Gateways: International Journal of Community Research and Engagement

Vol 9/No 1 (2016)

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Citation: Garinger, C, Reynolds, K, Walker, J, Firsten-Kaufman, E, Raimundo, A, Fogarty, P, Leonhart, M & Mobilizing Minds Research Group 2016, 'Mobilizing Minds: Integrated knowledge translation and youth engagement in the development of mental health information resources', Gateways: International Journal of Community Research and Engagement, vol. 9, no. 1, pp. 172–185. doi: 10.5130/ijcre.v9i1.4415

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**DOI:** http://dx.doi.org/10.5130/jjcre.v9i1.4415

ISSN 1836-3393
Published by UTS ePRESS
http://epress.lib.uts.edu.au/
journals/index.php/ijcre/index

# **Mobilizing Minds**

Integrated knowledge translation and youth engagement in the development of mental health information resources

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This article describes a novel Canadian research project that combined knowledge translation (KT) and youth engagement (YE) processes to develop mental health resources for and with young adults aged 18–25. There are several reasons why young adults were selected as the focus of this project. First, epidemiological data demonstrate a high prevalence of mental health problems in the adolescent and young adult period (Gravel & Béland 2005; Kessler et al. 2005). Among those between the ages of 14 and 24, 28.2 per cent have been shown to meet lifetime criteria for anxiety, while 12.8 per cent meet lifetime criteria for depression (Kessler 2007). The incidence of depressive disorders rises significantly during this period, peaking between ages 18 and 24 (Kessler 2007). Without treatment, these disorders are highly persistent and can have significantly damaging effects on young adults' social, academic and professional lives (Dozois & Westra 2004; Moreno & Delgado 2000; Solomon et al. 2000).

Despite the high prevalence of mental health problems in the young adult age group, young adults are less likely to seek treatment (Sareen et al. 2005). One reason for this is low mental health literacy within the young adult population. Mental health literacy is defined as knowledge and beliefs about mental health problems which aid their recognition, management and prevention (Jorm et al. 1997).

As information about mental health problems and treatment options appeared not to be reaching young adults in Canada in effective ways, a national mental health knowledge mobilisation project, *Mobilizing Minds: Pathways to Young Adult Mental Health*, was established. Funded by the Canadian Institutes of Health Research and the Mental Health Commission of Canada, the project ran from 2008 to 2013 (with an additional year granted to finalise the project). The *Mobilizing Minds* team included researchers/clinician-researchers from Canadian universities – York University, University of Manitoba, McMaster University, Brock University and Brandon University, experts in knowledge mobilisation (www.researchimpact.ca) and youth engagement (www.mindyourmind.ca), young adults and a variety of community partners. Broadly,

Mobilizing Minds sought to: 1) develop, evaluate and disseminate evidence-based mental health information and resources that would meet the needs of young adults aged 18–25 and assist them in making informed decisions about their mental health and mental health treatment options; and 2) build connections among researchers, decision-makers, young adults (mental health consumers and non-consumers) and community organisations that serve young adults to foster information sharing, collaboration and mobilisation of young adult mental health information and resources.

This article gives particular attention to YE and the KT processes and products of the *Mobilizing Minds* project. We discuss three aspects: 1) structures, processes and communication; 2) project products; and 3) challenges and responses specific to the Young Adult Team involved in the project. This case study will be of interest to youth as consumers of mental health information and services, and mental health practitioners and decision-makers seeking to improve mental health at a systemic level. More broadly, lessons learned specific to intergenerational collaboration will be of interest to youth-adult groups. The authors of this article were members of the *Mobilizing Minds* team: a community partner and YE facilitator (*mindyourmind*), members of the Young Adult Team, the project coordinator and the principal investigator.

## YOUTH ENGAGEMENT: USING KNOWLEDGE TRANSLATION TO CONVERT KNOWLEDGE TO ACTION

There are multiple terms describing the processes of involving young people in issues that impact them, such as *youth* engagement, youth participation, youth involvement, youth volunteering, youth empowerment and, more recently, youth-adult partnerships (Checkoway 2011; Haski-Leventhal & Bargal 2008; Pancer, Rose-Krasnor & Loiselle 2002; Wong, Zimmerman & Parker 2010; Zeldin, Christens & Powers 2012).

Campbell and Erbstein (2012) state that youth get involved in social issues in order to change their communities. Where there is access to relevant and reliable resources about youth mental health and strong social networks, participating in a youth-adult partnership promotes youth empowerment and resilience (Cattaneo & Chapman 2010). However, adult partners' (also known as allies) attitudes towards youth can impact youth involvement in social- or health-related issues. Zeldin, Christens and Powers (2012) suggest four core elements of optimal youthadult partnerships: 1) joint decision-making, where youth actively participate at the centre of collective decision-making, rather than at its margins; 2) adults acting as natural mentors, where decisionmaking occurs in relational and emotional contexts and is not just end-goal oriented; 3) reciprocal activity, where co-learning, information translation and joint responsibility are strongest; and 4) community connectedness, where decision-making incorporates access to partners' social capital and diverse networks.

The following sections present the *Mobilizing Minds* Young Adult Team as a case study of research-community knowledge translation and youth-adult partnership. Knowledge translation (KT) is defined as 'a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products, and strengthen the health care system' (CIHR 2014). Essentially, KT is aimed at improving decisions made by policy-makers, health service providers and consumers of health information through the creation and explicit assessment of the quality of the knowledge or evidence to be translated, and tailoring the knowledge to be user friendly for particular segments of the population. This definition is operationalised in the *knowledge to action* model put forth by Graham, Tetroe & KT Theories Research Group (2007). The model highlights eight steps for successful KT implementation: 1) create and synthesise knowledge; 2) identify and select knowledge; 3) adapt to local context; 4) assess barriers to use; 5) tailor and implement interventions; 6) monitor knowledge use; 7) evaluate outcomes; and 8) sustain use. Integrated knowledge translation encompasses similar steps but adds in a collaborative approach similar to participatory approaches. Knowledge users are engaged in research from the outset, shaping research questions, collecting and analysing data, and disseminating findings. In this way, findings are more contextually relevant and more likely to be incorporated into practice (Kothari & Wathen 2013; McLean et al. 2012). The Mobilizing Minds project adopted a KT goal of getting the *right* information (about stress, anxiety and depression) to the right people (i.e. young adults and their supporters) in the right ways (i.e. in the formats that most appeal to them) and at the right time to help them make informed decisions.

#### **OVERVIEW OF MOBILIZING MINDS**

Mobilizing Minds moved through five phases in its approach to KT: 1) listening to young adults express their information needs and preferences concerning common mental health problems; 2) locating evidence- and experience-based information to answer their questions; 3) developing resources to answer their questions; 4) evaluating the new resources; and 5) disseminating the new resources widely. Young adults were actively engaged early in the development of research questions. Along the way, these young adults from academic and community settings worked alongside researchers, shaping the research methodology, designing the data collection tools, and collecting data through interviews (Walker et al. 2009), focus groups (Ryan-Nicholls et al. 2009) and surveys (Cunningham et al. 2014; Marcus, Westra & Mobilizing Minds Research Group 2012; Nunes et al. 2014; Stewart et al. 2014). The young adults also worked with researchers to analyse data and respond to findings.

In total, the project developed five main teams: a Leadership Team, an Information Identification (later called Knowledge Synthesis) Team, a Community Partnership Team, a Partnership Evaluation Team and a Young Adult team. The Leadership Team and the Young Adult Team remained throughout the span of the project while the other teams either dissolved or evolved in response to the needs of the project. For example, the Knowledge Synthesis Team was active only during phases one and two and the Community Partnership Team developed and became active during phases three, four and five. This article presents a case study focusing on the work of the Young Adult Team within the larger project.

Young adults were involved as key partners in Mobilizing *Minds* in keeping with a YE and integrated KT approach. The main goal of the Young Adult Team was to ensure that young adults, as the ultimate end users of the new knowledge produced, were guiding the research and collaborating in decision-making through each phase of the project. In addition to participation in their own team within the project, young adults took part in all of the other teams, along with researchers, community partners and the project coordinator. At the outset, an advertisement for paid part-time employment as part of the Young Adult (YA) Team was delivered through organisations that work with young adults. Recruitment was based on the following criteria for applicants: 1) be between the ages of 18 and 24; 2) have expertise from diverse types of living, work, volunteer and educational experiences; 3) have life experience and/or education in the field of youth social services or mental health; and 4) priority given to consumers of mental health services. Nine people were hired initially, with the number of young adults involved in the project varying depending on their availability to participate (team members had other commitments such as school and work) and activities in the project. New team members were recruited as old ones moved on to other commitments. However, a number of young adults maintained engagement through the life of the project.

From project inception, the *Mobilizing Minds* team was committed to involving a community partner with expertise in young adult engagement. When serious problems were encountered in the first year with this YE partner (as described in a later section), the team engaged a new partner for the subsequent years of the project. The new YE partner, *mindyourmind*, aimed to harness youth-adult partnerships to reach youth and young adults in order to increase their emotional and mental wellness. They brought a unique method of participation and skill set regarding YE, and their objectives aligned consistently with those of *Mobilizing Minds. mindyourmind* viewed their involvement in a community research project as a means of capacity building and learning around research collaborations.

### YOUNG ADULT TEAM STRUCTURES, PROCESSES AND COMMUNICATIONS

mindyourmind focused on supporting and guiding the Young Adult Team and brokering relationships within the larger project throughout the phases of the project. In their partnership with researchers in years one and two, the YAs conducted qualitative research (i.e. interviews and focus groups) and quantitative research (i.e. surveys) to identify what information young adults would want if they were considering getting help for problems with stress, anxiety or depression.

mindyourmind adopted the role of 'boundary spanner', defined as a cross-boundary role to break down silos, to assist the teams to gain perspective about the other participants' world views and cultures (Greenhalgh et al. 2009, p. 399). As the YE facilitators, mindyourmind attempted to craft a balance between structure around processes and a sense of openness and adaptability. This allowed room for evolution, yet ensured there was enough direction to keep people feeling purposeful in regard to the notion of getting the right information, to the right people, in the right ways and at the right time to help them make informed decisions.

To build capacity within the YA team from the initial stages and to promote sufficient structure for the project to achieve its goals, the project coordinator hired a young adult as the team lead. The YA team lead and the mindyourmind facilitators cocoordinated the biweekly (or monthly) YA team meetings, which involved preparing agendas, delegating the writing of a blog (similar to taking minutes) and debriefing after the meeting. The YA team lead also worked with the project coordinator to complete detailed work plans for the YA team. During year three of the project the YA leadership role changed unexpectedly when one of the YAs expressed interest and self-nominated for the leadership role. At this time there were no previously agreed terms of reference regarding the general structure of the YA team other than stating that the team lead role would be part of the structure. The initial team leader decided it was a natural time for her to step out of the role and the new leader stepped in.

The YA team used teleconferencing and web conferencing to communicate across distances. During the team meetings the YA team lead opened with relationship building activities to encourage comfortable communication between members, to ease the discomfort of teleconferencing with a group of people and to offer time to get to know each other. Some warm-up activities were simple questions posed to the team about social or popculture topics, while some were more activity based, such as an online scavenger hunt. Between meetings the YA team used email to communicate, as well as an online subscription-based, private collaboration tool to post blogs about the meetings to communicate with members who were not in attendance and to keep other *Mobilizing Minds* project members updated on significant events. In total, 229 blogs were posted, many with comment

threads, indicating good engagement over the course of the project. Further postings to the online space included forums for discussion and wikis for sharing and archiving project-related documents.

One of the ways to structure the work of the YA team was co-developing work plans and timelines among the project coordinator, the YE facilitators and the YA team members. The purpose of the work plan was to identify sub-projects that the team would work on, which enabled members to build capacity by taking the lead in areas of interest and implementing the associated deliverables. Examples of sub-projects will be described in a later section of this article. Facilitators supported the process by identifying matches between YA team member strengths and associated tasks, with discussion around potential challenges and solutions.

The larger *Mobilizing Minds* team met annually, in person, to review movement through the project phases and plan. YA team members participated and contributed to this process of direction setting. The face-to-face meetings were co-planned by the project coordinator, the principle investigator, the YA team members and the YE facilitators to ensure all teams' work and needs were considered. In response to the need for YA team building during the fourth year, the YA team planned a dedicated YA only day. One of the activities was to translate project findings into rhythms using 'bucket drumming' techniques (led by a qualified music teacher). The team was challenged to create a drumming composition about the collective engagement experience. A YA team member filmed, edited and produced a video that captured the main messages (http://youtu.be/jduVoHfUPn8).

#### **PROJECT PRODUCTS**

During year four, the knowledge that had been created and synthesised in years one and two was ready to be adapted and tailored into resources (products) and implemented. YA team members formed sub-teams to develop resources and work on projects that revolved around their specific interests. *Mind Pack* is an example of one of the YA team products. *Mind Pack* is an online interactive resource aimed 'to give young adults the information they need to make decisions around stress and personal problems' (mindyourmind.ca). The resource evolved from the Knowledge Synthesis Team's work, YA team members' experiences and perspectives, and mindyourmind's expertise in technology and mental health. The concept of the digital backpack (in which all the content is housed) emerged from brainstorming discussions at one of the annual face-to-face meetings. To flesh out the resource after initial conception, the YA team met online and by teleconference and divided into sub-teams to create the various components of the Mind Pack tool which included: 1) a written personal story of a young person reaching out for help from a counsellor; 2) a self-assessment quiz; 3) brief written testimonials from young people who had accessed mental health help; and 4) written treatment options for stress, anxiety and depression,

including self-help options. In addition to coordinating the content and design development, *mindyourmind* staff contributed all of the technical development of the resource. Field-testing of the tool took place during a focus group with nine youth participants (separate from the *Mobilizing Minds* project) and usability researchers worked with the YA team to complete usability testing and make recommendations for improvement based on the results. (Usability is defined as 'a quality attribute that assesses how easy user interfaces are to use' – Nielsen 2003, p. 1.) The YA team worked through three versions of the *Mind Pack* tool. The tool is accessible in French and English via the website, <u>mindyourmind.ca</u>, and organisations can access the embed code to display *Mind Pack* on their own websites. This co-creative process, across distances, demonstrates an iterative, synergistic experience, integrating the expertise of YAs, community partners and researchers.

Another KT product was the development of a social media presence as a tool to engage allies and community partners while disseminating *Mobilizing Minds* research results. Members of this sub-team (consisting of three YAs, the project coordinator and two *mindyourmind* staff members) created a Facebook page, posting one to two times weekly, and hosted tweet chats on Twitter (see Table 1). A tweet chat is a live event at a set time, moderated and focused around a particular topic. To filter all the posts on Twitter into a single conversation, the team created a hashtag (#YAMH for young adult mental health) to delineate the conversation from other posts. Five tweet chats focused on young adult mental health topics and connected individuals and networks. During the planning of each subsequent tweet chat, as a strategy to spread the reach of the new knowledge, the YA team invited other mental health groups across Canada to participate.

Building on research findings, research summaries from the Knowledge Synthesis Team and the YA team also contributed to the creation of other knowledge products including a website, <u>depression.informedchoices.ca</u>, and two infographics available on the resources section of this website.

Table 1: Mobilizing Minds tweet chats

Date	Topic	Direct participants (individuals and organisations)	Estimated reach (tweets visible to followers of participants)
May 2012	Online engagement and young adult mental health	33	22 500
June 2012	Exploring models of young adult engagement and partnerships within mental health initiatives (including prevention, promotion and treatment)	16	22 500
Sept 2012	Young adults' transition to post-secondary school: ideas, supports and services	14	14 714
Jan 2013	Improving mental health conversations: youth, young adults and the media	37	26 000
Jan 2014	Reaching our audience: how to get depression resources into the hands of people who need them	88	57 898

#### **CHALLENGES AND RESPONSES**

Through the YA teamwork, all partners had an opportunity to learn about and negotiate youth-adult partnerships by contributing to a mutually meaningful issue: young adult mental health. However, there were challenges. Three main questions arose, which are explored in more detail below: 1) How can differing perceptions of collaboration be negotiated; 2) How can a person-centred approach that allows for self-determined involvement be enabled while adhering to the need to deliver outcomes; and 3) How can team members be empowered to benefit and develop through the partnership?

#### How Can Differing Perceptions of Collaboration be Negotiated?

The Mobilizing Minds team learned about the differences in understanding and practice of collaboration through its experience with YE facilitators. In year one, an organisation that had agreed to work with the YA team on youth engagement worked from an approach that did not value involvement from the adult researchers in the partnership. These facilitators viewed the partnership as interfering, and encouraged and supported mainly youth-led initiatives. As such, the adult researchers were explicitly excluded from YA team processes. At the end of the first year, the Mobilizing Minds Leadership Team was so concerned about this process of YA engagement that they decided to switch to another organisation for support, one that was more aligned with an integrated knowledge translation approach.

During this transition time, some of the YA team members were challenged by the change from what they perceived to be a strictly 'youth-led' framework to a more collaborative young adultresearcher partnership. This required a shift in the philosophical approaches of both the YA team and the Mobilizing Minds team. The new approach valued collaboration and created a space where all expertise was accepted and all voices were heard, rather than separating solely on generational differences (i.e. chronological age). mindyourmind was transparent about the power dynamics that are typically inherent in traditional hierarchy-based relationships and addressed this through ongoing negotiation with the YA team and the larger team (Larson, Walker & Pearce 2005). For example, during face-to-face meetings, art-based activities (collage) were encouraged as alternative ways to express and reflect on the work. Zeldin, Camino & Mook (2005) states that youth partners who sense that their contributions are respected can focus on the shared ownership of collaborative work. Shared ownership means openly acknowledging, communicating about and working with the strengths and challenges of partnerships. In another example, to explore the experience of this shift and to try to understand the YA team vision for future work together in year two and beyond, the team completed an arts-based exercise, designing a visual representation of their hopes for year two. This process began to articulate content for a terms-of-reference document.

In explaining her design, one YA team member said:

My inspiration for this was based off of the successes that we had in year 1 and looking forward to things that I would like to carry through or change in year two. Some of the themes include: working as a team, voicing your opinions and being engaged and inspired.

#### Other YA team members said:

I really look forward to seeing this project move forward and hope that it never becomes stagnant. The flower was meant to show growth. I hope that both the project and all the members find some way to grow as the project continues. The other hopes I had were that we could find better ways to communicate and we would begin to see results from our efforts.

I hoped for better, more open, and encouraging feedback and communication between the YAs and the adult members. I was trying to illustrate 'a constant, open, and encouraging dialogue, not just directives and responses', to build a conversation.

The shift to respectful and productive collaboration between partners was also facilitated through presentations (during in-person meetings) to the larger project team and ongoing reorienting conversations within the project sub-teams. To further this process, an agreed values statement by the YA team, along with a process to articulate the scope, possibilities and limitations of the YA team, helped develop an identity and stave off uncertainty.

#### How Can A Person-centred Approach That Allows For Selfdetermined Involvement Be Enabled While Adhering To The Need To Deliver Outcomes?

Keeping YA team members engaged was identified as a hope for the team as they entered year two of the project. At times, the length of the project competed with the developmental pulls of their lives (e.g. navigating personal, educational and employment milestones). However, YAs demonstrated ongoing commitment to the YA team and the project. For example, when teleconference meetings went through periods of low attendance, the facilitators checked in with team members to assess their ability and willingness to continue to participate in the current format. YA responses reflected a continued commitment to the project. With a refreshed forward focus, the YE facilitators remained flexible and adapted to the explicit and interpreted needs of the YA team members. The facilitators encouraged YAs to form sub-teams around emerging areas of interest such as on-campus mental health, social media, video development (e.g. collectively creating YouTube videos across distance) and usability testing of the Mind Pack tool. This enabled YA capacity building, productivity and flexibility to work on personally resonant projects, while ensuring they remained within the scope of the broad project. This also solved the recurring issue of finding a common teleconference

meeting time for all YA team partners, given personal commitments and time zone differences.

# How Can Team Members Be Empowered To Benefit And Develop Through The Partnership?

YA team members expressed a need to have their voices heard, to stay inspired and to experience a sense of accomplishment along the way. Through the YA team's work, partners (YAs and facilitators) developed in multiple ways: 1) they gained knowledge about young adult preferences for receiving mental health information (i.e. the research findings in year two); 2) they developed transferable skills as they co-presented at national conferences (e.g. the Canadian Mental Health Association and the Mental Health Commission of Canada); 3) they were involved in the collaborative development of resources across distances and over time, and partnered with new media specialists; and 4) they gained experience working with an information scientist on the usability of the *Mind Pack* tool.

One YA commented on the collective team climate:

We are a team of young adults who are passionate about mental health! We believe in an evidence-based approach to helping young people with mental health issues. We see a better way to transfer knowledge to young people in a way that appeals to them and integrates with their daily lives. Accepting you need help is hard enough, finding it and feeling welcome there shouldn't be even harder.

Another YA reflected on the authenticity and transparent tone of the team: 'At least we realized that we needed more structure and openness for more opportunity within our YA team.'

The project built inspired relationships while negotiating the challenges of communicating over distances. Table 2 summarises the main challenges and provides recommendations for youth engagement collaborative projects.

Challenges	Recommendations
Philosophical differences around youth involvement	<ul> <li>—Include all knowledge users as part of integrated model from inception of project.</li> <li>—Establish mutual understanding of youth/adult involvement and partnership.</li> <li>—Ensure understanding of parameters imposed by grant funding (deliverables and timelines).</li> <li>—Ensure representation of all partners on all teams.</li> <li>—Early on, clarify intellectual property, publication and copyright policies.</li> </ul>
Changing Young Adult team composition over time – as members move on to other commitments	<ul> <li>—Create shorter contractual opportunities and revisit regularly.</li> <li>—Adapt team composition, create sub-teams by interest.</li> <li>—Consider a diverse mix of youth (i.e. student and non-student).</li> <li>—Consider how project work can tie into a career/academic goals and enable opportunities.</li> <li>—Consider how to involve youth volunteers equitably.</li> </ul>

Challenges	Recommendations
Communication	<ul> <li>—Include all partners in decision making on use of communication tools.</li> <li>—Attend to ongoing relationship building.</li> <li>—Clarify processes for decision-making.</li> <li>—Ensure balance between talking and listening.</li> <li>—Ensure a variety of types of meetings (face to face, in person, individual, team).</li> <li>—Evaluate, adjust and adapt.</li> <li>—Make space for fun and informal communication.</li> </ul>
Young adult team roles and responsibilities — complexity and size of the project can create role and process confusion	<ul> <li>—Clarify expectations of all partners early and revisit them.</li> <li>—Co-create team structure and roles, with clear terms of reference and decision-making approaches.</li> <li>—Be aware of and mitigate traditional power imbalances between generations and roles.</li> </ul>

#### **CONCLUSION**

The Mobilizing Minds project was designed to contribute to the evidence on ways to inform young adults (and other adults) who deal with stress, anxiety and depression about available services supporting mental health. Knowledge products of the project were aimed to provide the public with the most up-to-date research findings on mental health services. Project processes demonstrated youth engagement and integrated knowledge translation approaches (a consumer-inclusive partnership model). The partnerships established between the researchers and the team of young adults demonstrated the fluid, iterative nature of knowledge translation work, collective decision-making and co-learning.

Lessons learned include the importance of including young adults in all of the decisions that will impact them, from the inception of a project to the dissemination of results. A transparent, articulated youth involvement philosophy is important from the outset, as is clarity around team member roles and responsibilities. Relevant and accessible communication formats enable relationship building and maintenance, and keep partners inspired and engaged in social change.

In future research on collaborative partnerships involving young adult consumers, community organisations and researchers, it will be important to understand the most effective ways to bridge and span the partners' varied worlds. As we broach new ways to approach complex health and social issues, more in-depth exploration of the workings of these unique partnerships may lead to improved systemic change.

#### **ACKNOWLEDGEMENTS**

Members of the Mobilizing Mind Research Group (mobilizingminds.ca) include the following (in alphabetical order). Young adult partners: Chris Amini, Amanda Aziz, Meagan DeJong, Emma Firsten-Kaufman, Pauline Fogarty, Mark Leonhart, Alicia Raimundo, Kristin Reynolds, Allan Sielski, Tara Syed, and Alex Yaeger; community partners: Maria Luisa Contursi, Christine Garinger, Heather Miko-Kelly and Melissa Taylor-Gates from mindyourmind (mindyourmind.ca); research partners: Lynne Angus, Chuck Cunningham, John D. Eastwood, Jack Ferrari,

Patricia Furer, Madalyn Marcus, Jennifer McPhee, David Phipps, Linda Rose-Krasnor, Kim Ryan-Nicholls, Richard Swinson, John Walker, and Henny Westra; and research associates Jennifer Volk and Brad Zacharias.

This project was supported by a Knowledge Translation Team Grant from the Canadian Institutes of Health Research and Mental Health Commission of Canada (Ref. No. TMF 88666).

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