

Transcending the Stigma Surrounding Mental Health Difficulties

*An International Research Collaboration
to Empower Children and Youth*

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An International Research Collaboration to Empower Children and Youth

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INTRODUCTION

An international workshop was held March 17-20, 2007 in Toronto. It was organized in response to the findings of a systematic review of specific published and unpublished, scientific evidence. The review revealed several serious limitations within the evidence base, which prevent us drawing conclusive inferences about the benefits or harms of school-based interventions that have been directed at students 18 years of age or younger to eliminate or prevent mental health discrimination.¹ No specific determinants of benefit could be identified.

The workshop was conceived to permit the creation of an international working group, whose first aim was to meet in person and identify future research directions that could advance the domain of inquiry beyond the state of affairs revealed by the systematic review. Youth, service users, advocates, volunteers, researchers, educators, clinicians, policy-makers and a representative from the justice system attended the two-and-one-half day workshop (Appendix 1). Such a diverse group made possible the type of rich discussion, which while grounded in the available scientific evidence, would also be child and youth-friendly, practical and creative. While younger children were not invited to attend, we felt that their interests would be well-represented by the youth.

A workshop plan was sent to participants prior to the workshop, which enabled them to familiarize themselves with many of the issues we might discuss and debate (Appendix 2). This confidential document briefly shared the key observations from our systematic review. A tentative agenda was included.

As part of the preparation for the workshop, we solicited input from youth (Appendix 3). Their recommendations for ways to develop and implement school-based interventions were identified via a focus group, which was facilitated by *Ms. Sarah Brandon*. *We thank the youth for graciously sharing their wisdom.*

A final agenda was created and given to workshop participants (Appendix 4). While the number of participants varied depending on the day, at its peak the workshop hosted 38 individuals (Appendix 5). All of the major and minor details concerning the workshop itself were handled by the heroic efforts of *Ms. Joyce McMahon*, who also attended the meeting. *We thank Joyce, Sarah and the three funders for their generous contributions, which made the workshop a major success. Likewise, we thank those who came from both far and near to share their insight.*

The workshop was initiated by a few presentations on the first morning. The rest of our time spent together involved small group discussions, which were followed by having everyone come back together to discuss issues raised within the smaller, breakout sessions. To facilitate these exchanges, participants had been provided with a document that restated the rationale and focus for the workshop, and which included a list of topic-relevant questions (Appendix 6). An evaluation was conducted (Appendix 7), and whose results will be communicated at a different time.

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We had hoped that Senator Michael Kirby would join us on the first morning, to discuss the topic of mental health discrimination which he and his colleagues so thoughtfully addressed in the landmark report, *Out of The Shadows At Last*.² Understandably, he was unable to attend. He was busy witnessing the birth of the Mental Health Commission of Canada, which was announced publicly at the same time that our workshop was taking place. Many of us who were in attendance saw this convergence of events as a herald that the subject of mental health and its difficulties would indeed be brought out from the shadows that have long been cast by ignorance and fear.

It is to those who have suffered the additional burden of the various forms of shadow, and to their champion, Mike Kirby, that we dedicate this report.

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THE PLAN

What follows is a collection of ideas and suggestions. These were provided and discussed over the course of the workshop with the intention of guiding the planning and conduct of future research to identify effective as well as harm-minimizing, school-based interventions to prevent and eliminate mental health discrimination. However, we do not wish to give the reader the impression that, because a point is highlighted in this report, it was explicitly or strongly supported by every workshop participant. Such was not the case. So, what we aimed to accomplish with this report is to organize and present all of the points, with each appreciated as an *issue requiring serious consideration in planning and conducting new research*.

The issues fell into two broad categories. The first one addresses the kinds of intervention, which might eventually prove to be necessary or sufficient to prevent and eliminate the perspectives and behaviours that discriminate against individuals or groups of individual on the basis of their mental health. The second category concerns those issues, which in being intended to assure rigorous and sensitive research strategies, should allow researchers to eventually draw conclusive inferences and clear recommendations regarding the value of specific school-based interventions.

Even an intense workshop, such as the one in which we participated, could not possibly address all of the issues or related nuances that require attention in planning and conducting new research. As a result, we ask for your feedback on issues that were not discussed, as well as those that were addressed. It is our hope that ongoing dialogue will help point us all in promising directions that will allow us to identify effective, evidence-informed ways to promote the kinds of perspectives and behaviours that respect and celebrate the fundamental unity of our diversity.

THE ISSUES

I. Things to consider about school-based interventions and their implementation

The scientific evidence does not yet permit us to identify those intervention types, interventions, activities, materials or contents that do and do not reliably yield benefits and minimize harm; almost none of the efforts to date have entailed appropriate scientific appraisals of this potential. Many interventions have yet to be evaluated at all. Therefore, all existing interventions are candidates for rigorous scientific investigation; and, given the plethora of approaches, there may be little sense in trying to create new ones. Nevertheless, “thinking outside the box” may be useful.

Candidates for an extensive evaluation include all of the interventions (e.g., programs; curricula) identified by the systematic review as well as those others mentioned at the workshop (e.g., *Talking About Mental Illness*; *Open Minds*; *Mind Matters*; *Youth Net*). The potential for the *Roots of Empathy* curriculum to influence mental health discrimination was widely discussed (see below).

Virtually no interventions that were identified by our systematic review involved more than a few of the components or characteristics that are highlighted below. At the workshop we discussed the possible individual and collective capacity of these components and characteristics to reliably produce sustainable benefits while also minimizing the possibility of even inadvertent harm.

Interventions which are developed, implemented and evaluated should be vetted by youth for their relevance and developmental appropriateness. One might consider establishing a school-based, youth advisory board to oversee activities relating to these tasks.

A *curriculum*—which entails early, ongoing and long-term intervention (i.e., multiple implementations) both within and across the school years (and stages of cognitive and affective development)—might be capable of promoting substantive and self-sustainable changes in one’s experiential capacity, which by their very nature prevent or eliminate perspectives and behavior that discriminate against individuals on the basis of their mental health (i.e., primary and secondary prevention, respectively). Given how early in life discriminatory viewpoints and behaviours can appear, early intervention is a reasonable aim. To be able to foster a deepening integration of the benefits afforded by such a curricular approach, its activities, materials and contents should be modified in ways, which over successive implementations, are incrementally challenging yet always developmentally-appropriate.

Facilitating a series of experiential engagements with other human beings was recommended as a necessary component of a curriculum, and whose purpose is to stimulate the development of empathy and, in turn, an orientation toward social inclusion and inclusiveness. “Experiential engagement” entails trying to stimulate, and thereby change, feelings and behaviours, not just cognitions (i.e., knowledge, attitudes, and stereotypes). The latter poorly predict behaviour.

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Likely the most promising way to establish an experiential engagement, which can have a positive impact on empathic and inclusive behaviour, involves setting up opportunities for *direct contact with other human beings*. But, especially the youngest children might need to be brought into direct contact first, or exclusively, with human beings who are not experiencing mental health difficulties or disorders. A generic approach to fostering the development of empathy as well as social inclusion and inclusiveness is likely indicated for the youngest children since they may not be able to appreciate—either cognitively or affectively—the pertinence of mental health suffering or related issues such as mental health discrimination.

Such a generic “contact” strategy is exemplified by the *Roots of Empathy* program, which for one school year brings into the classroom an infant and its parent. Its goals for kindergarten to grade eight students are the cultivation of empathy and emotional literacy, reduction of levels of bullying, aggression and violence, and promotion of pro-social behavior. Controlled, prospective studies have shown a significant decrease in aggression and bullying, along with an increase in pro-social behavior. These benefits have been observed immediately following completion of the program, and some were maintained after three years. In short, the program appears to promote “positive” facets of mental health as well as emotional-social literacy and civility. Its potential to affect mental health discrimination either directly or indirectly through the promotion of social inclusion and inclusiveness needs to be investigated.

But, even if a generic approach to fostering the development of empathy, social inclusion and inclusiveness were found to be an essential component of a curriculum, any plan to directly address mental health discrimination would likely need, at some point in time, to employ opportunities for direct contact that incrementally and appropriately expose students to individuals and issues with a specific focus on mental health, mental health difficulties and related discrimination (see below). Besides, for youth, alternatives to a program such as *Roots of Empathy* may be preferred.

So, starting with older children, direct contact could be arranged with those individuals who have experienced mental health difficulties, and who can be asked to recount their life story as well as interact with students. Many candidate approaches exist, some of which might eventually be found to reliably stimulate the development of empathy, social inclusion and inclusiveness, and in turn prevent or eliminate mental health discrimination. The challenge is to select and study the most promising one(s). Some workshop participants stated that this is a task with which they would like to help.

Over the years, activities, materials and contents within a curriculum could be modified in ways that deepen and extend the development of empathy. For example, exercises (e.g., perspective-taking) could make increasingly explicit the relevance of empathy for dealing with issues regarding mental health, mental health difficulties and mental health discrimination. However, given that there are logistical and financial barriers to implementing programs or curricula in every grade within a school or school system, decisions would have to be made concerning the most opportune times to intervene. Implementations could target “critical periods.” Manitoba selected kindergarten as well as grades four and eight as the key times to implement *Roots of Empathy*.

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Developmentally-appropriate discussions could also be scheduled strategically over the school years, which successively focus attention on issues concerning: 1) difference-making, which involves the identification of “differences” (e.g., “bad” versus “good”) that is integral to acts of social exclusion and discrimination; 2) the perception of “sameness,” which can be associated with acts of social inclusion; 3) mental health and wellness (e.g., resilience); 4) mental health difficulties, help-seeking and care (e.g., stress reduction); and, e) starting with older children, the power dynamics of mental health discrimination. Such opportunities for discussion might facilitate students’ help-seeking behavior in addition to mental health literacy. Engaging their conceptual frameworks would depend upon children’s cognitive and affective readiness.

Since direct contact alone may not be sufficient to bring about lasting change, educational materials could be added to reinforce and extend issues raised through contact (e.g., focusing on similarities). A good example of material, which could be used especially with young children to address the issue of “differences,” is titled *Clifford the Big Red Dog*. Certain program documents (e.g., *Respecting Differences*) could be consulted for guidance. Educational information could also pertain to brain development, temperament, and many other topics. The arts could be used for educational purposes (e.g., the film, *A Beautiful Mind*).

However, while school-based interventions are being employed, other work should likely be undertaken in parallel, which reaches the public at large through other means such as the media, advocacy and protest campaigns, and the like. Student-produced materials can serve as the basis for advocacy/protests on behalf of those individuals (e.g., peers) who experience mental health difficulties.

Implementers of any school-based intervention (e.g., program; curriculum) should likely be those with whom the children or youth are most likely to identify (e.g., those most similar to themselves). When individuals who experience mental health difficulties are brought in to meet students, it is likely best to introduce them in ways that establish their equal status with students. Interactions, which involve youth facilitators, are likely the most helpful way to reach youth (e.g., *Youth Net*). Individuals with reputable careers, yet who function well even though they experience mental health difficulties, can play a role within a curriculum. Yet, some celebrities may not be positive role models. Whatever the source, lecturing students is not productive.

Actively involving their teachers, other school staff, school healthcare/guidance workers, the school administration, school board, student council and parents/caregivers (e.g., parent councils) could maximize the likelihood of making a sustainable difference for children and youth. Gaining the support of a school community—and perhaps also the larger community in which it is embedded—is likely essential for achieving success in reaching young people. If, by virtue of its proposed benefits, teachers perceive the need for a curriculum, this will increase the likelihood of their support. Champions within the school could help bring acceptance of the value of a curriculum.

The implementation of any intervention should be made as simple and straightforward as possible. Teachers prefer pre-packaged approaches (e.g., *Terry Fox Marathon*, which exposes children to the subject of cancer). This way they might not have to draw

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up their own lesson plans. Teachers require some protected time to prepare for their role.

Education and training should be provided for teachers even if they do not implement (all of) the curriculum. This would permit them to address questions from, and hold discussions with, students in ways that are consistent with the messages conveyed by the curriculum. This education and training would also likely make them more able to identify and respond to mental health signs, symptoms and issues. If children were to self-disclose mental health issues, teachers would be able to prevent them from becoming the targets of teasing or more damaging forms of ostracism. The education and training might also help teachers deal with their own stigmatizing attitudes.

Teachers could therefore serve as an integral part of an in-school support group, which could deal with possible harm produced by an intervention. Yet, despite their training, teachers cannot be expected to be able to handle every scenario. Consequently, a child support network (e.g., mental health professionals; community mental health agency; child/youth workers) would be placed “on call.”

Having a parent/caregiver (e.g., education-related) component to complement the curriculum would likely be helpful. This could generate “buy-in” and, like teachers, would allow parents/caregivers to address questions from, and hold discussions with, their children in ways that are consistent with the messages conveyed by the curriculum. Due to their life histories, parents/caregivers may exhibit stigmatizing perspectives or behaviour; or, they themselves may have experienced mental health difficulties. The *COPE* program might help them deal with issues concerning mental health.

To be most salient for older children and youth, the mental health difficulties or disorders portrayed via contact and educational opportunities should likely be ones that are the most prevalent within this population. Instead of focusing on schizophrenia, which is the case within the *World Psychiatric Association* program, interventions could highlight mental health difficulties that students are more likely to encounter amongst peers. For adolescents, substance abuse and the addictions could be a very pertinent subject. Yet, across various sessions for older children it might be useful to vary the content of the mental health focus (e.g., depression; anxiety). Other characteristics of those individuals with whom students are brought into contact, or who serve as the focus within educational materials, can likewise be varied (e.g., different cultural backgrounds).

The developers of a curriculum should likely be mindful to avoid presenting, as “knowledge,” interpretations of mental health difficulties, which are not unequivocally supported by current scientific evidence (e.g., mental health disorders = brain diseases). Moreover, many explanations of the origin of disorders, which resort to observations based in physiology or biochemistry, for example, can actually discourage self-empowering behaviour on the part of those who experience mental health difficulties. Also, providers of any curriculum might want to provide a balanced view of “mental health” in that it is framed both from a “wellness” (e.g., mental health as the presence of empathy or resilience) and a “pathology” perspective (e.g., mental health as the absence of mental health difficulties or disorders).

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Guidance as to how to develop, implement and evaluate the value of a school-based curriculum can come from the scientific evidence concerning how the stigma surrounding developmental disabilities has been addressed. Lessons could likewise be imported from work done to implement school-based violence or substance ab/use prevention programs.

It would also be important to rely upon knowledge concerning how education about sexuality or healthy eating, for example, has been provided in ways that minimize the likelihood of stimulating concerns about things that students had not hitherto considered problematic. For some students, bringing attention to some issue can produce or aggravate the very things that this attention was intended to prevent or eliminate. Finally, it might be useful to seek lessons learned from realms where there has been success in changing the way the public thinks about and behaves toward children and youth (e.g., bicycle helmets; seat belts; nutrition).

Whole school initiatives/policies can work well (e.g., “safe and healthy schools”). Also, other programs could be combined with an initiative that addresses mental health discrimination. But, adding what is unique to an existing school program (e.g., anti-bullying) and a new one (e.g., mental health discrimination) to what is common to them (e.g., developing empathy and respect for others; inclusion/inclusiveness) could actually yield a lesser burden on the school or teachers than if these stakeholders had to accommodate these two programs based upon a superficial perception that they are wholly different.

Furthermore, as has been the case with *Roots of Empathy* in Manitoba, if it can be shown that the curriculum addresses issues (e.g., health; parenting; social inclusion) that touch the mandate of various ministries, then buy-in from multiple sectors can be achieved. The consequences of mental health discrimination as well as mental health difficulties are recognized from the points of view of various sectors (e.g., health; education; justice). All concerned parties might also become interested in primary prevention since in the long run it could cost each of them less in having to deal with both the human and economic consequences.

Each of the aforesaid details requires pilot-testing to assure its feasibility, in addition to its relevance and developmental appropriateness for students. For example, the effective intensity (i.e., “dose”) and timing (e.g., “critical periods”) with which curriculum elements are provided once, or repeatedly, needs to be established.

The *Teachers Union* (Ontario) could be a good partner in developing a curriculum. So might be the *Canadian Paediatric Society* as well as any grassroots organizations, which have a vested interest in the welfare of children and youth.

Consideration should be given to how to reach those children and youth who do not attend school. Implementing parts of a curriculum within community centres is a possibility. *Youth Net* enters areas where students do not attend school. For students living in rural or remote areas, podcasts or videotaped versions of intervention components could be used.

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Finally, one issue that was discussed the first morning of our gathering is how to define the term “stigma” as it pertains to mental health and its difficulties. Unsurprisingly, a consensus definition was not reached, although almost everyone in attendance recognized the following. Mental health stigmatization involves discriminatory perspectives (e.g., attitudes) and behaviour, which are directed at individuals on the basis of their mental health. But historically, the term “stigma” has been used to refer to more than these acts of stigmatizing attention. It has pointed to the “signs or symptoms” of one’s mental health status (e.g., facial grimaces), whose observed or presumed existence brings about the negative attention, *and* to the experiential burden that this attention yields (e.g., shame).

II. Things to consider when planning and conducting new research

Before evaluating the impact of any intervention, the objectives of the research should be clearly delineated. The objectives should be reflected in the outcomes, which could demonstrate proposed benefits. Possible benefits include increases in social acceptance or knowledge, decreases in fear, or a shift in the climate, culture or policy within a school or its larger community.

Principals are very busy, so to gain their interest and confidence, one might consider sending them a video, which outlines the objectives of the research. So as not to alienate school representatives, one could consider labelling it a “pilot program” rather than a “research project.”

Given its suggestive research evidence, it was hypothesized that *Roots of Empathy* could affect mental health discrimination directly or by way fostering social inclusion and inclusiveness, which could then preclude the development or deepening of existing proclivities for mental health discrimination. To establish its potential as primary and secondary prevention for mental health discrimination, one would have to add outcomes to the standard evaluation, which has been used to date to investigate possible benefits. Novel outcomes could reflect various definitions of a positive “bias” toward social inclusion and inclusiveness, in addition to the various forms of discrimination that can be directed at individuals on the basis of their mental health.

Following from the discussions regarding the promise of direct contact-related interventions, some fundamental research questions were posed: Does direct contact produce meaningful and significant changes with reference to social inclusion and inclusiveness, and mental health discrimination? Does adding education to direct contact produce significantly and meaningfully greater changes than those produced by direct contact? Finally, does education produce meaningful and significant changes, which are equivalent to those produced by direct contact?

The ideal research design for use within school environments is the cluster randomized controlled trial (RCT). Schools rather than individual children are allocated randomly to study conditions (e.g., direct contact *versus* direct contact + education). Its greatest strength is its capacity to minimize the likelihood of having possible “real effects” nullified due to the “contamination” that inevitably occurs when students within the same school are assigned to different study conditions and inevitably discuss their respective

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experiences. Yet, before employing such a sophisticated design, pilot-testing should be conducted, which uses less ideal research designs (e.g., non-randomized, yet controlled, prospective designs).

Larger questions such as the impact of a curriculum on cultural change are unlikely to be investigated using RCT designs. Moreover, it is virtually impossible to meaningfully evaluate the impact of a complex program, which allows schools, teachers or students to choose different intervention components, or their combination, from a “menu” of possibilities.

Since changes in knowledge, attitudes and stereotypes do not reliably predict behaviour, and it is discriminatory action or inaction that is particularly noxious, then the primary outcome should be behaviour that can be observed especially under naturalistic conditions. For younger children who might receive a generic, empathy-inducing program (e.g., *Roots of Empathy*), school yard play could be assessed to determine the inclusion/exclusion of peers who are perceived to be different on some or any basis. Starting with older children, who are exposed to individuals and issues that focus on issues of mental health, mental health difficulties or related discrimination, acts of inclusion/exclusion could be assessed with specific reference to others whose differences are defined by their experience of mental health difficulties.

Secondary outcomes could be used to assess students' *perceptions of social distance*—as a possible, proxy measure of one's inclination toward social inclusion and inclusiveness—from those who are noted as being different in some way (i.e., for the youngest children) or because they experience mental health difficulties (i.e., for the oldest children). The inclusion of a few tertiary measures such as mental health literacy, or knowledge, attitudes and stereotypes could allow researchers to begin to identify the possible intermediate causes or correlates of (failed) behaviour change. Additional outcomes could include inclinations to seek help, or comfort discussing issues relating to mental health. Each of the secondary or tertiary outcomes could exhibit short-term changes while meaningful shifts in behaviour could take longer to occur and be observed. A much broader outcome would be needed to assess changes in a school's “climate” or “culture.”

Quantitative outcomes should be validated as well as developmentally-appropriate. At what time intervals or developmental levels they should be assessed within a curriculum would need to be determined via pilot work. Possible harm requires a direct yet potentially subtle and qualitative evaluation. Insensitive assessments of harm, which provoke excessive self-questioning, can bring about the very circumstances they are intended to illumine.

The highest quality research also requires appropriate experimental or analytic control of possible co-influences on how an intervention is “processed” by students (e.g., pre-intervention exposure to those with mental health difficulties; a personal history of mental health difficulties and help-seeking; prior personal experiences of mental health discrimination; pre-study levels of empathy; and, pre-intervention types and intensities of discriminatory knowledge, attitudes or stereotypes). Pre-intervention or post-intervention questionnaires should be used sensitively since they can “turn off” youth.

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Qualitative research methods could help with the development and evaluation of the possible benefits of an intervention as a whole or its various components. Finally, since direct contact can encourage “liking” rather than empathy, this possibility could be explored via subtle debriefing interviews, which generate qualitative data.

CONCLUSION

It is hoped that any new research will involve the collaboration of many, if not all, of the individuals who attended the workshop. There exists enough suggestive evidence and ideas to inform this work. One promising course involves developing a curriculum, which in being implemented early as well as repeatedly both within and over the school years, would employ a generic form of direct contact for the youngest children, followed by direct contact with individuals experiencing mental health difficulties for older children. This could encourage the development of empathy and, in turn, an orientation toward social inclusion and inclusiveness. In this way, discrimination directed at others on the basis of their mental health might be prevented from emerging in some students' lives while for others, who already demonstrate such tendencies, it could be eliminated. To maximize the likelihood of identifying the value of any approach, the most sophisticated research designs and methods are ultimately required. The possible value of using educational activities, materials and contents to enhance hypothesized benefits accruing to direct contact also requires investigation.

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APPENDICES

RATIONALE AND DISCUSSION QUESTIONS

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I. WORKSHOP RATIONALE

Only one systematic review completed to date has investigated the published and unpublished scientific evidence concerning the benefits and harms, for children and youth (i.e., 18 years of age and younger), of school-based attempts to influence the stigma surrounding mental health difficulties (MHDs). However, this systematic, rigorous, and transparent synthesis and critical appraisal did not permit us to draw any conclusive inferences concerning the value of these interventions (e.g., programs) either as primary or secondary prevention for MHD-related, stigmatizing knowledge, perspectives (e.g., attitudes), attention or behavior on the part of our population of interest.

As a result, we decided to convene an international working group to facilitate combining expertise directly pertinent to, yet also somewhat “beyond,” this specific research domain in order to permit the development and realization of a multi-stepped research program to address the notable gaps identified by our synthesis, yet which is likewise and appropriately infused by what we know from a lifecycle developmental perspective. Our workshop constitutes the first meeting of this working group, and we have invited you to participate in helping to establish consensus regarding the details of such a research program.

The goal of our research program may be thought of as follows: to employ, or modify, existing interventions—or perhaps even create novel ones—whose feasibility as well as ability to reliably produce beneficial impacts by way of (modifications of) existing implementation and evaluation strategies can be determined first by conducting several pilot studies and then by translating the lessons learned from these initial efforts into the details defining a large multi-site, international study. The desired consequence of the research program is to have available, for implementation and evaluation, one or more school-based interventions that can reliably and harmlessly prevent the development and progression of MHD-related, stigmatizing proclivities in our population of interest. One possible result will be that certain characteristics of the intervention(s) need to be modified for use with children and youth within different countries.

That said, where possible and appropriate, we aim to make all decisions about next steps based on empirical evidence, and not merely on opinion. So, when you come to the workshop, please bring any materials that you feel will inform our decision-making process.

II. SPECIFIC QUESTIONS AND ISSUES TO CONSIDER

1. Which intervention(s), and for whom?

- Some thoughts about the aim of the ultimate international, multi-site study, which would be the culmination of our research program: Should we not consider investigating both the “comparative” and “absolute” effectiveness of the interventions within the context of a controlled study that would allow us to do so providing we

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assessed key outcomes at baseline? However, given that assessments prior to an intervention using key outcomes that are likewise assessed post-intervention (e.g., stigmatizing attitudes) have the potential—through the mechanism known as “demand characteristics”—to hint at participants to respond in socially desirable ways and thereby limit the extent of possible changes in outcomes related to the intervention, perhaps not all participants should have their outcome status assessed at baseline. In this light, how would pilot work help us design the ultimate study? What would we aim to do in the pilot studies?

- Some thoughts about the nature of the candidate intervention(s): If the goal is to change actual behavior—and not merely self-reported knowledge or attitudes that tend to correlate poorly with observed behavior—then a direct contact component may be more likely to do so by fostering an experience of increased empathy, compassion, and identification with individuals experiencing MHDs. The experience of contact might allow study participants to see themselves and those experiencing MHDs in terms of their common ground, or similarities, instead of the differences (and “otherness”) many people are often more attuned to notice first or exclusively. Various researchers who have evaluated the impact of review-relevant education-only interventions have likewise speculated that, compared with educational elements, contact components may be more likely to yield significant positive impacts on our population of interest. While educational elements at least in principle have the potential to evoke an affective response, they tend to target how individuals perceive, think and talk about reality.
 - So, without empirical knowledge from our evidence synthesis as to which (e.g., type of) intervention works better, or best, how can we choose one over the other? Moreover, do we even need to try to select one (type)? Given that education- and contact-related interventions likely afford different types of experience, which may influence the inclination to stigmatize via different “pathways” (i.e., “heart” vs. “head”), it may be important to include an element of each within a review-relevant intervention. Moreover, it might be important to see whether this “combination” intervention is more effective than when either of these two intervention components is provided alone. On the other hand, if the contact (or education) component proved to be as effective as the combination intervention, then these results might suggest that the more cost-effective route would be to implement the single component approach. In effect, what we are proposing is that the ultimate, larger study could or should be a three-arm controlled study. Below, we suggest the type of research design that could be employed.
- Some thoughts about the aim of the intervention(s): We also need to decide whether, by virtue of the fact that a study participant’s baseline levels of stigmatizing knowledge, perspective, attention or behaviour will essentially determine whether the intervention is an attempt at primary or secondary prevention, we should: a) select only one type of aim for the intervention, that is, one type of participant to receive it (e.g., only those who exhibit notable stigmatizing attitudes or behaviour); b) select participants so as to be able to compare the responses from the two types of participant (i.e., those who exhibit notable stigmatizing attitudes or behaviour vs.

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those who do not); or c) “merely” measure outcomes prior to the intervention in order to use these baseline data in data (e.g., covariate) analyses.

- For whom should the intervention(s) be selected, modified or created? At which age(s) or grade level(s) should the interventions be directed? Is early, or earlier, intervention better? How can we assure that all elements of each intervention, and their totality, are developmentally appropriate? How do we build in some flexibility such that a given intervention will be appropriate for all children in a grade despite the fact that they may differ developmentally-speaking (e.g., cognitively, emotionally)?
- How can we inform the nature of the interventions based on what we know from a lifecycle perspective (e.g., early childhood development), which transcends yet includes our population of interest?
- Other details about the intervention(s): Are there specific types of activity (e.g., interactive events; specific media) that will increase the likelihood of maintaining participants’ attention?
- How may different intervention components (e.g., education, contact) be combined meaningfully (e.g., in what order)? How for each of the education- and contact-alone interventions can we control for the total time spent—not to mention the attention and knowledge received—by participants receiving a compound, education+contact intervention?
- Number of sessions? Session lengths? How to establish the continuity of sessions (e.g., not relevant, since goal is to merely intervene once vs. continuity established via repeating the same session multiple times [How many times? How often, that is, what is the optimal timing?] vs. continuity established via progressions of the material [e.g., Increasing the complexity or abstract nature of the message? Change or expand the examples?])? Over how many weeks, months, terms/semesters/ trimesters, school years?
- How do we assure that no harm is produced (e.g., where one is somehow encouraged to begin questioning seriously one’s mental health)?
- The MHD content(s) to which the intervention(s) refers: Which type(s) of MHD will constitute the focal content, or information, as well as the MHD(s) experienced by those brought into contact with study participants? Should these two MHDs be the same? Should they be the MHDs that most participants may have witnessed or that they are likely to know about? Should these MHDs be those that are currently the most prevalent? Depression?
- How do we control for this factor, such that the MHD content is the same, irrespective of the intervention format?
- How shall we refer to MHDs within the interventions, especially since not all MHDs constitute symptoms or signs that warrant formal diagnosis of a disorder or impair functioning? Do we need to somehow represent the issue of comorbidity within the intervention(s), since this is likely a very common scenario?
- How concerned should we be regarding the veracity of the contents that are conveyed by the information provided? For example, should we suggest that mental health difficulties reflect brain disease when this point of view is in fact not well supported by the scientific evidence? Overall, to what extent should our intervention(s) be informed by empirical knowledge?

2. What should the implementation strategies look like, and how should they be developed?

- Should the intervention(s) be framed as coming from an outside agency, yet which are endorsed by the school vs. framed as being part of the curriculum?
- What are the effects on the effectiveness of interventions of teachers who have volunteered their classes or grades (or principals who have volunteered their schools) vs. having teachers agree to participate because someone important has recommended it vs. having teachers participate because someone important has mandated it?
- Should the intervention(s) be implemented in small groups, single classes or within a whole grade? (please see below re research design)
- Who should implement them? How similar (e.g., age, sex, race) to the participants should the implementers be? How do we control for this possible influence on study outcomes?
- How to control for the fact that the interventions themselves (i.e., education vs. contact vs education+contact) will vary format-wise, etc.?
- How can we inform the nature of the implementation strategies based on what we know from a lifecycle perspective (e.g., early childhood development), which transcends yet includes our population of interest?

3. What should the evaluation strategies look like?

- Pilot studies: What will the likely uncontrolled, pre-post (i.e., before-after) pilot studies be designed to achieve, what should be evaluated, and how should they be undertaken?
- Large, multi-site international study: If we assume that, for the multi-site trial, a randomized controlled trial (RCT) is required in order to increase the likelihood that any benefits can be attributable to the intervention(s) and not other factors such as unsystematic or systematic error (i.e., bias), then how would we go about achieving this?
 - To make possible the meaningful interpretation of the results from an evaluation of review-relevant interventions, we suggest undertaking an adequately powered (i.e., where enough participants are enrolled to be able to detect a pre-established, meaningful difference) RCT, whose participants are randomly assigned to receive whichever types of review-relevant intervention are compared (e.g., education-only *versus* contact-only *versus* education+contact), and whose effects are evaluated over the long-term (e.g., at least one school year). The choice of a cluster RCT, whereby schools—and not individuals—are randomized to the different study groups, can help investigators avoid situations whereby in a controlled study conducted within one school, students enrolled in an intervention group can “influence” the points of view of students who do not receive this same intervention.

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- Which outcome constructs? The timing of assessments, relative to intervention sessions? Reliable and valid instruments exclusively? How to evaluate harms (or benefits) without “harming?”
 - Where possible and appropriate, effectiveness outcomes should likely include the direct observation of behaviour. However, an emphasis on possible changes in observed behavior as well as empathy, compassion, identification, and the recognition of similarities would necessitate a shift in the types of outcome hitherto used in review-relevant evaluation studies. The use of a subtle, one-on-one debriefing might yield important harms data.
- What else should likely be considered regarding the evaluation of the impact of the intervention(s) in such a study? Known, likely or possible sources of confounding need to be controlled either through the research design or analytically. Our review topic’s list of confounders is likely not a long one, yet any factor individually or in some combination with each other, or the intervention, could directly affect study outcomes. The variables most likely to require this form of control include: study participants’ cognitive or affective (developmental) capacities; gender; nature and intensity of prior or present exposure to individuals experiencing mental health difficulties (or to mental health professionals, if this is the focus of a study); one’s own experience with mental health difficulties, and related stigma, and/or with the professionals who provide its care, and related stigma; socio-demographic factors; race or ethnicity; and, religious beliefs.
- How can we inform the nature of the evaluation strategies based on what we know from a lifecycle perspective (e.g., early childhood development), which transcends yet includes our population of interest?
- Statistical analyses should include data from the intention-to-treat population (i.e., all study enrollees) and take into account all experimental (i.e., intervention *and* control groups) and confounding factors
- Do we need to establish efficiency now?

4. What, if any, is the role of theory in developing and realizing our research plan?

AGENDA

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SATURDAY, MARCH 17, 2007

4:00–9:30pm Registration

6:30 Dinner

8:00-10:00 Reception (casual attire)

SUNDAY, MARCH 18, 2007

7:00-8:00am Breakfast

7:00-8:30 Registration

8:30-8:45 Welcome and Introduction to the rationale for our gathering*

8:45-9:15 Results & implications of the systematic review: a brief overview

9:15-9:30 Questions

9:30-10:15 Coming to a working understanding of what is meant by “stigma:”
clarifying verbs and nouns

10:15-10:30 Refreshment Break

10:30-11:15 Panel Discussion: Why what we intend to do is so important* (tbd)

11:15-11:45 General Discussion

11:45-12:00 Our plan* (breakout group assignment: facilitator, scribe, & reporter roles;
recommended actions noted; the “permeability” of our topic areas)

12:00-1:00 Lunch Break

1:00-3:15 Breakout Groups: “which intervention(s), and for whom?”*

3:15-3:30 Refreshment Break

3:30-5:00 Breakout Groups: “which intervention(s), and for whom?”*

5:00 Adjourn

6:30 Dinner

8:30 Open Discussion about funding opportunities

*Attend to each step of the research program: i.e., necessary pilot work,
which culminates in an international, multi-site trial

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MONDAY, MARCH 19, 2007

7:30-8:30am Breakfast

8:30-10:00 Brief presentations (reporters), then larger group discussion to come to consensus about issues discussed in breakout sessions regarding “which intervention(s), and for whom?”*

10:00-10:15 Refreshment Break

10:15-12:00 Further discussion, and consensus building*

12:00-1:00 Lunch Break

1:00-3:15 Breakout Groups: “which implementation and evaluation strategies?”*

3:15-3:30 Refreshment Break

3:30-5:00 Breakout Groups: “which implementation and evaluation strategies?”*
5:00 Adjourn

6:30 Dinner

8:30 Open Discussion

TUESDAY, MARCH 20, 2007

7:30-8:30am Breakfast

8:30-10:00 Brief presentations (reporters), then larger group discussion to come to consensus about issues discussed in breakout sessions regarding “which implementation and evaluation strategies?”*

10:00-10:15 Refreshment Break

10:15-11:15 Further discussion, and consensus building*
11:15-12:00 Closing remarks, and next steps*

12:00 Adjourn

*Attend to each step of the research program: i.e., necessary pilot work, which culminates in an international, multi-site trial

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EVALUATION FORM

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Evaluation Form

Question	Highly satisfied	Somewhat satisfied	Satisfied	Dissatisfied
1. How would you rate your overall satisfaction with the objectives set out for the workshop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. How would you rate your overall satisfaction with the format of the workshop (i.e., breakout sessions, followed by full-group consensus-building)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. How would you rate your overall satisfaction with the breadth and depth of the topics addressed by the workshop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. How would you rate your overall satisfaction with the presentations and opportunities for discussion on Sunday morning?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. How would you rate your overall satisfaction with the time allocated to address each of the topic areas (e.g., the nature of the interventions, and for whom)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. How would you rate your overall satisfaction with the venue for this event?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. How would you rate your overall satisfaction with the arrangements made to bring you to the workshop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. How would you rate your overall satisfaction with what was accomplished at the workshop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. How would you rate your overall satisfaction with the workshop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

