

## Before and After Conception . . . Engaging Parents of Today and Parents of Tomorrow

Keli Anderson<sup>1</sup>, Stanley Kutcher MD, FRCPC<sup>2</sup>, Caroline Connell<sup>3</sup>

### Abstract

**Objective:** This paper describes a unique relationship and engagement of a leading NGO Family Organization (The FORCE); a highly respected and extensively distributed magazine directed towards parents (*Today's Parent*) and an academic institution (The Sun Life Financial Chair in Adolescent Mental Health: Dalhousie University and the IWK Health Center in a project that was able to take the national pulse of parent perspectives on child and youth mental health. **Method:** A survey was co-created by parents, academia and media and went live in June 2009 on the *Today's Parent* website. Such a survey had not been done before.

**Results:** The national survey resulted in a response from almost 4,500 parents. Some of the preliminary findings included: parents do think about mental health concerns of children, including parents of children who don't have any problems and it is often media coverage often prompts parents to think about these issues. One quarter of the respondents were not aware of mental health programs and services for children and youth in their community. Many families waited for more than a year to obtain services. The respondents believed that schools should become more active in addressing mental health needs for children and youth.

**Conclusion:** Partnerships involving parent organizations, media and academia have the potential to collaboratively develop processes and methods that can provide a unique window on how to understand various aspects of child and youth mental health. Such partnerships should be considered for future research and information gathering activities.

**Key words:** *early intervention, parenting, partnerships, engagement*

### Résumé

**Objectif:** Décrire les liens particuliers établis entre une ONG axée sur l'organisation de la famille (FORCE), un magazine respectable à grande diffusion qui est destiné aux parents (*Today's Parent*), une université (Université Dalhousie - chaire *Financière Sun life sur la santé mentale des adolescents*) et le Centre de soins IWK dans un projet capable de prendre le pouls, à l'échelle nationale, de l'opinion des parents sur la santé mentale des enfants et des adolescents. **Méthodologie:** Affichage d'un sondage en juin 2009 sur le site web de *Today's Parent*. Créé en partenariat avec les parents, les universités et les médias, ce sondage est le premier de ce type. **Résultats:** Environ 4,500 parents ont répondu à ce sondage. Parmi les premières conclusions, les parents se préoccupent de la santé mentale des enfants, même si leurs propres enfants n'ont pas de problème de santé; ce sont les médias qui les amènent à se préoccuper de ces questions. Un quart des personnes sondés ne connaissait ni les programmes ni les services de santé mentale offerts aux enfants et adolescents de leur communauté. De nombreuses familles attendaient des services depuis plus d'un an. Les personnes qui ont répondu estimaient que les écoles devaient intervenir plus activement dans la manière dont elles répondent aux besoins des enfants et des adolescents. **Conclusion:** Les partenariats entre les organisations de parents, les médias et les universités peuvent mettre en place des processus et des méthodes qui expliqueront, de façon unique, les divers aspects de la santé mentale des enfants et des adolescents. Ces partenariats devront faire l'objet de projets de recherche, et leurs conclusions être compilées.

**Mots clés:** *intervention précoce, rôle des parents, partenariats, engagement*

<sup>1</sup> Executive Director and Founder of The F.O.R.C.E. Society for Kids' Mental Health, Vancouver, British Columbia, and Founding Director of National Institute of Families for Child & Youth Mental Health

<sup>2</sup> Sun Life Financial Chair for Adolescent Mental Health at IWK Health Center and Dalhousie University, Halifax, Nova Scotia

<sup>3</sup> Editor, *Today's Parent*, Toronto, Ontario

Corresponding Email: [kcadja@telus.net](mailto:kcadja@telus.net)

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## Introduction

Although the high prevalence, early age of onset of mental disorders and poor access to mental health care for children and youth has been well documented, (Kessler, Berglund, Demler, Jin, Merikangas & Walters, 2005, Waddell, McEwan, Shepherd, et al., 2005; Standing Senate Committee on Social Affairs, Science and Technology, 2004, Davidson & Manion, 1992), there have been few published studies that incorporate parents' views with respect to children's mental health. Effectively addressing child and youth mental health is built on many pillars. Ensuring that child and youth mental health policies are in place to guide programs and that these policies and programs are based on core values and best available scientific evidence is essential. However, it is also important that the input of children, youth and parents is used to help develop policies, programs and research priorities. This is a realization that is increasingly being applied today, in Canada and elsewhere. In some cases, this application occurs in the context of formal partnerships involving non-government organizations; policy makers; providers, academics; etc., in other cases it may consist of various options and opportunities for ad hoc participation in the development of policies, programs, research and evaluation. There are many different methods by which the input and engagement of children, youth and parents can be made and many different points of entry for engaging children, youth and parents.

Prevention and the earliest intervention is the most important entry point and needs to start with youth who may not even be considering that one day they may be parents; with young people who have decided to be parents; and with parents that already have children. As a leading family organization in British Columbia, the FORCE has heard from most parents whose children have mental health challenges that they knew something wasn't right. They also state that they wish they had known more, had thought more about their child being mentally well as much as physically well and that when they did seek professional advice, that they had been taken seriously. Parent's report that others' perspectives about their child's behaviours are generally negative. Indeed, the FORCE estimates that less than a quarter of parents report that their child's behaviour is understood by others. This suggests that long ago outmoded 'explanations' of mental disorders based on "mother blaming" or personal weakness may still be predominant in the public domain. Although there is evidence that now exists with respect to stigmatization related to mental disorders of adults, there is very little on the stigmatization of child disorders and the blaming of parents as the cause of these problems (Hinshaw, 2005).

Large scale epidemiologic studies addressing this issue -need to be done and effective and relevant education campaigns developed to change attitudes and behaviours.

Many parents have shared with the FORCE that opportunities to connect are sometimes rare for parents of children with mental

health challenges due to what they feel is misunderstanding and attitudes of others. In spite of this, or because of this, parents often look for acceptance or opportunity to engage with others. This was the case in New York City. A parent in need of respite went to New York City with some friends and struck up a conversation with someone in the line-up at a popular coffee shop. The conversation uncovered that they had something in common . . . parenting. One a parent of a child with mental health challenges, the other a deputy editor of a major parent magazine. This report describes what happened as a result of that conversation and the new partnership framework that resulted.

### **The Situation, Serendipity and the Project Partnership:**

The F.O.R.C.E. Society for Kids' Mental Health was founded in 2000 in British Columbia by 2 moms; one that had lost her son to suicide; and another who was determined to not have the same fate befall her son. The FORCE is a provincial organization offering support, resources, education and advocacy to parents, by parents. In 2000 the FORCE lobbied in British Columbia to have a child and youth mental health plan and saw Canada's first plan developed and funded. In its ten years of operation, the FORCE has grown from 2 parents to 18 and has connected to thousands of parents. It is the leading Parent organization specifically for child and youth mental health in Canada. The FORCE is also leading the development of the new National Institute of Families for Child & Youth Mental Health.

The Sun Life Financial Chair in Adolescent Mental Health is a recently established endowed chair located at IWK Health Center and Dalhousie University in Halifax, Nova Scotia. Its work is primarily in the field of knowledge translation of best available scientific information pertaining to youth mental health into formats that are useful for youth, parents, policy makers, professionals, service providers and the public for the purpose of improving mental health and enhancing the address of mental disorders in young people. It works collaboratively with many individuals, organizations, institutions, agencies and governments to address these needs locally, nationally and internationally.

*Today's Parent* is Canada's leading parenting magazine, established in 1984. Over its 26 years, the magazine has given extensive coverage to children's health, which is one of the main areas of interest to its readers. This coverage has included numerous articles on children's mental health. Some articles have explored specific problems such as anxiety, depression and ADHD in kids; others have looked more generally at preventive strategies and ways for parents to establish healthy habits for their families.

However, it was not until 2009 that the magazine took a broader, systemic look at children's mental health care in Canada. This came about through a unique partnership with one of the parent founders of the BC organization FORCE, and through her, with members of the child and youth advisory committee of the Mental Health Commission of Canada.

In late 2008, *Today's Parent* editors began to research a year-long series of articles that would shed light on some of the urgent and surprising shortcomings in Canadian health care for kids. This series, called Healthy Kids 2009, was being developed to mark the magazine's 25<sup>th</sup> anniversary in 2009. It was based on *Reaching for the Top*, the ground-breaking report by Dr. Kellie Leitch, then advisor to the federal health minister on healthy children and youth. The series zeroed in on four topic areas, one of them mental health. To get background and perspective on children's mental health, Dr. Leitch urged the *Today's Parent* team to talk to the founder of the FORCE, Keli Anderson.

Coincidentally, Ms. Anderson's name was already circulating at *Today's Parent* because of a fortuitous meeting a few months earlier between the magazine's deputy editor and one of the parent peer workers of the FORCE. They had struck up a conversation in a New York coffee shop, resulting in a recommendation that the FORCE would be a great source for future articles on children's mental health.

The pieces came together when *Today's Parent* editor Caroline Connell called Ms. Anderson and arranged a meeting that took place in January 2009. *Today's Parent* was looking for a parent's and advocate's perspective on the mental health system. The Leitch report had already shown the editors that Canadian children with mental health problems were shockingly underserved, and that their families were by long waits for care, lack of support and the stigma that too often accompanies mental illness. Ms. Anderson was able to flesh out the picture through her deep insights on families' experiences (including her own), and her knowledge of what would help those families most.

More than that, the editors were looking for some action their readers could take that would make a real difference to children's mental health. Ms. Anderson came up with a very practical suggestion: the magazine could survey Canadian parents about their views on mental health care for children. Such a survey had not been done before, and the results could be useful to mental health advocates, in particular the child and youth advisory committee at the Mental Health Commission of Canada, which was in the process of developing a child and youth mental health framework for Canada known as the Evergreen. Ms. Anderson connected with the Evergreen's lead, Dr. Stan Kutcher, and invited him to the group discussing the survey.

## Method

*Today's Parent* embraced the survey idea and a working group was established to develop questions that would both serve the magazine's editorial needs (for a future story) and provide useful information for policy makers, researchers and academics working in the field of child and youth mental health in Canada. Caroline Connell brought in the consumer research team from Rogers Publishing, owner of *Today's Parent* and together with the

FORCE Society and Sun Life Chair and the group created the survey.

One challenge was to ensure the survey would speak to the wide range of parents among the magazine's readership and beyond—including those with lived experience of mental health challenges in their kids, and those for whom it would be a new and unfamiliar topic. The Rogers research team used their expertise to tailor questions for both these audiences, and to draft close-ended questions that would elicit the most useful quantitative data.

It should be stated that everyone on the team was aware that such a survey, conducted through the *Today's Parent* website, would have some built-in limitations. For example, the respondents would be self-selected, not random, and so the data could not be claimed to be a representative sample of Canadian parents. Nevertheless it was felt that the project could provide some highly useful insights on parents' awareness of mental health issues, where they turn for help when problems occur and what they think of the resources available.

The online survey went live in June 2009 and stayed up for three months. *Today's Parent* solicited responses through its print editions, accompanying articles on key issues in child and youth mental health. The magazine also highlighted the survey in email newsletters and on its web homepage, and targeted invitations to members of its consumer panel (a group of about 5,000 readers who sign up to answer surveys). The FORCE Society also publicized the survey through their own networks in the children's mental health community.

The survey used a different URL for the respondents recruited through mental health community networks and those who came to it from *Today's Parent*. This allowed the researchers to analyse the responses separately or together, to allow for assessment of statistically significant as well as qualitative differences between the two groups.

## Results

In total almost 4,500 parents responded to the survey. The group working on the survey was delighted by this number. As expected, there were some qualitative differences between the *Today's Parent* readers who answered and the respondents who came through mental health community contacts. The latter group were much more likely to have children with mental health problems. When the Rogers researchers analysed the data, numerous interesting points emerged. Although the data has yet to be fully analysed and will be reported in future publications, it is instructive to provide a sample of the preliminary findings here.

Respondents mentioned that they think about their child's mental health—even those who haven't had any problems. More than half of those parents said it's an issue they think about occasionally or often.

In many cases it's the media that are prompting parents to think about these issues. More than one quarter of those whose children don't have a mental health problem said it was media coverage that got them thinking about children's mental health.

When young people do experience mental health problems, their parents turn to numerous sources for information and support—first the Internet, and second the medical community. Also ranking high were community organizations and resource centres.

Fully one-quarter of the respondents whose children have mental health problems *are not aware* of any treatment programs available where they live and about one half of respondents were not aware of any parent support groups in their community.

- Almost half of the survey respondents reported having to wait one year or more for mental health services.
- The majority of respondents identified the possibility for schools to become more active in addressing mental health needs for children and youth.
- Schools rank close to the bottom of the list of places where parents feel they can turn for help for their kids' mental health problems.

## Conclusion

The development and conduct of this survey illustrates a potentially positive development in addressing mental health research in children and youth. Although this study was not a comprehensive nor sophisticated analysis of this issue, it does demonstrate that collaboration between parents, media and academia may be fruitfully applied in the design, development and application of future research in this area.

The survey results were of interest to all partners: the *Today's Parent* editors; the FORCE and the Sun Life Financial Chair Team. For the magazine editors, mental health proved to be the most powerful of the four topics explored in the year-long Healthy Kids 2009 program. Readers embraced the chance to speak up on the issue, and showed their continuing interest in

reading about mental health issues as well as taking action for positive change. For the FORCE Society, the information provided data that could be used to develop current and future advocacy activities. For the academic team, the information obtained could be used to better target knowledge needs of parents pertaining to child and youth mental health.

Overall, this serendipitous interaction between a non-profit family organization, academic institution, and parent magazine has provided a potential partnership model that could be further defined and applied to address many aspects of child and youth mental health in Canada and perhaps, beyond.

It is our hope that partnerships like this one will strengthen the mental health of children and youth as there is no question that parents are thinking about this, and are ready to be engaged.

## Acknowledgements/Conflicts of Interest

The authors have no financial relationships or conflicts to disclose.

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