilities by assigning the role of gatekeeper to child care needs, health information and supports to family members.

Father-inclusive practice is a way of working with families that recognizes the diversity of family configurations and respects the needs, dynamics and patterns of children, mothers and fathers. It supports the complementary roles of mothers and fathers with an aim to keep fathers included when working with families. Father-inclusive practice is sensitive to the family as a complex social institution within which roles are negotiated, acquired or assigned. It aims to assess barriers to father involvement and works with families to optimize that involvement. Barriers to father involvement include individual, familial, cultural and societal factors. Clinical or research processes and practices that assume fathers' reluctance or disinterest in the care of their child may be a barrier to father involvement.

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WHY IS THIS RESEARCH NEEDED?

Parenting can be challenging under any circumstance. However, parenting a child with additional care and educational needs compounds those challenges, creating extraordinary caregiving demands for mothers and fathers. In these families, caregiving tasks extend well beyond those of families of children without developmental delays due to the time, resource, service and support demands required to care for the child. From a service delivery perspective, this means that clinicians must be aware of the global picture of the family. Research has demonstrated that the behaviours, beliefs and aspirations of fathers can have profound influences on their families, both negative and positive. Keeping fathers in mind and recognizing fathers as potential resources to their child and family can ensure that appropriate supports are provided to all members of the family to optimize the care of the child.

Survey research on the experiences of parents of children with neurodisabilities has primarily focused on the experiences of mothers as they have often been identified as the 'person most knowledgeable' about the child's care needs; or, because they have been easier to access within sites that recruit parents for research (hospitals, rehabilitation centres, schools). Research that has included fathers has

primarily focused on fathers' adaptation to their child's disability, how fathers cope with parenting their child (teasing apart different types of coping styles as better or worse for parent, child or family wellbeing) and the distresses associated to being the father of a child with developmental and behavioral challenges. For example, fathers may experience more stress in relation to their child's externalizing behaviours. They may feel more socially isolated and pessimistic about the future as a result of these behaviours. Conversely, research has revealed that when fathers feel more competent in their parenting, they experience more satisfaction with caregiving and less parenting stress.

A smaller body of research drawn from fathers' narratives about themselves has revealed a number of themes that may help future research and clinical work. Predominantly, caregiving fathers of children with neurodisabilities, when asked, conjure up intense feelings about parenting their child ranging from expressions of pride and joy to great distress and disillusionment. Most often fathers see their role of economic provider as paramount for the family and view their responsibility as one of protector of their child and family. Fathers also stress the importance of the co-parenting relationship and the complementary roles they and their spouse take on within the family unit. Finally, caregiving fathers express feeling invisible within pediatric health and social services establishments and schools.

GENERATING RECOMMENDATIONS FOR FATHER-INCLUSIVE PRACTICE

Taken together, these research findings pointed us to the importance of accessing, understanding and speaking to fathers. We recognize that the best way to support families is to remember the centrality of both the mother and father in their children's lives.

A group of researchers and graduate students from the Parenting Matters! team presented selected research findings at a symposium of the Canadian Network of Children and Youth Rehabilitation (CN-CYR) and the Canadian Family Advisory Network (CFAN) at the 2014 annual meeting of the Canadian Association of Paediatric Health Centres (CAPHC). The participants at this symposium were comprised of health care providers, parents, policy makers, managers/administrators and researchers.

HOW WAS THE DATA COLLECTED?

The participants were introduced to four "myths" relating to parenting children with neurodevelopmental diagnoses, followed by evidence from our work that counters each myth. Finally a discussion question was posed relating to how these findings might be integrated into clinical care. One of the myths presented was: Fathers aren't interested in being involved in their child's care plan. The question posed to the group was: how can we be more inclusive of fathers?

After each of the four presentations, participants were organized in small groups of five or six and asked to develop three priorities related to the discussion question; they were given ten minutes to do so. Each individual participant was then invited to select one of the three priorities that resonated for him or her and to write it down on a small cue card. Participants were then instructed to walk around the room and to switch cards with other participants for a period of thirty seconds. When the facilitator asked them to stop, participants were asked to read the recommendation on the card in their hand with the person in front of them. Together, the two participants were asked to rate each statement on each card on a scale of 1 (low priority) to 7 (high priority) and to write the number on the back of each card. The card exchange exercise was repeated two more times (each for a period of thirty seconds). At the end of the third round, each card had three rankings on it, for a maximum score of 21. The cards were collected at the end of the activity and reviewed by the research team to identify the highest ranked recommendations. These were read to the group. Later, these cards were analyzed thematically to determine the themes that appeared most frequently among the recommendations.

The participants at the workshop generated a total of 83 recommendations about how to be more father-inclusive. From those who indicated their role, 5 were administrators or mangers, 13 were parents or family members, 26 were service providers, 2 were policy makers and 1 identified as a researcher.

Two recommendations received a perfect score of 21. Listed below are the top five scoring recommendations generated by the group of participants. When the recommendations were analyzed thematically, four themes emerged as the most commonly endorsed by participants.

FOUR RECOMMENDATION THEMES

1. Integrate fathers and increase their visibility in clinical practice and research (32 recommendations)

Participants had a number of suggestions about integrating fathers and increasing their visibility in clinical practice and research, in summary:

- When working with families in which only one parent can attend appoints, clinicians should not assume that the caregiver present is speaking for both parents. When both parents are present (such as a mother and father), questions should be directed to both parents. Mothers *and* fathers should individually be asked whether they have noticed changes in the child, whether have concerns about the child, or whether they require information about the child and his care needs.

- When one parent is absent from clinic, clinicians could offer to contact the other parent in order to provide first-hand information and to obtain their input about goals and intervention planning. This would ensure that both parents are provided the same information from the same source and that both parents' understanding, goals/desires for the child are fully explored and considered. In the event that one parent can attend regular appointments, clinicians might try to schedule special appointments where changes to treatment plan, decisions and future plans can be made with all caregivers present. Clinicians can work with both parents to help divide care tasks in order to help fathers develop specific roles.

- The visibility of fathers in research could be improved by specifically targeting both parents as respondents to survey research and specifically inviting fathers to participate in interviews.

Finally, participants expressed that visual images on the websites and promotional/informational materials of pediatric care centres could be improved to increase the visibility of fathers and better represent the diversity of clientele and family configurations.

2. Flexibility in practice (24 recommendations)

Resoundingly participants endorsed the use of technologies to access parents who cannot attend meetings during general 'regular' clinic hours.

- Clinicians may try to use video-calling applications such as Skype and FaceTime to 'attend appointments', the use of teleconference/telehealth and email to share information and discuss care plans. Email and mobile applications could be used to contact fathers and relay information directly and to provide instructions for exercises that could be done with the child.

- Flexible clinic hours (outside of the regular 9:00 – 5:00) would be well-received not only by fathers, but by all working parents. Teaching segments and workshops could be delivered outside of the 'regular work day' in order to maximize access by a majority of caregivers. Alternatives to clinic meetings such as meeting families in their homes when all caregivers are present.

3. Family-focused practice (14 recommendations)

Many participants endorsed that there should be an increased focus on the 'family' and that clinicians must ensure the needs and strengths of the entire family, including fathers, are incorporated into an integrated plan. This meant the creation of an intentional mindset to be inclusive of the 'whole' family, whatever the dynamics based on diversity of families and practice guidelines that ensure information is gathered from all those involved in a child's life, not just those who fill in the forms or attend clinics. At an organizational level, they suggested that clinicians receive training to change the language they use in face-to-face encounters and on paper to include 'parent' or 'caregiver' rather than 'mother/father'

4. Peer-to-peer support (4 recommendations)

Participants suggested that clinicians should think of creative ways to engage fathers in peer support. Suggestions included: (1) build a peer support network for fathers in a comfortable venue (group discussion)/hockey game, help to normalize feelings; (2) find things that are anchored in 'doing' not 'talking' and (3) survey fathers' needs and concerns, hire a father to organize a meaningful activity where these themes could be discussed.

TOP FIVE RECOMMENDATIONS FOR FATHER-INCLUSIVE PRACTICE

1. Allow working fathers the opportunity to participate in appointments and treatment sessions by using technology or offering appointment sessions that allow both parents to attend (for example, evenings and weekends) (Score: 21)

2. Father-to-father support groups with facilitation at convenient times (evenings and not on hockey nights) over pizza & beer/cola to look at dads long term (Score: 21)

3. As a parent, I recommend the creation of an inclusive environment for fathers (ie: extended clinic hours, inclusive language, inclusive behaviours). Create these environments with dads, and not just for dads. (Score: 20)

4. Offer flexibility in the hours clinics are held and when other services are offered and state: "fathers welcome". (Score: 20)

5. Ask parents/caregivers how they would like to be accommodated (for example, would both parents like to attend clinic?) and then offer scheduling (evenings/weekends) that is accommodating. (Score: 20)

WHAT CAN BE DONE WITH THESE RECOMMENDATIONS?

The clinical recommendations generated from this activity can be taken up by healthcare settings at both a systemic and an individual level to enhance the services provided to families of children with neurodevelopmental diagnoses. Our hope is that these ideas might spark discussion in your team about how recommendations such as these might be taken up. Perhaps you might take one or more of the recommendations and consider how they might be helpful to you in your particular context with your particular clientele. We look forward to hearing about how you have incorporated, expanded, and promoted these important practical recommendations.

ABOUT PARENTING MATTERS!

Parenting Matters! is a project to explore the biopsychosocial context of parenting children with neurodevelopmental disorders (NDD) in Canada. The aim of this project is to better understand the extent to which parenting children with NDD differs from parenting in general, what makes a difference to parenting, the difference that parenting makes to child outcomes, and whether there are ways of understanding parenting that is unique to this population. This project consists of four multi-method studies:

1. A systematic review of quantitative and qualitative research to understand parenting behavior, cognition and style as well as social, family and child correlates of parenting;
2. Secondary data analyses of the Canadian population-based National Longitudinal Survey of Children and Youth (NLSCY) to quantitatively compare parenting children with NDD to parenting typically developing children;
3. A clinical study to examine predictors and experiences of parenting children with NDD;
4. A review of the legislation and a survey of existing policies and programs to document those services available to Canadian parents of children with NDD in the areas of income support, respite/alternative care and case management.

The Research Team is comprised of Peter Rosenbaum (nominated principal investigator); L. Lach and D. Kohen (co-principal investigators); R. Birnbaum, J. Brehaut, R. Garner, M. McKenzie, T. McNeill, A. Niccols, D. Nicholas & M. Saini (co-investigators); S. Bailey, A. Bogossian, G.Glidden, R.MacCulloch, & A. Ritzema (doctoral research assistants), as well as additional graduate research assistants.

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(Below) From left to right: Aline Bogossian, Sacha Bailey, Lucyna Lach, Gina Glidden and Radha MacCulloch

RÉSUMÉ EXÉCUTIF

L'apport des soins prodigués par les pères pour le développement, la santé et le bien-être de leurs enfants sont largement méconnus des milieux cliniques et de la recherche sur les parents d'enfants souffrant de handicap neurologique. La pratique d'inclusion paternelle constitue une approche de travail auprès des familles qui reconnaît la diversité des compositions familiales et respecte les besoins, la dynamique et les schémas familiaux d'enfants, de pères et de mères. Elle appuie la complémentarité des rôles paternels et maternels afin d'inclure les pères en contexte de travail auprès des familles.

Recommandations pour la pratique d'inclusion paternelle

Un groupe de chercheurs et d'étudiants diplômés de l'équipe Parenting Matters! a présenté certaines conclusions de recherche lors d'un symposium du Réseau canadien de réadaptation enfance-jeunesse (CN-CYR) et du Canadian Family Advisory Network (CFAN) au cours de l'assemblée générale en 2014 de l'Association canadienne des centres de santé pédiatrique (CAPHC). Les participants à ce symposium englobaient des intervenants en soins de santé, des parents, des décideurs politiques, des gestionnaires-administrateurs et des chercheurs.

Collecte de données

Les quatre « mythes » relatifs aux parents d'enfants souffrant de troubles de neurodéveloppement ont été présentés aux participants, de même que des conclusions inverses tirées de notre travail. Enfin, une question à débattre a été posée, sur la façon d'intégrer ces constats dans les soins cliniques. Ce feuillet informatif fait référence à l'un des mythes présentés: *Les pères ne souhaitent pas s'impliquer dans le plan de traitement de leur enfant*. La question posée au groupe était la suivante: *Comment pouvons-nous favoriser l'inclusion paternelle?*

Les participants à l'atelier ont formulé au total 83 recommandations pour promouvoir l'inclusion paternelle.

Trois thématiques de recommandations

1. Intégrer les pères et accroître leur visibilité en pratique clinique et en recherche
   - Augmenter la souplesse de la pratique par l'intégration technologie, l'élargissement ou l'offre d'un horaire clinique flexible, la création d'alternatives de réunions cliniques
2. Développer la pratique orientée sur la famille
   - Reconnaître les besoins et les forces de la famille entière, notamment les pères
   - Reconnaître la diversité familiale afin de s'assurer du recueil de l'information auprès de toutes les personnes impliquées dans la vie d'un enfant
   - Utiliser un langage facilement compréhensible par les familles, dont les termes « parent » ou « soignant » plutôt que « mère/père »
3. Créer un soutien entre pairs
   - Développer des façons créatives favorisant l'engagement des pères dans le soutien entre pairs, par exemple :
     a. Réseau de soutien pour les pères dans un endroit convivial (discussion de groupe, match de hockey)
     b. Projets axés davantage sur l'action que la conversation
     c. Sondages sur les besoins et préoccupations des pères, engagement d'un père pour organiser une activité intéressante où ces thèmes seront discutés

Cinq recommandations principales pour la pratique d'inclusion paternelle

1. Permettre aux pères qui travaillent de participer aux rendez-vous et aux séances de traitement par le recours à la technologie ou l'offre de rendez-vous permettant aux deux parents d'y assister (par exemple, les soirs et fins de semaine)
2. Développer des groupes de soutien entre pères qui se tiendront à des moments opportuns (soirs) en vue d'une implication paternelle de long terme
3. Créer un environnement inclusif pour les pères (par exemple, un horaire clinique élargi, un langage inclusif, des comportements inclusifs), et créer cet environnement avec et pour les pères.
4. Offrir une flexibilité d'horaires lors des séances et lors de l'offre d'autres services et bien indiquer « Bienvenue aux pères ».
5. Demander aux parents et aux soignants quelle adaptation leur conviendrait (par exemple, les deux parents assisteront-ils à la séance?), puis offrir le rendez-vous (soirs et fins de semaine) adéquat.

Comment aller plus loin avec ces recommandations?

Les recommandations cliniques issues de cette activité peuvent être portées par les établissements de santé aux échelons supérieurs administratifs et individuels afin de promouvoir les services prodigués aux familles d'enfants diagnostiqués de troubles en neurodéveloppement.

À propos de Parenting Matters!

Parenting Matters! est un projet qui examine le contexte biopsychosocial des parents d'enfants souffrant de troubles de neurodéveloppement au Canada. Ce projet vise une meilleure compréhension de la différence entre les parents souffrant de troubles de neurodéveloppement et les autres parents en général, ce qui les différencie en tant que parents, l'incidence sur l'enfant et les possibilités de comprendre les caractéristiques uniques à cette population.

L'équipe de recherche est composée de Peter Rosenbaum (nommé chercheur principal) ; L. Lach et D. Kohen (cochercheurs principaux); R. Birnbaum, J. Brehaut, R. Garner, M. McKenzie, T. McNeill, A. Niccols, D. Nicholas & M. Saini (cochercheurs); S. Bailey, A. Bogossian, G. Glidden, R. MacCulloch & A. Ritzema (auxiliaires de recherche et doctorants), et plusieurs autres auxiliaires de recherche diplômés.

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ON THE RADAR is a dissemination initiative from the Centre for Research on Children and Families that promotes its members' research work.

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