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CENTRE FOR RESEARCH ON CHILDREN AND FAMILIES
CENTRE DE RECHERCHE SUR L'ENFANCE ET LA FAMILLE

WHY FOCUS ON SUPPORTS AND SERVICES INSTEAD OF ONLY CHILD FUNCTION?

Focaliser sur les services et le soutien plutôt que sur le fonctionnement de l'enfant: Pourquoi?

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

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BACKGROUND

Little is known about the factors affecting the well-being of children with neurodevelopmental disorders (NDD). Both child function and supports and services have been found to impact the well-being of parents of children with NDD. The majority of studies examining well-being in children have investigated conditions of a more physical or medical nature, or high-functioning forms of NDD. Using data from a large multi-site Canadian study of parents of children with NDD, the current project assessed whether the adequacy of supports and services as well as child level of function were predictive of child well-being. This outcome would be in line with International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY) guidelines that stipulate the importance of providing adequate supports in order to bridge the gap between children's functional limitations and their ability to participate in activities that are meaningful to them.

WHY IS THIS RESEARCH NEEDED?

Publicly funded institutions across Canada face increasing fiscal pressures and benefits evaluation plays an important role in deciding which programs receive funding. Benefits evaluation schemes tend to evaluate programs in isolation. That is, they assume there is a simple causal link between a service and one or several measurable outcomes. However, there is reason to believe that evaluating programs in isolation will not always reveal their effect when combined with other programs. If we focus on a specific service and the impact of that particular service on a defined outcome, we may be inclined to conclude that the service is unimportant if the observed outcome is smaller than desired. Similarly, a narrow view of program efficacy might lead to the belief that a specific service can only be expected to effect change on a single designated outcome.

The results of the current study indicate that when parents perceive that they are supported in general across areas of both child and family need, they have a more positive view of their children's well-being. This implies that many support programs may produce greater benefits to a child's overall well-being as part of a package of programs than they would individually. Measuring any one program individually, in the absence of broader supports and services, may therefore fail to reveal its potential.

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GENERATING RECOMMENDATIONS FOR SUPPORTING FAMILIES

A group of researchers and students from the Parenting Matters! team presented selected findings from our work 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 included health care providers, parents, policy makers, managers/administrators and researchers.

HOW WAS THE DATA COLLECTED?

Four "myths" related to parenting children with neurodevelopmental diagnoses were introduced, followed by evidence from our work that counters the myth, and finally a discussion question was posed relating to how these findings might be integrated into clinical care. One of the myths presented was that services should focus exclusively on improving child function and nothing else. The question posed to the group was: What are the implications of these findings for policy and practice?

In small groups of five or six, participants were asked to develop three priorities related to the discussion question; they were given ten minutes to do so. Each participant was then invited to select one of the three priorities that resonated for him or her and write it down on a small cue card. Participants were then given thirty seconds to walk around the room and switch cards with each participant they saw. When the facilitator told them to stop, participants were to read the recommendation on the card in their hand to the person in front of them. Together, the two participants were 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 was repeated twice more so that at the end of the activity, each recommendation 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 and then analyzed thematically to determine the themes that appeared most frequently among the recommendations.

A total of 90 recommendations were collected for this activity from the participants at the workshop. From those who indicated their role, 11 were administrators or mangers, 18 were parents or family members, 22 were service providers, and 1 was a student researcher.

Four recommendations received perfect scores from participants (i.e., three scores of 7 out of 7 for a total rank of 21). When the recommendations were analyzed thematically, three themes emerged as the most endorsed by participants.

THREE RECOMMENDATION THEMES

1. **Continuity of care (29 recommendations)**

Participants indicated that there was a need for services to be integrated, not only across time and space, but also across disciplines. Therefore, continuity of care encompassed notions of coordination, integration, and longitudinal following. A smaller number of participants expanded upon this need for continuity of care, suggesting a greater role for service coordinators to help parents navigate the many systems of care. Similarly, some respondents indicated that part of providing continuity of care involves less rigid thinking about the locations in which support is provided, suggesting that services should be available wherever families need them.

2. Ask parents for their input (24 recommendations)

Asking parents what is important to them was the second most highly endorsed theme to emerge. In general, respondents who wrote about the need to ask parents did so in relation to gaining parent and family input on individual needs, priorities, and goals. Some attendees recommended that tools be used to help families identify their priorities and track progress toward individual goals.

3. Parent mental health (19 recommendations)

The recommendations indicated the importance of promoting the mental health of parents as part of support provided to children. For instance, it was suggested that service agencies must be aware of parent well-being and should build in both formal and informal parent support as part of service delivery for children. In a similar vein, some participants indicated that parents must be informed about the resources available to them, and these supports should be provided on an on-going basis whenever families need them, and not only at times of crisis.

TOP FOUR RECOMMENDATIONS FOR SUPPORTING FAMILIES

1. As a parent I think supports for parents' mental health/well-being need to be made known to parents and made available.
2. As a parent, mental health services and system integrated with rehab services in community and school. Holistic approach to my child and family.
3. As a parent I want to have the child followed by services, so that at school, home, hospital there is continuity of care for the child. Feeling that your child is accepted "as is" not to be "fixed."
4. Include/invite parents to discuss and identify what they perceive their needs are when contemplating/designing services.

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 on 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.

Funding for this project comes from the Canadian Institutes of Health Research.

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

RÉSUMÉ EXÉCUTIF

L'incidence de la complexité du handicap de l'enfant, des services et du soutien sur le bien-être des parents et des enfants souffrant de handicap neurologique est méconnue. La recherche s'est principalement orientée sur l'aspect physique et médical du handicap neurologique de l'enfant; l'*adéquation* des services et du soutien *ainsi que* le niveau de fonctionnement de l'enfant, éléments prédictifs du bien-être des parents et de l'enfant, n'ont suscité que peu d'intérêt. Les nouvelles recherches soulignent l'importance de réexaminer l'adéquation des services et du soutien afin de combler l'écart entre les limitations fonctionnelles de l'enfant et sa capacité à participer à des activités qui lui sont pertinentes.

Les résultats de la présente étude indiquent que lorsque les parents perçoivent le soutien global en matière de besoins de l'enfant et de la famille, leur vision du bien-être de leur enfant est davantage positive. Par conséquent, plusieurs programmes de soutien produiraient des bénéfices accrus sur le bien-être général de l'enfant s'ils constituent un volet d'une gamme de programmes, que ceux dont ils se prévalent individuellement.

Recommandations pour le soutien à la famille

Un groupe de chercheurs et d'étudiants du groupe Parenting Matters! a présenté certaines conclusions de leurs travaux lors d'un symposium du Réseau canadien de réadaptation enfance-jeunesse (CN-CYR) et du Canadian Family Advisory Network (CFAN) [Réseau consultatif de la famille canadienne (RCFC)] 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 services devraient cibler exclusivement l'amélioration du fonctionnement de l'enfant et rien d'autre*. La question posée au groupe était la suivante : *quelles sont les répercussions de ces conclusions sur la pratique et la politique*?

Les participants à cet atelier ont formulé au total 90 recommandations issues de l'activité.

Trois thématiques de recommandations

1. Continuité des soins
    - Les services doivent être intégrés, dans l'espace et dans le temps, mais aussi de façon interdisciplinaire.
2. Demande de rétroaction parentale
    - Il faut obtenir la rétroaction familiale sur les besoins individuels, les priorités, les objectifs, et utiliser les outils afin d'aider les familles à identifier leurs priorités et suivre les progrès accomplis vers les objectifs individuels.
3. Promotion de la santé mentale parentale comme partie intégrante du soutien à l'enfant
    - Conscientisation au bien-être parental et mise en place de soutien parental tant formel qu'informel comme partie intégrante de l'offre de services à l'enfant.

Quatre recommandations principales pour le soutien familial

1. Le soutien à la santé mentale parentale et au bien-être, ainsi que sa disponibilité, doit être connu des parents.
2. Les services de santé mentale doivent être intégrés aux services de réhabilitation en milieu communautaire et scolaire.
3. La continuité des soins réfère à la coordination entre l'école, la maison et l'hôpital, aux fins de continuité des soins à l'enfant.
4. L'inclusion et l'invitation des parents à la discussion et à l'identification de leurs besoins seront nécessaires au moment d'envisager et d'élaborer les services.

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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