A MULTIFACETED INTEGRATED KNOWLEDGE TRANSLATION PROJECT

PARTNERING WITH FAMILIES TO MOBILIZE A HOLISTIC FAMILY-CENTRED APPROACH TO CHILDHOOD DISABILITY: A MULTIFACETED INTEGRATED KNOWLEDGE TRANSLATION PROJECT

By

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TITLE: **Partnering with families to mobilize a holistic family-centred approach to childhood disability: A multi-faceted integrated knowledge translation project**

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LAY ABSTRACT

In the 21st century, research supports a holistic family-centred approach to childhood disability. Unfortunately, a research to practice gap remains, and the professional-led biomedical approach still informs many practices. In 2012, Rosenbaum and Gorter published “The ‘F-words’ in childhood disability: I swear this is how we should think!” They highlighted the importance of ‘Function, Family, Fitness, Fun, Friends, and Future’, grounded in the World Health Organization’s framework for health. This thesis developed and evaluated a knowledge translation research program to move the ‘F-words’ into practice. Objectives, all achieved, were to: i) apply strategies to spread awareness of the ‘F-words’ and explore people’s reception of these ideas; ii) identify and assess strategies to share research with families; iii) develop and evaluate an online resource to support use of the ‘F-words’; and iv) study the processes involved and factors that contributed to the ‘F-words’ adoption. These findings have implications for both doing and studying knowledge translation.

ABSTRACT

Background: This thesis aimed to develop, implement, and evaluate a multi-faceted integrated knowledge translation (iKT) intervention to disseminate and support adoption of the ‘F-words in Childhood Disability’. Grounded in the WHO’s ICF framework, the ‘F-words’ (Function, Family, Fitness, Fun, Friends, and Future) offer a holistic family-centred approach to childhood disability.

Methods: This thesis was guided by the *action cycle* of Graham et al.’s (2006) knowledge-to-action (KTA) framework. Chapter 2 reports a knowledge translation (KT) initiative (i.e., an online video) to disseminate the ‘F-words’ and explore people’s reception of these ideas. Chapter 3’s scoping review identifies and assesses KT strategies that directly target families raising children and youth with special health care needs. Chapter 4 describes a pilot study to evaluate the usability and utility of an online ‘F-words’ KT resource. Chapter 5 reports a case study of our longitudinal KT research program, and uses Diffusion of Innovation (DOI) theory to understand the factors that contributed to the adoption of the ‘F-words’.

Results: Multi-faceted KT strategies, co-developed with stakeholders, were essential to moving the ‘F-words’ into practice. The video (Chapter 2) reached >700 views in two months and 98% of 137 survey respondents indicated they ‘extremely liked’/‘liked’ the ideas. The scoping review (Chapter 3) identified six studies, all of which evaluated educational materials and deemed them to be useful and important to families. The pilot evaluation (Chapter 4) revealed the online resource to have positive usability and utility for families and service providers. The case study (Chapter 5) highlighted that diffusion, dissemination and implementation strategies were all needed and that DOI factors (i.e., the innovation characteristics, communication channels, social networks, and time) contributed to the adoption of the ‘F-words’. Based on a multi-faceted integrated KT research program we now have extensive examples of ‘F-words’ adoption by families, service providers, and health care organizations.

Conclusions: This thesis illustrates a step-wise theory-informed approach to the development and evaluation of a multi-faceted iKT intervention. By studying each step of the *action cycle*, this work contributes new knowledge to both the processes involved in disseminating research evidence, and associated outcomes from a multi-faceted iKT intervention. Findings from this thesis contribute new discoveries to both KT practice and science.

ACKNOWLEDGEMENTS

Looking back on my doctoral degree, I don’t know where the time went. It feels like just yesterday that I was new to McMaster University, the School of Rehabilitation Science (SRS), and *CanChild* Centre for Childhood Disability Research. Over the years this place has become a supportive community and I would like to thank all of the staff, faculty, and fellow students who have contributed to my doctoral experience.

I would like to start by extending my deepest gratitude to my mentor, supervisor and friend, Dr. Peter Rosenbaum. Peter’s enthusiasm and dedication to teaching and childhood disability research is a constant inspiration. From the beginning of my degree, Peter has provided unending support, wisdom, and guidance. I am forever appreciative for his tireless dedication and for continually challenging me to take chances and not be afraid to fall down. My sincerest thanks also go to my committee members Dr. Jan Willem Gorter and Professor Sue Baptiste. Their belief in me as a student, commitment to my academic growth, and constant support and guidance have been invaluable. Collectively, my doctoral committee has provided me with multiple opportunities outside of my doctoral thesis to grow as an academic researcher and teacher. I feel extremely fortunate for their exceptional mentorship and I now feel well prepared to take the next steps in academia.

My research wouldn’t have been possible without all of the families I had the pleasure of collaborating with. I would especially like to thank the three

fabulous mothers who are members of our ‘F-words’ Research team. Danijela, Diane, and Julie, thank you for your time, patience, and dedication to this work. I can’t tell you how grateful I am for your support, guidance, and friendship. It has been my privilege to work with and learn from you. Thank you as well to all the families, service providers, administrators, and researchers who are knowledge brokers of the ‘F-words’ ideas. I have learned so much from connecting and collaborating with people around the world who share a similar passion to change the way we think, talk about, and approach disability.

My sincere appreciation also extends to my *CanChild* and SRS family. My research training with *CanChild* and the SRS program has been exceptional and I feel fortunate to be part of such a supportive research and teaching community. I would also like to acknowledge and thank Dr. Patty Solomon for her support and mentorship. In addition to my doctoral studies, having the opportunity to teach in the Master of Health Management Program has fostered my passion for teaching and research and has significantly contributed to my academic growth. I am also grateful for the funding support I received, including an Ontario Graduate Scholarship and scholarships through the School of Rehabilitation Science program.

Finally, thank you to my husband, family and friends, who have always encouraged me to pursue my dreams. Thank you for your patience and support throughout my years of graduate school. Your belief in me kept me focused and your constant love kept me inspired. To this end, I dedicate my thesis to all of the people who have contributed to my journey.

PRELUDE TO MY THESIS: PERSONAL INTRODUCTION

Looking back and learning will enable you to move forward. – Eileen Brown

The starting gate: My introduction to the field of childhood disability research

In 2012, I graduated from Wilfrid Laurier University with my Master of Science degree. I had at that point spent the previous six years at Laurier studying in the Kinesiology Department. I originally chose to study kinesiology as I was always passionate about physical activity and overall health and well-being. Soccer, swimming, snowboarding, and skiing were my hobbies, but also the precedents to my first jobs. In the winter, I would teach snowboarding and in the summer months I would trade in my snowboard for my swimsuit and teach backyard summer swim lessons. Little did I know at the time that my twin passions for sports and teaching would lead to my future career.

I always loved working with children. Their bright smiles, creative imaginations, and infectious energy were contagious. For a long time, I debated going into teaching but was also drawn to health care services such as physiotherapy and occupational therapy. This uncertainty left me, in the fourth year of my undergraduate degree, without a clear path ahead.

At that time, I chose to do an undergraduate thesis with Dr. Margaret Schneider, a qualitative researcher with a diverse background in health and recreational therapy. In our first meeting, she asked what I was interested in studying. My response: “I don’t know…” I had never been involved in research before and didn't have any idea where to begin. Fortunately, I found my way and my undergraduate thesis ended up being a pivotal point in my life, providing the starting gate to my career as a life-long learner and academic researcher.

My master's thesis was conducted in collaboration with a local children's treatment centre (CTC) and explored the benefits of swimming for children with autism spectrum disorder and developmental delay. This topic was driven by my experience teaching children with disabilities how to swim. Throughout my undergraduate degree, I had run a backyard summer swim program and volunteered for a local adapted swim program. As an instructor, I noticed one commonality: all children loved the water. With a particular interest in the effects of the water on children with disabilities, I turned to the literature to see what I could find. Not surprisingly there was limited research in this area, indicating a clear evidence gap and an area where research was needed.

Reflecting back on my master's thesis, there were many fundamental moments that would end up influencing my future direction as a health services researcher. First, my thesis work provided my initial introduction to paediatric rehabilitation. While many of the graduate students enrolled in McMaster's School of Rehabilitation Science master's and doctoral programs come from rehabilitation backgrounds (e.g., physiotherapy, occupational therapy, speech language pathology), I was drawn to rehabilitation sciences based on my overall interest in health and well-being and my volunteer experiences working in rehabilitation centres.

Second, my master's project introduced me to community-based research. Conducting my thesis in collaboration with a local CTC, I worked closely with the classroom teachers to develop, implement, and evaluate the swim program. Working with the teachers showed me the importance of building partnerships with service providers and working together from the beginning of a project to ensure the research questions are useful and meaningful for the target audience.

Third, the teachers also helped me expand my focus beyond 'body structure and function' towards more 'activity/ participation'-focused goals. For example, the teachers identified that while the physiological benefits of swimming were important (e.g., increase muscle strength, cardio-respiratory fitness), they were particularly interested in the potential psychosocial benefits, such as improved social interaction and communication skills. While at the time I wasn't familiar with the World Health Organization's (WHO, 2001) International Classification of Functioning, Disability and Health (ICF) framework, in hindsight, I recognize that the teachers provided my first introduction to a biopsychosocial approach to health and disability.

Overall, my master's thesis was a wonderful learning opportunity that ignited my drive for childhood disability research. Completing my master's degree, I now had a clear direction and path ahead, with hopes of continuing my education at *CanChild* Centre for Childhood Disability Research at McMaster University.

The next step: Pursuing doctoral studies at *CanChild* Centre for Childhood Disability Research

CanChild Centre for Childhood Disability Research was co-founded in 1989 by Drs. Peter Rosenbaum and Mary Law and is recognized as a world leader in childhood disability research and knowledge translation (*CanChild*, 2018). For over 28 years, *CanChild* has been working with families, service providers, educators, and researchers to "maximize the quality of life and participation of children and youth with a variety of developmental conditions, along with their families, through evidence-based clinical and health services research" (*CanChild*, 2018). Children and youth with disabilities and their families have always been at the heart of *CanChild's* research.

In 2012, I started my doctoral studies in the School of Rehabilitation Science (SRS) and at *CanChild*. In my first year, I completed graduate courses and began exploring tentative areas of research. At the time, all I knew was that I was interested in working with parents and caregivers of children with disabilities and exploring interventions to support holistic well-being of the family unit.

Reflecting back on the last five years of my doctoral degree, my journey has been filled with lots of turns, speed bumps, accelerations, and rolling hills. Through *CanChild* and the SRS I have had opportunities to expand my knowledge and skill sets in both research and teaching. Two of the pivotal points were my introductions to knowledge translation (KT) and to the WHO's ICF – a framework for health for everyone. Both KT and the ICF were new concepts to me, but captured my attention and quickly became a focus of both my teaching and research.

The story that unfolds throughout my thesis offers readers a guide to how these new concepts informed my thinking, and our efforts to move the ICF and related developments in the field of childhood disability into practice. This work stemmed from the realization that there was a significant gap between what we 'know' from the last two decades of childhood disability research, and what is 'done' in practice. KT is the process that is meant to bridge the research-to-practice gap, and includes both 'doing KT' (i.e., *KT Practice*) and 'studying KT' (i.e., *KT Science*). For my thesis, I was interested in further exploring both of these areas (i.e., *KT Practice* and *KT Science*) in order to assess, systematically, both what we were doing and what impact those activities were having. To this end I conducted four studies as part of my thesis.

Furthermore, I was specifically interested in sharing the developments in the field of childhood disability with families raising children with disabilities. Recognizing families as the primary target audience, I chose to take an integrated knowledge translation (iKT) approach. iKT involves working with knowledge users (in my case families) from the beginning of the research process. As such, in 2014, we formed an integrated research team, including three mothers of children with disabilities, who in addition to my committee members have been integral members of my thesis team. Following *CanChild's* vision, ***families are truly at the heart of this thesis.***

PREFACE

The following preface summarizes the doctoral candidate's and other authors' contributions to each scholarly manuscript (Chapters 2 – 5) included in this dissertation.

Manuscript 1: ***Knowledge mobilization to spread awareness of the 'F-words' in childhood disability: Lessons from a family-researcher partnership***

This study was conducted in 2014 and was our first project working together as an integrated 'F-words' research team. I led all stages of the project including developing the project proposal, creating the video, consulting with families and researchers at each stage of the video development, designing and implementing the evaluation strategy, organizing and analyzing the data, and preparing the written manuscript. Two parents (DG, DK) were involved in all stages of the project. Both parents provided pictures and quotes for the video and provided feedback throughout the video development process. Two additional parents previewed the video and provided feedback before it was disseminated. A media specialist helped upload the video to *CanChild's* website and Vimeo page and distribute the video through *CanChild's* social media channels. The authors of the 'F-words' publication (PR, JWG) were consulted throughout each stage of the project. All co-authors reviewed and provided feedback on the manuscript before it was submitted for publication.

Manuscript 2: ***Getting children's health research into families' hands: A scoping review of knowledge translation studies targeting families of children and youth with special health care needs in Canada***

I was responsible for leading all stages of this project including: conducting a preliminary literature review; identifying the research question; searching for relevant studies; selecting studies; charting the data; collating, summarizing, and reporting the results; and preparing the manuscript. I initially conducted this scoping review in the Summer of 2015. At that time, a *CanChild* summer student (Katelyn Rolfe) assisted with data extraction and data organization. Unfortunately, we did not publish the paper in 2015, and thus the scoping review needed to be updated by the time we went to prepare for publication (2016/2017). I re-did the search February 2017 and a second *CanChild* research student (Sofia Zhang) assisted with data extraction and organization at this time. Changes were made to the search strategy and inclusion/exclusion criteria. No new studies were added, but two studies were removed upon further analysis of the studies. Revisions were also made to how the data were charted and organized. My supervisor (PR) provided guidance and consultation throughout the entire process and my committee members (SB, JWG) provided feedback on the initial manuscript and its subsequent revisions.

Manuscript 3: ***Development and pilot evaluation of an online knowledge translation resource for families and service providers: The 'F-words' in Childhood Disability Knowledge Hub***

The initial planning for the Knowledge Hub started in early 2015. At that time, two new people joined our ‘F-Words’ Research team, including a parent (JB) and a health services researcher (SB). From 2015 – 2017, we co-developed the online hub. This was an iterative process, as the hub constantly evolved as more people began to adopt the ‘F-words’. While our integrated research team led the development, we collaborated with families and service providers outside of our research team to share stories and examples of how people were adapting and adopting the ‘F-words’ in their local contexts. As the project co-ordinator, I led all stages of the study including designing the hub; gathering, synthesizing, and tailoring materials; writing the key messages and instructions (i.e., all written text); communicating and collaborating with stakeholders; designing and implementing the evaluation; organizing and analyzing the data; and preparing the manuscript. Many *CanChild* students provided knowledge translation (KT)/media support with designing the ‘F-words’ tools and uploading and updating content to the Knowledge Hub. Brie Chauncey (*CanChild’s* Communications Officer) provided communication/social media support throughout the entire project. All co-authors were involved from the beginning of this project and consulted at each stage. As the project coordinator, I communicated both individually with research team members and facilitated group discussions through email and Skype/phone meetings. All co-authors reviewed and provided feedback on the manuscript before it was submitted for publication.

Manuscript 4: ***A multi-faceted integrated knowledge translation case study: Using Diffusion of Innovation theory to explore the adoption of the 'F-words' in Childhood Disability***

This longitudinal case study reports on our team's integrated knowledge translation (iKT) research program to disseminate and support the adoption of the 'F-words'. From November 2011 – February 2018, we used multiple KT strategies to disseminate the 'F-words'. Some of the KT strategies were planned ahead of time, while others evolved over time due to stakeholder adoption. In July 2016, I proposed to my committee (PR, SB, JWG) to study the 'F-words' research program as a KT case study. As the project coordinator, I had been tracking the dissemination and uptake of the 'F-words' and recognized that the 'F-words' research program had grown well beyond the Knowledge Hub and that we had a story to tell. While many people were involved in the dissemination and implementation activities, I led the KT science component (i.e., studying the processes involved and associated outcomes). Over the years, I collected multiple forms of data on our 'F-words' KT research program (e.g., emails, online blogs and newsletters, our KT intervention documents and evaluation data, etc.). In order to study *how* and *why* the 'F-words' moved into practice, I analyzed the data through a case study design (using both a chronological time series analysis and the Diffusion of Innovation theory). My supervisor (PR) and committee members (SB, JWG) provided guidance and consultation throughout the data analysis process and reviewed and provided written feedback on the manuscript.

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LIST OF ABBREVIATIONS

CHREHI	Calgary Health Region Evaluation of Health Information
CIHR	Canadian Institutes of Health Research
CTC	Children's Treatment Centre
CYSHCN	Children and youth with special health care needs
DOI	Diffusion of Innovation
ECHO	Evidence in Child Health to enhance Outcomes
ED	Emergency Department
EPOC	Effective Practice and Organization of Care
FCS	Family Centred Service
HCPs	Healthcare Providers
HD	Hirschsprung's Disease
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health – Child and Youth Version
ICIDH	International Classification of Functioning, Disabilities, and Handicaps
IES	Impact of Event Score
iKT	Integrated Knowledge Translation
KB	Knowledge Broker
KT	Knowledge Translation
KTA	Knowledge-to-Action
KM	Knowledge Mobilization
MPOC	Measure of Processes of Care
OBI	Ontario Brain Institute
PKT	Patient-Mediated KT
RCT	Randomized Controlled Trial
SRS	School of Rehabilitation Science
TOP	Telephone Outpatient Score for Clinical Status
YPIR	Youth Partnering in Research

LIST OF APPENDICES

DECLARATION OF ACADEMIC ACHIEVEMENT

The work presented in this dissertation is the original work of the doctoral candidate. This dissertation contains four individual studies that were part of an integrated knowledge translation (iKT) research program. Since this was an integrated project (i.e., including researchers and knowledge users throughout the research process), an integrated research team was formed at the beginning of the candidate's doctoral thesis to support this work. Specifically, three mothers raising children with disabilities were invited to be part of the research team. Thus, in addition to the candidate's doctoral committee (supervisor and two committee members), the three mothers were integral members of the research team. The candidate led all stages of the research program including forming the research team, deciding on the research questions, completing the data collection and analysis, and writing the manuscripts. The doctoral candidate is the primary author of this work, but has benefited from the mentorship and feedback from all research team members.

CHAPTER ONE: INTRODUCTION

Before introducing a new idea or way of thinking it is important to look back to see whence we have come (Rosenbaum, 2015). Thirty years ago, our thinking and approach to childhood disability were strongly rooted within the biomedical model (i.e., a focus on impairment) (Miller & Rosenbaum, 2016; Novak et al., 2013). Impairments were perceived to be 'within' the individual, and as such there was a strong focus on 'fixing' the child to achieve 'normal' development (Law & Darrah, 2014; Miller & Rosenbaum, 2016; Rosenbaum & Gorter, 2012). This perception led clinicians and therapists to focus on biologically/medically-based treatments (e.g., neurodevelopmental treatments) and to neglect other important areas in child development (e.g., social participation) (Gibson et al., 2009; Novak et al., 2013; Rosenbaum & Gorter, 2012). To date, there remains a lack of empirical evidence supporting this 'impairment-based' approach in the field of childhood disability (Butler & Darrah, 2001; Law et al., 2011; Novak, 2012).

Fortunately, in the 21st century there have been significant changes in our *frameworks*, *philosophies*, and *approaches* to childhood disability and a *holistic family-centred approach to children's health and development* is now recognized as best practice (Arcuri et al., 2015; King & Chiarello, 2014; Law & Darrah, 2014). This approach involves working with families as equal partners and placing major emphasis on factors that are important to all children's development – their activities, participation and environments. Over the last two decades, researchers around the world have studied these contemporary issues and written about the implications of these changes at the family, clinical, research, and organizational levels (Arcuri et al., 2015; Gibson et al., 2009; Law & Darrah, 2014; Miller & Rosenbaum, 2016). Unfortunately, despite research evidence, a knowledge-to-action (KTA) gap persists, with the traditional professional-led biomedical approaches still informing people's thinking and practices (Darrah, Wiart, Magill-Evans, Ray & Anderson, 2010; Kuo et al., 2012; Rosenbaum, 2015).

The focus of my thesis research is on narrowing this KTA gap and moving contemporary views on how we should think, talk about, and approach childhood disability into practice. The introductory chapter is divided into three parts. In **Part I**, I set the context by providing background information on two of the main developments in the field of childhood disability that have informed my thinking and inspired my program of research. In **Part II**, I introduce the focus area of my thesis (i.e., knowledge translation (KT)). In this section, I define KT and integrated KT, explore reasons for the KTA gap and the need for KT strategies, and introduce the KTA framework (Graham et al., 2006), which has provided the guiding conceptual lens for my thesis. In **Part III**, I introduce the 'F-words' in Childhood Disability (Rosenbaum & Gorter, 2012) – a paper written in response to this KTA gap – and describe the development of the 'F-words' KT Research Program. In this section, I outline the objectives of my thesis and provide a brief overview of my thesis papers.

Part I - Setting the context: The changing landscape in the field of childhood disability

This is an exciting time in the field of childhood disability. As identified above, the field is in the midst of paradigm shifts regarding how we understand and approach disability. Two primary developments in the field were the introduction of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) and the evolution of family-centred service (FCS) (Rosenbaum, King, Law, King, & Evans, 1998). I explore both of these developments below.

Change in conceptual framework: Introducing the ICF

The first framework for disability was released in 1980 by the WHO and was a reflection of the *biomedical approach* taken at that time. This framework, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (Figure 1), illustrates that any disease/disorder is associated with 'impairments' in the body, which may in turn interfere with an individual's functioning (called 'disability'), which then may lead to 'handicaps' (i.e., the social consequences of disability) (WHO, 1980). This linear unidirectional framework focuses solely on the level of 'impairment' and does not give consideration to outside contextual factors (e.g., environmental factors) (Gaebler-Spira, 2016; Rosenbaum & Stewart, 2004).

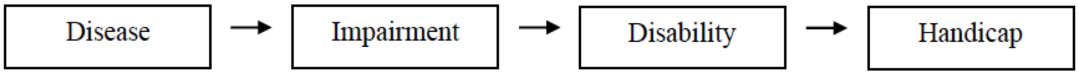

Figure 1. International Classification of Impairments, Disabilities, and Handicaps (ICIDH) Framework (WHO, 1980)

After many years of the ICIDH, in 2001 the WHO endorsed a new classification system and conceptual framework called the International Classification of Functioning, Disability and Health (ICF) (Figure 2). Embracing a *biopsychosocial approach*, the ICF reflects a significant shift and expansion in our thinking and understanding of disability. As seen in Figure 2, the ICF introduces new domains of functioning (i.e., ‘activities’, ‘participation’) and contextual factors (i.e., ‘personal’ and ‘environmental’ factors) that are equally as important as ‘body structure and function’ (WHO, 2001). The ICF highlights that ‘disability’ is a product of the interaction of the person and their environment (Rosenbaum & Stewart, 2004; Simeonsson, 2009).

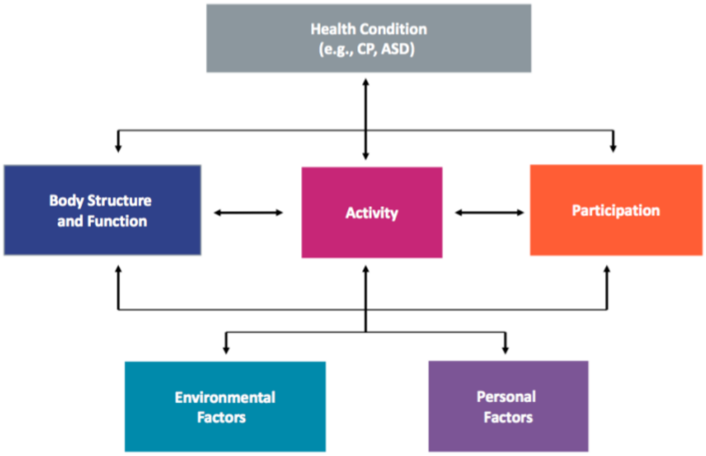

Figure 2. International Classification of Functioning, Disability, and Health (ICF) Framework (WHO, 2001)

Shortly after the release of the ICF, it was apparent that distinct aspects related to children's development were not adequately represented (Lollar & Simeonsson, 2005). Consequently, in 2007 the International Classification of Functioning, Disability and Health – Children and Youth Version (ICF-CY) was published (WHO, 2007). The ICF-CY introduces the first model of health that is specific for children and youth (Cramm, Aiken, & Stewart, 2012; WHO, 2007). While the ICF and ICF-CY have separate detailed classification systems, they share a conceptual framework (Figure 2). The conceptual framework is what has guided my thinking, and thus for the remainder of this thesis when talking about 'the ICF' I refer specifically to the framework and not the classification.

One of the key developments of the ICF is the use of *neutral language*. ICIDH words such as 'impairment', 'disability' and 'handicap' have been replaced with 'body structure and function', 'activities' and 'participation', respectively (WHO, 2001; WHO, 2007). In the ICF, *body structure and function* describes physiological functions (including psychological functions) and anatomical features in the body. Abnormalities at the body structure and function level are termed 'impairments'. *Activities* are defined as "the execution of a task or action by an individual" (e.g., kicking a soccer ball) and *participation* is defined as "involvement in a life situation" (e.g. playing in a soccer game). *Environmental factors* are extrinsic to the individual and include the "physical, social, attitudinal environment in which people live and conduct their lives". Environmental factors can be seen as either facilitators or barriers to an individual's functioning. Lastly, *personal factors* are intrinsic to the individual and include any factors that influence how disability is experienced by the individual (e.g., gender, age, education, profession, etc.) (WHO, 2001; WHO, 2007).

Another major development of the ICF is the replacement of a linear unidirectional system with a dynamic non-hierarchical system (reflected through the bi-directional arrows) (WHO, 2001; WHO, 2007). This means that we can start interventions anywhere in the framework, and changes at one level of functioning (e.g., participation) may influence one or more other areas (e.g., activities and body structure function) (Rosenbaum & Stewart, 2004). It is important to note that a change at one level does not guarantee changes at other levels, but by using the ICF, we are able to explore interventions at various levels and choose interventions that best meet the individual needs and goals of the person (Darrah, 2008; Gibson et al., 2009; Novak et al., 2013) This dynamic lens is quite different from the traditional linear approach (i.e., impairment leads to disability) and reflects a modern holistic view of health and disability (Simeonsson, 2009; Rosenbaum & Gorter, 2012; Vargus-Adams & Majnemer, 2014; WHO, 2001).

Despite this major paradigm shift and expansion of our thinking about health, as embodied in the ICF, there remains a gap in the uptake and application of these ideas in daily practice (Darrah, 2008; Vargus-Adams & Majnemer, 2014; Wiegand, Belting, Fekete, Gutenbrunner, & Reinhardt, 2012). Reported reasons for not adopting the ICF in practice include the perceived level of complexity, lack of clarity regarding the various components (e.g., difference between activities and participation), and anticipated time and training needed for implementation (Cramm et al., 2012; Darrah, 2008). Consequently, since service providers are not actively utilizing the ICF within their practices, many families remain unaware of it (Darrah, 2008; Jindal, MacDermid, Rosebaum, DiRezze, & Narayan, 2017). This creates a significant knowledge gap between what we 'know' from research and the new concepts regarding 'health', and what is happening in practice.

It is important that families are informed on the modern ways we are thinking about and approaching childhood disability (McDougall, Horgan, Baldwin, Tucker, & Frid, 2008; Jindal et al., 2017). Families play an integral role in their children's health care and thus deserve equal access to current health research evidence (McHugh, Bailey, Shilling, & Morris, 2013; Palisano et al., 2010). In the family-centred service (FCS) literature, it has been reported that providing general and specific information is often rated the lowest by both families and service providers when evaluating FCS (Arcuri et al., 2015; Cunningham & Rosenbaum, 2014; Terwiel et al., 2017). While both groups acknowledge the importance of sharing information, strategies and tools are needed to facilitate the conversation between families and service providers.

Researchers have shown that the ICF provides a framework that can be used by service providers and families across a variety of settings and that it offers both an *organizational* and *communication* tool (Adolfsson, Malmqvist, Pless & Granlund, 2010; Atkinson & Nixon-Cave, 2011; Cramm et al., 2012; Martinuzzi et al., 2010; Simeonsson et al., 2003). For example, the ICF framework can be used as an *organizational tool* to guide service planning with families and a *communication tool* to support collaborative goal-setting (Darrah, 2008; McDougall et al., 2008; Vargus-Adams & Majnemer, 2014).

Over the last sixteen years, health care organizations have made significant strides to embrace the ICF (McDougall et al., 2008; Vargus-Adams & Majnemer, 2014), but there is still much work to be done for the ICF to be fully embedded into clinical care (Benson & Oakland, 2011; Wiegand et al., 2012). In order for the ICF to truly make a difference in the lives of children with disabilities and their families, it must become universal language for everyone. As clearly stated by Gaebler-Spira (2016) "language matters", and how we think and talk about disability can have substantial implications for our actions. The ICF is currently in the transition phase from 'research' to 'practice', and now more than ever KT strategies are needed to support its full integration and ensure its use and sustainability in practice.

Change in philosophies and approach to services: Evolution of Family-Centred Service

Early interest in family-centred service (FCS) dates back to the 1960s, when people referred to 'care' rather than 'service'. At this time, organizations began to recognize the family as the constant in the child's life and to appreciate the expertise they bring (Rosenbaum et al., 1998). Families were no longer seen as passive recipients of services, but as active contributors to the decision-making and service planning for their children (King, Teplicky, King, & Rosenbaum, 2004). Over the next 30 years (1960s-1990s), many researchers (including researchers at *CanChild*) attempted to conceptualize and define FCS. While many definitions evolved, the expansion of the ideas helped service providers and families better understand the primary components of FCS (Rosenbaum et al., 1998; King et al., 2004). At *CanChild*, our work has been guided by the following definition:

> *"Family-centred service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centred service recognizes that each family is unique, that the family is the constant in the child's life, and that they are the experts on the child's abilities and needs. The family works together with service providers to make informed decisions about the services and supports the child and family receive. In family-centred service, the strengths and needs of all family members are consider."* (Rosenbaum et al., 1998).

FCS has reshaped our philosophy of service delivery and is now recognized as best practice in the field of childhood disability (King et al., 2004; Dempsey & Keen, 2008; King & Chiarello, 2014). Research evidence over the last 20 years indicates that FCS has positive outcomes at the child, family, and service delivery levels (King et al., 2004). Outcomes of better FCS at the child and family levels include child developmental gains and skill acquisition, improved child psychological adjustment, increase in parents' skills and knowledge regarding child development, reductions in parent stress, and improvements in parents' emotional well-being (King, Rosenbaum & King, 1996; Rosenbaum et al., 1998; King, King, Rosenbaum & Goffin, 1999; King et al., 2004). Positive impacts at the service delivery level include increased family satisfaction with care when it is family-centred (Law et al., 2003).

In 2014, Cunningham and Rosenbaum conducted a literature review on studies that have implemented the Measure of Processes of Care (MPOC) – a validated and reliable tool developed in the late 1990s by *CanChild* researchers to measure FCS (King et al., 1996). Their search revealed 55 studies in 11 countries that utilized the MPOC to measure FCS. Overall, findings from these studies showed that parents reported services to be family-centred and that service providers are providing respectful and comprehensive services in partnership with parents. Interestingly, across all studies '*providing general information'* was the lowest-rated item (Cunningham & Rosenbaum, 2014). This indicates an area for which more research is needed as to how to share information with families.

In 2018, FCS is an established practice in many health care organizations in the western world (King & Chiarello, 2014). Today, not only are families involved in their children's health care, but many families sit on committees and advisory boards to help inform organizational policies and protocols (Washington, 2016). Families' voices are now at the forefront of decision-making from the individual to the organizational level and we are witnessing firsthand the impact of the evolution of FCS on practice. At the same time, it must be acknowledged that in many organizations FCS remains a work in progress and there is a need to better understand how to optimize the uptake of FCS across cultures and contexts (Arcuri et al., 2015; Darrah et al., 2012; Kuo et al., 2012). Similar to Cunningham and Rosenbaum's (2014) findings, a recent study conducted by Arcuri and colleagues (2015) reported that parents expressed a need for more information, especially information that used less medical jargon and was tailored to family's needs.

Part II – Focus of thesis: Introduction to Knowledge Translation (KT)

Defining KT

In the 21st century, it is well recognized that traditional knowledge transfer strategies (e.g., publications and conference presentations) are necessary but not sufficient to move research evidence into practice (Grimshaw, Eccles, Lavis, Hill & Squires, 2012; Straus, Tetroe, & Graham, 2013). Globally, there is an urgency for better methods and understanding of the structures and strategies needed to support the uptake of current research evidence in practice (Sussman, Valente, Rohrbach, Skara, & Pentz, 2006; Curran, Grimshaw, Hayden, & Campbell, 2011). Inefficiencies in the translation process are having significant impacts on both individual and societal health care (McGlynn et al., 2003; Curran et al., 2011).

The Canadian Institutes of Health Research (CIHR) defines KT as "*a dynamic and iterative process that includes the synthesis, dissemination,* *exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system*" (CIHR, 2012). As highlighted in the definition, the primary goals of KT are to: 1) improve health outcomes; 2) provide more effective health services and products; and 3) strengthen our health care systems. Internationally, billions of dollars go into research each year, yet many research discoveries don't translate into practice (Grimshaw et al., 2012). Furthermore, research shows that it takes approximately 17 years for what is known in research to be translated into practice (Morris, Wooding & Grant, 2011). Recognizing this global issue, KT is now a required component in most research grants in order to help reduce the amount of research waste and support the uptake and implementation of research findings (Straus et al., 2009). However, since the field of KT is a relatively new area of research that has evolved over the last 10 to 15 years, many questions still remain as to best practices.

A number of terms have been identified to define and describe the KT process (including knowledge mobilization, dissemination and implementation, knowledge transfer and exchange, etc.) (McKibbon et al., 2010). A key component to all definitions is that KT moves beyond the simple passive dissemination of knowledge into the promotion of the use of knowledge (Straus et al., 2013). It is now well understood that KT is a complex multi-dimensional process that takes both time and resources. Depending on the target audience and type of knowledge being transferred, various KT strategies are needed (Davis et al., 2003; Straus et al., 2013).

Defining Integrated Knowledge Translation

One significant change in thinking about KT is the recognition that rather than being a *one-way transfer* of knowledge, from researcher to knowledge user (at the end of a research project), KT is a *two-way process* that involves the exchange of knowledge between researchers (i.e., those who produce research) and knowledge users (i.e., those who can use it) (Gagliardi, Berta, Kothari, Boyko, & Urquhart, 2016; Jacobson, Butterill, & Goering, 2003; Lavis, Robertson, Woodside, McLeod, & Abelson, 2003). CIHR defines a knowledge user as "*an individual who is likely to be able to use the knowledge generated through research to make informed decisions about health policies, programs, and/or practices*" (CIHR, 2016). Knowledge users may include health care professionals, decision-makers, and health care consumers (Grimshaw et al., 2012). In the childhood disability field, the primary knowledge users are families of children and youth with disabilities and service providers who work with them (e.g., allied health professionals, physicians, teachers, etc.).

A number of terms are used to describe the partnership process throughout the research cycle, but in Canada we use the term **integrated knowledge translation (iKT).** CIHR defines iKT as the process of "*engaging and integrating those who will need to act on the findings, the knowledge users, into the research process*" (CIHR, 2015). It is important to recognize that iKT does not mean that particular knowledge user's take on researcher roles; rather the knowledge users (e.g., families) are respected for their distinct knowledge and the expertise they bring to the project (Shen et al., 2017).

Exploring the KTA Gap: Need for KT

There is a growing interest in understanding *why* these gaps exist and *how* to increase the speed and uptake of research in practice (Curran et al., 2011; Mallonee, Fowler, & Istre, 2006; Morris, Shilling, McHugh, & Wyatt, 2011). KTA gaps are often classified as either a *knowledge translation* problem (i.e., knowledge fails to transfer to its intended audience) or a *knowledge production* problem (i.e., the intended audience fails to use the research, as it does not address their needs or apply to the local context) (Bowen & Graham, 2013). It is important to address *why* the KTA gap exists before designing and implementing KT interventions to narrow any gap. We elaborate on both of these identified 'problems' below.

Knowledge Translation Problem

Until the early 21st century the research cycle commonly ended at the publication stage. It was researchers' perception that their responsibility was to publish their findings, with no significant investment in what happens afterwards (Ketelaar, Russell & Gorter, 2008). For the most part, it was assumed that people would find, read, understand, and be able to apply relevant findings to their settings (i.e., the responsibility was placed on the knowledge user) (Rosenbaum, 2005). It is now recognized that much work is needed beyond the publication phase, and that tailored KT strategies are essential (Straus et al., 2009; Waddell, 2001).

Knowledge Production Problem

In comparison to a knowledge translation problem, which is an issue at the level of dissemination, a *knowledge production problem* arises at the beginning of the research or KT process when the research team does not plan ahead to think about how to address the needs of the target audience (i.e., findings are not relevant or meaningful to the potential knowledge users and thus are unlikely to be adopted) (Bowen & Graham, 2013). To address this issue, as identified above, there is growing interest in *engaging knowledge users* throughout the research/KT process (Morris et al., 2011; Esmali, Moore, & Rein, 2015; Shen et al., 2017). Through this partnership approach it is believed that we can improve the relevance of the questions we study (Chovil & Panagiotopoulous, 2010; McAnuff et al., 2017; Shen et al., 2017) and enhance the speed and uptake of research in practice (Camden et al., 2015; Domecq et al., 2014; Gagliardi et al., 2016).

A model for KT: The KTA Framework

KT is a complex process that requires a series of structured steps. Various theories, models and frameworks are available to guide, implement, and analyze the KT process. The most widely used framework in Canada is Graham and colleagues' (2006) 'knowledge-to-action cycle' – a conceptual framework based on over 30 planned action theories to help inform the KT process (Figure 4). Conceptual frameworks are useful as they are broad and provide "a frame of reference for organizing thinking, a guide for action and interpretation" (Field, Booth, Illott, & Gerrish, 2014). CIHR has accepted the KTA framework as its model for KT and endorses its use when planning KT projects (Straus et al., 2009).

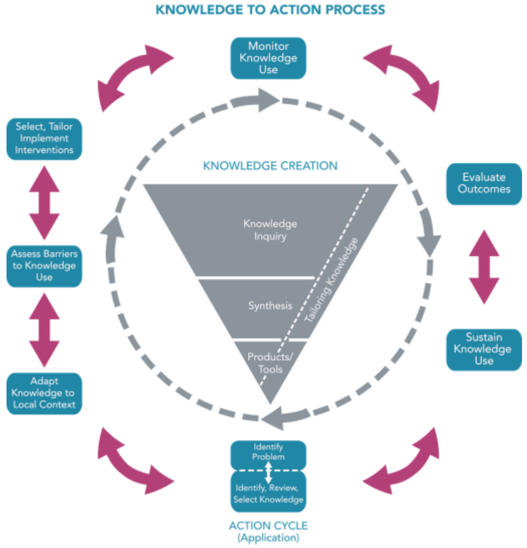

Figure 3. Knowledge-to-Action Framework (Graham et al., 2006)

The KTA framework divides the knowledge translation process into two phases: 'knowledge creation' and 'knowledge application'. Knowledge creation involves three sequential steps for distilling research evidence into useable formats. The knowledge creation funnel begins at the level of *knowledge inquiry* (i.e., individual research studies), followed by *knowledge synthesis* (i.e., compilation of studies in the form of systematic reviews, meta-analyses, scoping reviews, etc.), and ends with the development of *knowledge tools and products* (e.g., clinical practice guidelines, patient decision aids, etc.). As knowledge moves through each stage it becomes more refined and useful to the target audience.

While knowledge can move into the action cycle at any stage, it is recommended that knowledge synthesis be the basic unit for knowledge transfer (Graham et al., 2006).

The ‘knowledge application’ phase (also called the *action cycle*) outlines a seven-step process to support the uptake, evaluation, and sustainability of knowledge in practice. While each step is distinct, the steps can be completed at the same time and the boundaries are fluid, allowing people to move backwards and forwards throughout the cycle. The seven steps of the *action cycle* include: 1) *identify the problem and identify, review, select knowledge*; 2) *adapt knowledge to local context*; 3) *assess barriers to knowledge use*; 4) *select, tailor, implement interventions*; 5) *monitor knowledge use*; 6) *evaluate outcomes*; and 7) *sustain knowledge use* (Graham et al., 2006).

The KTA framework is useful for both researchers and knowledge users. While the two groups of stakeholders can use the framework separately, the framework can also be used by integrated research teams (Straus et al., 2013). The framework is meant to help facilitate the knowledge transfer process through the creation of sustainable and evidence-based interventions (Field et al., 2014). It is believed that by making the KT process systematic, there is greater likelihood of knowledge uptake and associated changes in practice (Eccles, Grimshaw, Walker, Johnston, & Pitts, 2005; Rycroft-Malone & Bucknail, 2010).

Part III - Response to KTA gap: Introducing the 'F-words in Childhood Disability'

In an effort to try to raise awareness of the ICF and the accompanying developments in the field of childhood disability, in 2012 Rosenbaum and Gorter published a concept paper titled: *"The 'F-words' in childhood disability: I swear this is how we should think!"* In the article, they embedded six 'F-words' (Function, Family, Fitness, Fun, Friends, Future) onto the WHO (2001) ICF framework (Figure 4). The 'F-words' represent strengths-based ICF themes and are grounded in over two decades of childhood disability research. In the article, the authors argue that these six 'F-words' should be the focus of all children's health and development. Their hope was that the 'F-words' would provide "an appealing way for people to incorporate these concepts into every aspect of clinical service, research, and advocacy regarding disabled children and their families" (Rosenbaum & Gorter, 2012, p. 457).

In the 'F-words' framework (Figure 4), the first 'F-word' **function** replaces the ICF term 'activity'. Function refers to what people do, and not 'how' things are done. The authors state that the goal should not be for children to do things 'normally', but for them to perform ***'activities'*** in ways that are 'functional' for them. The second 'F-word' is **family**. In the field of childhood disability, family is the central ***'environment'*** in children's lives. Thus, families must be treated as equal partners in the care of their children, and the whole family should be considered when working with children with disabilities. The third 'F-word' is

fitness. It is important for everyone to stay fit and healthy, but unfortunately fitness is often a neglected aspect of childhood disability. Fitness reminds us to look for opportunities to incorporate physical activity into the lives of children with disabilities and the important role fitness can have on children's ***'body structure and function'***. The fourth 'F-word' is **fun**. As Rosenbaum and Gorter (2012) ask, "isn't that what childhood is all about?" Life should be about fun for all children. This requires finding out what children like to do and fostering opportunities for children to engage in ways that are important to, and possible for, them (i.e., ***'personal factors'***). The fifth 'F-word' is **friends**. Social development is an important component of child development, but children with disabilities may miss opportunities to develop friendships. ***'Participation-based'*** activities encourage and nurture meaningful friendships. The sixth 'F-word' is **future**. Future does not fit in the original ICF framework, but was added to the 'F-words' framework because children with disabilities eventually become adults with disabilities. Thus, it is important, from the beginning, to consider the future and take a lifespan approach when working with children with disabilities and their families (Palisano et al., 2017).

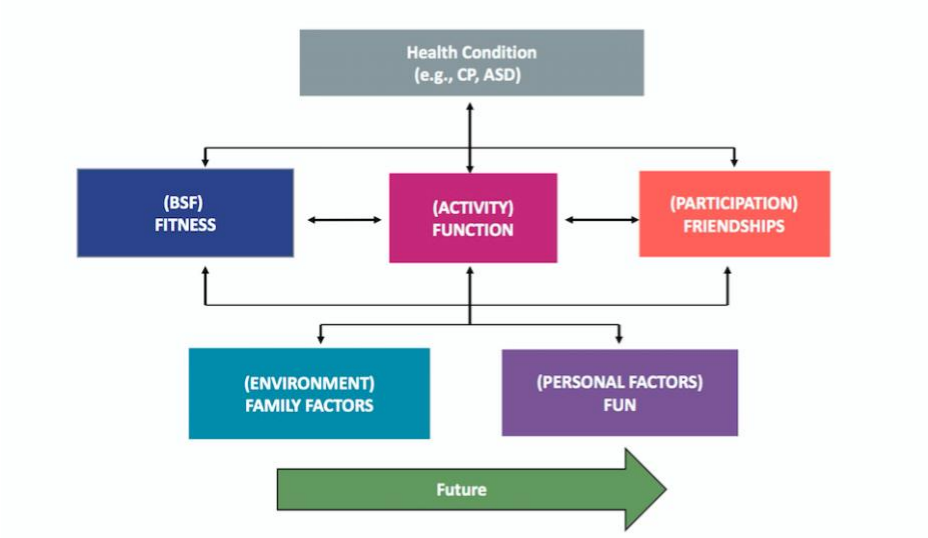

Figure 4. The ‘F-words’ adaptation of WHO (2001) ICF (Rosenbaum & Gorter, 2012)

While directly implementing the ICF within clinical practice is one strategy for supporting a *holistic family-centred biopsychosocial approach* to children’s health care, the ‘F-words’ constellation proposes an alternative strategy and offers specific illustrations of how to operationalize these ICF ideas in plain language. Beginning in November 2011, Rosenbaum and Gorter shared the ‘F-words’ ideas with colleagues at conferences, and with families during clinic visits. In 2012-2013, the ‘F-words’ paper was downloaded > 3,000 times, and presented 22 times at local, national, and international meetings. The ‘F-words’ concepts also began to spread over social media with six newsletters and blog posts written by both families and service providers. It was soon clear that the ‘F-words’ were resonating with people, and in particular parents and service providers really liked these ideas.

The 'F-words' in Childhood Disability KT Research Program

Acknowledging the early uptake/acceptance of the 'F-words' ideas by families inspired the development of a KT research program dedicated to moving the 'F-words' ideas into practice. Recognizing the value of involving families from the beginning of the research process (i.e., the importance to respond to the *knowledge production* problem and ensure the research questions/dissemination strategies were relevant and meaningful to families), I chose to take an iKT approach. In 2014, at the project development stage, I invited three mothers of children with disabilities to be part of the research team. All three were 'early adopters' of the 'F-words' concepts and had shown previous interest in the 'F-words' ideas.

In the childhood disability field, there is growing interest in *engaging families* along all stages of the research-to-practice continuum (Morris et al., 2011; Esmali et al., 2015). *CanChild's* adaptation of PenCRU's (2018) research process guided out integrated KT strategy (*CanChild*, 2018). All team members were involved at each stage of the research process (Figure 5).

Figure 5. *CanChild's* adaptation of PenCRU's (2018) research process (*CanChild*, 2018)

Initially, our research team was primarily interested in addressing families' knowledge needs and promoting families' uptake of the F-words concepts. However, our target audience quickly grew beyond families as service providers and health care organizations began to show interest in the 'F-words'. Thus, in 2015, united by a shared interest in disseminating and supporting the adoption of the 'F-words' concepts, our goal became to promote systematically, and to study, the diffusion, dissemination, and implementation of the 'F-words' at the family, clinician, and organizational levels.

The KTA framework (Graham et al., 2006) provided a guiding conceptual framework for our KT research program (and my thesis). Our team chose the KTA framework (with a specific focus on the *action cycle)*, as it provides a holistic step-wise (yet flexible) framework to design and implement a KT project systematically. I also liked that the KTA framework recognizes the importance of researchers and knowledge users collaborating throughout all steps of the KT process. It is important to note that this research program was developed as a doctoral thesis, and as such, as the PhD candidate, I acted as the project coordinator and led all stages of the research program. The following sections outline my thesis aim/objectives, and provide a brief overview of the scholarly papers included in this thesis.

Thesis Objectives

The overall aim of this thesis is to develop, implement, and evaluate a theory-informed multi-faceted integrated knowledge translation (iKT) intervention to disseminate and support the adoption of the 'F-words' concepts.

Specific objectives were to:

1. Apply knowledge translation (KT) practice strategies to disseminate the 'F-words' and explore people's knowledge and attitudes towards these ideas.
2. Identify and assess KT strategies that directly target families of children and youth with special health care needs.
3. Develop and evaluate the usability and utility of an online knowledge translation resource (i.e., the 'F-Words in Childhood Disability Knowledge Hub') to support the dissemination and implementation of the 'F-words'.
4. Explore the processes involved, and associated outcomes, of a longitudinal multi-faceted integrated knowledge translation project aimed to promote the adoption of the 'F-words in Childhood Disability' in practice.

Overview of thesis papers

This thesis is comprised of a series of four scholarly papers (Chapters 2 – 5). Guided by the *action cycle* of the KTA framework (Graham et al., 2006), each chapter acts as a check point and focuses on a particular step or steps of the *action cycle.*

Chapter 2 reports on our knowledge mobilization (KM) initiative designed to disseminate the 'F-words' ideas to a wide audience and explore people's response (i.e., knowledge and attitudes towards these ideas) (*Objective 1)*. This study was conducted in 2014 and at the time we only had anecdotal evidence that people liked the 'F-words' ideas. We also recognized that our current strategies (i.e., publication and conference presentations) were primarily reaching the scientific community, and that tailored KT strategies were needed to disseminate to our target audience (i.e., families raising children with disabilities, and service providers working with such families). Thus, as a feasible and low-cost project we developed, disseminated, and evaluated an online 'F-words' awareness video. This was our first project working together as an integrated research team. This study targeted *Step 2 of the action cycle* (*adapt knowledge to the local context*), as we aimed to gather insight into the reception of the 'F-words' ideas and to determine the value and usefulness of the 'F-words' ideas for families and service providers before undertaking a larger KM initiative. It is important to clarify that the term 'knowledge mobilization (KM)' was used in this chapter, based on feedback from the editors of the journal who are located in the

UK and use the term ‘knowledge mobilization’ instead of ‘knowledge translation’. The manuscript is published in *Child: Care, Health and Development* (Cross, Rosenbaum, Grahovac, Kay, & Gorter, 2015).

Chapter 3 is a scoping review exploring the current state of science on KT strategies that target families raising children and youth with special health care needs. The scoping review targeted *Step 3 of the action cycle* (*assess barriers to knowledge use*) to help us better understand the best ways to share health research evidence with families (*Objective 2*). The video project (Chapter 2) had confirmed that people liked the ‘F-words’ ideas and wanted to learn more, but it was not clear how best to share and exchange research knowledge with families. Previous scoping and systematic reviews were published on KT strategies targeting health care professionals; for this reason, we focused solely on families for the purpose of this review. The primary objectives of the scoping review were to: (1) identify and describe the KT strategies being used to disseminate health research to families of children and youth with special health care needs in Canada; and (2) explore the evaluation strategies and current state of evidence supporting these KT strategies. A secondary objective was to identify the barriers and facilitators perceived to influence the translation process. Findings from this scoping review informed our choice of interventions for disseminating and supporting the implementation of the ‘F-words’ in practice. This manuscript has been submitted to *Patient Education & Counselling.*

Chapter 4 describes the development process and pilot evaluation of the

‘F-words’ in Childhood Disability Knowledge Hub (*Objective 3*). The Knowledge Hub was chosen as the primary KT intervention strategy to inform people about the ‘F-words’ and to provide action-oriented tools to support the implementation of the ‘F-words’ in practice. Everything on the Knowledge Hub is freely available to share and adapt in one’s own practice settings. While some of the tools and resources on the Knowledge Hub were created by our research team, many of the items were created and shared, with permission, by stakeholders around the world. To ensure the Knowledge Hub meets the needs of stakeholders, we conducted a pilot evaluation to explore the usability and utility (i.e., the reach, usefulness, and use) of the Knowledge Hub. This study focuses on ***Steps 4 - 6 (select, tailor, and implement the intervention; monitor knowledge use; and evaluate outcomes) of the action cycle.*** This manuscript has been accepted by the *Journal of Medical Internet Research* and is currently in press.

Chapter 5 was a longitudinal case study to describe our KT research program and use the Diffusion of Innovation (DOI) theory to understand the factors that contributed to the dissemination and adoption of the ‘F-words’ in practice. Using an integrated multi-faceted KT strategy, we worked with a diverse group of stakeholders (e.g., parents, allied health care providers, health care organizations) to promote and study the diffusion, dissemination, and implementation of the ‘F-words’ concepts in a systematic way. A case study design allowed us to explore our ‘F-words’ KT research program in a real-life context and to utilize multiple unstructured data sources to capture a holistic understanding of the KT processes involved and associated outcomes (*Objective 4*). The Diffusion of Innovation (DOI) theory (Rogers, 2003) guided our KT research program and thus was used to delineate the factors that we believe contributed to the successful dissemination and adoption of the ‘F-words’ concepts. This study reflects on our entire KT research program and thus touches on ***all steps of the action cycle***. A journal-length version of this manuscript will be submitted to the *Journal of Developmental and Behavioral Pediatrics*, as an invited paper.

Chapter 6 discusses the overall implications of my thesis and the planned next steps. As the project coordinator, I have gained in-depth knowledge and skills with regards to KT practice and science. Seeing part of my role as being a ‘knowledge broker’ (KB), I share lessons learned from the perspective of a KB. Overall, I have learned that KT is an ongoing process. Working as an integrated research team we made significant progress in moving the ‘F-words’ into practice. The next step is to support the implementation of the ‘F-words’ further, as well as to evaluate the outcomes of these efforts over time at the family, clinician, and organizational levels. This will include delivering educational outreach visits to new organizations, as well as developing more tools and resources that have been requested by managers and service providers to support the implementation of the ‘F-words’ at the organizational level. While there is anecdotal evidence that the ‘F-words’ approach to childhood disability is making a difference, a formal evaluation study is needed to understand its impact more thoroughly. This thesis marks only the beginning of an evolving research program. I hope to continue working with families, service providers, and health care organizations to support the implementation and sustainability of the 'F-words' in practice.

*** Please note that references for Chapter 1 are found at the end of Chapter 6.**

CHAPTER TWO:

KNOWLEDGE MOBILIZATION TO SPREAD AWARENESS OF THE ‘F-WORDS’ IN CHILDHOOD DISABILITY: LESSONS FROM A FAMILY-RESEARCHER PARTNERSHIP

Introduction to Chapter Two

Authors: Andrea Cross, Peter Rosenbaum, Danijela Grahovac, Diane Kay, Jan Willem Gorter

Publication Status: This manuscript is published in *Child: Care, Health and Development*. Permission has been granted from the journal to include the manuscript in this doctoral thesis.

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Summary: The aim of this study was to spread awareness of the ‘F-words’ ideas to a wide audience (*Objective 1 of thesis)*. This study was conducted in 2014 and was our first project working together as an integrated ‘F-words’ research team. Initially, we recruited five families affiliated with *CanChild* who had shown previous interest in the ‘F-words’ ideas to be part of the research team and four mothers agreed to participate. Two mothers (DK, DG) ended up being integrally involved in all stages of the project, while two mothers were involved more on the periphery. As such, the initial ‘F-words’ research team included two clinician-researchers (PR, JWG), two mothers raising a child with a disability (DK, DG), and a doctoral student (AC).

This study involved the development, implementation and evaluation of an online awareness video promoting the ‘F-words’ key messages. An online awareness video was chosen as it was a feasible and low-cost project that would allow us to popularize the ‘F-words’ to a broad audience. Also, at the time of these early developments we only had anecdotal evidence that people liked the ‘F-words’ ideas; evaluating the video allowed us to collect broad feedback regarding stakeholders’ preliminary reception of these ideas. Determining the value and usefulness of the ‘F-words’ ideas (i.e., the innovation) for the target audience (i.e., families and service providers) is an important step to the knowledge translation process. Specifically, this study responded to ***Step 2 of the action cycle (adapt knowledge to the local context)***.

For two months (May – June 2014), we tracked the reach of the video (i.e., number of views and location of views) and collected anonymous survey responses. After 2-months, there were 715 views and 137 survey responses. Of the survey respondents, 55% had not previously heard of the ‘F-words’, 98% ‘extremely liked’/‘liked the ideas’, and 93% indicated they would like to learn more. These findings told us that: i) creating a short and captivating video and disseminating it through various communication channels was an effective way to spread awareness to a wide audience; and ii) the ‘F-words’ concepts resonated with people and there was interest among stakeholders in receiving more information. These findings encouraged us to continue working together as an integrated research team and develop, implement, and evaluate a larger KT intervention.

Abstract

Background: In 2012, two *CanChild* researchers published an article in *Child: Care, Health and Development* titled 'The 'F-words' in childhood disability: I swear this is how we should think!' Building on the World Health Organization's International Classification of Functioning, Disability and Health (ICF) framework, the article featured key strengths-based ICF themes (i.e., the 'F-words' – Function, Family, Fitness, Fun, Friends, and Future). This paper reports on a knowledge mobilization (KM) initiative designed to spread awareness of the 'F-words' ideas.

Methods: Families and researchers collaborated to develop, disseminate and evaluate an online awareness video. The video used written descriptions, parents' reflections and their pictures, music and graphics to captivate the audience. Posted on the *CanChild* website in May 2014, information about the video was distributed via various dissemination strategies and evaluated by tracking its views and through an online survey.

Results: After a 2-month evaluation, there were 715 views and 137 survey responses. Of the survey responses, 89% lived in Canada, 55% had not previously heard of the 'F-words', 98% 'extremely liked'/'liked the ideas' and 88% indicated they would share the video.

Conclusions: By creating a short and captivating video, we were able to spread awareness to a wide audience in a short period of time. Engaging families throughout the project was critical to the success of the video. By working

together, we hope to continue bridging research and practice and moving the 'F-words' concepts forward one 'word' at a time.

Introduction

In 2012, Rosenbaum and Gorter published an article: 'The 'F-words' in Childhood Disability: I swear this is how we should think!' Inspired by changes in their own thinking and over two decades of childhood disability research, the authors proposed a series of 'F-words' (Function, Family, Fitness, Fun, Friends, and Future) that they feel should be the focus of all children's development. These 'F-words' are based on the World Health Organization's International Classification of Functioning, Disability and Health (ICF) Framework (World Health Organization 2001). Unbeknownst to them at the time of publication, the 'F-words' would soon take flight and begin to capture the attention of families, practitioners and researchers around the world.

Since the publication of the 'F-words' paper in 2012, the article has been downloaded over 800 times from *Child: Care, Health and Development,* and presented about 30 times at local, national and international meetings. Conference presentations have included posters, oral presentations, invited speaker talks and keynote addresses. Several presentations have been co-created and presented by researchers and families. Although these diffusion strategies (i.e. publications and presentations) are useful for targeting the scientific community, additional knowledge mobilization (KM) strategies are needed to capture the attention of a broader audience, especially the potential knowledge users – families and practitioners.

KM is about bridging research and practice. Depending on the target audience and the type of knowledge being transferred, varied KM strategies are needed to share research findings and move knowledge into action (Davis *et al.* 2003; Strauss *et al.* 2011). Recent advances in the science of KM have transformed our understanding of the dissemination process from a one-way transfer of knowledge by researchers to a collaborative process that involves the exchange of knowledge between researchers and knowledge users (Camden *et al.* 2014). Researchers are now encouraged to involve key stakeholders (i.e., knowledge users) throughout the entire research/KM process. It is believed that engaging knowledge users is likely to facilitate the uptake of knowledge and to address the needs of all partners more effectively (Shikako-Thomas *et al.* 2013; Camden *et al.* 2014).

Acknowledging families as key stakeholders in children's lives, we recruited families that had shown a previous interest in the 'F-words' concepts to be part of an integrated 'F-words in Childhood Disability' research team. Working together, our first goal was to spread awareness of the 'F-words' ideas to a broad audience through an online video. The objectives of this article are to (1) describe the KM process and timeline; and (2) share our findings and key learning outcomes from this family-researcher KM initiative.

Methods

Conceptual Framework

The diffusion of innovation (DOI) theory provided a guiding conceptual framework for this project (Rogers 2003). The DOI theory aims to explain how and why an innovation (or an idea) is adopted (Barth & Sherlock 2003). The four key aspects of this theory are time, communication channels, social systems and the innovation itself (Rogers 2003; Graham *et al.* 2006). Each key aspect was considered when developing and disseminating the video.

KT Process

This project followed a multi-staged KM process and timeline. A PhD student at *CanChild* (AC) acted as the project coordinator and was responsible for organizing and leading all stages of the project. The project was carried out over a five-month time period.

Stage 1: forming the research team

In February 2014, AC invited five families affiliated with *CanChild* who had shown previous interests in the 'F-words' ideas to be part of a research team composed of families and researchers. Four of the five families were enthusiastic and agreed to participate. Families individually decided on their level of involvement in the research group. Example roles included participating in team discussions, providing pictures and quotes to include in the video, giving feedback during video development and disseminating the video.

The final research team can be divided into two groups based on individuals' level of involvement. The primary group consisted of the project coordinator (AC), two researchers (PR, JWG), and two families (DG, DK). These individuals were involved in all stages of the project. The second group included two additional families and a media specialist at *CanChild*, who were not as extensively involved in the project. These families provided feedback during video development and the media specialist was responsible for posting the video on the *CanChild* website.

Stage 2: video development

The 3-minute awareness video combines research evidence with parents' personal reflections to relay the key messages behind the 'F-words' concepts. To ensure accurate information was provided, feedback was sought by the research team throughout the development process. This included iterative rounds of discussion and feedback, until all members were satisfied with the video. The video was developed over a 2-month period (March/April 2014).

Videos are a creative means of displaying information, by which graphic effects, pictures, written words and music can be used to gain attention, provoke emotion and inspire a response (Graham *et al.* 2006). This video used all of these effects to captivate and educate its audience. Written descriptions included parents' reflections of the 'F-words', as well as key points taken from the 'F-words' publication. Families shared personal pictures that represented each of the 'F-words'. The music was chosen by the research team and downloaded from FreeMusicArchive (http://freemusicarchive.org/) – a free website hosting high-quality, legal audio downloads that can be used for making videos. The project coordinator was responsible for creating the video using PowerPoint and iMovie (a free application on Mac Computers used to create videos).

Stage 3: video implementation & dissemination

The video was previewed by *CanChild* KT consultants before being posted on the *CanChild* website. Media specialists created a webpage to host the video and provided a link to the video on the *CanChild* homepage (http://canchild.ca/en/ourresearch/f-words-childhood-disability.asp). While the video was hosted on the *CanChild* website, it could also be viewed on YouTube and was later posted on *CanChild's* Vimeo page, Facebook, and Twitter accounts. The *CanChild* website alone has 5000 visits per week, providing a valuable network for disseminating information.

The video was formally posted on the *CanChild* website on 2 May 2014. Over the following month, various dissemination strategies were used to distribute the video. These included presenting the video during conferences, sending emails to colleagues, friends and family members, and posting the video on social networks. The specific dissemination strategies were not planned ahead of time and thus were sporadically implemented throughout the four weeks following the posting of the video (Table 1). No specific dissemination strategies were implemented during the second month of the evaluation.

< Please insert Table 1 here >

The DOI theory informed our thinking surrounding dissemination strategies, as it offers important insight into how an idea is spread through communication channels. In addition to team-implemented dissemination strategies, the ‘F-words’ video also spread through communication channels external to the research team. While we do not know how many people shared the video or with whom they shared it, the research team was approached on three occasions for permission to share the video on other people’s websites or in professional development sessions. This is an illustration of how the video was disseminated through various social systems.

Stage 4: video evaluation

This project included a two-part evaluation plan. First, to evaluate whether the ‘F-words’ ideas were disseminated to a wide audience, the number of views and location of views was recorded for 2 months, using YouTube and Vimeo analytics. By recording these data, we were able to track the spread of awareness. Second, viewers were asked to complete a brief online SurveyMonkey® (SurveyMonkey Inc., Palo Alto, California, USA) questionnaire (10 questions) after watching the video. The questionnaire was used to gain insights into viewers’ initial perceptions of the video and the ‘F-words’ concepts. Viewers voluntarily completed the questionnaire and all feedback was anonymous.

Results

YouTube and Vimeo analytic data (tracking the spread of awareness)

After a 2-month evaluation period (May/June 2014), there were 715 views of the video (Fig. 1) from over 34 countries around the world (Fig. 2). Following the DOI theory, the spread of awareness slightly resembled an ‘s-shaped curve’ –

slower during week one, significantly increased from weeks 2 to 6, and then reaching a plateau at weeks 7 and 8. The weekly increases in the number of views appeared to correspond with the dissemination strategies implemented by the research team. Weeks where dissemination strategies (i.e., weeks 1, 3 and 4) were used were associated with greater increases in the number of views (Table 1/Fig. 1).

< Please insert Figure 1/Figure 2 here >

Survey responses

While there were 715 views of the video, there were fewer (137) survey responses. The following results are based on these 137 responses.

Respondent demographics

Similar to the viewer location distribution, the majority of people that completed the survey resided in Canada (89%). In order to understand who was viewing the video viewers were asked: 'From what perspective are you viewing the video?' There was a wide distribution of perspectives, with some viewers having more than one perspective (e.g., a physician and researcher; Table 2).

When viewers were asked how they heard about the video, the majority indicated they heard about it from a family member/friend (43%) or colleague (34%). About a quarter of the viewers found the video through online social networks (15%) and by browsing the *CanChild* website (12%).

Viewers' perceptions of the 'F-words' concepts

Of the 137 survey responses, 75 people (55%) indicated that they had not previously heard of the ‘F-words’ in childhood disability. In order to evaluate viewers’ initial perceptions of the ‘F-words’, respondents were asked to rate their initial thoughts of the ‘F-words’ ideas. Overall, 67% of viewers indicated on a five-point scale that they ‘extremely liked the ideas’ and 31% indicated they ‘liked the ideas’, for a total of 98% positive responses. One person indicated they had ‘no opinion either way’ and one person ‘disliked the ideas’. When the viewers were asked if they we were interested in learning more about the ‘F-words’ and if so, how they would like to receive this information, 93% indicated they would like to learn more by receiving information in one or more of the following ways: *CanChild* website (61%), email (53%), social networks (32%), journal publications (25%), workshops (25%) and/or webinars (22%).

Viewers’ perceptions of the online awareness video

To evaluate the effectiveness of the video, viewers were asked to indicate what they liked and disliked about the video. All viewers indicated that they liked at least one component of the video. Overall, items that were rated highest included the content (61%), parent quotes (59%), and length (52%) of the video. In regard to items that viewers disliked, the quantity of words/speed of transitions (21%) and the music (13%) were rated the highest. Table 3 shows the breakdown of what people liked and disliked about the video.

< Please insert Table 3 here >

Open-ended feedback

The majority of viewers liked the video and 88% indicated they would share it with others. The last question of the survey garnered generalized open-ended feedback by asking: 'Do you have any additional comments/ feedback/advice for us?' Sixty-two individuals provided written feedback. Viewers' responses focused on the video content, video format and the use of video as a KM tool (Table 4).

< Please insert Table 4 here >

Discussion

The overall goal of the 'F-words' video was to spread awareness to a wide audience of knowledge users. With a total of 715 views in two months, we were successful in reaching this self-assigned goal in a short period of time. By families and researchers working together, we were able to tailor the 'F-words' message in a medium that allowed the 'F-words' to take *flight* and be available to various communication channels to people around the world.

Recently, there has been increasing emphasis on engaging knowledge users to help craft messages and share research findings (Gagnon 2011; Camden *et al.* 2014). Working with families was a crucial component in the success of this KM initiative. As researchers and families, we brought specific and complementary perspectives and different expertise to the research team. While the researchers had more knowledge on the research and KM process, families had a better understanding of families' knowledge needs, the context, and potential facilitators and barriers that would influence the adoption process.

Families’ ownership of the topic strongly influenced families’ overall commitment to the project. Both the parents in the primary research group and the co-authors of this paper (DG and DK) had previously worked with *CanChild* researchers (PR and JWG) on separate projects to disseminate the ‘F-words’ ideas. Their belief in the potential of the ‘F-words’ ideas to make a difference in the lives of children with disabilities and families and their involvement from the very beginning of the research/KM process (see *CanChild* KT Process Cycle - http://kte.canchild.ca/en/kt-process.asp) both contributed to their dedication to the research team.

A key component to the success of the video was telling the ‘F-words’ story through parent quotes and families’ personal pictures. Families’ acceptance of these ideas added credibility to the ‘F-words’ concepts and the personalization added meaning. Families also played a critical role in sharing the video, as they have their own social networks. Families posted the video on their Facebook and Twitter pages, shared the video with family and friends, and posted video flyers at their children’s schools.

Building an integrated research team takes time and commitment. Recognizing that all team members have busy lives and other commitments, it can be difficult to organize team discussions and get feedback from team members. Having a project coordinator (AC) who was responsible for communicating with all team members and managing each stage of the KM process was crucial to the successful completion of the video in a timely fashion.

In order to truly work as a team, it was also crucial that an inclusive and supportive environment was created. The project coordinator (AC) took the time to develop effective communication strategies with each team member, as well as ensure all team members were provided multiple opportunities to give feedback. All team members were kept up to date with the project's progress through weekly/bi-weekly group emails.

Through this KM initiative, our team faced challenges, but through these challenges, we learned valuable KM lessons. First, in order for a video to disseminate passively amongst members of various social systems, viewers must be 'emotionally' drawn to the video, in turn inspiring/persuading them to share it with others. While our video was thought to be a good piece of KM, viewers made suggestions that would enhance the video to make it 'excellent' and increase the chances of it being spread and adopted. These included changing the music, slowing the transitions and having audio commentary or video clips to accompany the video. Second, active dissemination/publicity strategies are needed to draw attention and spread awareness to a broad audience. As a research team, it is important to plan dissemination/publicity strategies and the timing of these strategies very thoughtfully. Moving forward in KM research, we will ensure that various active dissemination strategies are considered and included early in our research plans. Third, as an integrated research team, it is important to take the time to develop a strong partnership between researchers and knowledge users. Reflecting on our team experience, we believe that effective communication, a collaborative approach and a commitment to the project are key facilitators to successful integrated KM initiatives. While we faced challenges (e.g. time, resources) our team worked well together and it was a positive experience for all members. Having established a strong partnership, we now believe we are in an excellent position to move forward with larger scale projects.

Creating an online video was only the first step in moving the 'F-words' forward into practice. As a feasible and low cost project, the online video allowed us to spread awareness to a wide audience, inspire new ideas, and gather insight into the reception of the 'F-words' concepts, before undergoing a larger KM initiative. As we continue to learn about KM, we encourage researchers and knowledge users to work together, to reflect on their KM experiences and to share their learning outcomes. It is through this communication, collaboration and commitment that we will advance KM science and practice and truly begin to bridge research and practice.

Conclusion

By creating a short and captivating video, we were able to spread awareness of specific concepts to a wide audience in a short time. Engaging families throughout the entire project was a critical factor in the success of our project. We plan to continue working together to build up the 'talk' on the 'F-words' and hope by doing this together, we will move the 'F-words' forward one 'word' at a time.

Key Messages

- Similar to family-centred care, it is important that we recognize families as the experts in children's lives and work collaboratively with families in research and knowledge mobilization.
- Short and captivating online awareness videos are an effective way to spread awareness on a topic to a wide audience.
- The 'F-words' in childhood disability have sparked the interest of a global audience. Action-oriented tools are now needed to support the uptake of the 'F-words' in the lives of children with disabilities and their families.

Acknowledgements

We would like to thank all of the families and researchers at *CanChild* who were involved in this project. Developing, disseminating and evaluating the video was truly a team effort and we greatly appreciate all team members' time and support. A special thank you to the KT and media staff at *CanChild* who previewed the video and made it possible to post it on the *CanChild* website. And finally, thank you to everyone who viewed the video, completed the survey and shared the video with others. By working together, we will continue to make a difference in the lives of children with disabilities and their families.

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Figure 1. Line graph depicting the number of views of the video over a 2-month time period

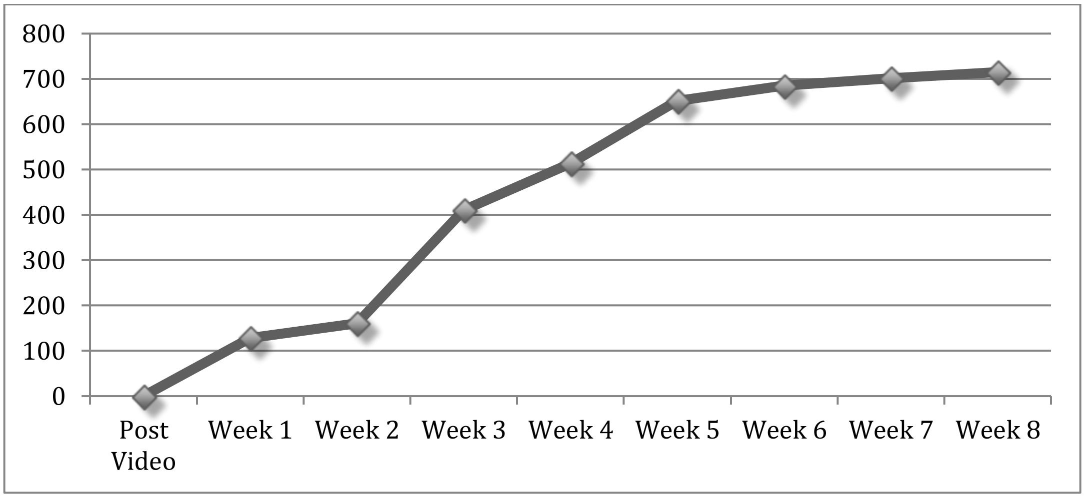

Figure 2. Bar graph showing the countries that had more than five views

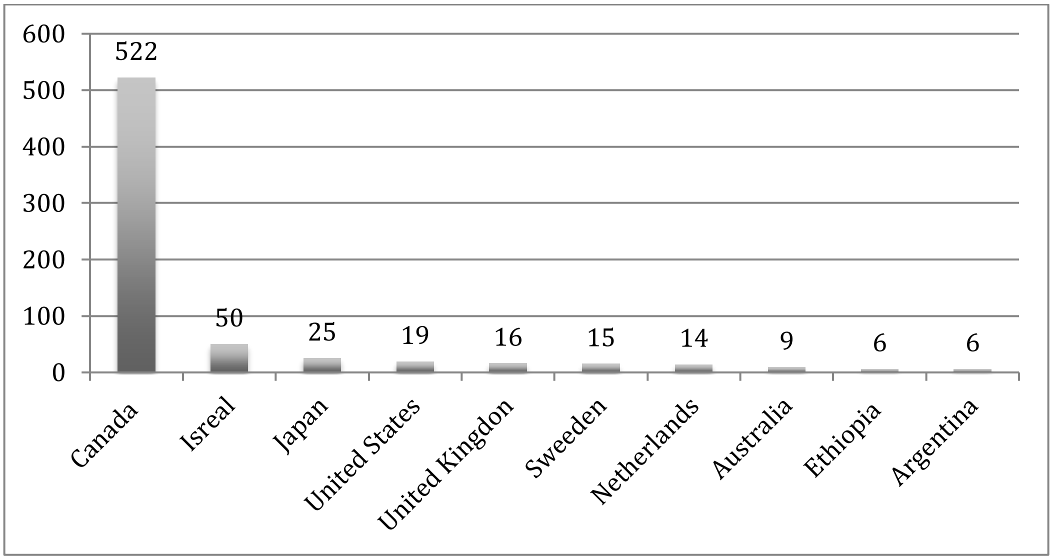

Table 1. Research team-implemented dissemination strategies

Week	**Research team dissemination strategies**
Week 1	• Video posted on *CanChild* Website • Presentations and flyers on video distributed at two local/national conferences on childhood disability
Week 2	• No specific strategies implemented
Week 3	• Emails sent to physician colleagues, McMaster SRS graduate students, CanChild network, affiliated organizations, local school, family and friends
Week 4	• Posted on *CanChild* Facebook and Twitter pages
Weeks 5 – 8	• No specific strategies implemented

Table 2. Distribution of viewers' perspectives*

Viewer perspective	**Percentage of viewers**
Physician	27%
Researcher	26%
Therapist	22%
Educator	18%
Student	16 %
Friend of someone with a disability	15%
Family member of someone with a disability	13%
Other health care workers	8%
Friend/family member of research team	3%
Individual with a disability	1%

*Note: Some viewers had more than one perspective.

Table 3. The breakdown of what people liked and disliked about the video

Item	**Like** ***n* (%)**	**Dislike** ***n* (%)**
Content	84 (61%)	5 (4%)
Parent quotes	81 (59%)	2 (2%)
Length	71 (52%)	4 (3%)
Pictures	56 (41%)	8 (6%)
Graphics	37 (27%)	5 (4%)
Music	36 (26%)	18 (14%)
All of the above	57 (42%)	2 (2%)
None of the above	0 (0%)	72 (55%)
Other	7 (5%)	41 (31%)

Table 4. Open-ended feedback themes with representative quotes

Feedback themes	Sample quotes
Video Content	'Great fun ideas, esp. the focus on holistic child and the importance of staying healthy… the message may be even stronger, more transformational and impactful, if it included at least briefly/or alluded to health/medical aspects of a holistic child and ways parents, developmental pediatricians, and various medical professionals could work together on reaching the impossible…and minimizing child's disability?' (Family member, Researcher)
	'Well done. In our community a great deal of emphasis is put on "is it functional?" by many therapists…therapists seem to forget they are children and should play, have fun, experience childhood as other "able bodied children"…. Too much emphasis on therapy.' (Parent Support Group Facilitator and Community Developer)
	'Great video, will make me view childhood impairments in a different and more positive way.' *(*Physician)
Video Format	'Great work! The quotes are powerful and the important messages come through in an accessible way. The video is the right length too.' (Researcher, Therapist, Educator)
	'The pace was too quick for a "read only" format accompanied by one small photo (when viewed on a tablet photos are really small) – more time is needed to absorb each of these important concepts.' (Therapist, Educator)
	'I think it would be more effective if you didn't have to read everything. Perhaps the quotes should alternate with a voiceover of an individual or parent reading what the quote says while the viewer looks at the picture.' (Family member)
Video as a KM tool	'I will likely send to all of our parents. And I will ask the staff to watch and send feedback to you. I will send to new enrolling families with our intake package that we revised based on the F words. Can you tell I am really excited by this approach/philosophy?*'* (Therapist, Educator)
	'This is going to be an awesome way to start my Pediatric PT course in the spring semester. I love the short and sweet video that delivers an awesome message for novice therapists to remember! Thank you for this.' (Researcher)

Appendices

Appendix A. The ‘F-words’ in Childhood Disability: Awareness Video Feedback
Link to live survey: F-words Awareness Video Survey

1. **In what country do you currently reside?**

2. **Are you viewing this video as: (Please check all that apply.)**
    - ☐ Family Member
    - ☐ Friend of someone with a disability
    - ☐ Researcher
    - ☐ Student
    - ☐ Therapist
    - ☐ Physician
    - ☐ Educator
    - ☐ Other (please specify)

3. **How did you hear about this video? (Please check all that apply.)**
    - ☐ Friend/Family member
    - ☐ CanChild website
    - ☐ Internet/Google
    - ☐ Social Networks
    - ☐ Other (please specify)

4. **Have you previously heard of the ‘F-words’ in childhood disability?**
    - ☐ Yes
    - ☐ No

5. **What are your initial thoughts on the ‘F-words’ ideas?**
    - ☐ Extremely like the ideas
    - ☐ Like the ideas
    - ☐ No opinion either way
    - ☐ Dislike the ideas
    - ☐ Extremely dislike the ideas

6. **If you were interested in learning more about the ‘F-words’, how would you like to receive this information? (Please check all that apply.)**
    - ☐ Email
    - ☐ CanChild Website
    - ☐ Social Networks: Facebook, Twitter
    - ☐ Journal Publications
    - ☐ Workshop
    - ☐ Webinar

- ☐ Other (please specify)

7. **What did you like about the video? (Please check all that apply.)**
    - ☐ Length
    - ☐ Content
    - ☐ Pictures
    - ☐ Parent Quotes
    - ☐ Music
    - ☐ Graphics
    - ☐ All of the above
    - ☐ None of the above
    - ☐ Other (please specify)

8. **What did you not like about the video? (Please check all that apply.)**
    - ☐ Length
    - ☐ Content
    - ☐ Pictures
    - ☐ Parent Quotes
    - ☐ Music
    - ☐ Graphics
    - ☐ All of the above
    - ☐ None of the above (I liked everything)
    - ☐ Other (please specify)

9. **Will you share this video with others?**
    - ☐ Yes
    - ☐ No

10. **Thank you for taking the time to complete this survey. Do you have any additional comments/feedback/advice for us? Please share this video to increase awareness.**

CHAPTER THREE:

GETTING CHILDREN'S HEALTH RESEARCH INTO FAMILIES' HANDS: A SCOPING REVIEW OF KNOWLEDGE TRANSLATION STUDIES TARGETING FAMILIES OF CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS IN CANADA

Introduction to Chapter Three

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Summary: This study targeted ***Step 3 of the action cycle*** (***assess barriers to knowledge use***). From the online awareness video project (Chapter 2) we learned that people wanted to know more about the 'F-words' concepts, but we were not clear regarding the best ways to do this. A scoping review was conducted to: i) help us better understand what knowledge translation (KT) strategies have been used to translate health research evidence to families of children or youth with special health care needs; and ii) explore the types of evaluations conducted and the associated outcomes. A secondary aim was to identify any reported barriers/facilitators to transferring research to families.

Through a preliminary search of the literature we identified scoping/systematic reviews that were published on KT strategies targeting health care professionals, but for the most part reviews on KT strategies targeting patients and families were missing. To the best of our knowledge, this is the first review to summarize the literature on KT strategies that directly target families of children and youth with special health care needs.

Through our search strategy, we identified six articles that met our inclusion criteria. All of the studies were conducted between 2005 – 2015, in Canada, and evaluated educational materials. The materials included: lay research summaries, educational sheets, storybooks, and a video. The type of evaluation varied across studies: three studies monitored conceptual knowledge use (i.e., change in knowledge, attitudes, and intent to change behaviour); five studies used process evaluations (i.e., evaluated parents' perceptions and satisfaction with the KT materials); one study included an observational evaluation; and one study used an experimental evaluation.

Overall, the educational materials were deemed to be useful and important to families and confirmed that families want access to health research evidence through tailored KT strategies. Key KT recommendations were: i) involve knowledge users throughout the KT process; ii) use active multi-faceted KT strategies; iii) create engaging and user-friendly materials. Findings from the scoping review helped to inform our KT intervention (i.e., development of an online KT resource) and evaluation strategy (i.e., step-wise evaluation) (see Chapter 4). With only six published studies, it also confirmed the gap in evidence in this area and the need for more KT science.

Abstract

Objective: As partners in their children's health care parents need access to evidence-informed information. This scoping review mapped current knowledge translation (KT) strategies to disseminate research to families of children and youth with special health care needs (CYSHCN).

Methods: Arksey and O'Malley's (2005) framework guided this review. Electronic databases, reference lists of relevant articles, and CIHR's KT Grants (2014 – 2016) were searched for studies. Studies must have been conducted in Canada, written in English, published 2002 – 2016, and described/evaluated KT interventions targeted to families of CYSHCN.

Results: Twenty-five articles (of 804 identified) were accessed and six were included. All evaluated educational materials by monitoring knowledge use (n = 3) or processes (n = 5). Overall, the interventions were deemed to be useful and important to families.

Conclusion: This review reports how Canadian researchers are disseminating and evaluating KT strategies for families of CYSHCN. With only six published studies, there is a clear need to advance this field.

Practice Implications: Patients and families are getting more involved in health care and health research, thus there is a need for the development of KT tools to better inform, educate and engage patients. Equally important is the evaluation of these efforts. **Keywords:** knowledge translation; patient engagement; educational materials; family-centred service; scoping review

Introduction

Family-centred service (FCS) is considered a best practice in children's health care [1-3]. Built on the philosophy and belief that families know their children best, FCS requires health care providers (HCPs) to collaborate with families on health care plans and decision-making [3-5]. Sharing this responsibility means that both HCPs and families must be aware of the latest health research evidence to make informed decisions.

Unfortunately, there is often a lengthy gap between what is *known* from research and what is *done* in practice [6-8]. HCPs and consumers (i.e., patients and families) cannot easily find, utilize and benefit from advances in research [9,10]. Hence, knowledge translation (KT) has emerged as a key construct in health research in Canada [11,12].

KT is the process of bridging research and practice, and includes all steps between 'knowledge generation' and 'knowledge application' [6,13]. Traditional KT strategies involved journal publications and conference presentations at the end of a research study, directed to professionals. We now recognize that these strategies are not sufficient to move knowledge into action, and that more active targeted strategies are needed [13,14].

Multiple terms are used to describe the translation process, including knowledge mobilization, knowledge transfer and exchange, and knowledge utilization [6,15]. In this paper, we refer to 'knowledge translation', the term formally accepted by the Canadian Institutes of Health Research (CIHR) and most often used in Canada [13]. CIHR defines KT as "*a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system*" [16].

At *CanChild* Centre for Childhood Disability Research in Hamilton, Ontario our research team is specifically interested in KT strategies that directly target families (i.e., parents/caregivers) of children and youth with special health care needs. These include children or youth with chronic health conditions, long-term intellectual or physical impairments, or temporary illness. We believe that parents and caregivers, as primary stakeholders in their children's health care, deserve full access to research findings, using appropriate KT strategies to do this [17,18]. A preliminary review of the literature revealed that while the majority of KT research has focused on how to transfer research effectively to HCPs [19-21], researchers are beginning to expand their dissemination efforts and evaluate KT strategies that directly target families. In this emerging area of KT Science, it is important to understand what strategies have been used, tested and shown to be effective.

This paper reports findings of a scoping review to map the breadth and nature of KT strategies used and studied to disseminate health research to families of children and youth with special health care needs. We focused on KT studies conducted in Canada as this country is recognized for its leadership and innovation in the field of KT [22,23]. We were especially interested to explore the

Canadian context and understand how researchers in our country have been implementing and evaluating KT strategies that target family stakeholders. The primary objectives of this scoping review were to: (1) identify and describe the KT strategies being used to disseminate health research to families of children and youth with special health care needs in Canada; and (2) explore the evaluation strategies and current state of evidence supporting these KT strategies. A secondary objective was to identify the barriers and facilitators perceived to influence the translation process.

Methods

Scoping reviews are particularly useful in emerging fields where randomized controlled trials are lacking and various other evidence exists of variable quality and methodology [24, 25]. Unlike systematic reviews, scoping reviews do not assess the quality of the included studies, and thus a range of study designs in both published and grey literature may be included. Arksey and O'Malley's [24] methodological framework for conducting scoping studies guided this review. The steps include: identifying the research question; identifying relevant studies; selecting studies; charting the data; collating, summarizing, and reporting the results. Ethics approval was exempt as no human data collection was required.

Identifying the Research Question

The research question guiding this review was: **What is the current state of science and evidence in Canada surrounding KT strategies used to translate health research directly to families of children and youth with special health**

care needs? Specifically, we wanted to know: i) What types of KT strategies are used? ii) How are these KT strategies evaluated? iii) What are the main findings, including the perceived barriers and facilitators to translating health research to families?

Identifying Relevant Studies

The published literature was searched through the CINHAL and OVID electronic databases, and OVID includes Medline, EMBASE, and PsychInfo (Strategy 1). A list of the keywords and search terms can be found in Table 1.

< Please insert Table 1 about here >

The reference lists of included articles from Strategy 1 and systematic reviews that appeared to be related to the topic were then searched for relevant articles (Strategy 2). Lastly, CIHR's Knowledge to Action, Knowledge Planning & Dissemination, and Patient Oriented Research Grants Funding Decisions (2014–2016) were searched for recently-funded KT projects related to disseminating health research to families of children and youth with special health care needs (Strategy 3). For projects that appeared to be relevant to our topic, a Google search was performed to find more information using the Principal Investigator's name and project title.

Study Selection

Studies were included in the final review if they met the following inclusion criteria: (1) written in English; (2) published 2002 – 2016; (3) conducted in

Canada; (4) described a KT intervention with the primary purpose of disseminating health research; (5) evaluated the KT intervention; (6) primary target audience included families (parents/caregivers) of children and youth with special health care needs; and (7) full article was available (conference abstracts/research summaries were not included). Qualitative and quantitative studies were included, but opinions/commentaries were excluded.

Charting the Data

All articles that met the inclusion criteria were read in their entirety. A data charting form was piloted with three articles and required only minor refinements. Data were extracted by one reviewer (AC) and checked by second and third reviewers (KR, SZJ). Two data forms (describing the study characteristics and the evaluation strategy) were used to chart the data of the published studies. In addition, a separate data form was used for the KT interventions currently in progress in Canada.

Collating, Summarizing, and Reporting the Results

Thematic analysis addressed the research questions (i.e., types of KT strategies, evaluation methods, and main findings/facilitators and barriers). Trends and differences across studies were explored, though no statistical analyses were undertaken. Emerging themes were discussed with team members to provide new perspectives to the interpretations and to ensure clarity and consistency of the final results.

Results

Three search strategies were used to identify relevant articles (Figure 1): Strategy 1 revealed 773 potential articles, and Strategies 2 and 3 identified another 31 potential articles. Of the 804 articles, 779 were considered ineligible, while 25 full-text articles were read in entirety. In the end, six studies met all our inclusion criteria. Reasons for excluding articles included that the primary focus was not on evaluating KT strategies for transferring health research to families of children and youth with special health care needs (N= 6); the articles were systematic reviews/protocols (only initially included to search for relevant articles in the reference lists) (N= 7); or there was no full peer-reviewed publication (N= 6).

< Please insert Figure 1 about here >

The included studies were published between 2005 and 2015. All were conducted in Canada and the primary target audience included families of children and youth with special health care needs. Three studies indicated multiple target audiences, including health care professionals [26-28], educators [28], industry providers [26], and researchers [28]. Three articles were part of one study that explored the development and evaluation of three storybooks to deliver health evidence to parents of children with croup presenting to the emergency department [29-31]. All the studies came from two childhood disability research centres in Canada – *CanChild* Centre for Childhood Disability Research at McMaster University in Hamilton, Ontario [26-28], and Evidence in Child Health to enhance Outcomes (ECHO) Research Program at the University of Alberta in

Calgary, Alberta [29-31]. In addition to the published literature, three KT projects were found that are currently in progress in Canada, two of which are also being conducted at ECHO.

What type of KT interventions are used?

All six studies developed and evaluated educational materials [26-31]. We used Cochrane's Effective Practice and Organization of Care (EPOC) taxonomy definition of educational materials: "*published or printed recommendations for clinical care, including clinical practice guidelines, audio-visual materials, and electronical publications*" [32]. Educational materials included educational sheets/research summaries [26,27], storybooks [29-31], and an online awareness video [28]. Table 2 provides a description of each KT intervention.

< Please insert Table 2 about here >

Of the three projects currently in progress in Canada, two studies involve the development and evaluation of electronic tools (e-tools) including animation whiteboards and eBooks [33]. The third study uses an integrated knowledge translation approach by partnering families within the Hirschsprung's Disease (HD) social media community with clinicians and researchers to explore families' information needs related to caring for a child with HD. The information needs and KT preferences of the families will inform the KT strategies eventually utilize (Table 3) [34].

< Please insert Table 3 here >

How are these KT interventions evaluated?

Of the six studies, three used quantitative methods [26,27,31], two were qualitative studies [29,30], and one used mixed methods [28]. Of the quantitative studies, two were descriptive evaluations [26,27] and one used an RCT [31]. The qualitative studies were both part of the same research program (i.e., evaluating the storybooks) as the RCT. One qualitative study was conducted to explore parents' perceptions of the storybooks during the development process [29] and the other qualitative study explored parents' experience using the storybooks after the RCT intervention [30].

According to Graham and colleagues' [6] knowledge-to-action (KTA) framework, evaluating KT interventions includes both: (1) monitoring knowledge use; and (2) evaluating outcomes. 'Monitoring Knowledge Use' examines ***how*** knowledge is being used by the target audience. Several models have been proposed to classify knowledge use; we used Graham and colleagues' [6] definitions of *conceptual knowledge use* (i.e., changes in knowledge, understanding, or attitudes), and *instrumental knowledge use* (i.e., changes in behaviour) to classify the types of knowledge use being evaluated.

Three of six studies monitored *conceptual knowledge use* [26,27,30]. In Teplicky et al. [26] and Law et al. [27], one section of the evaluation form included 'Impact' questions that measured changes in knowledge, attitudes, and anticipated usefulness of the KT products. Scott and colleagues [36] used semi-structured interviews to examine parents' perceptions of the effectiveness of the storybooks, which included exploring their perceived change in knowledge and attitudes. The remaining three studies did not monitor change in knowledge use, and no studies were believed to measure *instrumental knowledge use.*

The next step in the KTA cycle, 'Evaluating Outcomes', explores the impact of the intervention [6]. Similar to the different categories of knowledge use, there are different levels and types of evaluation. The *level of evaluation* depends on the target audience (i.e., patient, provider, system) and the *type of evaluation* depends on the research question (i.e., experimental, observational, process).

Five of six studies used process evaluations to assess study outcomes. These evaluations mainly examined parents' perceptions of the educational materials (e.g., evaluated the content, format, impact) [26-30] and experience using the educational materials (e.g., what made the KT products effective and how were the products used) [28,30]. These evaluations were primarily used as a first step of the evaluation process, with two research teams indicating they could use the information to revise/enhance the materials before further evaluation is conducted [28,29]. The storybook intervention is an example of a step-wise evaluation process, as first the process level evaluation was completed [29], followed by observational and experimental evaluations [30,31]. The observational evaluation explored parents' perceived outcomes from using the storybooks (e.g., how the books impacted how they feel) [30], while the experimental evaluation examined the impact of storybooks in comparison to traditional information sheets on parent outcomes such as anxiety, clinical status, and decisional regret [31]. Both the observational and experimental evaluations assessed outcomes at the level of the patient (Table 4) [30,31].

< Please insert Table 4 about here >

What are the main findings, including the perceived barriers and facilitators to translating health research to families?

All educational materials were viewed positively and were deemed by parents to be useful [26-31]. Overall, the lay research summaries and educational sheets were rated highly on format, content, and impact [26,27]. Both studies had a variety of stakeholders (e.g., parents, clinicians, students, etc.) evaluate the educational materials. In both studies [26,27], no significant between-group differences were found in regard to impact of the materials (i.e., all groups rated the materials highly and perceived them to be useful).

Furthermore, parents' perceptions of the storybooks were also largely positive [29-31]. During the initial focus groups, parents shared that they found the stories interesting and easy to read, and the information to be helpful. One recurring theme was the importance of the reader being able to relate to the stories and identify with the characters [29]. Parents participating in the semi-structured interviews shared this sentiment [30]. After using the stories as part of the RCT, parents expressed that the stories helped them better understand the treatment of croup, in turn helping them feel reassured, reducing their uncertainty, normalizing the experience, and increasing their feelings of empowerment [30]. Despite parents' positive perceptions of the storybooks, Hartling et al. [31] found no significant difference in level of anxiety between the intervention group (i.e., storybooks) and the control group (i.e., standard informational sheets). The only two items that differed significantly between groups were parents' decision regret regarding the decision to go to the ED, and shorter time to symptom resolution, with parents in the storybook intervention showing significantly greater decision regret and shorter time to symptom resolution [31].

Lastly, the awareness video created by Cross and colleagues [28] was found to be an effective strategy to spread awareness to a wide audience. In two months, there were 715 views of the video from over 34 countries. Findings from the anonymous online questionnaire revealed that 98% of 137 viewers who completed the survey 'extremely liked'/'liked' the content of the video and 88% indicated they would share the video. A recurring theme from the open-ended feedback was the importance of viewers to be emotionally drawn to the video.

Perceived Barriers and Facilitators to Translating Health Research to Families

The papers included in this scoping review did not primarily focus on understanding the barriers that influence the translation of health research knowledge. Three papers did not report any barriers [26,27,31]; two that did so identified limited time and resources as barriers to creating the KT products [28,29]. Hartling et al. [29] also reported that one of their main challenges when creating the storybooks was ensuring they were generalizable and applicable to a wide audience. Lastly, in terms of evaluating the KT products, three studies reported recruitment of parents to participate in the studies as a barrier [28-30].

In contrast to limited recognition of the barriers, attention was given to the facilitators perceived to influence the translation of the health research to families. Researchers commented on a range of facilitators, which we have synthesized into two main themes: i) *format & content of the educational materials*; and ii) *a multi-faceted and integrated KT strategy.*

The *format and content of the educational materials* were perceived to be key facilitators in all six studies [26-31]. In particular, parents stated that it was important that the materials were user-friendly (e.g., clear and understandable) [26-31], engaging (e.g., creative, using stories, pictures, etc.) [26-31], accessible (e.g., succinct, portable, and available for free) [26-31], credible [29–31], and triggered an emotional response (i.e., facilitated through combination of evidence-based information and stories/experiences) [28–31]. Additional facilitators were identified with regard to format and content, but these were the key facilitators mentioned on multiple occasions.

Several studies indicated the importance of *involving end-users/stakeholders* throughout the project [28-31] and using a *multi-faceted* approach to knowledge dissemination [27,28]. One reason involving end users was believed to be important was to ensure that the project met the needs and preferences of the end users (in turn increasing the potential impact) [28-31]. Multiple studies also identified that end-users' involvement was critical to the design and creation of the educational materials [28-31]. Active multi-faceted dissemination strategies were recommended in order to share and increase the use of the educational materials (e.g., use of social media and/or educational materials in combination with educational workshops) (Table 5) [27,28].

< Please insert Table 5 about here >

Discussion and Conclusion

Discussion

This scoping review aimed to map the breadth and nature of KT strategies being implemented and evaluated in Canada to disseminate health research to families of children and youth with special health care needs. To the best of our knowledge, this is the first review to focus on KT strategies that specifically target families of children and youth with special health care needs. While researchers have completed other reviews of KT strategies, most reviews have targeted health care providers [20,21,30], or focused on a specific KT strategy, for example the use of tool kits [35], arts-based approaches [36], mentoring [37], and educational outreach [38].

In 2016, two reviews explored KT strategies that target patients and their families [39, 40]. While Gagliardi and colleagues' [39] target population (i.e., adult patients with arthritis or cancer) differed from ours, Albrecht and colleagues' [40] also explored KT tools for parents. Key differences in Albrecht et al.'s [40] scoping review, in comparison to this review, are that the population was inclusive of all child health topics, international studies were included, years of publication (1985 – 2011) differed, feasibility/usability studies were excluded, and only one KT strategy (i.e., KT tools) was explored. None of the studies identified in Albrecht et al.'s [40] review overlapped with the studies included in this review. Thus, despite the small sample size, our review both complements and extends the existing knowledge syntheses on KT interventions targeting family stakeholders.

All studies included in our scoping review evaluated educational materials. Interestingly, there appears to be a shift in format of the educational materials that are currently being studied. While the majority of studies in our review evaluated paper-based educational materials [26,27,29-31], all three studies identified that are in progress in Canada are evaluating online educational strategies (including e-books, animated whiteboards, and social media strategies) [33].

Subsequent to our scoping review data collection (February 2017) one of the studies currently in progress was completed and a manuscript has been published [41]. Overall, the researchers found that parents' perceptions of the online educational resource (i.e., an e-book on pediatric chronic pain management) were positive and, similar to the paper-based educational tools, parents stated they preferred the narrative storytelling format compared to standard information sheets. No specific evaluation was completed comparing paper-based tools to online methods. However, with the advancements in online technology and society's growing comfort and expectation of online education, the transition to online materials is understood [42,43].

Furthermore, another key theme that emerged was the similar purpose and goals for the educational interventions. Using Coulter and Ellins' [44] framework for classifying patient-direct KT interventions (i.e., to improve *health literacy*, *clinical decision making*, *self-care*, and *patient safety*) we identified that all of the educational materials aimed to improve ***health literacy***. According to Coulter and Ellins [44], health literacy is "*central to enhancing involvement of patients in their care*." Thus, we can hypothesize that not only can educational materials improve families' health literacy, but the resources can also be used to foster communication and collaborative decision-making between HCPs and families. In turn, this supports a family-centred approach, which has been shown to improve parents' satisfaction with care [2,4]. As such, we believe that educational materials have the potential to enhance the quality of care and health outcomes for patients and families [44].

Coulter and Ellins [44] also provide a useful framework for classifying outcomes of patient-focused interventions. The framework includes four categories: patients' knowledge, patients' experience, use of services and costs, and health behaviour/health status. The studies included in our review mainly evaluated impact on parents' knowledge (n= 4), and two studies evaluated impact on parents' experience. The disparity of outcomes measured across categories is likely due to the fact that our review included mostly process evaluations (evaluating parents' perceptions and satisfaction with the KT materials). Coulter and Ellins' [44] framework draws our attention to the spectrum of outcomes that should be measured, and also provides a way to categorize outcomes. Hopefully, implementation of this framework will help standardized patient-focused interventions allowing for better comparisons across studies in the future. Albrecht and colleagues [40] used Coulter and Ellins' [44] framework and reported that it helped to classify the outcomes of the studies and "reduce the noise".

Overall, all educational interventions reviewed here were deemed to be useful and important to families. The findings highlight that families want access to health research evidence via tailored KT strategies. This review provides preliminary insight into how this is being done in Canada and the utility of the identified KT strategies. Lastly, across the six studies multiple KT recommendations were provided, which should be considered when planning future KT interventions. We believe the three key 'take-away' recommendations are: 1) involve knowledge users throughout the KT process; 2) use active multi-faceted KT strategies; and 3) create engaging and user-friendly materials.

Limitations and Future Research Directions

It is important to identify the limitations of this review. One is that three of the six articles included were part of one study exploring the development and evaluation of storybooks [29-31]. While the same storybooks were used in each article the participants and purpose of the studies varied. Second, all six studies came from only two childhood disability research centres. While other research centres are implementing KT strategies to share health research evidence with families, many are not yet evaluating the KT strategies and/or publishing their experiences and findings. Third, this review is limited to KT studies conducted in Canada. The fact that the large number of studies identified in the Albrecht et al. [40] review were not included in our review indicates that more can be learned from exploring studies beyond Canada and within the field of child health at large. Fourth, most of the studies included in this review were process evaluations. Further research is needed to explore the impact of these KT strategies on parent/caregiver' outcomes (such as knowledge, experiences, use of services/costs, and health behaviour/outcomes). Lastly, our search strategy may not have identified all relevant studies, and a more thorough exploration of the grey literature should be conducted in the future. The limited sample size and paucity of literature on this topic also must be recognized as a limitation.

With increasing emphasis placed on how to move research evidence into practice, this review provides critical insight into an area of research that is not well understood. As we continue to move towards patient-oriented research in Canada [45], we hope to see more active and purposeful strategies being used to share – and evaluate the impact of – health research with patients and their families. While we believe that this review adds to the literature, future updates to this review will be needed within the next few years as the number of research studies on KT interventions continues to increase.

Conclusion

Despite advances in our understanding of KT, there remains a ‘black box’ surrounding family-focused KT interventions (i.e., many unknown factors that contribute to successful interventions). In an era when evidence-based health care is increasingly expected, it is vitally important that we evaluate the impact of our KT activities. Mixed-methods study designs may be helpful for understanding *why* KT strategies work or not, *how* the implementation process works, and *what* the effectiveness outcomes mean for consumers, clinicians, and health organizations at large [23]. In the future, we encourage researchers to critically expand, and then explore and evaluate, their KT strategies and share lessons learned.

Practice Implications

We are entering a new era in regards to how research is conducted and disseminated. In the field of childhood disability, patients and families are getting more involved in both health care and health research. With these advancements, patients and families are advocating for the development and implementation of knowledge-based tools to better inform, educate and engage patients and as such we must rise to the occasion.

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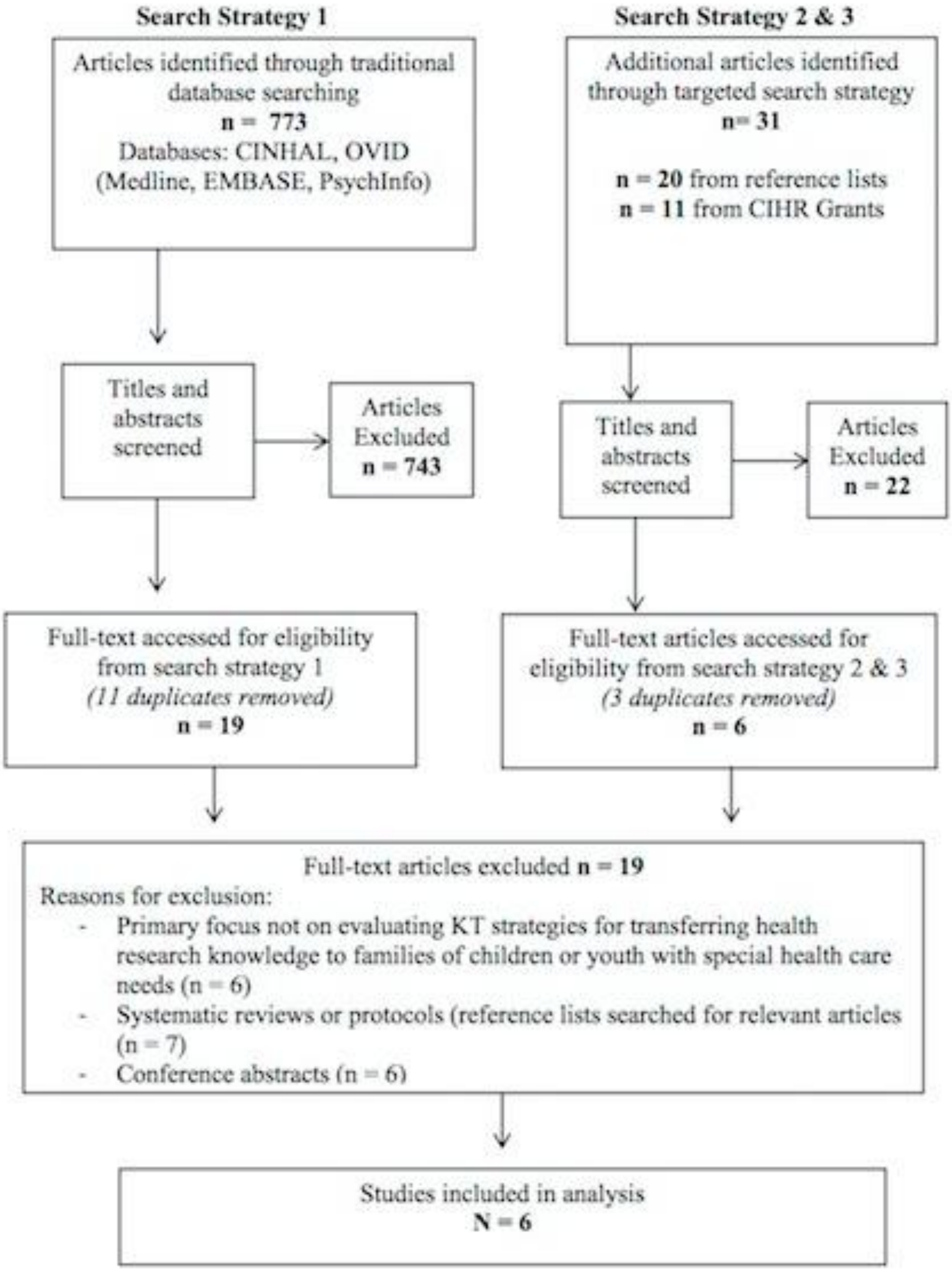
Figure 1. Search Strategy



Reasons for exclusion:

- Primary focus not on evaluating KT strategies for transferring health research knowledge to families of children or youth with special health care needs (n = 6)
- Systematic reviews or protocols (reference lists searched for relevant articles (n = 7)
- Conference abstracts (n = 6)

Table 1. Search Strategy 1 Keywords and Subject Headings

POPULATION	CONCEPT	CONTEXT
“parents of disabled children”, “child, disabled”, “family”, “caregivers”, “parents”, “pediatrics”	“knowledge trans*”, “knowledge translation”, “knowledge mobilization”, “knowledge mobil*”, “implementation science”, “research dissemination”, “social media”	“health service research”, “health research”

Table 2. KT Intervention Characteristics

Year [Ref]	**EPOC Intervention *(KT Product)***	**Target Audience**	**Content Area**	**Study Design *(Participants)***	**Data Collection Methods *Data Collection Tools***
2005 [26]	Educational Materials *(Lay Research Summaries)*	Parents of children with brain injury, service providers, insurance industry representatives	Rehabilitation interventions for children with brain injury	Quantitative Descriptive Study *(N =48; 18 parents of children with brain injury, 18 service providers, and 12 insurance industry representatives)*	Participants randomly assigned one of three packages each containing two research summaries and completed an *evaluation form (13 questions, 7-point Likert scale)* on each summary.[a]
2005 [27]	Educational Materials *(Educational Sheets)*	Parents of children with a developmental disability, service providers, health science students	Family Centred Service (FCS)	Quantitative Descriptive Study *(N =36; 12 families, 12 service providers, and 12 rehabilitation science students)*	Participants randomly assigned one of six educational packages, each containing three FCS educational sheets and completed an *evaluation form (12 questions, 7-point Likert scale)* on each educational sheet.[b]
2010 [29]	Educational Materials *(Storybooks)*	Parents of children with croup	Treatment of croup	Qualitative Descriptive Study	Data collected in two phases. Phase I, *semi-*

		presenting to the emergency department (ED)		*(Phase 1: N = 10 people; Phase 2: N=8 parents)*	*structured interviews* with variety of participants on initial five stories. Phase II, *focus groups* with parents on final three revised stories.
2012 [30]	Educational Materials *(Storybooks)*	Parents of children with croup presenting to the ED	Treatment of croup	Qualitative Observational Study *(N = 23 parents)*	This study complements Hartling et al. [31] RCT. Participants assigned to storybook intervention participated in follow-*up semi-structured interviews*.
2013 [31]	Educational Materials *(Storybooks)*	Parents of children with croup presenting to the ED	Treatment of croup	Quantitative Experimental Randomized Controlled Trial (RCT) *(N= 413; 208 parents received storybooks, and 205 parents received standard sheets)*	Parents randomized to receive storybooks or standard information sheets during ED visit. *The State-Trait Anxiety Inventory (20 questions, 4-point Likert scale)* measured change in anxiety between triage to ED

					discharge *(primary outcome)*. Follow-up interviews conducted at 1- and 3-days post-discharge and then every other day until 9 days or symptoms resolved and at 1 year. *Secondary measures* completed at various time points included *telephone outpatient score for clinical status (TOP), impact of event score (IES), parent knowledge & satisfaction questionnaires, parental decisional regret scale, and parent self-report interview questions.*
2015 [28]	Educational Materials *(Online Video)*	Broad Audience - Families, Service Providers, Educators, Researchers,	Modern themes in childhood disability	Mixed-Methods Descriptive Study (*N = 137 people)*	*Google analytics* recorded number & location of views over 2-months. Viewers asked

		Children, Youth			to complete an *anonymous 10-question online survey, which included open- and close-ended questions.*

[a] The evaluation form was adapted from another study conducted by members of the research team (Law & Rosenbaum, unpublished data, 2004).
[b] The evaluation form was adapted from (Teplicky, 2005) study.

Table 3. Currently Funded KT Projects being conducted in Canada.

Project Title ***(Primary Investigator)***	**Content Area** ***(Target Audience)***	**EPOC Intervention** ***(KT Product)***	**Project Description**
Developing E-tools for parents of children with croup and gastroenteritis *(Shannon Scott)*	Croup and gastroenteritis (*Parents)*	Educational materials (*Animation Whiteboards, eBooks*)	Work with parents and other decision makers to develop, implement and evaluate the usability of 3 innovative KT tools (Animation whiteboards, eBooks). Social media (e.g., Internet, Twitter, Facebook) will be used for widespread implementation.
E-book for Parents of children with chronic pain (*Shannon Scott)*[a]	Chronic Pain *(Parents)*	Educational materials (*E-book*)	This study used a multi-method approach to design and evaluate an e-book. The process included: semi-structured interviews with children and their parents; using interview information to create an e-book; share resource with pediatric chronic pain experts to ensure evidence accuracy; test for usability by parents and children; and dissemination of e-book.
Shit Happens: an iKT project in HD *(Kristy Wittmeier)*	Hirschsprung's Disease (HD) *(Families)*	Not yet determined	Families and pediatric surgeons have been surveyed and top information needs have been identified. The research team is now searching the literature that addresses the identified issues. Using standardized approaches, this evidence will be reviewed, evaluated, and summarized to share with caregivers and back to the surgeons.

[a]Subsequent to scoping review search (conducted February 2017), this project has been completed and a manuscript has been published Reid et al. [46]

Table 4. Evaluation of KT Interventions

Year [Ref]	**Type of Knowledge Use**	**Type of Evaluation** *(Level of Evaluation)*	**Main Findings**
2005 [26]	**Conceptual:** Impact questions measured changes in knowledge, attitudes, and anticipated usefulness of the research summaries.	**Process Evaluation** *(Patient + Service Provider):* Rated the research summaries on familiarity, format, content, and impact.	Research summaries were found to be useful to all groups. No significant differences were found between target audiences' ratings on format, content, and impact. Ratings for format and content were high (avg. 5.0 -6.9 of 7-point scale), with impact ratings slightly lower (avg. 4.7 – 5.0). Correlations found between format, content, and impact (i.e., when format and content ratings higher, so was impact).
2005 [27]	**Conceptual:** Impact questions measured changes in knowledge, attitudes, and anticipated usefulness of the educational sheets.	**Process Evaluation** *(Patient + Service Provider):* Rated the educational sheets on familiarity, format, content, and impact.	Educational sheets were found to be important to all groups. No significant differences were found between target audiences' ratings on format, content, and impact (all high overall means above 5.0 on a 7-point scale). Each group reported materials had impact on knowledge, thinking and intention to change behavior.
2010 [29]	Nil	**Process Evaluation** *(Patient):* Provided feedback on perceptions of the stories (including general perceptions,	General perceptions were mostly positive, but one parent concerned about the cost.

		content, emotional response, presentation style, and clarity).	Parents found the stories interesting, easy to read, and found the informational helpful (informative and provide emotional reassurance). Parents felt it was important to identify with the stories (characters and content). Parents liked the presentation style – pictures, layout, first person narrative, catchy titles, etc.
2010 [30]	**Conceptual:** Interviews explored parents' perceptions of the effectiveness of the storybooks (changes in knowledge and attitude).	**Process Evaluation** *(Patient)*: Described the characteristics of stories that make them effective for knowledge transfer and developed a rich description of how parents used the stories. **Observational Evaluation** *(Patient):* Explored parents' perceived outcomes from using the storybooks.	Parents' perceptions of the storybooks were largely positive. Stories accurately reflected their own experiences, were engaging, easy to read/succinct, and informative. Parents consistently reported four outcomes associated with using the storybooks: feeling reassured, reduced uncertainty, normalization of the experience, and feeling of empowerment.
2013 [31]	Nil	**Experimental Evaluation** *(Patient)*: Primary outcome measured was change in anxiety between triage to ED discharge. Secondary outcomes included: expected future anxiety, event impact, parental knowledge, satisfaction, decision regret, healthcare utilization, time to	No significant difference in anxiety (primary outcome) between groups (p=0.78). Storybook group showed significantly greater decision regret regarding decision to go to ED (6.7% vs. 1.5%, p < 0.001) and shorter time to resolution of symptoms (mean 3.7 days vs. 4.0 days, p=0.04).

		symptom resolution.	No other significant differences found.
2015 [28]	Nil	**Process Evaluation** (*Patient + Service Provider*): Survey explored viewers' perceptions of the content, format, and impact of the video.	The video had a wide reach. After 2 months there were 715 views of the video from over 34 countries. 98% of viewers 'extremely liked'/'liked' the content of the video. Viewers also liked the parent quotes, and length of the video (3-minutes). In regard to items that viewers disliked, the quantity of words/speed of transition and the music were rated the highest. 88% indicated they would share the video.

Table 5. Facilitators and barriers to translating health research to families

Type of facilitators	**List of common facilitators**	**Studies reporting the facilitator**
Format & Content of Educational Materials	Materials are user-friendly (clear, understandable) and engaging (creative)	26 - 31
	Materials are succinct, portable, and freely accessible	26 - 31
	Materials trigger an emotional response; combine evidence-based information with stories/experiences	28 - 31
	Materials are credible: developer of information is visible and evidence-based information is used	29 - 31
Multi-faceted Integrated KT	Involvement of end-user group throughout to identify needs and preferences	28 - 31
	Clear identification of the purpose and goals of the end-product at outset; need to match needs of end users	29 - 31
	Active multi-faceted dissemination (e.g., use educational materials in combination with workshops, social media, etc.)	27, 28
Type of barriers	**List of common barriers**	**Studies reporting the barrier**
Participant Recruitment	Recruitment of participants; competing priorities and time constraints	28 - 30
Time & Resources	Limited time and resources to create KT products	28, 29
Generalizability of Resources	Developing materials that would be generalizable and useful to a wide audience	29

CHAPTER FOUR:

DEVELOPMENT AND PILOT EVALUATION OF AN ONLINE KNOWLEDGE TRANSLATION RESOURCE FOR FAMILIES AND SERVICE PROVIDERS: THE ‘F-WORDS’ IN CHILDHOOD DISABILITY KNOWLEDGE HUB

Introduction to Chapter Four

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Summary: This project builds upon/follows the previous chapters and focuses on *Steps four – six (select, tailor, and implement the intervention, monitor knowledge use, and evaluate outcomes)* of the knowledge to action cycle (Graham et al., 2006). Based on stakeholders’ identified needs (i.e., more educational resources needed to inform people about the ‘F-words’ ideas; Chapter 2) and findings from our scoping review (i.e., online educational materials recommended as a KT strategy for sharing health research evidence with families; Chapter 3), the ‘F-Words’ research team identified a need for a KT intervention and decided to develop “The ‘F-words’ in Childhood Disability Knowledge Hub”’. The ‘F-words’ Knowledge Hub is an online KT resource that aims to inform people about the ‘F-words’/ICF concepts, share and exchange knowledge on the ideas, and provides action-oriented tools to support the implementation of the ‘F-words’ in practice.

The initial planning for the Knowledge Hub started in early 2015. At that time, two new people joined our ‘F-Words’ research team, including a parent (JB) and a health services researcher (SB). All team members were involved throughout each stage of the project, beginning in the initial planning phase. From 2015 – 2017, we co-developed the Knowledge Hub with families and service providers and it was officially launched on the *CanChild* website on July 28th 2017.

To ensure the Knowledge Hub met the needs of stakeholders, we conducted a pilot evaluation to explore the usability and utility of the hub. In one month, 87 people completed an online survey. Responding to *Step 5 of the action cycle (monitor knowledge use),* the survey intentionally collected data on respondents’ self-reported changes in *conceptual knowledge use.* Overall, 95% reported the hub increased their understanding, 80% reported the hub influenced what they think of the ‘F-words’, and many people (n= 52) reported the hub would influence the things they do when working with others.

Responding to *Step 6 of the action cycle (evaluate outcomes),* the survey collected feedback on visitors’ perceptions and satisfaction of the Knowledge Hub (i.e., a *process evaluation*). This information helped us to understand what people liked and what changes could be made to improve the hub. 96% found the hub user friendly and 94% perceived the content to be meaningful and relevant for families and service providers. In particular, people liked the ‘F-words’ tools, videos, and families’/clinicians’ voices. One suggestion to improve the hub was better navigation from the homepage. Based on these findings we plan to make minor changes to the hub and then conduct a larger experimental study to evaluate the impact at the family, service provider, and organizational levels.

Abstract

Background: The ‘F-words in Childhood Disability’ (Function, Family, Fitness, Fun, Friends, and Future) are an adaptation of the World Health Organization’s (2001) International Classification of Functioning, Disability and Health (ICF) framework, and an effort to operationalize these ideas. Since the paper was published (early online November 2011), the ‘F-words’ have garnered global attention (> 12,000 downloads as of January 2018). Internationally people have adopted the ‘F-words’ ideas and many families and service providers have expressed a need for more information, tools, and resources on the ‘F-words’.

Objective: This paper reports on the development and pilot evaluation of an online knowledge translation (KT) resource (i.e., the ‘F-words’ Knowledge Hub) created to inform people about the ‘F-words’ and to provide action-oriented tools to support the use of the ‘F-words’ in practice.

Methods: An integrated research team of families and researchers at *CanChild* Centre for Childhood Disability Research collaborated to develop, implement and evaluate the Knowledge Hub. A pilot study design was chosen to assess the usability and utility of the online hub before implementing a larger evaluation study. Data were collected through a brief anonymous online survey, which included both closed- and open-ended questions, with closed-ended responses based on a five-point Likert-type scale. Descriptive statistics and a summary of key themes are used to report our findings.

Results: From August to November 2017, the Knowledge Hub received over 6,800 unique visitors. In one month (November 2017), 87 people completed the survey of whom 63 completed the full survey and 24 completed one or two sections. Respondents included 42 clinicians and 30 family members or individuals with a disability. The majority of people had visited the Knowledge Hub one to five times (n= 63) and had spent up to 45 minutes exploring it (n= 61) prior to providing feedback. Overall, 66 people provided information on the perceived usefulness of the Knowledge Hub. Of these people, 92% (n= 61) found the Knowledge Hub user friendly, and stated that they enjoyed exploring the hub. Many people (n= 52) reported the Knowledge Hub would influence the things they do when working with others. From the open-ended responses (n= 48), the 'F-words' videos (n= 21) and the 'F-words' Tools (n= 15) were rated the best features of the Knowledge Hub.

Conclusions: The 'F-words' Knowledge Hub is an evidence-informed online KT resource that appears to be useful for respondents who are considered 'early adopters' of the 'F-words' concepts. Based on our findings minor changes will be made to improve the Knowledge Hub before completing a larger evaluation study of the impact at the family, clinician and organizational levels in a wider group of users. Our hope is that the 'F-words' Knowledge Hub will become a go-to resource for knowledge sharing and exchange amongst families and service providers.

Key Words*:* knowledge translation; family engagement in research; collaborative research; ICF framework; online resource; childhood disability; evidence-based practice; knowledge-to-action framework; family-centred service; child health

Introduction

It has been several years since the paper *"The 'F-words' in Childhood Disability: I swear this is how we should think!"* was published in Child: Care, Health and Development [1]. The 'F-words' (Function, Family, Fitness, Fun, Friends, and Future) are an adaptation and operationalization of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) [2]. The initial aim of the 'F-words' paper was to spread awareness of the ICF and to encourage people to apply these modern ways of thinking and a 'developmental' approach to childhood disability [1]. Since it was first published (early online November 2011) to December 2017, the paper has been cited over 126 times and downloaded over 12,000 times.

In 2014, based on considerable interest in the paper, we formed an integrated research team at *CanChild* Centre for Childhood Disability Research dedicated to disseminating and studying the process of moving the 'F-words' into practice. At that time, a handful of parents (i.e., *early adopters*) had learned about the 'F-words', liked the ideas, and were interested in how to share the 'F-words' message with more families. Recognizing the potential impact of an integrated approach to this work (i.e., families and researchers working together), we partnered with family stakeholders to develop and evaluate knowledge translation (KT) strategies tailored to meet families' needs and preferences.

Our first project involved the development, dissemination and evaluation of a three-minute awareness video [3]. A video was chosen as an initial dissemination strategy as it was engaging, relatively easy to produce, and could be shared freely with a broad audience. At that time, the 'F-words' paper was not open access and thus was reaching a limited audience in the scientific and clinical communities.

We evaluated the video by tracking its reach and asking viewers to complete an anonymous online survey. In two months, there were 715 views and 137 survey responses. Overall, we learned that 98% people 'extremely liked'/'liked' the 'F-words' ideas, 88% indicated they would share the video, and 93% of people wanted to learn more. The *CanChild* website was identified (by 66% of respondents) as the most popular strategy for sharing further information on the 'F-words' concepts. A complete report of our findings and lessons learned from this project is published [3].

The awareness video was only the first step to moving the 'F-words' into practice. By January 2015, we had given > 30 presentations internationally, and the 'F-words' ideas had continued to spread over social media. We were gratified by the uptake of these ideas around the world and were excited to see the imaginative ways that people were adapting and adopting the 'F-words' in their local contexts. We were also learning a great deal about the application of the 'F-words' by connecting and working with families and other stakeholders, primarily service providers and health care administrators, across the globe. As a research team, we were acting as 'knowledge brokers' (KBs) [4], working with people to share and exchange knowledge on the 'F-words' concepts.

From our conversations with families and service providers it was evident that there was interest in having access to more information on the ‘F-words’, and action-oriented resources and tools to assist with the application of the ‘F-words’ in practice. Furthermore, as the ‘F-words’ ideas continued to spread, we recognized the need (and opportunity) to compile all that was being done and shared on the ‘F-words’ ideas, and to build a centralized online community for knowledge sharing and exchange. Thus, in 2015 our research team decided to develop, implement and evaluate the usability and utility of an online KT resource – a website we called “The ‘F-words’ in Childhood Disability Knowledge Hub”.

The purpose of the ‘F-words’ Knowledge Hub is to inform families and service providers about the ‘F-words’/ICF concepts and to provide action-oriented tools to support the uptake and use of the ‘F-words’ in practice. The Knowledge Hub is hosted on *CanChild’s* website [5] and is meant to be an ever-growing resource for knowledge sharing and exchange. The *CanChild* website is world-renowned in the field of childhood disability, and receives over 12,000 unique visitors each month from over 205 countries [6].

Modern Approaches to KT

In the last several years, there has be increasing interest in the Internet as a platform for KT and the use of online KT resources as a strategy for disseminating health research evidence in the field of childhood disability [7-10]. Levac and colleagues [7] define online KT resources as “*e-learning products that translate evidence-based knowledge to disseminate information that increases* *awareness, informs clinical practice, and stimulates practice change.*" Online KT resources include items such as websites, educational modules, downloadable PDFs, blogs, and wikis [7,11]. Some of the recognized advantages of online resources include: 1) the ability to be self-paced/self-directed; 2) accessibility and broad reach; 3) incorporation of engaging multi-media content; and 4) promotion of knowledge sharing and exchange [7,12].

While the current evidence base for online KT strategies is limited, some studies have shown promising findings [12,13], but more research is still needed to identify the most effective types of online KT strategies and to understand the impact on behaviour change and patient outcomes [13,14]. Additionally, research is needed to explore the impact of online KT resources as a single intervention in comparison to their inclusion in multi-faceted interventions (e.g., use of online KT resources and educational outreach visits) [12,13].

This paper reports on the Knowledge Hub development process and shares our findings with respect to the usability and utility of the Knowledge Hub. The Knowledge-to-Action (KTA) framework provided the guiding theoretical underpinning for this research [15]. Knowledge translation theories, models and frameworks are recommended to guide the development, implementation and evaluation of KT strategies [16-18]. The KTA framework parses the KT process by providing a conceptual map of the steps involved in transferring knowledge to practice [15]. For the purpose of this study, we focused on three steps of the *action cycle:* '*select, tailor, and implement the intervention*', '*monitor knowledge* *use',* and *'evaluate outcomes'*. This study was part of a larger program of research, which had already addressed the earlier stages of the *action cycle* [3].

Methods

We implemented a formal integrated knowledge translation (iKT) strategy to develop, implement, and evaluate the Knowledge Hub. iKT involves the collaboration of researchers and knowledge users (e.g., families and service providers) throughout all stages of the research/KT process [19] and is believed to increase the effectiveness and sustainability of KT interventions [20,21]. This project was led by an integrated team of children's health researchers (PR, SB, JWG), family stakeholders (DG, JB, DK), and a doctoral student (AC) who co-ordinated the project.

All team members were involved in each stage of the project including: (i) participating in the initial planning stages; (ii) providing feedback on the content and design of the Knowledge Hub; (iii) creating and sharing tools/resources; (iv) assisting with evaluation; and (v) disseminating the hub amongst their social networks. During the initial planning stages team meetings were held through teleconference. We initially planned to develop an 'F-words' Tool Kit (i.e., a paper-based resource designed to share knowledge and provide tools/resources to support the use of the 'F-words' in practice). However, based on conversations with stakeholders and a review of the literature we turned towards online KT strategies (i.e., the Knowledge Hub). AC led the development of the hub, but feedback was sought and received from all team members throughout the development process. Most team correspondence was done through email.

One area in which all three family stakeholders were very involved was creating the ‘F-words’ Tools (i.e., the ‘F-words’ agreement, photo collage, goal sheet, and profile). Many of the ideas for the tools came from their personal experiences working with service providers, and their perceptions of how the ‘F-words’ could be used in practice. As an integrated research team we discussed the purpose and goals for each tool, and then with the support of *CanChild* students we developed draft tool templates that could be distributed amongst all team members for feedback. Once all team members approved the tools, they were posted on the Knowledge Hub.

Knowledge Hub Development Process

To help with the planning and development of the Knowledge Hub, we used Levac and colleagues’ [7] best practice recommendations for designing online KT resources. These were based on their experiences developing and evaluating online KT resources, as well as a review of the KT and instructional design literature [7]. They identified four main recommendations: 1) develop evidence-based user-centred content; 2) tailor content to online format; 3) evaluate impact; and 4) share results and disseminate knowledge. Each recommendation outlined a number of specific steps. A description of our application of Levac et al.’s [7] recommendations for this study is provided as a multimedia appendix (Multimedia Appendix 1).

Description of Knowledge Hub

The purpose of the Knowledge Hub is to have one place where people can go to learn about and share ideas for moving the 'F-words' into practice. The online hub [22] includes tools and resources created by our research team, as well as materials that have been generously shared by stakeholders from around the world. Everything on the Knowledge Hub is freely available to share and adapt in people's own practice settings. The Knowledge Hub has six main sections: 1) The F-words Homepage; 2) ICF Resources; 3) F-words Footprint; 4) Family & Clinician Voices; 5) F-words Tools; and 6) F-words Research Team. A full description of the Knowledge Hub is also provided as a multimedia appendix (Multimedia Appendix 2).

Knowledge Hub Evaluation

A pilot study design was chosen to assess the usability and utility of the Knowledge Hub, and to make any necessary changes, before implementing a larger evaluation study. Usability was measured by the 'usefulness' questions (i.e., purpose clear, user friendly, content meaningful/relevant, etc.) and utility was measured by the 'use' questions (i.e., impact and intent to use, change in knowledge, attitude, behaviour, etc.). Usability and utility testing is a critical component to the success of KT interventions [7,23]. Visitors to the Knowledge Hub were asked to review the hub and voluntarily provide feedback by completing a brief anonymous online open survey through McMaster University's LimeSurvey system. Participants were told that by completing the survey they were giving their consent to participate in the study. A survey link was posted on the Knowledge Hub and a recruitment email and poster were distributed through *CanChild's* social networks. The recruitment poster is provided as a multimedia appendix (Multimedia Appendix 3).

The survey included both closed- and open-ended questions, with closed-ended responses based on a five-point Likert-type scale, that evaluated visitors' prior familiarity with the 'F-words', perceived usefulness and reported/intended use of the Knowledge Hub. Adaptive questioning was used (i.e., some questions were conditionally displayed, based on responses to previous questions) to reduce the complexity of the survey. There was a total of 37 questions in the survey. Google analytics evaluated the reach by tracking the number of visitors to the hub in a four-month period. Descriptive statistics were used to analyze the quantitative information, and descriptive content analysis was used to identify and synthesize the key themes from the open-ended questions. Ethics approval was obtained from Hamilton Integrated Research Ethics Board (Project# 2017-0977).

Results

Google analytic data (tracking the reach)

After a four-month evaluation period (August - November 2017), there were over 6,800 unique visitors to the Knowledge Hub, with an increasing number each month (Figure 1). This could correspond with KT strategies implemented by the research team (e.g., conference presentations, educational outreach visits, monthly *CanChild* newsletters featuring the Knowledge Hub) and/or spread of the

Knowledge Hub by people who liked and were sharing it within their communication channels and social networks.

< Please insert Figure 1 here >

Survey responses

The survey went live on 3 November 2017 and data were collected for one month. During this time, a total of 87 respondents provided information: 63 people completed the full survey and 24 people partially completed the survey (i.e., one or two sections), for a completion rate of 72%. Most people had visited the Knowledge Hub one to five times (n= 63) and had spent up to 45 minutes exploring the hub (n= 61) prior to providing feedback. The following results are based on these survey data.

Respondent demographics

Just under half of the people that completed the survey resided in Canada (n= 42, 48%). The only other country with more than 10 respondents was the United States (n= 17, 20%). The remainder of respondents came from 13 countries. Respondents were asked to state the perspective from which they were viewing the Knowledge Hub (e.g., family member, clinician etc.). Of the 87 people who completed the survey, 42 were clinicians and 30 were family members (n= 20) or individuals with a disability (n= 10). There was a wide distribution of perspectives with many respondents (n= 36) falling into more than one stakeholder category (Table 1).

< Please insert Table 1 here >

Respondents' familiarity with the 'F-words'

The majority of people (n= 62; 71%) had heard of the 'F-words' prior to visiting the Knowledge Hub and either 'extremely liked the ideas' (n= 38; 61%) or 'liked the ideas' (n= 21, 34%). Of the 62 people who were familiar with the 'F-words', 69% (n= 43) felt confident identifying and explaining the 'F-words' ideas, 60% (n= 37) had shared them with others, and 56% (n= 35) indicated they had used/applied them in practice prior to exploring the hub. To understand how people were using/applying the 'F-words' we asked for open-ended feedback. The majority of people who provided written responses were clinicians, researchers, people with disabilities, or family members. Depending on the stakeholder group, the use of the 'F-words' concepts varied. Examples of how the 'F-words' concepts have been used by each stakeholder group are provided in Table 2.

< Please insert Table 2 here >

Perceived usefulness of the Knowledge Hub

To evaluate the usefulness of the Knowledge Hub, respondents were asked to rate their overall satisfaction with it. Of the 87 people who started the survey, 66 people completed this section. Thus, the following data are based on these 66 responses. Overall, 86% of respondents (n= 57) felt the purpose was clear, 92% (n= 61) found the Knowledge Hub user friendly, and 92 - 94% perceived the content to be meaningful and relevant for families (n= 61) and service providers (n= 62). Average scores ranged from 4.23 to 4.39 out of 5 for each category (Table 3).

< Please insert Table 3 here >

Respondents were also asked to indicate what sections of the Knowledge Hub they liked and what could be improved. 65 people answered this question, all whom indicated they liked at least one section of the Knowledge Hub. 57% (n= 37) indicated that they liked all sections and 45% (n= 29) indicated they had no suggestions for improvements. Table 4 shows the breakdown of what people liked and areas for improvement.

< Please insert Table 4 here >

The survey also collected open-ended feedback to gain a better understanding of what were perceived to be the best features of the Knowledge Hub (48 respondents) and areas for improvement (25 respondents). The best features and areas for improvement were categorized into two aspects: 1) content, and 2) format/design of the Knowledge Hub. Key themes within each of these areas were then identified based on the number of responses. Table 5 highlights the reported best features and Table 6 summarizes the reported main areas for improvement.

< Please insert Tables 5 & 6 here >

Reported use

The final section of the survey explored the use/intended use of the Knowledge Hub and the 'F-words' concepts. Of the 87 people who started the survey, 63 people (72%) completed this final section. The following data are based on responses from these 63 people (Table 7).

Overall, 97% (n= 61) people indicated that they either ‘extremely liked’ (n= 42, 67%) or ‘liked’ (n= 19, 30%) the ‘F-words’ concepts; 58 people (92%) reported that the hub increased their understanding of the ‘F-words’; and 49 people (78%) reported the hub influenced what they think of the ‘F-words’. We were also interested in participants’ confidence in identifying and explaining the ‘F-words’ after exploring the Knowledge Hub. Of the 63 people, 90% (n= 57) indicated that they were either ‘extremely confident’ (n = 19, 30%) or ‘confident’ (n = 38, 60%). When asked whether the Knowledge Hub would be useful to them, 52 people (83%) reported that it would influence the things they do when working with others.

< Please insert Table 7 here >

Lastly, respondents were asked to rate the Knowledge Hub as a KT tool for sharing information with families and service providers. Overall, 90% (n= 57) rated it 4 or 5 (on the 5-point Likert scale) as a KT tool for families, and 98% (n= 60) rated it as 4 or 5 as a KT tool for service providers. 97% of people (n= 58) planned to share the Knowledge Hub.

Discussion

Reflections on the Development Process

From the beginning, it was important to us that the Knowledge Hub be co-created with stakeholders. While our integrated team of families and researchers led the development process, many stakeholders outside of our research team were involved. For example, we worked with clinicians and health care administrators, who we knew were applying the ‘F-words’ to share examples of how they were using the ‘F-words’ within their organizations. These examples then served as examples of application for other service providers.

We believe early stakeholder involvement was crucial not only to developing a meaningful and relevant resource, but also to the dissemination of the Knowledge Hub. Individuals invested in the online hub were more likely to share it with their own communities, in turn increasing its reach and potential impact (i.e., spread through broad communication channels and social networks) [24]. The importance of involving stakeholders (including families and service providers) in the development of KT resources has been recognized by other children’s health researchers [25-27].

Another key feature of the Knowledge Hub is its promotion of knowledge sharing and exchange [28]. In comparison with other online KT resources (such as an online learning module that, once complete, is difficult to change), the Knowledge Hub is organic – it can be easily adapted, and thus can grow with time. This not only encourages people to return to the Knowledge Hub, but also inspires people to get involved and contribute to the conversation (i.e., become ‘knowledge brokers’ of the ‘F-words’) [4,29]. Having the Knowledge Hub freely available is crucial to supporting this global dissemination and uptake.

One common barrier reported in the literature is the amount of time and resources involved in developing and implementing KT interventions [3,25,30]. While our research team was responsible for developing and collating the content for the Knowledge Hub, we leveraged many of *CanChild's* resources (e.g., the *CanChild* website, *CanChild* KT staff /students' time) to design and maintain the Knowledge Hub. Creating and collating the content for the Knowledge Hub also took a lot more time than initially expected. The development process involved iterative rounds of feedback from various stakeholders. We did not follow a structured system/timeline to collecting feedback, which led to a longer process. In the future, we would recommend the use of a structured process tailored to collecting feedback from a diverse group of stakeholders [7].

A key facilitator for this project was the use of theory and best practice guidelines to inform the KT intervention [18,31]. The KTA framework [15], the Diffusion of Innovation (DOI) theory [24], and Levac and colleagues' [7] best practice guidelines for developing online educational resources all informed the development process. Specifically, the KTA framework [15] provided the 'big picture' and was used as an overarching guide for the KT process. Levac et al.'s [7] best practice guidelines for online KT resources helped us with specific details/steps needed in designing the Knowledge Hub. These guidelines were useful as they were specifically tailored to our chosen KT strategy. Lastly, the DOI theory informed the design and implementation of the Knowledge Hub through consideration of the characteristics of the innovation that support adoption (i.e., relative advantage, complexity, compatibility, trialability, and observability), as well as consideration of the key factors that influence dissemination of an innovation (i.e., time, social networks and communication channels) [24].

Reflections on the Evaluation

The main goal of the Knowledge Hub is to inform families and service providers about the 'F-words'/ICF concepts and to provide action-oriented tools to support the uptake and use of the 'F-words' in practice. As such, the goal of this pilot evaluation was to evaluate the usability and utility of the Knowledge Hub. Findings from this study revealed that we attained these self-assigned goals. Overall, respondents reported that: i) the Knowledge Hub was informative and useful, and ii) the 'F-words' tools were one of the best features of the Knowledge Hub.

In general, the hub received high ratings with regard to both its *perceived usefulness* and *potential use*. While mixed-model analyses between groups were not completed, the high rating across all participants implies that the Knowledge Hub was perceived to be a meaningful resource for both service providers and families. This finding is consistent with earlier research from *CanChild* that found when educational materials are clearly-written and user-friendly they can be useful and impactful for multiple target audiences (i.e., families and service providers) [32,33]. Furthermore, while more structured research is still needed to evaluate the impact of the Knowledge Hub on family and service provider behaviour, people's reported intention to use the hub is an encouraging preliminary finding. We know from the behaviour change literature that people's attitudes have a significant influence on whether a change will happen [34,35].

We recognize that prior to exploring the Knowledge Hub, over 70% of people who completed the survey had previously heard of the 'F-words'. Of these respondents, the majority felt confident identifying and explaining the 'F-words' ideas, and about half indicated they had used/applied the 'F-words' in practice. Despite many respondents already being familiar with the 'F-words' concepts, the majority stated that the Knowledge Hub increased their understanding of the 'F-words' ideas. This is an important finding as it implies that the Knowledge Hub can increase perceived knowledge even if individuals have prior familiarity with the concepts. Most likely this happened because the resources provide tangible materials that move beyond simple familiarity with the concepts. Unfortunately, due to a low response rate from people to whom the 'F-words' are new, we cannot say whether the Knowledge Hub is useful to people across adopter categories (i.e., from the *early adopters* – those who are already using the 'F-words' – to the *late adopters* – those to whom the 'F-words' are new) [24].

Conducting a pilot evaluation of the usability and utility of the Knowledge Hub is an important step toward ensuring its overall impact and sustainability [7,23]. This pilot evaluation helped us to understand what people liked about the Knowledge Hub (e.g., the videos, 'F-words' tools, families' and clinicians' voices, etc.) and what changes could be made to improve it (e.g., re-organizing the homepage to support navigation throughout the hub). The evaluation also helped us to understand who was accessing the Knowledge Hub (i.e., mostly the *early adopters* of the ‘F-words’ concepts) and what is needed to broaden the applicability of the Knowledge Hub to a wider audience (e.g., extending the ‘F-words’ to other populations and conducting research on the impact of using the ‘F-words’ tools). These findings will both inform and complement future evaluations of the Knowledge Hub. Recognizing that experimental evaluations only identify whether an intervention is effective, process evaluations such as this are recommended to understand the reasons why an intervention is (or is not) effective [36,37].

Study limitations and future directions

Based on respondents’ positive feedback, we anticipate the Knowledge Hub will be a useful resource for both families and service providers. A limitation to this work is that feedback was gained from only a small sample of the people who visited the hub during this period. It is important to consider that the majority of people providing feedback are those who were already familiar with the ‘F-words’ concepts and also like the ‘F-words’ ideas. Thus, their potential biases must be recognized.

In order to reach a broader audience, more time is needed to disseminate the Knowledge Hub actively. While we report here the preliminary findings after a one-month evaluation, in order to overcome selection bias (i.e., those who already like the ‘F-words’ ideas), the evaluation will remain posted on the Knowledge Hub and we will continue to monitor feedback received. Our hope is that over time more people (including those who are not already familiar with the ‘F-words’) will complete the survey.

The next step is to evaluate the impact of the Knowledge Hub and ‘F-words’ concepts at the family, clinician, and organizational levels. Recognizing that active implementation strategies are useful in supporting the dissemination and uptake of educational materials, we plan to combine the Knowledge Hub intervention with tailored invitational outreach visits to local children’s treatment centres (CTCs). Once again, this is a stakeholder-driven strategy as CTCs have been contacting us and expressing a need for in-person educational training on the ‘F-words’ concepts. Based on our positive experience working with families and service providers to develop the Knowledge Hub, this project will continue to be informed by an iKT strategy.

Conclusions

Working with families and service providers, we designed a theory- and evidence-informed online KT resource that is perceived to be relevant and meaningful to families raising children with disabilities and to service providers working in this field. To date, the Knowledge Hub has mainly reached the ‘*early adopters*’ (i.e., people who like the ‘F-words’ ideas and are seeking more information) [24]. In order to reach a wider audience (i.e., the ‘*early majority*’), active implementation strategies are needed.

KT is not only the ‘doing’, but also the ‘studying’ of the KT process and outcomes. By evaluating the usability and utility of the Knowledge Hub we now have a good understanding of what was done well and what can be improved. Based on the findings from this pilot study, we will make minor changes to the Knowledge Hub before conducting a larger evaluation study of the impact at the family, clinician and organizational levels. Knowledge gained from this study is transferrable to other KT initiatives involving families and service providers. We hope that reporting our findings and lessons learned through this integrated KT project will assist others in the advancement of iKT science and practice in other areas of childhood disability research.

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Figure 1. Number of visits to the Knowledge Hub

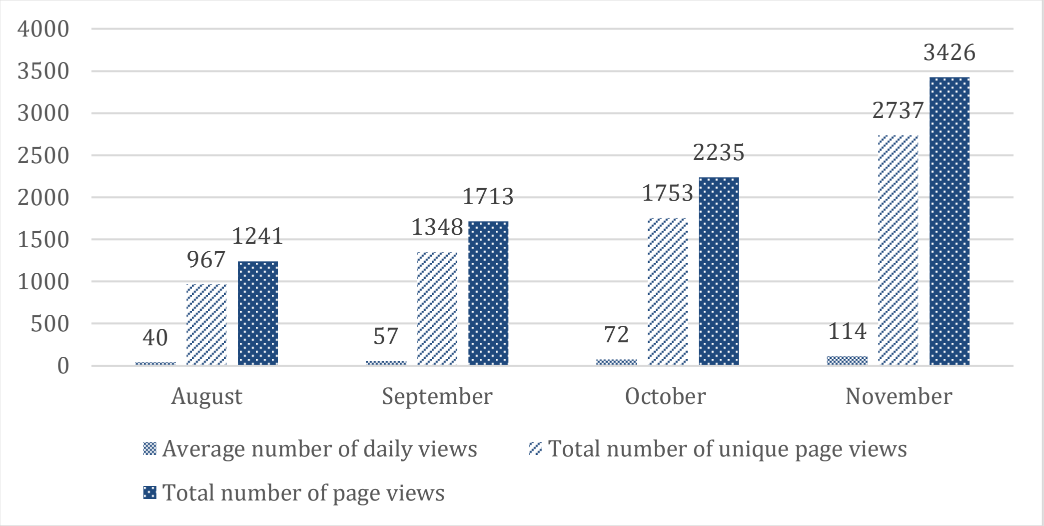

Table 1. Demographic characteristics of respondents (N= 87).

Characteristic		**n (%)**
Country of Residence[a]		
	Canada	42 (48%)
	United States	17 (20%)
	Australia	4 (5%)
	Spain	3 (3%)
	Brazil	3 (3%)
	United Kingdom	2 (2%)
	Ethiopia	2 (2%)
	South Africa	2 (2%)
	No answer	5 (6%)
Type of Stakeholder[b,c]		
	Clinician[d]	42 (48%)
	Researcher	24 (28%)
	Family Member[d]	20 (23%)
	Educator	17 (20%)
	Friend of someone with a disability	17 (20%)
	Student	13 (15%)
	Person with a disability[d]	10 (11%)
	No answer	2 (2%)
Gender		
	Female	69 (79%)
	Male	13 (15%)
	No answer	5 (6%)
Previously aware of the 'F-words'		
	Yes	62 (71%)
	No	19 (22%)
	No answer	6 (7%)

[a] Includes countries with more than one respondent.
[b] Includes stakeholder groups with more than five respondents.
[c] Some respondents fit into more than one group (e.g., clinician and educator).
[d] Primary target audience.

Table 2. Examples of use of the ‘F-words’ concepts prior to exploring the hub.

Level of Uptake		**Sample Quotes**
Family		
	• Applied the F-words to their own lives. (n= 5)	*The F-words are very applicable to my own life. I’m happy to share them with others I feel could also benefit from this framework. [Person with a disability, Canada]*
	• Used the F-words when speaking with therapists and teachers to assist with goal-setting and planning for their child. (n= 2)	*When speaking to therapists and teachers in relation to goals for my child. [Family member, Canada]*
Clinical		
	• Implemented the F-words to help with goal-setting with families, to frame conversations with families, and to help guide program planning and decision making. (n= 15)	*When discussing outcomes and goal planning with the family, we discussed the ICF model and used the F words as descriptors of the various categories. [Clinician, US]* *Through discussion with families and creating goals that fit families’ lives. [Clinician-researcher, Canada]*
Research/Education		
	• Incorporated the F-words into training for students. (n= 3)	*Especially in educational settings, such as the training of graduates in physiotherapy, multi-professional residence in children's health, as well as the master's degree in collective health and PhD on rehabilitation sciences. [Clinician-researcher/Educator, Brazil]*

	• Incorporated the F-words into publications and grant writing applications. (n= 1)	*Used in talks to families and professional groups. Used in publications and in grant applications. [Clinician-researcher, Australia]*
Health Care Organization		
	• The F-words are influencing organizations in items such as facility planning, departmental missions, and the development of programs. (n= 2)	*Facility planning, restructuring. [Administrator, US]* *Used them to guide collaborative goal-setting with families/clients; to focus our departmental mission; to develop programs. [Clinician-researcher/Educator, US]*

Table 3. Overall satisfaction with the Knowledge Hub (N= 66).

Item	**Strongly Agree n (%)**	**Agree n (%)**	**Neutral n (%)**	**Disagree n (%)**	**Strongly Disagree n (%)**	**No Answer n (%)**
The purpose is clear.	32 (48%)	25 (38%)	5 (8%)	4 (6%)	0	0
The hub is user friendly.	19 (29%)	42 (64%)	2 (3%)	1 (2%)	0	2 (3%)
I enjoyed exploring the Knowledge Hub.	26 (39%)	35 (53%)	3 (5%)	0	0	2 (3%)
The content is meaningful and relevant for families.	32 (48%)	29 (44%)	4 (6%)	1 (2%)	0	0
The content is meaningful and relevant for service providers	31 (47%)	31 (47%)	3 (5%)	1 (2%)	0	0

Table 4. The breakdown of what people liked and what can be improved (N= 65).[a]

Item	**Liked** ***n*** **(%)**	**Areas for Improvement** ***n*** **(%)**
Homepage	26 (40%)	6 (9%)
ICF Resources	12 (18%)	8 (12%)
F-words Footprint	14 (22%)	2 (3%)
Family & Clinician Voices	17 (26%)	4 (6%)
F-words Tools	23 (35%)	7 (11%)
Research Team	10 (15%)	3 (5%)
All of the Above	37 (57%)	1 (2%)
None of the Above	0	29 (45%)
Other	1 (2%)	9 (14%)

[a] People could select more than one item.

Table 5. Open-ended feedback on the best features of the Knowledge Hub.

Category	Sample quotes
Content	
• Overall, the videos (n= 21) and ‘F-words Tools’ (n= 15) were identified as the best features of the Knowledge Hub.	*My favourite part of the Hub is the F-words Tools section! As an educator, access to tools and examples from children helps me to understand how the F-words come into practice in the classroom and at home. [Educator, Canada]*
• Many people also valued the stories and examples shared by families and clinicians on what the ‘F-words’ mean to them and how they are using the ‘F-words’ in practice (n= 9).	*The writings by families and by therapists were also quite valuable in seeing how these principles are applied in many different situations. They are also very engaging to read. [Researcher, US]*
Format/Design	
• Key design features included that the hub was easy to navigate (n= 8), user-friendly (n=7), and interesting/engaging (n= 7).	*It's simple to use and navigate, visually interesting and love the video content. [Family member, friend, researcher, Canada]*
• The hub being publically available with sharable, downloadable content (n= 5).	*Sharing the information is great but also providing the tools and resources for families and providers alike is crucial to getting the word out and to helping these families. [Clinician, US]*

Table 6. Open-ended feedback on areas for improvement.

Category	Sample quotes
Content	
• More examples of application of the F-words and its impact. This includes more case vignettes, as well as formal research studies implementing and evaluating the F-words tools (n= 7).	*I think it would be important to expand the dissemination of the six F-words by conducting studies on its application and results obtained. [Clinician-researcher, Brazil]*
• Also, extending the F-words to other populations, including teachers, young children, and increasing the diversity of representation (n= 4).	*Improve representation of diverse (SES, racial, ethnic, disabilities) families and practitioners to discuss barriers and different strategies possible in a wide lens. [Person with a disability, family member, friend, student, researcher, educator, US]*
Format/Design	
• Overall organization (e.g., clearly identifying the different sections, resources, purpose of the hub, etc.) (n= 8)	*The content is excellent, some of the formatting could be improved to make it more user friendly (lots of scrolling currently and hard to orient to all the great materials with that format) [Student, researcher, support worker, Canada]*
• The need for better navigation from the homepage (n= 5).	*Better navigation. From the home page I would like a "how to use this site" section that will guide me to what I need to be looking at use - either as a parent, as a therapist, as a researcher. [Family member, Canada]*

Table 7. Reported use of Knowledge Hub (N= 63).

The Knowledge Hub…	Strongly Agree n (%)	Agree n (%)	Neutral n (%)	Disagree n (%)	Strongly Disagree n (%)	No Answer n (%)
… increased my understanding of the F-words concepts.	27 (43%)	31 (49%)	2 (3%)	1 (2%)	0	2 (3%)
… influenced what I think about the F-words concepts.	20 (32%)	29 (46%)	11 (17%)	1 (2%)	0	2 (3%)
…will be useful to me.	23 (37%)	32 (51%)	7 (11%)	0	0	1 (2%)
… will influence the things I do when I am working with others.	22 (35%)	30 (48%)	5 (8%)	2 (3%)	1 (2%)	3 (5%)

Appendices

Appendix A. Application of Levac et al.'s (2015) recommended best practices of online KT resources

Recommendations	Steps	Application in the Current Study
1. Develop evidence-based, user-centered content	1. Assess audience needs	• Informal needs assessment through 'F-words' awareness video survey and consultation with families and service providers • Scoping review conducted to explore KT strategies targeting family stakeholders
	2. Summarize evidence to address audience needs	• Research team brainstormed information and sections to include in online resource • Key messages re: 'F-words' & ICF concepts identified for families + service providers • Categorized information based on 'need to know' vs. 'nice to know' • 'Need to know' (text embedded in website) vs. 'Nice to know' (links provided to papers and other resources for more information)
	3. Use theory, framework, or model	• KTA framework informed the development process • The Diffusion of Innovation theory characteristics of innovation considered when designing the resource
	4. Select an appropriate KT format	• Online Knowledge Hub hosted on *CanChild* website • Incorporated content to meet the needs of different learning styles (e.g., included written information, videos, podcasts, downloadable fillable tools, etc.) • Included information created by people outside of the research team to build connections and an environment for knowledge

		sharing and exchange
	5. Develop learning objectives	• Identified goals and learning objectives for Knowledge Hub • Developed a purpose statement
	6. Include multimedia content	• Videos, webinars, podcasts, presentation recordings posted on Knowledge Hub
2. Tailor content to online format	1. Partner with a web developer	• Worked with *CanChild's* media and website specialists and students
	2. "Mock up" content and navigational structure	• Used PowerPoint to mock up website and then transferred content to website • Mapped out each section including navigational structure
	3. Consider web sustainability	• Goal for website to be a 'living' document that can be continually updated • Designated internal *CanChild* staff member and KT students assist with keeping the website up to date
	4. Pilot test with intended audience	• Informal pilot test with families, service providers, students and researchers affiliated with *CanChild* to pilot website
3. Evaluate impact	1. Embed evaluation within resource	• Pilot evaluation (anonymous survey) to evaluate utility (reach, usefulness, and use) of the Knowledge Hub
	2. Collect usage data	• Google analytics used to track number of visits to Knowledge Hub • Further analysis can be run (e.g., number of times people access, avg. time spent per visit, popular resources vs. those overlooked, etc.)
	3. Build in methods to evaluate short-term and long-term	• Will be incorporated into follow-up studies to evaluate impact of Knowledge Hub at the family, clinician, and organizational levels • Mixed-methods evaluation

	learning, retention, and behavior change	including quantitative questionnaires exploring participants' self-reported change in knowledge, attitudes, behaviour and qualitative interviews to gain more in-depth understanding
4. Share results and disseminate the knowledge	1. Write scientific papers to report your results	• This article reports on the development process and preliminary findings from the pilot evaluation of the Knowledge Hub.
	2. Share results with participants to disseminate information to your target audience	• An 'In Brief' (lay summary) will be written on findings from the pilot evaluation and posted on the Knowledge Hub • Will also share findings through presentations and webinars • Social media and *CanChild* Today newsletter will share updates
	3. Maintain knowledge "currency"	• KT specialists at *CanChild* will be responsible for keeping Knowledge Hub up to date

Appendix B. Description of 'F-words' Knowledge Hub

Section	**Description**
F-words Homepage	• General introduction to the Knowledge Hub. • Introduction video welcomes people to the hub and provides an overview of the various sections, tools, and resources. • Includes written text that identifies and defines the six 'F-words', provides a brief summary of the ICF framework, and shows both the ICF and 'F-words' frameworks. • Two 'F-words' awareness videos, created by parents and youth with disabilities featured to capture visitors' attention and engage the audience. • Embedded link to the open access 'F-words' publication provided.
ICF Resources	• Written text provides key messages regarding the ICF framework. • Sub-headings include: 1) What is the ICF Framework? 2) Why is it important? and 3) What does it mean for families and service providers? • Links to additional ICF resources for people who are interested in learning more provided.
F-words Footprint	• Highlights how the 'F-words' are being shared and used around the world. People are invited to contribute to this section – foster knowledge sharing and exchange. • Includes a list of the publications, an interactive map highlighting the presentations given around the world, videos on the 'F-words', podcasts, webinars, downloadable PDFs of posters presented on the 'F-words', and links to online blogs and news articles that have featured the 'F-words' ideas. • Features the 'F-words' poster, created in collaboration with World CP Day in 2016, and now translated into < 25 languages.
Family & Clinician Voices	• Features how parents, youth with disabilities and clinicians are talking about and applying the 'F-words' (bring the 'F-words' to life). • The quotes are taken from articles and online

	blogs written by people around the world and the pictures have been shared by families and service providers.
F-words Tools	• Section 1: Interactive, downloadable tools created by our research team, including the 'F-words Agreement', 'F-words Photo Collage', 'F-words Goal Sheet', and 'F-words Profile'. • Section 2: Real-life examples of how clinicians and organizations have applied the 'F-words' in their individual work settings.
F-words Research Team	• Introduces each member of our integrated research team (picture and bio provided).

Appendix C. ‘F-words’ Pilot Evaluation Recruitment Poster

The ‘F-words’ in Childhood Disability Knowledge Hub

Promoting what ALL children CAN do!

Help us evaluate the Knowledge Hub created by a team of families and researchers

What will you be asked to do?
Explore the Knowledge Hub at your leisure.
Complete a brief online feedback form.

Who can join?
The Knowledge Hub is meant for everyone! Anyone can provide feedback.

F-words Knowledge Hub link:
www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability

Survey link:
surveys.mcmaster.ca/limesurvey/index.php/639957?newtest=Y&lang=en

the f-words in childhood disability

FOR MORE INFORMATION PLEASE CONTACT
Andrea Cross, PhD Candidate
CanChild Centre for Childhood Disability Research
crossac@mcmaster.ca

This study has been reviewed by, and received ethics approval by the Hamilton Integrated Research Ethics Board (HiREB).

McMaster University

CanChild
Version 3 © 09/01/2017

Appendix D. The 'F-words' in Childhood Disability Knowledge Hub Feedback Form

Link to actual survey: Knowledge Hub Feedback Form

HOMEPAGE INTRODUCTION:

Thank you for visiting the **F-words in Childhood Disability Knowledge Hub** and for taking the time to provide us with feedback.

The Knowledge Hub was created by an integrated team of families and children's health researchers at *CanChild* Centre for Childhood Disability Research. **The purpose of the Knowledge Hub** is to have one place where people can go to learn about and share ideas for moving the F-words (Function, Family, Fitness, Fun, Friends, and Future) into practice.

There are six main sections in the Knowledge Hub: 1) The F-words Homepage; 2) ICF Resources; 3) F-words Footprint; 4) Family & Clinician Voices; 5) F-words Tools; and 6) F-words Research Team. We hope you have taken some time to explore the Knowledge Hub. Once you have a general understanding of the Knowledge Hub, please take a moment to share your feedback with us.

The following survey explores your thoughts on the Knowledge Hub. **This is an anonymous survey and your participation is voluntary.** By clicking **'next'** and completing the survey questions you have given consent to participate.

The survey is divided into three sections: 1) Background Information; 2) Ideas about Usefulness; and 3) Use.

If you have any questions or need more information, please contact Andrea Cross, at crossac@mcmaster.ca.

We would like to thank you in advance for your time. Your feedback is greatly appreciated.

Sincerely,

The F-words in Childhood Disability Research Team

Part A - Background Information:
Part A collects general demographic information and explores your prior familiarity with the F-words concepts.

1. In what country do you currently reside? ____________________

2. Gender:
    - ☐ Male
    - ☐ Female
    - ☐ No answer

3. Are you visiting the Knowledge Hub as: (Please check **<u>all</u>** that apply)
    - ☐ Person with a disability
    - ☐ Family member
    - ☐ Friend of someone with a disability
    - ☐ Researcher
    - ☐ Student
    - ☐ Clinician
    - ☐ Physician
    - ☐ Educator
    - ☐ Recreational Leader
    - ☐ Other: ____________________

4. How did you **HEAR** about the Knowledge Hub? (Please check **<u>all</u>** that apply)
    - ☐ Friend/Family member
    - ☐ Service Provider
    - ☐ Health Care Organization
    - ☐ *CanChild* Website
    - ☐ Internet/Google
    - ☐ Social Networks
    - ☐ Conference presentation
    - ☐ Workshop on the F-words
    - ☐ Other: ________________

5. <u>Prior to exploring the Knowledge Hub,</u> had you previously heard of the F-words in Childhood Disability?
    - ☐ Yes
    - ☐ No
    - ☐ No answer

Note: If you select 'Yes' to Question 5 → Questions 6 – 12 will appear.

If you select 'No' or 'No answer' to Question 5 → Skip to Question 13.

6. What were your **INITIAL PERCEPTIONS** of the F-words concepts?
    - ☐ Extremely liked the ideas
    - ☐ Liked the ideas

- ☐ No opinion either way
- ☐ Disliked the ideas
- ☐ Extremely disliked the ideas
- ☐ No answer

7. Prior to exploring the Knowledge Hub, how **FAMILIAR** were you with the F-words?
   - ☐ Very familiar
   - ☐ Familiar
   - ☐ Somewhat familiar
   - ☐ Not familiar
   - ☐ Not at all familiar
   - ☐ No answer

8. Prior to exploring the Knowledge Hub, how **CONFIDENT** did you feel in your ability to **IDENTIFY** and **EXPLAIN** the F-words to someone who hadn't heard of them?
   - ☐ Extremely Confident
   - ☐ Confident
   - ☐ Neutral
   - ☐ Not Confident
   - ☐ Not at all confident
   - ☐ No answer

9. Prior to exploring the Knowledge Hub, had you **SHARED** the F-words concepts with others?
   - ☐ Yes
   - ☐ No
   - ☐ No answer

Note: If you answer 'Yes' to question 9 → Question 10 appears.

10. **WHO** have you shared the F-words with? (Please check **all** that apply)
    - ☐ Family members
    - ☐ Friends
    - ☐ Service Providers
    - ☐ Health Care Organization
    - ☐ Educators
    - ☐ Recreational Leaders
    - ☐ Other: ___________

11. Prior to exploring the Knowledge Hub, had you **USED/APPLIED** the F-words in practice?
    - ☐ Yes

- ☐ No
- ☐ No answer

Note: If you answer ‘Yes’ to question 11 → Question 12 appears.

12. **HOW** had you **USED/APPLIED** the F-words in practice?
    ____

13. How many times have you **ACCESSED** the Knowledge Hub?
    - ☐ 1 time
    - ☐ 2 - 5 times
    - ☐ 6 – 10 times
    - ☐ 11 – 15 times
    - ☐ > 15 times
    - ☐ No answer

14. What is the **TOTAL AMOUNT OF TIME SPENT** on the Knowledge Hub?
    - ☐ < 5 minutes
    - ☐ 5 - 15 minutes
    - ☐ 15 - 30 minutes
    - ☐ 30 – 45 minutes
    - ☐ 45 – 60 minutes
    - ☐ > 60 minutes
    - ☐ No answer

15. This survey evaluates your **initial perceptions** of the Knowledge Hub. Within the next year, we plan to **evaluate the impact** of the Knowledge Hub and F-words concepts.

    Do you agree to be contacted for follow-up studies on the Knowledge Hub/F-words?
    - ☐ Yes
    - ☐ No
    - ☐ No answer

Part B - Exploring the USEFULNESS of the Knowledge Hub:
Part B explores your general perceptions and satisfaction with the Knowledge Hub.

1. The **PURPOSE** of the Knowledge Hub is clear.
   - ☐ Strongly Agree
   - ☐ Agree
   - ☐ Neutral

- ☐ Disagree
- ☐ Strongly Disagree
- ☐ No answer

2. I found the Knowledge Hub to be **USER FRIENDLY.**
- ☐ Strongly Agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly Disagree
- ☐ No answer

3. I **ENJOYED** exploring the Knowledge Hub.
- ☐ Strongly Agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly Disagree
- ☐ No answer

4. I think the **CONTENT** is going to be meaningful and relevant **FOR FAMILIES**.
- ☐ Strongly Agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly Disagree
- ☐ No answer

5. I think the **CONTENT** is going to be meaningful and relevant **TO SERVICE PROVIDERS**.
- ☐ Strongly Agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly Disagree
- ☐ No answer

6. What sections of the Knowledge Hub did you **LIKE**? (Please check **all** that apply).
- ☐ F-words in Childhood Disability Homepage
- ☐ ICF Resources
- ☐ F-words Footprint
- ☐ Family & Clinician Voices

- ☐ F-words Tools
- ☐ F-words Research Team
- ☐ All sections (I liked all sections of the Knowledge Hub!)
- ☐ No sections (I did NOT like the Knowledge Hub)
- ☐ Other: ____________________

7. Please describe what you think are the **BEST FEATURES** of the Knowledge Hub.

8. What sections of the Knowledge Hub do you think can be **IMPROVED**? (Please check **<u>all</u>** that apply).
   - ☐ F-words in Childhood Disability Homepage
   - ☐ ICF Resources
   - ☐ F-words Footprint
   - ☐ Family & Clinician Voices
   - ☐ F-words Tools
   - ☐ F-words Research Team
   - ☐ All sections (I think all sections need improvement)
   - ☐ No sections (Everything is great!)
   - ☐ Other: ____________________

9. How can we **IMPROVE the Knowledge Hub?**

Part C - Exploring the USE of the Knowledge Hub:
Part C explores the initial impact and your intention to use the Knowledge Hub.

1. Overall, the Knowledge Hub will be **USEFUL** to me.
   - ☐ Strongly Agree
   - ☐ Agree
   - ☐ Neutral
   - ☐ Disagree
   - ☐ Strongly Disagree
   - ☐ No answer

2. The Knowledge Hub **INCREASED MY UNDERSTANDING** of the F-words concepts.
   - ☐ Strongly Agree
   - ☐ Agree
   - ☐ Neutral
   - ☐ Disagree
   - ☐ Strongly Disagree
   - ☐ No answer

3. After exploring the Knowledge Hub, how **CONFIDENT** do you feel in your ability to **IDENTIFY and EXPLAIN** the F-words to someone who hasn't heard of them before?
   - ☐ Extremely Confident
   - ☐ Confident
   - ☐ Neutral
   - ☐ Not Confident
   - ☐ Not at all Confident
   - ☐ No answer

4. The Knowledge Hub **INFLUENCED WHAT I THINK** about the F-words concepts.
   - ☐ Strongly Agree
   - ☐ Agree
   - ☐ Neutral
   - ☐ Disagree
   - ☐ Strongly Disagree
   - ☐ No answer

5. After exploring the Knowledge Hub, what are your **OVERALL PERCEPTIONS** of the F-words concepts?
   - ☐ Extremely like the ideas
   - ☐ Like the ideas
   - ☐ No opinion either way
   - ☐ Dislike the ideas
   - ☐ Extremely dislike the ideas
   - ☐ No answer

6. The Knowledge Hub will **INFLUENCE THE THINGS I DO** when I am working with others.
   - ☐ Strongly Agree
   - ☐ Agree
   - ☐ Neutral
   - ☐ Disagree
   - ☐ Strongly Disagree
   - ☐ No answer

7. Do you plan to **SHARE** the Knowledge Hub with others?
   - ☐ Yes
   - ☐ No
   - ☐ No answer

Note: If you select 'Yes' to Question 8 → Question 9 appears.

8. **WITH WHOM** would you share it? (Please check **all** that apply).

- ☐ Families
- ☐ Friends
- ☐ Clinicians
- ☐ Health Care Organizations
- ☐ Physicians
- ☐ Educators
- ☐ Recreational Leaders
- ☐ Other: ______________

9. How would you **<u>rate the Knowledge Hub as a tool</u> for sharing information WITH FAMILIES**? (1 = poor; 5 = excellent)
    - ☐ 1
    - ☐ 2
    - ☐ 3
    - ☐ 4
    - ☐ 5
    - ☐ No answer

10. How would you **<u>rate the Knowledge Hub as a tool</u> for sharing information WITH SERVICE PROVIDERS**? (1 = poor; 5 = excellent)
    - ☐ 1
    - ☐ 2
    - ☐ 3
    - ☐ 4
    - ☐ 5
    - ☐ No answer

11. Do you wish to be **KEPT INFORMED** on updates to the Knowledge Hub?
    - ☐ Yes
    - ☐ No
    - ☐ No answer

Note: If you select 'Yes' to Question 12 → Question 13 appears.

12. **HOW** would you like to be kept informed? (Please check **<u>all</u>** that apply)
    - ☐ Email – *CanChild* Today Newsletter
    - ☐ Social Media: Facebook, Twitter
    - ☐ Posts on CanChild Website
    - ☐ Other: _______________

13. Do you have any additional comments/feedback/advice for us?

Closing Message:

Thank you for visiting the F-words in Childhood Disability Knowledge Hub and taking the time to complete this survey.

If you agreed to be contacted for future studies on the Knowledge Hub/F-words please go to the following link: https://surveys.mcmaster.ca/limesurvey/index.php/257154?newtest=Y&lang=en to provide your contact information.
Please note your responses on the Knowledge Hub Feedback Form will remain anonymous and this link will direct you to a separate survey to provide your contact information.

Thank you so much for your time and feedback. We greatly appreciate your involvement in this study.

CHAPTER FIVE:

A MULTI-FACETED INTEGRATED KNOWLEDGE TRANSLATION CASE STUDY: USING DIFFUSION OF INNOVATION THEORY TO EXPLORE THE ADOPTION OF ‘F-WORDS’ IN CHILDHOOD DISABILITY

Introduction to Chapter Five

Authors: Andrea Cross, Peter Rosenbaum, Sue Baptiste, Jan Willem Gorter

Publication Status: A journal-length version of this manuscript will be submitted to the *Journal of Developmental & Behavioral Pediatrics,* as an invited paper. The full version of the paper is included here for the purpose of my thesis.

Summary: A longitudinal case study (2012 – 2018) was conducted to explore our team’s KT research program to disseminate and support the adoption of the ‘F-words’ in practice. We used a two-part analysis: (1) a chronological time series analysis to describe the processes involved and associated outcomes (i.e., **how** did the ‘F-words’ disseminate and **what** was the uptake/impact); and (2) the DOI theory to explore the factors we believe contributed to the adoption of the ‘F-words’ (i.e., **why** was this KT research program successful). A case study design allowed us to explore our F-words KT research program in a real-life context and to utilize multiple unstructured data sources to capture a holistic understanding of what happened (*Objective 4*). This study reflects on our entire KT journey and thus touches on *all steps of the action cycle.*

In this study, we provide a detailed overview of the diffusion, dissemination, and implementation strategies we used, as well as the timing and uptake/impact of these strategies. Key take away messages include: i) diffusion strategies are useful, but dissemination and implementation strategies tailored to the target audience are needed to move research into practice most effectively; and ii) partnerships with knowledge users (e.g., families, service providers, administrators, etc.) are crucial to supporting the implementation of an innovation in practice. Furthermore, we found the DOI theory to be informative in both the study planning and design phase, as well as the analysis phase.

In just over six years, the 'F-words' moved from a research publication to being adopted and adapted by people around the world. We now have multiple examples of adoption at the family, clinician, and organizational levels and anecdotal evidence to support the impact of 'F-words'. From studying our KT research program, we contribute new knowledge to both KT practice and KT science. KT is still a relatively new area of research and so many questions remain regarding the KT process (i.e., how to effectively and efficiently transfer research evidence into practice). Moving forward, our next step is to formally evaluate outcomes at the family, clinician, and organizational levels.

Abstract

Objective: There is growing interest in exploring how to *engage families in research and in health care*, and how to move research into practice (i.e., *knowledge translation (KT)*). Since 2014, an integrated research team (families and health researchers) at *CanChild* has been on a KT journey to promote and study the diffusion, dissemination, and implementation of the 'F-words' in Childhood Disability. The 'F-words' (Function, Family, Fitness, Fun, Friends, and Future) – grounded in the WHO's ICF framework – offer a strengths-based family-centred approach to childhood disability. This longitudinal case study describes our KT research program and uses the diffusion of innovation (DOI) theory to understand the factors contributing to the dissemination and adoption of the 'F-words' in practice.

Method: Between November 2011 and February 2018 we collected multiple unstructured data sources: our KT strategies, including the documents/artifacts (e.g., videos, presentations, etc.) and evaluation data (e.g., surveys, Google/video analytics); e-mail correspondence related to the 'F-words'; and online blogs and news articles written on the 'F-words'. We used a two-step analysis: (1) a chronological time series described the processes involved and associated outcomes (i.e., **how** did the 'F-words' disseminate and **what** was the uptake/impact); and (2) DOI theory to explore the factors we believe contributed to the adoption of the 'F-words' (i.e., **why** was this KT research program successful).

Results: Multi-faceted KT strategies co-developed with stakeholders were essential to moving the ‘F-words’ from research ideas to practice. Strategies used included educational materials (e.g., awareness videos, infographic posters, online KT resources, etc.) and tailored educational outreach visits. Using diffusion, dissemination, and implementation strategies the ‘F-words’ bridged the knowledge-to-action gap and we now have extensive examples of families’, service providers’, and health care organizations’ adaptations and adoption of the ‘F-words’.

Conclusion: Diffusion, dissemination and implementation strategies are all needed in order for innovations to be adopted in practice. Partnerships with community stakeholders are an essential component of the KT process.

Key terms: diffusion of innovation; knowledge translation; family engagement in research; childhood disability; case study

Introduction

In the 21st century there have been significant paradigm shifts in our thinking and approaches to childhood disability.[1-3] Influenced by decades of childhood disability research and adoption of family-centred philosophies, a holistic family-centred approach to children's health and development is now believed to be best practice.[4,5] This contemporary approach involves working with families as equal partners, and adoption of the World Health Organization's (WHO's) 2001 International Classification of Functioning, Disability and Health (ICF) framework to guide thinking and practice.[6]

The ICF expands our focus beyond 'body structure and function' and emphasizes other important factors (such as children's 'activities', 'participation' and 'environments').[6] Many children's health researchers have written about the implications of these changes at the family, clinical, and organizational levels.[7-9] Unfortunately, despite considerable research evidence, a knowledge-to-action (KTA) gap persists, with traditional professional-led biomedical approaches (i.e., a primary focus on 'body structure & function', with the service provider as the 'expert') still informing many people's thinking and practices.[10,11]

Understanding the KTA gap

There is a growing interest in understanding *why* these gaps exist and *how* to increase the speed and uptake of research in practice.[12-14] KTA gaps are often classified as either a *knowledge translation* problem (i.e., knowledge fails to transfer to its intended audience) or a *knowledge production* problem (i.e., the intended audience fails to use the research, as it does not address their needs or apply to the local context).[15] In our scenario, the target audience is families of children and youth with disabilities and service providers who work with them (e.g., allied health professionals, physicians, teachers, etc.). It is important to address ***why*** the KTA gap exists before designing and implementing KT interventions to narrow any gap. In our field, researchers have concluded that the gap is a result of both the research not reaching the target audience and the research/KT strategies not addressing the knowledge users' needs.[16-18]

Contextual Background

In Canada, it is evident that a KT movement is happening in health services research.[19,20] There has been a significant change to federal grant applications to the Canadian Institutes of Health Research (CIHR) by embedding KT as a key component of the research cycle and expecting a structured KT plan as a requirement for successful funding.[19,21,22] This comes as a result of a shift in focus to the utilization and application of knowledge.[23] Recognizing the substantial gaps between what we 'know' from research and what is actually happening in practice,[14,22] research centres and research funders around the world are dedicating time and resources to explore how to work with knowledge users, and to find the best ways to transfer research evidence into practice.[24-26]

Our local context: CanChild Centre for Childhood Disability Research

Our research team is located at *CanChild* Centre for Childhood Disability Research at McMaster University in Hamilton, Ontario. Founded in 1989, *CanChild* is respected as an international leader in childhood disability research, education and knowledge translation. Since its early years, *CanChild* has had an active program in integrated knowledge translation (iKT), a process that involves working with knowledge users throughout the research process, and has prioritized the dissemination of research in a "user-friendly and accessible way that is relevant and meaningful for youth, families, and health care providers."[27]

In the last five years, *CanChild* researchers have expanded their focus beyond KT *practice* (i.e., 'doing' KT), to advancing KT *science* (i.e., studying the translation process).[25] In 2012, *CanChild* implemented a formal KT Strategic Plan (2013 – 2018) to prioritize KT activities for the research centre. The priority areas included: engaging with families and youth; nurturing partnerships; optimizing access to knowledge; building KT capacity; advancing KT science; and securing funding. *CanChild's* commitment to KT provided a solid foundation for the development of our integrated KT research program.

The 'F-words' in Childhood Disability KT Research Program

In 2012, two *CanChild* scientists, Drs. Rosenbaum and Gorter, published *"The 'F-words' in Childhood Disability: I swear this is how we should think!"*[8] Their intention for the paper was to operationalize the WHO's ICF framework for health.[6] The 'F-words' (Function, Family, Fitness, Fun, Friends, and Future) are grounded in ICF themes and over two decades of childhood disability research at *CanChild* and elsewhere. In the article, the authors argue that these six 'F-words' should be the focus of all children's health and development.[8]

Based on families' early interest in the 'F-words' ideas, in 2014 we formed an integrated research team composed of three early adopter mothers raising a child with a disability (DG, DK, JB), three child health researchers (PR, SB, JWG), and a PhD Candidate (AC, who acted as the project coordinator). Our initial goal was to address the knowledge needs of families raising children/youth with disabilities and aimed to promote families' uptake of the F-words concepts. However, our target audience quickly grew beyond families as service providers and health care organizations began to show interest in the 'F-words'. Thus, in 2015, our goal became to promote systematically, and to study, the diffusion, dissemination, and implementation of the 'F-words' at the family, clinician, and organizational levels. The 'F-words' KT research program is now one of *CanChild's* primary integrated KT projects.

Over the last four years, we have developed, implemented, and evaluated a theory-informed multi-faceted KT intervention to disseminate and support the adoption of the 'F-words' in practice. Throughout our research program, multiple KT theories have informed our work, with the Diffusion of Innovation (DOI) theory[28] providing the overarching conceptual lens. Using theory can be helpful in both planning and studying KT interventions.[29,30] The following section describes the DOI theory and explains how it informed our research program.

The DOI Theory

The DOI theory is based on a sociological perspective that perceives ideas/innovations as being communicated over time amongst members of a social system.[28] It includes multiple components that help us to understand: i) **how** an innovation moves from being unknown to adopted or rejected (i.e., the *innovation-decision process*); and ii) **why** an innovation is adopted or rejected. The DOI theory identifies four key factors that help to answer the **why**: the *innovation, communication channels*, *time,* and *social systems*. A brief description of the key concepts of the DOI theory, and our application of them, is presented below.

The Innovation-Decision Process

This five-step process outlines **how** an innovation is adopted. The steps include: i) knowledge; ii) persuasion; iii) decision; iv) implementation; and v) confirmation. The result at the end of the process is either adoption or rejection of the innovation.[28]

Each step of the innovation-decision process was considered throughout our project. In the beginning our goal was to disseminate the 'F-words' concepts widely in order to increase knowledge (*Step one*) and to capture people's attention (i.e., persuade people to want to learn more – *Step two*). We created a three-minute online video and disseminated it through various social media channels. In two months, 715 people viewed the video and an evaluation confirmed that people liked the 'F-words' ideas and wanted to learn more.[31] Thus, for our next project we developed the 'F-words' in Childhood Disability Knowledge Hub.[32,33] The purpose of the hub was to further inform people about the 'F-words' (i.e., increase knowledge – *Step one*), share families' and clinicians' perceptions of the 'F-words' (i.e., persuade and support decisions – *Steps two and three*), and provide freely available tools and resources to support people's use of the 'F-words' (i.e., implementation – *Step four*). While we have anecdotal evidence that people are using (or plan to use) the Knowledge Hub and the 'F-words' concepts, research is needed to evaluate formally, and to confirm, implementation (i.e., confirmation – *Step five*).

Next, we describe the four key factors that help to explain ***why*** an innovation is adopted or rejected (i.e., the *innovation*, *communication channels, time,* and *social systems).*

The Innovation

Rogers[28] identified several key characteristics of an innovation that support adoption, including *relative advantage*, *compatibility, complexity*, *trialability,* and *observability*. These factors were considered when developing the content and format of each KT strategy. A description of the characteristics and considerations in the development of the KT strategies are provided (Table 1).

< Please insert Table 1 about here >

Communication Channels

Communication channels refer to the ways in which people share information (i.e., either broadly through mass media or individually through interpersonal communication).[28] The best communication channels depend on the purpose of information sharing. For example, we initially used mass-media channels (e.g., social media, online videos) for widespread dissemination to increase knowledge of the 'F-words'. As people learned about them we then turned to interpersonal channels (e.g., educational outreach) to support the implementation of the 'F-words' in practice.

Time

Time is an important part of the DOI theory that can be considered at three levels.[28] First, it takes time for an innovation to move through the innovation-decision process. It is important to consider the timing of the process for each target audience and to plan KT interventions accordingly. For example, recognizing that it takes longer for an innovation to be adopted at the organizational level, our initial focus was on individuals' adoption of the 'F-words' concepts.

Second, depending on the time of adoption, individuals fall into one of five adopter categories: innovators (i.e., first to adopt, information seekers); early adopters; early majority; late majority; and laggards (i.e., last to adopt, resisters of change).[28] Each adopter category is associated with certain personality characteristics. We used the adopter categories to help identify our target audience (e.g., early adopters – role models, local champions, and knowledge brokers who might influence the uptake by others).

Third, the rate of adoption of an innovation is measured by the speed with which it is adopted within a social system.[28] Innovations are thought to have an "S-shaped" rate of adoption (i.e., slow to start, gradually increasing, and then levelling off). Acknowledging that innovations that embody the key characteristics (e.g., relative advantage, observability, etc.) are perceived to have faster rates of adoption, we focused on ensuring our KT strategies had these supportive qualities.

Social Systems

Rogers[28] defines a social system as a “set of interrelated units that are engaged in joint problem solving to accomplish a goal” (p. 24). The members may be individuals, informal groups, organizations, communities, etc. The social system provides a boundary through which the diffusion takes place. We were interested in multiple social systems, including the field of childhood disability at large (i.e., disseminating the ‘F-words’ to anyone interested in children’s health and disability), as well as smaller social systems (i.e., supporting the implementation of the ‘F-words’ within individual organizations). Social system factors that are believed to be important include cultural norms, opinion leaders, the structure of the social system, etc.[28,34] We considered these factors when planning our KT strategies.

Purpose of case study

The purpose of this case study is to report on our integrated research team’s KT journey. Case studies play a particularly important role in advancing new fields of science.[35] Although the importance of KT is now widely accepted, our understanding of the processes involved and associated outcomes of KT interventions remains limited.[36] As such, case studies can be used to address gaps in our understanding and provide concrete examples to help other researchers and stakeholders working to transfer research into practice.[37,38]

This study complements other evaluations of the individual KT strategies implemented[32,33] and provides a deeper understanding of the sequence of events and the evolution of the 'F-words' research program. Our objectives are to: i) describe the KT interventions used (i.e., diffusion, dissemination, and implementation strategies) and explore the associated outcomes of these strategies; and ii) provide examples of 'F-words' adoption at the family, clinician and organizational levels. In the discussion, we return to the DOI theory[28] to delineate the factors that we believe have contributed to the adoption of the 'F-words' concepts. Lastly, we conclude with next steps and implications for research and practice.

Methods

Descriptive Case Study Design

A longitudinal descriptive case study design was chosen as it allowed us to explore the 'F-words' KT journey in *real life context*.[35,39] The case study design supports "the deconstruction and the subsequent reconstruction" of a case.[39] Thus, in our scenario the case study allowed us to 'deconstruct' **how** the 'F-words' disseminated and **what** the outcomes were, and then 'reconstruct' **why** the project was successful. This process enhanced our understanding of the intricacies of complex interventions, in turn generating new knowledge that can be used to inform future KT projects.

Data Collection

One of the strengths and hallmarks of the case study design is the use of a variety of unstructured data sources to gain in-depth understanding of the phenomenon of study.[35,39] Each data source offers one piece of the picture, thus requiring the convergence of data sources to gain a more complete picture/greater understanding of the case.[39] Data sources used in this project encompassed: our KT strategies, including the affiliated documents/artifacts (e.g., videos, presentations, etc.) and evaluation data (e.g., surveys, Google/video analytics); e-mail correspondence related to the 'F-words'; and online blogs and news articles written on the 'F-words' (Table 2). Data were collected between *November 2011* and *February 2018*.

< Please insert Table 2 about here >

Data Analysis

A two-step analysis was completed. First, a chronological time series[35] described the processes involved and associated outcomes over time (i.e., ***how*** did the 'F-words' disseminate and ***what*** were the associated outcomes). Second, the DOI theory[28] was used to explore what factors contributed to the adoption of the 'F-words' (i.e., ***why*** this KT research program was successful). Descriptive statistics were used to analyze the quantitative information and descriptive content analyses were used to explore the qualitative information and identify key themes.

Results

Diffusion and dissemination of the 'F-words'

Moving the 'F-words' into practice involved a multi-faceted approach (i.e., more than one KT strategy) and can best be described according to the timeline in which the KT strategies were introduced. Reflecting back, we can divide our journey into three phases: i) Diffusion 'Let it happen' (commenced 2011); ii) Dissemination 'Help it happen' (commenced 2014); and iii) Implementation 'Make it happen' (commenced 2016).[34,40] This section describes the main KT strategies within the first two phases (i.e., diffusion and dissemination) (Table 3) and highlights the associated outcomes of these strategies. The next section describes the implementation strategies and identifies some preliminary examples of adoption at the family, clinician, and organizational levels.

< Please insert Table 3 about here >

Diffusion: 'Let it happen' (commenced 2011)

Lomas[40] describes 'diffusion' as the passive, untargeted and largely unplanned spread of information. It has also been defined as the 'let it happen' phase.[34] People who adopt innovations based on diffused messages are those who are actively seeking out information and are open to change (i.e., the *innovators/early adopters*).[28,40] Diffusion strategies typically reflect the traditional KT strategies used at the end of a research project (e.g., publications and presentations).[41]

Diffusion of the 'F-words' concepts began when the 'F-words' paper[8] was first published early online in November 2011. It is important to note that this was two years prior to the commencement of our integrated research team. Thus, for the first two years (2011-2013) only diffusion strategies were used, mainly by the authors of the 'F-words' paper (PR and JWG) sharing the 'F-words' message. During this early phase, their objectives were to spread awareness of the 'F-words' concepts and to introduce new ways to think, talk about, and approach childhood disability. Their KT strategies included sharing the 'F-words' publication through mass media channels and presenting on the 'F-words' at educational meetings. Common presentation titles included: 'The F-words in Childhood Disability: I swear this is how we should think!' 'Why is this so hard to do?' 'Can we really do this [or…is talk cheap?]' and 'How do we actually do this?'

Until 2014 no formal evaluation was conducted. However, we were able to explore the outcomes of the KT strategies by looking back and accessing the number of yearly downloads and citations of the 'F-words' paper and analyzing the number, type, and location of presentations. As of January 1st 2018, the paper had been downloaded over 12,400 times and according to Google Scholar has been cited in the peer-reviewed literature 126 times. In November 2016, the paper was made open access, which contributed to a significant increase in the number of yearly downloads (> 4,600 in 2017 alone). The paper has also been translated into Spanish.[42]

Regarding the educational meetings, over 90 invitational 'F-words' presentations have been delivered, including 52 local presentations (within Ontario), 10 national presentations (across Canada), and 33 international presentations. The type of presentation has varied – 40 invited speaker talks, 16 keynote addresses, and 37 conference presentations (including workshops, posters, and oral presentations). Of these presentations, over one-third (n = 35) were co-presented with stakeholders (i.e., families, youth with disabilities, and service providers). With each presentation, we were reaching a new audience (i.e., *social network*) and opening up more *communication channels* and opportunities for knowledge sharing and exchange.

Dissemination: 'Help it happen' (commenced 2014)

Dissemination involves the active spread and tailoring of information to the target audience[40] and can be thought of as strategies that 'help it happen'.[34] Contrary to diffusion strategies, dissemination strategies are planned processes.[43] The formation of our integrated research team in 2014 marked our transition to the 'dissemination phase'. Our primary goal was to disseminate the 'F-words' to families and service providers through tailored KT strategies.

For our first project, in 2014, we developed, implemented, and evaluated a three-minute online 'F-words' awareness video (as described earlier).[31] At that time, the 'F-words' paper was not open access and we sought a way to disseminate the 'F-words' message widely (i.e., through *multi-media communication channels*). We evaluated the video by monitoring the reach and asking viewers to complete a short online survey. In two months, there were 715 views and 137 survey responses.

Overall, the video was an effective way to reach a broad audience. Not only could we disseminate the video personally (through our own social media channels), but also having it publicly available made it easy for other people to share (i.e., increase *communication channels* and reach to other *social networks*). One clinician stated *"I work as a Social Worker in a pediatric rehab, I will be sending it on to all of my colleagues. It's a very thought provoking video! I am so glad I had an opportunity to see it."* Multiple viewers stated that they liked the positive message of the video and that it was shared in a clear, compelling (through parents' voices and pictures), and accessible way. A full report on the development and evaluation of the video is published.[31] The 'F-words' awareness video continues to be shared and there are now > 3,700 views on *CanChild's* Vimeo page.

By 2015, we had become aware that the 'F-words' ideas had started to spread over social media. At that point, there were nine published news articles and five online blogs (including blogs from clinicians in Nepal, Finland, and Australia). We were thrilled to see that the 'F-words' were capturing worldwide attention and that people were sharing the 'F-words' message with their own social networks. A common theme across cultures was the importance of focusing on what is meaningful for children and their families. This message appeared to resonate with both families and service providers (i.e., was consistent with their values, in turn enhancing the *compatibility* of the 'F-words' ideas). For example, Deepa Bajracharya (Physiotherapist, Nepal) challenged her colleagues to ask themselves: *"As a therapist do I really focus on function, family, fitness, fun, and* *friends so that the children I work with can develop a meaningful rather than a "normal" future?"*

Based on the global interest in the 'F-words', we recognized that we needed a centralized platform on which to share and exchange information on the 'F-words' ideas. For this reason, we decided to develop, implement and evaluate an online KT resource – a subsite of the *CanChild* website we called "The 'F-words' in Childhood Disability Knowledge Hub".[32,33] Hosting the Knowledge Hub on *CanChild's* website supported its reach/uptake due to its international reputation as a leading childhood disability research centre. *CanChild's* website attracts >12,000 unique visitors per month from 205 countries. Active dissemination strategies (e.g., *CanChild* newsletters, social media posts, presentations, etc.) were used to promote the Knowledge Hub.

The goals of the Knowledge Hub were to inform families and service providers about the 'F-words'; promote a community of knowledge sharing and exchange; and provide action-oriented tools to support the use of the 'F-words'.[33] While our integrated research team led the development of the hub, we partnered with other families and service providers who were using the 'F-words' to share their stories and adaptations of the 'F-words'. This increased the *observability* of how the 'F-words' are being used to inform people's thinking and practices. As more people started to use the 'F-words', many connected with us and the Knowledge Hub continued to grow.

In July 2017, we officially launched the Knowledge Hub. A preliminary evaluation of its usability and utility was conducted.[33] The Knowledge Hub reached a wide audience in a short time period (>6,800 unique visitors in four months). In one month, 87 people completed the utility survey, including 42 clinicians and 30 family members or individuals with a disability. Overall, 94% perceived the content to be meaningful and relevant for families and service providers and many people (n= 52) reported the hub would influence the things they do when working with others.[33]

It is important to note that it took two years to develop the Knowledge Hub, and during this time the ‘F-words’ continued to spread through other dissemination strategies. It is also important to recognize that not all of the KT strategies were planned ahead of time; some evolved as people learned about the ‘F-words’ concepts and were interested in partnering with us to disseminate the ‘F-words’. From the beginning, we encouraged people to connect with us, ask questions, share perspectives, and to adapt the ‘F-words’ to their own settings. The following strategies were initiated by community, health care, and research organizations and were conducted in partnership with our research team.

In 2016, we were contacted by the World CP Day manager (based in Australia) about creating an ‘F-words’ infographic poster. World CP Day is a non-profit organization made up of partner organizations in more than 60 countries. Their vision is to “ensure that children and adults with cerebral palsy have the same rights, access and opportunities as anyone else in their communities."[44] The poster was created in collaboration with our research team (including parents) and with the support of a graphic designer and typesetter. It was released in July 2016 and disseminated through World CP Day's social media channels. It didn't take long for the poster to capture people's attention and we were soon receiving requests to translate the poster into different languages. By the time World CP Day arrived on October 5th 2016 there were already eight translations of the poster and four in progress. There are now >25 translations of the 'F-words' poster (and counting). Since in other languages the 'F-words' don't translate into words that all start with the letter 'F', we have adapted 'F-words' to be "My Favourite Words". As nicely stated by the World CP Day manager, *"The F(avourite) words are certainly taking on a life of their own!"* The posters have been downloaded >3,500 times from the World CP Day website.

Similarly, in 2017 the 'F-words' caught the attention of the Ontario Brain Institute (OBI) and its CP-NET Stakeholder Advisory Council. As part of CP-NET's Knowledge Translation Program, *CanChild* received funding from OBI to produce two additional 'F-words' videos. The first was co-developed with youth with disabilities to share what the 'F-words' mean to them. The youth video was launched by CP-NET on World CP Day (October 6th 2017) and was actively disseminated by CP-NET and *CanChild* over social media. The video was entered into the 2017 Canadian Institutes of Health Research (CIHR) Institute of Human Development, Child and Youth Health Video Talks Competition and in January 2018 won an award.[45] In the first five months, the video had received >9,000 views. An evaluation of the Youth F-words video using an anonymous online survey is ongoing. The second video was developed in partnership with the Instituto Nossa Casa in Brazil, based on an animated video they created to share ‘My Favourite Words’ in Portuguese.[46] The video was translated into English and launched in early 2018. Dissemination and evaluation of the ‘My Favourite Words’ video is ongoing.

Implementation of the ‘F-words’

Implementation, also known as the ‘making it happen’ phase, involves identifying and overcoming barriers to knowledge use in order to support the adoption of research in practice.[34,40] It is the most active of the phases, and thus requires action-oriented tools to support people’s use of the research in the local context, and a willingness among the audience to adopt the innovation. Implementation strategies included educational materials (specifically action-oriented tools) and educational outreach visits. While we have yet to undertake a formal evaluation of the implementation of the ‘F-words’, we have anecdotal evidence and examples of implementation at the family, clinician, and organizational levels.

Family level

In order to support the use of the ‘F-words’ concepts by families, the parents on our research team have created several **‘F-words’ tools** (i.e., an F-Words agreement, photo collage, and profile). The first tool, **‘F-words Agreement’**, was created by DK before the formation of our research team. The agreement is a one-page laminated print-out that states what each ‘F-word’ means to her son. To the best of our knowledge this was the first family adaptation of the 'F-words'. In an article DK wrote for Holland Bloorview's Bloom Magazine,[47] she stated:

> "*In thinking about my role negotiating with service providers, I decided to create an "F-words agreement" that we would share with professionals. This laminated print-out would be Alfie's document: he owned it, and he would show it at clinic visits as a starting point for discussion. To me it represents an informal but serious pact between the child and whoever they rely on for support."*

The 'F-words' agreement template is available on the Knowledge Hub and can be customized for each child by inserting their picture, name, and age. Families have shared that they have used the Agreement in a variety of ways, including taping it to the back of their child's wheelchair, sharing it with educators, and putting it at the top of their child's file to be a constant reminder of what is important to them. One parent stated, *"I love the [F-words Agreement]. I will save it and print it out… I am going to my son's classroom to talk about inclusion, people with disabilities, and stigma on World CP Day. I am going to print this out for all the kids in his classroom."* Service providers also like the Agreement as a way to introduce the 'F-words' to families. One clinician stated, *"We really like the one-page F-word agreement – what a great way to introduce this concept to families and child care centres."*

In 2015, the **'F-words Collage'** was created by another parent stakeholder on our research team (DK). She created the collage as a means of sharing a visual representation of what the ‘F-words’ mean to her family. The collage template is available on the Knowledge Hub as a downloadable PDF file. This allows people to insert their own pictures. Families have shared that not only is the collage a useful communication tool, but creating the collage is a fun family activity. Clinicians have also commented on the value of the collage as a communication tool. A supervisor of an Infant Development Program writes *“The photo collage will be a great tool to use when transitioning to school or other services in the community (and a nice way to introduce the concept of the F-words to other agencies).”*

In 2017, the **‘F-words Profile’** was created as a one-page document to highlight what each ‘F-word’ means to the child and family. The idea stemmed from our third parent stakeholder who stated in her ‘F-words’ blog *“reading my son’s file (as large as it is!) does not give a complete picture of him as a whole person.”*[48] The profile is meant to be used as an introductory document for the initial meetings with new service providers/educators. The profile is designed to highlight the child as a person, their strengths, what they like to do, who their support systems are, and their hopes for the future. As the child grows older, the ‘F-words’ Profile will likely change and thus can be updated at any time.

In August 2017, a mother wrote a blog titled “A parent’s letter to her child’s new teacher: You’ve seen the diagnosis, now meet my child.”[49] In the blog, she shared her son’s ‘F-words’ Profile and a letter to her son’s new school teacher. In the letter she wrote, “*You will gather information from reports, testing* *and IEP goals and this will give you invaluable insight into my son's needs. For a fuller picture of my awesome child, however, I would like to present you with the following document* ***from*** *my child,* ***about*** *my child."* At the end of the article McIssac[49] encourages other parents to create an 'F-words' Profile; she states *"Attach it to the front of your IEP, bring it with your child to meet the teacher or better yet, if possible, ask your child to carry it along. How empowering!"*

Since the beginning of our KT research program we have heard from many families that they like the 'F-words' concepts. Families have shared with us that the 'F-words' are empowering and provide a simple way to communicate the most important information. One parent stated *"It's a great approach and one that is very supportive to children and to whole families. I wish that we had been able to benefit from this approach in my family when our son was young."*

Recognizing that the 'F-words' were meaningful to families is what inspired us to create the F-words Knowledge Hub. While it is too soon to know the impact of the tools on families (launched with the Knowledge Hub July 2017), from the pilot evaluation we know that the 'F-words' Tool section was identified as one of the best features of the Knowledge Hub.[33] As one clinician stated, "*Sharing the information is great but also providing the tools and resources for families and providers alike is crucial to getting the word out and to helping these families."*

Recently, as part of our educational outreach visits, we have been introducing the 'F-words' tools to family representatives prior to the outreach visit through an online webinar. The purpose of the webinar is to introduce families to the ‘F-words’ concepts and tools and to discuss what the ‘F-words’ mean to them, how they might use the tools, and what they would like to share with service providers and administrators. Families are then asked to explore the Knowledge Hub and tools, and if comfortable to share their completed tools, perspectives of the ‘F-words’, and hopes of how the ‘F-words’ could be implemented by service providers and a health care organization as part of the workshop. Overall, the feedback has been very positive: the families have enjoyed completing the tools and have found them to be useful, and the service providers love hearing from families. For example, a clinician stated: “*Having personal experiences delivered by parents was powerful and helped make F-words more meaningful and relatable. Helps to see how it can be applied to service delivery and help with goal setting”*

Clinician level

As of February 2018, we have many examples of clinical uptake of the ‘F-words’. Clinicians around the world have shared with us that they are using the ‘F-words’ to inform their thinking, practices, and program planning. For example, a physiotherapist from Canada wrote to us saying, *“The ‘F-words’ approach is such a healthy way for families and ourselves to live through the experience of raising or treating a child with special needs. I’m so glad it is becoming the approach of choice. Congratulations!”* Similarly, a physiotherapist and occupational therapist in Germany wrote, *“We were delighted about your* *marvelous message applying the 'F-words' ideas within the framework of the ICF! That's what we really need to work effectively and joyfully with our multi-disciplinary team together."* These messages confirm that the 'F-words' are making their way into clinical practice.

One of the main ways the 'F-words' are being implemented in clinical settings is for goal setting with families. In 2015, Fuller & Susini created a **'ICF Family Goal Sheet'** to be used by physiotherapists to help families participate in the goal setting process. Their intention was to *"…better establish family-centred collaborative goal setting to improve follow through of home programming activities given by therapists."* While they started with a single clinical discipline their goal is to adapt the goal sheet to be utilized by interdisciplinary teams.

In 2017, our 'F-words' research team created a generic goal sheet that could be used for a variety of settings (e.g., at home, school, in therapy) (adapted from Fuller & Susini's, 2015). On the **'F-words Goal Sheet'** there is space to fill in one goal for each 'F-word'. A unique feature of this goal sheet is that after every goal there is question that asks "why?" this goal is being formulated. This question was raised by a parent (DK), who identified that it is important not only to identify a goal, but also to share why that goal is important to the child and family.

The 'F-words' and goal setting are now common topics in our educational outreach visits. Clinicians are interested not only in how to set goals with families using the 'F-words' Goal Sheet, but also how to transfer these family-driven goals to organization-mandated care plans (i.e., that have certain criteria in terms of goals). This issue has been an interesting exercise for us to navigate and one that we continue to explore with service providers and administrators. It also identifies the reality that to support implementation of the 'F-words' in clinical practice they must be adopted at the organizational level.

Organizational level

In 2016, we started to be invited to deliver workshops to health care organizations and school boards. That year, we delivered two workshops; in 2017 we delivered eight; and as this paper in being prepared in early 2018 we already have 10 educational outreach visits scheduled. Each educational outreach visit is developed in partnership with the organization, so that we tailor the workshop to the needs of the organization. Workshops range in length (3 hours to full day) and size (20 – 200 people). While the 'F-words' provide the framework for each workshop, the specific goals and objectives of the workshops vary. Common themes include exploring how the 'F-words' can support family-centred service, inter-professional collaboration and communication, and goal-setting. An evaluation form is distributed after each workshop to evaluate participants' perceptions of the workshop. To date 157 evaluations have been completed. Table 4 summarizes the evaluation data.

< Please insert Table 4 here >

The increasing number of educational outreach visits that we are invited to give each year is a testament to the fact that the 'F-words' are beginning to be adopted at the organization level. The first organization to contact us about implementing the ‘F-words’ was a local Infant Development Program. They were interested in re-designing their family plan to incorporate the ‘F-words’. The purpose of the Family Plan is to document a family’s goals at the initial visit and then every six-months.

In order to support the re-design of the Family Plan, the program put together an ‘F-words’ Working Group with service providers from three agencies. The Working Group developed a draft of the Family Plan and our research team provided feedback and conducted a pilot evaluation to gather families’ perspectives of the Plan before it was implemented. Working together was a key component to tailoring the ‘F-words’ to the Infant Development Program’s local context. Also, administration and leadership support has been a critical factor in moving the ‘F-words’ into the organization. In an email, the manager of the program stated *“We are really excited to be incorporating the F-words into our service delivery model and if any of the work we have done will help others recognize the opportunities the F-words approach brings to their service we are happy to share.”* Her words reflect that she is not only a local champion of the ‘F-words’, but also a ‘knowledge broker’ to the broader community. The Family Plan was officially launched on December 1 2017 and we are now working together to develop and implement an evaluation of the impact of the ‘F-words’ at the family, service provider, and organizational levels.

Another example of organizational implementation is a Children's Services Centre in Ireland. In spring 2017, a senior clinical psychologist and physiotherapist at the centre contacted us about using the 'F-words' to reshape their program. Their organization had already launched an 'F-words' message board in the waiting room to share information on the 'F-words' with families, and they were interested in learning how else they could incorporate the 'F-words' into their practices. Through email and teleconference correspondence we exchanged information and ideas for implementation. Once again, we acted as 'knowledge brokers', sharing what we had learned from other clinicians and organizations throughout our journey. Having the Knowledge Hub available to share as a resource for further information was also incredibly valuable. After sharing the hub, one of the clinicians wrote to us:

> *"This is great! Thanks for including us! We love the idea of the Hub, and exchanging ideas and information with other organizations who are doing this! I love the tools and examples, and to see the other service providers! Our manager has also forwarded the link to all of the other teams in the region. I hope to hear from some curious colleagues when I get back to work on Monday!"*

Both of these examples highlight how implementation at the organizational level requires active participation from service providers and managers (local champions) within the local context. At this stage, knowledge of the local context is necessary in order to overcome barriers and support integration of the innovation. As a research team, we can provide support at a distance (and offer tools and resources to support implementation), but adoption of the ‘F-words’ now depends on the local knowledge users (i.e., the service providers and administrators).

Discussion

As a research team our goal was to support the dissemination and adoption of the ‘F-words’ concepts in practice. Since November 2011, the ‘F-words’ have had a reach and impact far beyond what the authors (PR and JWG) ever imagined. As identified above, we now have many examples of adoption at the family, clinician, and organizational levels.

It is important to recognize that our case study focuses on those who have adopted the ‘F-words’. Due to the nature of the study, we do not know who, or how many, people have rejected the ‘F-words’ ideas, or why they might do so. We have heard from a handful of people that they don’t like the term ‘F-words’ or that they are already doing this and that the ‘F-words’ are not new information, but other than that the people who have reached out to us are supporters of the ‘F-words’ ideas (i.e., *early adopters*). Thus, in this case study we focused specifically on the experiences of early adopters, and have attempted to understand what factors led to their adoption.

Using Rogers’ DOI theory[28], as outlined in the introduction to this report, we identified that the *innovation characteristics*, *communication channels*, *social systems*, and *time* to be contributing factors to knowledge translation and uptake.

The ‘F-words’ were published at a time in which family-centred service was already accepted as best practice and people were beginning to talk about, and adopt, a biopsychosocial approach. Thus, the alignment of the ‘F-words’ with: i) people’s values and experiences (i.e., high *compatibility*); and ii) a biopsychosocial lens (i.e., *relative advantage* over traditional biomedical model) both helped to support its uptake. Additionally, in comparison to the ICF framework, people perceived the ‘F-words’ to be easier to remember and more family-friendly, thus further supporting their uptake (i.e., low level of *complexity).* The final two characteristics, *observability and trialability,* were supported by the development of the Knowledge Hub. Publically sharing examples of how families, service providers, and organizations were thinking about and applying the ‘F-words’ increased the *observability,* while providing the tools and resources supported the *trialability*. Collectively these characteristics supported people’s decision to use and implement the ‘F-words’ in practice.

Both *mass media* and *interpersonal channels* were essential to the dissemination and implementation of the ‘F-words’ through various *social systems*. Throughout our project, we used multiple mass media channels to disseminate the ‘F-words’ message widely. While *CanChild’s* communication channels have a large reach (e.g., the monthly *CanChild* newsletter goes out to >4,100 people and >3,000 of Twitter followers), leveraging the communication channels of our partners allowed us to reach social networks that we would not have accessed on our own. For example, World CP Day created Facebook posts to disseminate the ‘F-words’ infographic poster, which have reached 141,300 people. In addition, *interpersonal channels* (e.g., e-mail correspondence with interested stakeholders, educational outreach visits) helped us to support people’s use of the ‘F-words’. As a research team, we encouraged people to connect with us and we found that our openness to broker new relationships and support people’s use of the ‘F-words’ facilitated the implementation process.

Lastly, as Rogers[28] identified, the DOI process takes *time* and it is important to consider the time and resources required to plan and implement KT interventions. This project was supported by PhD student AC’s thesis project. Having a PhD student dedicated to planning, implementing, and studying the translation process as well as coordinating the engagement activities was necessary to supporting the project. Furthermore, as we moved through the *innovation-decision process* and more people started to adopt the ‘F-words’, the demand for implementation support increased (e.g., for educational outreach visits). *CanChild’s* infrastructure support to knowledge translation as prioritized in the *CanChild* Strategic KT Plan[25] and the research team’s dedication to this work were both crucial to being able to respond to these requests and support implementation on a larger level.

Next Steps

We are now at a place where the ‘F-words’ have disseminated through various communication channels and social networks and individuals are adopting them in a number of ways. While we started out interested in families’ and service providers' individual adoption of the 'F-words' we are now moving towards organizational adoption. By working with people at the organizational level we aim to reach a larger audience (i.e., the *early majority*).

Recognizing the complexity of organizational adoption, we are currently only working with organizations who reach out to us. Through this journey, we have learned the importance of organizational leadership and management support (i.e., local opinion leaders/champions).[34] Practice and program changes at this level require both time and resources on the behalf of the organization and thus must be organization-driven.[50,51]

As identified earlier, we already (two months into the calendar year of 2018) have 10 invitational educational outreach visits scheduled. These visits are often a first step towards moving the 'F-words' into organizations. We will continue to offer educational outreach visits tailored to the individual needs of each organization. We also plan to develop and implement an experimental study to evaluate the impact of the 'F-words' at the family, clinician, and organizational level. Once again, this will be an integrated knowledge translation study conducted in partnership with families, clinicians, and health care managers.

Study Implications

This case study provides one example of an integrated KT research program. Through this study, we identified the processes involved in disseminating and implementing the 'F-words', as well as highlighted some of the associated outcomes. In addition, we explored factors that facilitated the KT process through the application of the DOI theory.[28]

The F-words KT Research Program involved both KT practice (i.e., 'doing' KT), as well as KT science (i.e., 'studying' the process), and thus has implications at both levels. In regards to *KT practice*, our main lesson learned was the *value of researcher-knowledge user partnerships*. Not only were the partnerships within our research team incredibly influential, but our openness to new partnerships allowed our project to evolve well beyond what we had initially planned. Thus, while we encourage people to think about KT early on in a study and to plan and budget time and resources accordingly, we also encourage research teams to have some flexibility to react to knowledge users' needs and to respond to new opportunities for knowledge translation as they present themselves. Finally, not only is it important to do KT, but it is equally important to study the translation process (i.e., *KT science*).[52,53] We encourage both researchers and knowledge users who are working on KT projects to evaluate their KT strategies and share challenges, lessons learned, and outcomes/impacts.

Study Limitations

There are three main limitations to this work that must be identified. First, we only focused on the 'early adopters'. While the case study provided a rich description of how the 'F-words' disseminated, and why some people were adopting the concepts, we have only heard one side of the story. What remains to be understood are the reasons why the 'F-words' fail to capture people's imagination/attention. Second, the case study design provides anecdotal evidence. We still need to design and implement an evaluation study to measure impact formally. Third, while multiple data sources were used in this case study, we did not conduct any formal interviews. In the future, semi-structured interviews with families, clinicians, and administrators who are using the ‘F-words’ will provide more rich details on the KT process from the knowledge user perspective.

Conclusion

The success of the ‘F-words’ KT research program is a product of people adopting the ‘F-words’ ideas, adapting them to their own settings, and then sharing their experiences with others. In this case study, we have shared how diffusion, dissemination, and implementation strategies were used to move the ‘F-words’ from a publication to adoption in practice. We have shown that while traditional diffusion strategies are useful (i.e., publications and conference presentations), dissemination strategies tailored to the target audience are needed to move research into practice most effectively.

The uptake of the ‘F-words’ videos and ‘F-words’ infographic poster are examples of how tailored strategies can reach and captivate a much broader audience. Having the Knowledge Hub as a resource available to share with people interested in the ‘F-words’ concepts has been invaluable in supporting the implementation of the ‘F-words’ ideas. Furthermore, we have found that tailored educational outreach visits co-developed with opinion leaders and families are important to supporting implementation at the organizational level.

We hope that the examples of adoption at the family, clinician, and organizational levels will prompt others to think of additional ways the ‘F-words’ can be used by families, in therapy sessions, and in developing programs. Moving forward we challenge everyone to continue to be ‘Knowledge Brokers’ and to share and exchange ideas.[54,55] We have learned so much from people who are sharing with us how they are adapting and adopting the ‘F-words’ in their local context.

It has been reported that it can take up to 17 years to transfer research into practice.[14] Through the ‘F-words’ KT research program we have shown the impact that tailored multi-faceted KT strategies can have on narrowing this gap. In just over six years, the ‘F-words’ have crossed the bridge from research to practice. As identified above, many factors have contributed to the adoption (i.e., the *innovation, communication channels, social networks,* etc.).

Following the *innovation-decision process*, there are now multiple organizations working at the *implementation* and *confirmation* stages. Moving forward, our next step is to formally evaluate outcomes at the family, clinician, and organizational levels. While we cannot mandate that these ideas are used, nor do we wish to do so, the more we can highlight the impact of these ideas, the more chances there are for societal adoption and driving changes in how we think, talk about, and approach childhood disability.

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Table 1. Characteristics of the innovation that are relevant to the KT strategies

Characteristics of the Innovation *(all quotes from Rogers[28])*	**Considerations for the development of the KT strategies**
Relative Advantage *"The degree to which an innovation is perceived as better than the idea it supersedes"*	It is important to highlight how the 'F-words' (i.e., a biopsychosocial approach) are better than the traditional (i.e., a biomedical) approach to health.
Compatibility *"The degree to which an innovation is consistent with existing values, experiences, and needs of potential adopters."*	It is important to describe how the 'F-words' are consistent with family-centred service (i.e., a best practice in children's health care) and how the 'F-words' can be used to implement family-centred principles (e.g., support a collaborative approach).
Complexity *"The degree to which an innovation is difficult to understand and use."*	The 'F-words' provide a simplistic means for operationalizing the ICF. It is important that a clear description of the 'F-words' and examples of application of the 'F-words' are provided.
Trialability *"The degree to which an innovation can be experimented with on a limited basis."*	It is important that action-oriented tools and resources are freely available to help people trial the 'F-words' in practice. It is also important to encourage people to adapt the 'F-words' in their own ways.
Observability *"The degree to which the results of an innovation are visible to others"*	It is important to share stories on how the 'F-words' are informing families and service providers thinking and approach to disability. By sharing examples of uptake we can see the impact and learn from others.

Table 2. Data sources

Data Source	**Description**
KT Strategies Documents/Artifacts and Evaluation Data	Multiple KT strategies were used to disseminate the 'F-words' from 2011 - 2017. Any documents or artifacts affiliated with the KT strategies (e.g., videos, Knowledge Hub materials, infographic posters, etc.) were used as data sources. All evaluation data with respect to the individual KT strategies were also included (e.g., surveys and Google/video analytics).
E-mail correspondence related to the 'F-words'	E-mail correspondence with relation to the 'F-words' and that was shared with the Project Coordinator (AC) was included. All e-mail correspondence starting from January 2013 (first e-mail regarding starting the project) was put into a 'F-words' folder. The project co-ordinator developed an e-mail trail of all correspondence with families, service providers, and/or healthcare/childhood disability organizations regarding the 'F-words'.
Online blogs and news articles written on the 'F-words'	Semi-annual google searches were conducted (beginning January 2013) to monitor public online blogs and news articles written on the 'F-words'. A Word Document was used to record blogs/news articles. Once the Knowledge Hub was created a section called the 'F-words' Footprint was created to host these materials.

Table 3. Diffusion and dissemination strategies used in this study

Phase of KT Journey ***(Year of commencement)***	**KT Strategies**	**Description of KT Strategy**	**Evaluation Strategy**
Diffusion 'Let it happen' *(commenced 2011)*	• Educational Materials	• 'F-words' Publication	• Publication metrics (# of yearly downloads and citations)
	• Educational Meetings	• Conference Presentations	• Monitor # of yearly presentations, types of presentations, and location of presentations
Dissemination 'Help it happen' *(commenced 2014)*	• Educational Materials	• 'F-words' awareness videos	• Video analytics (# of views) and anonymous surveys evaluating viewers' perceptions of videos
		• 'F-words' Infographic Poster	• Monitor # of yearly downloads • Count # of language translations
		• 'F-words' Knowledge Hub	• Monitor number of monthly visitors to the Knowledge Hub • Usability Evaluation (anonymous online survey)

Table 4. Educational Outreach Visit Evaluation Data (N = 157)

Educational Outreach Survey	**Strongly Agree n (%)**	**Agree n (%)**	**Neutral n (%)**	**Disagree n (%)**	**Strongly Disagree n (%)**
Content of the workshop					
Workshop covered all the stated objectives	107 (68%)	49 (31%)	1 (0.01%)	0	0
The information provided was useful for my needs	115 (73%)	41 (26%)	1 (0.01%)	0	0
The depth and breadth of the information were appropriate	105 (69%)	51(32%)	1 (0.01%)	0	0
Presenters					
The presenters demonstrated effective presentation skills	125 (80%)	31 (20%)	1 (0.01%)	0	0
The presenters were knowledgeable about the topic	135 (86%)	22 (14%)	0	0	0
The presenters adequately responded to questions	128 (82%)	25(16%)	4 (2.5%)	0	0
Overall Experiences					
The pace of the workshop was just right	104 (66%)	51(32%)	2 (1.2%)	0	0
The amount of content covered was adequate	104 (66%)	52 (33%)	1 (0.01%)	0	0
The format was a good way for me to learn this information	114 (73%)	41(26%)	1 (0.01%)	1 (0.01%)	0

CHAPTER SIX: CONCLUSIONS

In the prelude to my thesis I provided the following quote: "*Looking back and learning will enable you to move forward."* As I reflect on my doctoral degree I am filled with gratitude for the journey that I have experienced. I entered the program with an interest in research and teaching, and I can say with confidence that I have gained new knowledge and skills in both of these areas. As I complete the final phase of my doctoral program, I feel competent and ready to take the next steps in my academic journey.

My thesis focused on two primary areas: 'knowledge translation' (KT) practice and KT science. Six years ago, these were both new terms to me. While I understood the importance of moving research into practice, I used the traditional diffusion strategies (i.e., publish and present at meetings). After spending several years immersed in the field of KT, I now have a deeper understanding of KT and the complexities that underlie it.

In the introductory chapter, I identified four specific learning objectives: i) apply KT practice strategies to disseminate the 'F-words' and explore people's knowledge and attitudes towards these ideas; ii) identify and assess KT strategies that directly target families of children and youth with special health care needs; iii) develop and evaluate the utility of an online KT resource to support the implementation of the 'F-words'; and iv) explore the processes involved in, and associated outcomes of, a longitudinal multi-faceted integrated KT project aimed to promote the adoption of the 'F-words in Childhood Disability' in practice.

Collectively, my overall goals were to: i) move the 'F-words' from research to practice (i.e., advance KT practice); and ii) evaluate the implemented KT strategies and study the processes involved and associated outcomes (i.e., advance KT science). Reflecting on the outcomes of this dissertation, I believe I have achieved both of these self-assigned goals.

An innovative feature of my doctoral thesis was that it was an *integrated Knowledge Translation* (iKT) *research project.* This means that I received mentorship not only from three health services researchers, but also from three mothers of children with disabilities who were integral members of our research team. As the project coordinator, I acted as the 'Knowledge Broker' between the researchers and the family partners, and while I didn't study the integrated process per se, I learned a lot about iKT through immersion in this project.

This chapter provides me the opportunity to offer *personal reflections* on the implications of my dissertation. First, I highlight what I believe are the key implications for KT practice. Second, I identify the main implications for KT science. Lastly, I discuss the future directions for the F-words KT Research Program and my own next steps as a KT practitioner and researcher.

KT Practice Implications

KT practice focuses on the strategies and processes involved in implementing research evidence into practice and evaluating its impact (Straus, Tetroe, & Graham, 2013). My thesis involved the development, implementation, and evaluation of a *multi-faceted integrated KT intervention*. It was *multi-faceted* insofar as multiple KT strategies were used, and *integrated* by means of working with stakeholders (in my case families) throughout the entire research/KT process. In the end, both of these components were critical to supporting the dissemination and adoption of the 'F-word in Childhood Disability'. While the content focus of my thesis was the 'F-words', the integrated approach and KT strategies used can apply to any research project. Thus, the study implications and lessons learned are generalizable to a wide audience.

The Power of Partnership

Over the last five to ten years in Canada there has been growing interest in *engaging patients and families* along all stages of the research-to-practice continuum (CIHR, 2016). This means involving patients and families in identifying the research questions, planning the study design, carrying out the research, and sharing the findings (Morris, Shilling, McHugh, & Wyatt, 2011; Esmali, Moore, & Rein, 2015). This is a significant shift beyond the traditional approach (where researchers were solely responsible for the research process), and is based on the belief that by partnering with stakeholders we can improve the relevance of the questions we ask (i.e., ensure that what we study is meaningful to our target audience) and enhance the speed and uptake of relevant research in practice (CIHR, 2016; Morris et al., 2011; Palisano, 2016).

While our research team did not specifically evaluate our integrated strategy, it emerged as a key construct in each study. Our first study involved the development of an online awareness video to spread awareness of the 'F-words' to a broad audience. This was our first time working together as an integrated research team and as a small project it provided a good opportunity for us to develop a partnership. Looking back now, I believe that this initial time spent building a meaningful relationship with our family partners contributed to the sustainability of our integrated research team.

In addition, the video was enhanced by having both researchers' and families' perspectives. Working together, we were able to combine the research evidence with parents' pictures and quotes, which helped bring the 'F-words' to life and captivate our audiences. This was confirmed in the evaluation where families' quotes and pictures were one of the highest-rated features of the video (Cross, Rosenbaum, Grahovac, Kay, & Gorter, 2015). Four years later, the 'F-words' video continues to be shared through various communication channels and social networks and now has > 3,700 views.

The video helped us reach a broad audience in a relatively short time. Furthermore, by evaluating the video, we were able to explore people's knowledge and attitudes towards these ideas in order to ensure the 'F-words' were relevant and meaningful to stakeholders before investing more time and resources in a larger KT initiative. Through the evaluation, we learned that people liked the 'F-words' ideas and wanted to learn more. This confirmed that a larger KT project was warranted. Based on our research team's experience, I recommend short online videos that are created in partnership with stakeholders as a dissemination strategy. Videos can be created at any stage in the research process and are a useful strategy for both garnering attention at the beginning of a project, and sharing findings at the end. Other children's health researchers who have created awareness videos have reported similar findings (Campbell-Yeo et al., 2017; Harrison et al., 2016).

Since disseminating our initial video in 2014, our research team has created two more 'F-words' videos with other stakeholder groups. While the 'F-words' content remains the same, the message is delivered in a slightly different way each time as the stakeholders shape the story. In the last few years, the Canadian Institutes of Health Research (CIHR)'s Institute of Human Development, Child and Youth Health (IHDCYH) has recognized the value of online awareness videos to share research findings and since 2014 they have hosted an annual Video Talks Competition (CIHR, 2018). This competition encourages researchers to develop a short online video to disseminate key messages from their research. As identified in the case study paper, in 2017 we received funding from the Ontario Brain Institute (OBI) to co-create a Youth 'F-words' with youth with disabilities to share what the 'F-words' mean to them. We entered the video into the 2017 IHDCYH competition and won second place.

Once again, I found that creating the video with the youth provided an opportunity to develop relationships amongst the researchers and stakeholders. We partnered with the Youth Partnering in Research (YPIR) Facebook group to create the video. The YPIR is an online research community consisting of *CanChild* graduate student researchers and youth with disabilities. Over the summer 2017, we co-wrote the script using a shared Google Document, and in late August we filmed the video at McMaster University. The filming day was a great opportunity for us to meet in person and further strengthen our relationship. Youth Video was released in October 2017, has already had over 9,000 views, and in fact has had a much wider uptake than our initial F-words video. While many factors may contribute to this reality, I feel that the funding we received from OBI made a significant difference, as we were able to hire a local production company to film and edit the video. The Youth Video was also created three years after the original F-words video, and thus people were now more familiar with the 'F-words' concepts. This time we also partnered with provincial networks such as OBI and CP-NET to disseminate the video. This is yet another example of the power of partnerships.

In the scoping review, engaging families was also identified as a key facilitator of the KT interventions. All studies included in the review evaluated educational materials including educational sheets, research summaries, storybooks, and our awareness video. In addition to our video study (Cross et al., 2015), the storybook intervention, which included three separate studies, reported that involving families was critical to the creation of engaging and user-friendly KT materials (Hartling et al., 2010; Hartling, Scott, Johnson, Bishop, & Klassen, 2013; Scott, Hartling, O'Leary, Archibald, & Klassen, 2012).

In developing the Knowledge Hub, our partnerships with stakeholders grew outside of our research team. Once again, working with stakeholders had a huge impact and allowed us to create a more meaningful and relevant KT product. Similar to the 'F-words' videos, people reported that a highlight of the Knowledge Hub was seeing families' and service providers' uptake of the 'F-words' ideas (Cross et al., in press). By sharing pictures, quotes, stories, and the 'F-words' tools/resources that were created by families and service providers we were able, once again, to bring the 'F-words' to life. By exploring the Knowledge Hub, people could not only learn about the research and theories behind the 'F-words', but also observe real-life applications. This would not have been possible without our partnership with community stakeholders (including families, service providers, and health care administrators) who were adopting the 'F-words' in practice and sharing their experiences with us.

Working with stakeholders also assisted with the dissemination of the 'F-words' message (i.e., increased the speed and uptake of moving the 'F-words' into practice). For example, the World CP Day 'F-words' Infographic Poster has now been translated into >25 languages. This uptake is a product of World CP Day's international wide social networks. World CP Day includes members from over 60 countries; being able to partner with them to access their pre-established communication channels allowed the poster and 'F-words' message to disseminate widely.

As highlighted in the case study paper, over the last four years our research team has used a variety of diffusion, dissemination, and implementation strategies to move the 'F-words' into practice. While some of these strategies were planned ahead of time (e.g., the ‘F-words’ video and Knowledge Hub), others developed over time thanks to increasing partnerships (e.g., the ‘F-words’ infographic poster and educational outreach visits). Although I encourage people to plan ahead and to think about KT strategies from the beginning of a research project, I also believe in a flexible and iterative approach to KT that responds to opportunities as they arise.

Reflecting back on our journey, the partnerships we developed along the way and the time we invested in fostering those partnerships were critical to supporting the dissemination and eventual adoption of the ‘F-words’ in practice. For example, this involved being responsive to people approaching *CanChild*. In particular, the first author of the ‘F-words’ paper (PR) has received numerous emails from people around the world regarding the paper and how to implement the ‘F-words’ into their research, clinical practices, and/or organizations. Being open and willing to connect with these partners has significantly increased our ability to support moving the ‘F-words’ into practice. Furthermore, we have encouraged people who are visiting the Knowledge Hub to connect with us, ask questions, and share their experiences. While this all takes time, we have seen the impact that working with people in the community (who are local opinion leaders and knowledge brokers) can have on moving the ‘F-words’ into practice. As the African proverb states, *“If you want to go quickly, go alone. If you want to go far, go together.”*

Moving forward, my top recommendation to other research teams interested in KT would be to reach out to your target audience and build and invest in relationships early on. This requires time and ongoing commitment of researchers, which is new and can be challenging as it is not part of the traditional researcher role (e.g., write grants, design and conduct studies, mentor students, etc.). In order to support this process, researchers need resources (e.g., staff time, funding for stakeholder engagement) and infrastructure support. For this project, I was able to utilize *CanChild's* previously established networks (i.e., years of developing relationships with stakeholders) and infrastructure support (e.g., student and staff time, *CanChild* website, etc.). Being part of an established research centre, had a huge impact on being able to implement this project.

A multi-faceted approach to KT

A multi-faceted approach to KT is an intervention that includes two or more components. To date, there has been a lot of discussion as to whether a multi-faceted approach is more effective than single interventions (Wensing & Grol, 1994; Squires, Sullivan, Eccles, Worswick, & Grimshaw, 2014; Grimshaw et al., 2004). In 2014, Squires and colleagues conducted an overview of systematic reviews to explore whether multi-faceted interventions were more effective than single-component interventions in changing health-care professionals' behaviours. Twenty-five reviews were included in the overview and in the end the results were inconclusive. Based on their findings the authors encouraged researchers to consider carefully the design and implementation of single versus multi-faceted interventions in different contexts and to attempt to balance effectiveness and efficiency (Squires et al., 2014).

The purpose of my dissertation was not to evaluate the effectiveness of a multi-faceted KT intervention, but more to understand the processes involved and associated outcomes of a multi-faceted KT strategy in a real-life context (as described in the case study paper). While individual studies were conducted to evaluate the ‘F-words’ video and the Knowledge Hub, both were *process evaluations* (i.e., evaluating stakeholders’ perceptions of the interventions and areas for improvement). Thus, at this time I cannot comment on the overall effectiveness of our multi-faceted intervention. However, I will share my personal perceptions of our KT experience and why I believe a multi-faceted approach in our situation enhanced the adoption of the ‘F-words’ in practice.

As highlighted in the case study paper, from 2011-2018 we used diffusion, dissemination, and implementation strategies to disseminate and support the adoption of the ‘F-words’ in practice. Implemented KT strategies included a variety of educational materials (e.g., publications, videos, infographic posters, the Knowledge Hub, etc.), educational meetings (e.g., conference presentations), and educational outreach visits (i.e., tailored workshops delivered in health care organizations). As stated earlier, not all of the strategies were planned ahead of time and many evolved as we developed partnerships with families, service providers, and health care organizations who shared a common goal of moving the ‘F-words’ into practice. Furthermore, each of the strategies responded to a specific need and had a certain purpose.

For example, the original ‘F-words’ video was created to spread awareness to a broad audience. As a low-cost project that could be completed in a fairly short time, this was both an effective and efficient strategy for disseminating the ‘F-words’ and gathering feedback on stakeholders’ reception to the ideas (Cross et al., 2012). On the other hand, the Knowledge Hub was developed based on the identified need for more information on the ‘F-words’, as well as the call for action-oriented tools to support the implementation of the ‘F-words’. The Knowledge Hub was much more time-intensive (took two years to develop) and required significant resources (e.g., both staff/student time and *CanChild* infrastructure support). While we now have an evidence-based resource that has the ability to continue to grow and impact practices around the world, it is crucial that we recognize the investment needed to create this online KT resource. Furthermore, if people are not aware of the Knowledge Hub it is unlikely to have much of an impact. This is where active dissemination and implementation strategies play a significant role in supporting the uptake.

The Knowledge Hub was launched in July 2017 and to date we have used *CanChild’s* social networks and communication channels to disseminate the hub. In November 2017, we conducted a pilot evaluation of the usability and utility of the Knowledge Hub (Cross et al., in press). Findings from the evaluation showed that the hub has a wide reach (>6,800 unique visitors in four months) and high usability and utility ratings. However, we must acknowledge that the majority of people who provided feedback are *early adopters* of the ‘F-words’ concepts (i.e., were already familiar with the ‘F-words’ and liked the ideas). This points to the need for further dissemination and implementation strategies (in other words a multi-faceted approach to support the uptake).

Recently, we have been contacted by a number of health care and community organizations to deliver educational outreach visits on the ‘F-words’. While the uptake of these visits is fairly recent (numbers have increased significantly over the last year), from delivering these workshops I have seen the impact they are making to support the adoption of the ‘F-words’ at an organizational level. One thing that is important to highlight is that all of the educational outreach visits have been initiated by the organization. In other words, we are not pushing information outwards to organizations (i.e., trying to persuade people to adopt the ‘F-words’); rather, the organizations have already made the decision to adopt and are coming to us for support and guidance with implementation. In preparing the educational outreach visits, we work closely with the local opinion leaders in the organizations to tailor the ‘F-words’ to meet the needs of the local context.

The Knowledge Hub has been an excellent resource to incorporate into the educational outreach visits. During the visit, we introduce some of the tools and resources housed on the Knowledge Hub and then provide opportunities for participants to trial them during the workshop. Having the Knowledge Hub freely available online allows people to go back to the hub and further explore the content and resources on their own time. This is a clear example of how a multi-faceted approach (i.e., the education outreach visits plus access to the Knowledge Hub) is facilitating the implementation of the 'F-words' into practice.

To this end, over the last four years we have implemented multiple KT strategies to disseminate and support the adoption of the 'F-words'. While we did not evaluate the effectiveness of our multi-faceted KT approach, we have evidence of impact. The 'F-words' paper has been downloaded >12,000 times; we have delivered >90 presentations worldwide; the 'F-words' videos and the Knowledge Hub have been viewed/accessed thousands of times; and we continue to receive requests for educational outreach visits. The uptake of the 'F-words' has been much greater than we ever imagined and I have been fortunate to have a front row seat in watching it all unfold. As a member of the 'F-words' research team and the project coordinator, I can say that from my observations the multiple KT strategies and the partnerships developed with stakeholders have been the keys to the success of this integrated KT research program.

KT Science Implications

The field of KT science is still in its infancy, and as a result many questions remain regarding best practices. KT science, which is also commonly referred to as implementation research, includes: i) the measurement of evidence to practice gaps; ii) studies to improve knowledge synthesis and the distillation of research; iii) examination of the determinants of knowledge uptake; and iv) studies that determine the effectiveness and sustainability of different KT approaches (Straus et al., 2013). The studies included in my dissertation respond to points two and three (as described below).

Contributions to knowledge synthesis and the distillation of research

Chapter 3 was a scoping review that aimed to map the breadth and nature of KT strategies used to disseminate health research to families of children and youth with special health care needs. Through a preliminary search of the literature we identified scoping/systematic reviews that were published on KT strategies targeting health care professionals, but for the most part reviews on KT strategies targeting patients and families were missing. To the best of our knowledge, this is the first review to summarize the literature on KT strategies that directly target families of children and youth with special health care needs in Canada, thus addressing an important gap in the literature.

New insights into the evaluation of the determinants of knowledge uptake

My dissertation was guided by Graham and colleagues' (2006) knowledge-to-action (KTA) framework. Our research team chose the KTA framework (with a specific focus on the *action cycle),* as it provided a holistic step-wise (yet flexible) framework to design, implement, and evaluate a KT project systematically. In the early planning phases of this thesis, I initially thought we would be able to make our way through the entire *action cycle.* Looking back now this was an unrealistic expectation as each step of the cycle takes time to address properly. After four years, I now feel that we are at a point that we can begin to evaluate outcomes (*step 5 of the action cycle*).

As identified in the introductory chapter, each study corresponded with a certain step of the action cycle. Chapter 2 reported on the 'F-words' video which aimed to disseminate the 'F-words' to a wide audience and to explore stakeholders' knowledge and attitudes towards the ideas. This study targeted *Step 2 of the action cycle* (*adapt knowledge to the local context*), as we wanted to gather insight into the reception of the 'F-words' ideas and to determine the value and usefulness of the 'F-words' ideas for families and service providers before undertaking a larger KM initiative.

Conducting an evaluation of the video was an important first step to our project. By developing and implementing a brief online anonymous survey we were able to collect feedback from over 137 stakeholders in two-months (Cross et al., 2015). The feedback was useful not only to evaluate the impact of the video as a KT strategy, but also to inform the next steps of our project. For example, through the evaluation we learned that the *CanChild* website was the preferred platform to receive more information on the 'F-words'. This feedback led us to develop the Knowledge Hub. I highly encourage researchers not only to develop KT materials, but also to develop and evaluate their strategies for dissemination. As shown by this example, the evaluations don't need to be complex, as even a brief online anonymous survey can result in valuable information.

In Chapter 3 the scoping review targeted *Step 3 of the action cycle* (*identify barriers and facilitators*). We conducted the scoping review to help us better understand: i) the best ways to share health research evidence with families; and ii) the evaluation strategies and current state of evidence supporting these KT strategies. A secondary objective was to explore the barriers and facilitators to translating health research to families. To me, one of the most helpful components of the scoping review was analyzing the types of evaluations across studies. While the data collection tools varied, the evaluations either monitored conceptual knowledge use (i.e., change in knowledge, attitudes, and intent to change behaviour), and/or used process evaluations to evaluate participants' perceptions and satisfaction with the KT materials. An important finding from the scoping review was the recommendation to use a step-wise evaluation (i.e., first conduct a process evaluation and then an experimental evaluation) and the value of mixed methods. Using mixed-methods to evaluate KT interventions is a common recommendation in the KT literature (Straus et al., 2013). Overall, exploring the different types of evaluations helped to inform our evaluation strategy for the Knowledge Hub.

Chapter 4 reported on the development process and pilot evaluation of the Knowledge Hub. Conducting a usability and utility evaluation was an important first step to evaluating the Knowledge Hub, as it helped us to ensure the Knowledge Hub was meeting the needs of parents and service providers. Based on the findings from the pilot evaluation we plan to make minor changes to the

Knowledge Hub before conducting an experimental evaluation to evaluate the impact at the family, clinician, and organizational levels (Cross et al., in press).

Lastly, Chapter 5 involved a longitudinal case study to describe our KT research program and use the Diffusion of Innovation (DOI) theory (Rogers, 2003) to understand the factors that contributed to the dissemination and adoption of the ‘F-words’ in practice. A case study design allowed us to explore our ‘F-words’ KT research program in real-life context. In analyzing the data, I found the DOI theory to be a helpful resource. By using the key characteristics of the DOI theory I was able to delineate the factors in our integrated KT research program that contributed to the successful dissemination and adoption of the ‘F-words’ concepts. Overall, through this study I gained a clearer picture of how the ‘F-words’ disseminated, and why our research program was successful in supporting adoption. Findings from the case study can be used to complement future experimental evaluations.

To this end, my dissertation provides one example of a step-wise theory-informed mixed methods approach to evaluating a multi-faceted KT intervention. This was a large project and thus required a comprehensive step-wise evaluation strategy. Using Graham and colleagues’ (2006) KTA framework was a helpful tool to guide the design, implementation and evaluation. I recommend future researchers, especially those who are new to the field of KT, to use a theoretical framework such as the KTA framework to guide their intervention.

Future Directions & Personal Next Steps

It has been approximately seven years since the ‘F-words’ paper was initially published and we now have many examples of adoption at the family, clinician, and organizational levels. We are thus at a stage that we are ready to evaluate impact. As identified throughout this thesis we have taken an iterative approach to KT and have adapted our strategies to the needs of stakeholders. Currently, we are at the implementation phase of our KT journey and our attention has shifted towards educational outreach visits and knowledge brokering with local opinion leaders to help support the implementation of the ‘F-words’ at the organizational level.

At their request, we have started to work with two local community organizations to plan an evaluation intervention to measure the impact within their organizations. Both organizations have implemented the ‘F-words’ into their programs (e.g., through care plans, goal-setting practices, etc.) and are interested in evaluating the impact on families’ and service providers’ perceptions of family-centred service and satisfaction with the services. We also plan to conduct focus groups with both staff and families to gain a deeper understanding of their perceptions of the ‘F-words’ approach to services.

We will also continue to deliver educational outreach visits and to work with stakeholders who reach out to us. We have learned so much from connecting and collaborating with people around the world about these ideas and hope to continue this process. I also plan to make minor changes to the Knowledge Hub based on the feedback we received from the pilot evaluation. I hope the Knowledge Hub will be a go-to resource for families and services providers to support the adoption of the ‘F-words’ and that it will continue to grow over time with the ultimate goal of improving the lives of children with disabilities and their families.

Personally, I hope to continue developing my knowledge and skills as a KT practitioner and researcher. As a KT practitioner, I plan to apply what I have learned throughout my thesis to help other *CanChild* researchers with their KT strategies. Preliminary conversations have already begun with *CanChild* researchers regarding the development of a KT intervention for the FOCUS measure, a clinical speech-language tool that has attracted a lot of international attention and requires the same systematic planning for dissemination that has been done with the F-words (Thomas-Stonell, Oddson, Robertson, & Rosenbaum, 2010). I also plan to continue to build my knowledge and skills as a KT researcher. Regarding KT science, I am interested in learning more about KT evaluation, in particular how to evaluate the effectiveness and sustainability of KT interventions, as well as exploring the science of family engagement in research.

In closing, I feel like my journey in KT is just beginning. I am fortunate to have found an area of research about which I am passionate and look forward to continued personal education and academic growth in this area.

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