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RECOMMENDATIONS FOR INTEGRATING EVIDENCE INTO FUNDING DECISIONS

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

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BACKGROUND

Supports and programs for parents of children with NDD are funded differently across Canada based, in part, on varying provincial funding schemes (e.g., ongoing historical approaches, population and needs-based approaches). *Outputs* that enumerate and describe the number of children who receive services and the types of services delivered are typically collected by individual organizations but a regulated system for tracking this information does not exist within or across provinces. Thus, while valuable information is gathered internally, it is often diluted as it makes its way up the various levels of policy, from internal, to regional, to ministry. Additionally, evaluating the impact of supports and programs on parents and their children is challenging for organizations, therefore little information is available regarding which supports and programs are experienced as helpful or not. So how, exactly, are decisions made regarding which supports and programs to finance, and how much to fund?



WHY IS THIS RESEARCH NEEDED?

A vast amount of research has demonstrated a link between the acquisition of support and positive health outcomes for parents of children with NDD. Parents who perceive the support they receive as beneficial and useful experience lower symptoms of anxiety, stress and depression than do other parents, and they also report better quality of life. Currently, in Canada, there is no national disability law that sets the conditions and criteria for universal supports and programs for children with NDD and their families. Unlike health care, which is regulated by the *Canada Health Act*, the regulation of supports and programs in Canada falls within provincial jurisdictions, leading to a wide variation in the policies and guidelines that ultimately determine subsidized supports and programs. In addition, while many supports and programs are based on a non-categorical approach to service delivery that focuses on children's functional needs rather than their diagnosis, funding is sometimes allocated to diagnosis-specific supports and programs, resulting in some parents and their children receiving support while others do not, even if the function needs were similar. The provision of equitable supports and programs to all parents and their children with NDD in Canada is thus greatly influenced by varying funding schemes, resulting in considerable diversity in their availability and access depending on where people live. But how are final funding decisions made? While funding decisions for programs are sometimes evidence-based, there is always room for capturing and integrating more evidence.

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DATA COLLECTION

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. The participants at this symposium included health care providers, parents, policy makers, managers/administrators and researchers. 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.

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. One of the four myths presented was that decisions related to the funding of programs for children with neurodevelopmental disorder are based primarily on all available evidence. The question posed to the group was: If there was one piece of information that policy makers should have, what would it be?

A total of 81 recommendations were put forward by participants. Of those who indicated their role, 8 were clinicians, 2 were managers, and 8 were parents.



THREE RECOMMENDED THEMES

1. *Capturing outcomes (43 recommendations)*

The most prominent theme was that of the importance of capturing outcomes. Participants emphasized the importance of collecting meaningful data on parent and youth quality of life and participation. Respondents highlighted the importance of obtaining parent, family and staff perspectives, of collecting personal narratives that provide nuanced insights into service impact and of measuring outcomes that are based on individualized goals (e.g., something like GAS I suppose). Participants were cognizant that significant resources and infrastructure would be needed to capture outcomes but that outcome data should be carried forward to inform policy decisions nonetheless (EBP).

2. *Input at the point of policy development (10 recommendations)*

The second most prominent theme was that of ensuring input from and representation of families at the point of policy development. Participants noted that that policy development concerning families of children with NDD should be derived from direct consultations with families, taking into account families’ real lived experiences and needs. Additionally, the sense that the complexity of policy development warranted “... asking the right people...” and learning from previous policies was highlighted, where an important component was to always keep the “... end-users’...” in mind.

3. Tracking access and diagnosis (5 recommendations)

The third theme called for a better method of tracking the take-up of services that includes diagnostic and functional characteristics of the youth (5 suggestions). Respondents expressed that the development of a centralized Canadian database to track service access information would ensure consistency across organizations and provinces. They pointed to the necessity of tracking data on families that received services as well as on those that did not, in addition to tracking specific services being offered, "...per diagnosis will enable policy makers to better match 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 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.



FOUR TOP RECOMMENDATIONS FOR FURTHER INTEGRATING EVIDENCE INTO FUNDING DECISIONS

Four recommendations received perfect scores of 7 out of 7 for a total rank of 21 from participants.

1. "As a parent I feel that parent and family-centered care (PFCC) needs to be taken to a national level and patients on all committees"
2. "Evaluations should focus on service value, effectiveness and satisfaction through the eyes of the customer (the family) as opposed to how many seen/outputs"
3. "Parent at the policy making table (their perspective acknowledged and included)"
4. "Outcomes of previous policy decisions (unintended consequences) and where previous policy has had positive effect"



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



RÉSUMÉ EXÉCUTIF

Rétrospective

Le financement des programmes et des mesures de soutien destinés aux parents d'enfants souffrant de troubles en neurodéveloppement (TND) diffère à travers le Canada, en partie, selon divers régimes de financement provinciaux (par ex. : les approches historiques régulières, les approches fondées sur la population et sur les besoins). Les organismes respectifs collectent généralement les *conclusions* qui énumèrent et décrivent le nombre d'enfants ayant bénéficié des services et les catégories de services offerts; toutefois, un système réglementé de suivi de ces données n'existe pas dans les provinces. Cependant, en dépit de la pertinence des renseignements recueillis à l'interne, l'information est souvent diluée lors de son cheminement à travers des différents niveaux de politiques, internes, régionales et ministérielles. En outre, l'évaluation des retombées des programmes et des mesures de soutien sur les parents et leurs enfants constitue un défi pour les organismes; aussi, peu de données sont disponibles pour déterminer leur utilité ou non. Alors comment, précisément, sont prises les décisions relatives au choix de financement des programmes et des mesures de soutien et aux montants à financer?

Qu'est-ce qui justifie cette recherche?

D'amples recherches ont prouvé le lien entre l'obtention de soutien et des résultats positifs en matière de santé pour les parents et les enfants souffrant de TND. Les parents dont la perception du soutien reçu est avantageuse et utile éprouvent moins de symptômes d'anxiété, de stress et de dépression que les autres parents. Actuellement, au Canada, les programmes relèvent des juridictions provinciales, ce qui engendre une variation étendue des politiques et des directives qui déterminent, au final, les programmes et les mesures de soutien subventionnés. De plus, tandis que certains programmes et mesures de soutien focalisent sur les besoins fonctionnels des enfants plutôt que leur diagnostic, le financement est parfois alloué à des programmes et mesures de soutien spécifiquement dirigés vers le diagnostic; par conséquent, certains parents et enfants reçoivent de l'appui, mais pas d'autres, même si leurs besoins fonctionnels s'équivalaient. L'offre de programmes et de mesures de soutien équitables est ainsi largement influencée par des régimes de financement variables, causant une diversité considérable en matière d'accessibilité et de disponibilité selon le lieu de résidence. Bien que les décisions de financement de programmes se fondent parfois sur les preuves, il est toujours possible d'analyser et d'intégrer davantage de preuves.

Collecte de données

Un groupe de chercheurs et d'étudiants de l'équipe Parents vous comptez! a présenté certaines conclusions de travaux lors de l'assemblée générale 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. 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. L'un des mythes présentés était le suivant : les décisions relatives au financement de programmes destinés aux enfants souffrant de troubles en neurodéveloppement se fondent essentiellement sur l'ensemble des preuves disponibles. La question posée au groupe était la suivante : quel est l'élément d'information dont les décideurs politiques devraient disposer?

Les participants ont pris part à un exercice de concertation dans lequel des recommandations cliniques étaient formulées et notées sur une échelle de priorité de 7 points, de basse (1) à élevée (7). La revue des recommandations a déterminé le plus haut classement et permis d'analyser les thématiques revenant le plus fréquemment dans ces recommandations. Les participants ont principalement retenu trois thèmes :

1. *Analyse des conclusions* (43 recommandations)

Importance d'analyser les résultats et les données pertinentes sur la qualité de vie et la participation des parents et des jeunes selon leurs perspectives personnelles.

2. *Apport de la politique de développement* (10 recommandations)

Assurance que la politique de développement afférente aux familles d'enfants souffrant de TND découle des consultations directes avec les familles, tenant compte de leurs expériences réelles de vie et de leurs besoins.

3. *Suivi de l'accès et du diagnostic* (5 recommandations)

Développement d'une base de données canadienne centralisée aux fins de suivi du service d'accès à l'information (les familles bénéficiant ou non de ces services), par diagnostic, afin d'assurer l'uniformité parmi les organismes et les provinces.

Quatre recommandations principales ont reçu des notations parfaites de 7 sur 7 sur un classement total de 21 des participants.

- « Comme parent, j'ai senti que les soins axés sur les parents et la famille doivent être abordés à l'échelle nationale et que les patients doivent siéger à tous les comités ».
- « Les évaluations doivent focaliser sur la valeur du service, l'efficacité et la satisfaction, évalués par le client (la famille) et non par le nombre de résultats observés. »
- « Les parents à la table de décision politique (reconnaissance et inclusion de leur perspective) »
- « Conclusions des décisions politiques précédentes (conséquences non intentionnelles) et éléments qui ont bénéficié de l'incidence positive de la politique précédente »

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.

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