



Ontario Centre of Excellence
for Child and Youth
Mental Health
Centre d'excellence de l'Ontario
en santé mentale des
enfants et des adolescents

**Bringing People and Knowledge Together to Strengthen Care.
Rassembler les gens et les connaissances pour renforcer les soins.**

Evidence In-Sight: Effective stigma reduction strategies in child and youth mental health

Date:

March, 2012

The following Evidence In-Sight report involved a non-systematic search and summary of the research and grey literature. These findings are intended to inform the requesting organization, in a timely fashion, rather than providing an exhaustive search or systematic review. This report reflects the literature and evidence available at the time of writing. As new evidence emerges, knowledge on evidence-informed practices can evolve. It may be useful to re-examine and update the evidence over time and/or as new findings emerge.

Evidence In-Sight primarily presents research findings, along with consultations with experts where feasible and constructive. Since scientific research represents only one type of evidence, we encourage you to combine these findings with the expertise of practitioners and the experiences of children, youth and families to develop the best evidence-informed practices for your setting.

While this report may describe best practices or models of evidence-informed programs, Evidence In-Sight does not include direct recommendations or endorsement of a particular practice or program.

This report was researched and written to address the questions:

- What does the research indicate is effective in anti-stigma efforts for child and youth mental health? What are the links to existing resources?

We prepared the report given the contextual information provided in our first communications (see Overview of inquiry). We are available at any time to discuss potential next steps.

We appreciate your responding to a brief satisfaction survey that the Centre will e-mail to you within two weeks. We would also like to schedule a brief phone call to assess your satisfaction with the information provided in the report. Please let us know when you would be available to schedule a 15-minute phone conversation.

Thank you for contacting Evidence In-Sight. Please do not hesitate to follow up or contact us at evidenceinsight@cheo.on.ca or by phone at 613-737-2297.

1. Overview of inquiry

This request was submitted by the evidence based practice committee of a large multi-service agency. It emerged from discussions being simultaneously held among a youth engagement group, Mental Health First Aid instructors, and the communications department. As this organization considers anti-stigma efforts in the coming year, they are looking for information to help make informed decisions about effective ways to address the stigma of mental health problems. While some work will be in community settings, much of it is to be done in schools and with school-aged groups.

Question statement: *What does the research say is effective in anti-stigma efforts for child and youth mental health? What are the links to existing resources?*

2. Summary of findings

- While the general literature on stigma is extensive, the quality of findings is limited by the complexity of evaluating changes in behavior that result from a multi-component intervention.
- The literature on stigma that is specific to children and youth is much less developed than the adult literature, therefore some of the findings in this report are drawn from the adult literature. This raises a further limitation because the stigma experience for children, youth, and their families may be different in significant ways than that of adults.
- In the context of child and youth mental health, stigma can be understood as negative stereotypes about mental illness and as devaluation of and discrimination towards those affected by mental health problems – including children, youth, their families, and even those who provide services to them.
- Three methods of stigma reduction have the best empirical support, and a three-pronged approach that includes all methods is the most effective:
 - Education: to dispel myths about mental illness
 - Protest: to suppress discriminatory attitudes and challenge commonly held stigmatizing images, such as in popular media
 - Contact: to put a human face on mental illness
- Studies have repeatedly found that contact is the most effective single strategy in countering stigma and discrimination. However, contact in combination with education seems to be the most promising approach.

3. Answer search strategy

We searched sources for research articles on stigma:

- Search Tools: University of Ottawa electronic database, Google scholar
- Search Terms: stigma; mental health; stigma reduction; synthesis; review

We also conducted an internet search for existing resources pertaining to stigma reduction efforts, in parallel with another Centre of Excellence program that is developing an anti-stigma training resource.

4. Findings

With regard to this report, while the general literature on stigma is extensive, the quality of conclusions may be questionable. A 2007 systematic review of school-based interventions on mental health stigmatization (Schachter et al) clearly states the limitations of the extant research: “*poor reporting quality, a dearth of randomized controlled trial evidence, poor methods quality in research design, considerable clinical heterogeneity, and inconsistent or null results*”. Furthermore, a review by Mukolo et al. (2010) concluded that children are subject to stigmatizing contexts but that stigma in the child and youth mental health sphere has not been adequately studied. Nonetheless, there is enough of an evidence base founded upon community experience and community based research to suggest certain best- and promising-practices.

Compared to adults, children are subject to unique stigmatizing contexts; nevertheless there are relatively fewer studies particular to children and youth (Mukolo et al, 2010).

4.1 Stigma – a brief overview

Stigma can be understood as negative stereotypes about mental illness and as devaluation of and discrimination towards people affected by mental health problems. It affects patients, their families, caretakers, and even those who work to provide services for those in need. Stigma in relation to people with mental illness is a combination of knowledge (ignorance), attitudes (prejudice), and behavior (discrimination) (Thornicroft et al, 2008).

There are multiple types of stigma, but three stand out as particularly relevant to this request: public, self, and courtesy stigma.

- *Public stigma* is the reactions of the general public towards a group, based on stigmatized attitudes about that group. It is part of the natural human tendency to label others and separate them into groups (‘other’).
- *Self stigma* refers to the reactions of individuals who belong to a stigmatized group and who turn then stigmatizing attitudes upon themselves. Like public stigma, self stigma consists of stereotyping, prejudice, and discrimination (Rusch, Angermeyer, Corrigan, 2005).
- *Courtesy stigma* is the stigma-by-association experienced by those who are closely associated with stigmatized people. Family, friends, and mental health professionals may be seen by the rest of society as “normal yet different” by virtue of affiliation. They may distance themselves from the stigmatized person, thus reinforcing the us/them dichotomy. Some researchers have suggested that chronic underfunding of mental health services is partly due to courtesy stigma on the part of policy makers (Martin and Johnston, 2007).

Public attitudes

A recent systematic review and meta-analysis showed a consistent evolution of public attitudes over the past 20 years. The public’s general *literacy* about mental illness has greatly increased, but at the same time, *attitudes* towards people with mental illness have not improved and in some cases have even deteriorated (Schomerus et al, 2012). This review focused on the notion of biological correlates of mental illness, the concept at the center of the biomedical model of psychiatry, that characterizes mental health fundamentally as a product of the brain. For instance, the increased use of psychotropic medications may be a result of the increased focus on brain-centred treatments. However, the review found that while public awareness of mental illness has increased in parallel with the increased focus on the medical

model, social acceptance of mentally ill persons has not improved. Some researchers suggest that a biogenetic causal explanation reinforces the notion of ‘otherness’ that is central to stigma.

Barrier to service

As a topic of commentary and research, stigma cuts throughout the child and youth mental health literature. Many studies have identified stigma as a significant barrier to service access and data from the Canadian Youth Mental Health & Illness survey (Davidson & Manion, 1996) indicate that 63 percent of youth point to embarrassment, fear, peer pressure, and/or stigma as most likely to keep someone their age from seeking help. Furthermore, slightly more than one third of Canadians would be embarrassed to admit that their children suffer from anxiety or depression, which creates a further significant barrier to children and youth accessing help (Davidson et al, 2010).

4.2 Effective strategies to address stigma

In spite of flaws in the existing research base on stigma reduction, efforts are widespread in Canada and internationally. There is a consensus around the effectiveness or promise of a general, three-pronged approach that uses education, protest, and contact (Rusch, Angermeyer, Corrigan, 2005):

	Description	Effectiveness	Limitations
Education	Education tries to diminish stigma by dispelling myths about mental illness. It is a process of using information to contradict commonly held myths and is presented through various formats such as structured teaching programs, books, videos, and other media outlets.	Brief educational courses on mental illness have been found to effectively reduce stigmatizing attitudes in police officers, industrial workers, government employees, and high school students.	Behavior change is often not measured in educational campaigns, effect sizes are limited, and programmes are most effective for those who already had good knowledge on mental health. Educational campaigns tend to reach those that already agree with the message.
Protest	Protest is used to suppress discriminatory attitudes and to challenge commonly held stigmatizing images. It often targets stigmatizing public statements, media reports, and advertisements. Given the limitations and the risks associated with suppression, protest is only useful as a way to reduce stigmatizing public images.	Some research indicates that protest can effectively stop stigmatizing public messaging, such as those portrayed in advertisements and media reports.	The research does not have evidence that protest is effective in diminishing negative public stigma and stereotypes. Some research has found that protest leads to suppressed thoughts and behaviors, not a change in attitudes.
Contact	Contact puts a human face on mental illness. Contact can augment the effects of education	Research indicates that members of the majority who meet members of the minority are less likely to	Contact is more likely to succeed if certain environmental factors are

	and protest, whether the person making the contact is a celebrity or a typical citizen.	stigmatize against members of the minority. Of the studies reviewed by Rusch et al, interventions with secondary school students indicate that contact is more effective than education and when combined with education, contact has the larger effect within the overall change in stigmatizing attitudes.	leveraged. This includes equal status among participants, cooperative interaction, and institutional support.
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A Canada-wide survey to gather community input on current anti-stigma initiatives including education, protest and contact provided some qualitative data on what people think are important elements of effective programs (Martin & Johnston, 2007):

- Have a clear, consistent message
- Be sustained over time
- Focus on personal stories that are authentic in tone and delivery
- Challenge myths and provide accurate information
- Be delivered locally
- Be intended to
 - Normalize mental illness
 - Develop a sense of shared humanity
 - Raise sympathy
 - Provide opportunities for personal contact and discussion

In terms of school-based interventions, a systemic review of the literature conducted by Schachter et al (2008) found too many methodological and other shortcomings to conclusively identify “what works”, however they did make several general recommendations:

- Interventions should involve experiential activities that facilitate interactions and engage students’ feelings and behavior, not just cognition-based points of view. In other words, contact-based program that supplements education.
- Interventions should be implemented multiple times within and across the school years, and starting early could maximize exposure. The curriculum should be designed to be progressively appropriate and challenging. In general, a promising curriculum would be implemented early and repeatedly and would employ a generic form of direct contact for the youngest children followed by more direct contact with people experiencing mental health disorders for older children.
- Implementers, including contact agents, should be similar enough to children and youth for them to identify with.
- An evidence-informed program for an empathy-centred curriculum is the Roots of Empathy. This review notes that in evaluation, benefits were observed immediately post-program and after three years. More information at <http://www.rootsofempathy.org/>

4.3 Implementation Considerations

A 2007 report to the Mental Health Commission of Canada summarized the research to-date and outlined key programmatic recommendations drawn from a wide array of existing stigma reduction efforts worldwide (Martin & Johnston, 2007). Given the inadequacy of any single approach, such as education or protest or contact alone, a multi-faceted approach should use a comprehensive set of principles.

Program goals and objectives

- The campaign's goals should be clearly articulated
- Mental health consumers and their families should be active participants in goal setting

Participation and leadership

- Mental health consumer involvement and leadership is important
- Having a dedicated "champion" can help in delivering a successful campaign
- Active participants should make an ongoing commitment to the project

Selection of change targets and key messages

- Programs should target carefully defined groups rather than the public at large
- Each target audience needs an appropriately tailored message
- Focus energy and resources on areas in which success is likely, and on people who are interested in change
- Start with early wins to encourage ongoing participation and build program success and momentum

Sustainability

- Campaigns that intend to change attitudes and behavior need to be sustained over time, with associated funding requirements
- Evaluation protocols need to be embedded
- An information dissemination plan to share outcomes and process information can help with sustainability

A 2008 article reinforced that the strongest evidence for active ingredients to reduce stigma involves direct social contact, particularly for school children, journalists, and police officers (Thorncroft et al, 2008). This article also made recommendations for stigma reduction actions at the individual, employer, local, national, and international levels. Local level activities are intended to promote social inclusion and include:

- Provision of mental health treatment to improve cognition, self-esteem, and confidence
- Implement targeted programs
- Collect and provide accurate data
- Implement care plans involving workers and consumers

4.4 Evaluation considerations

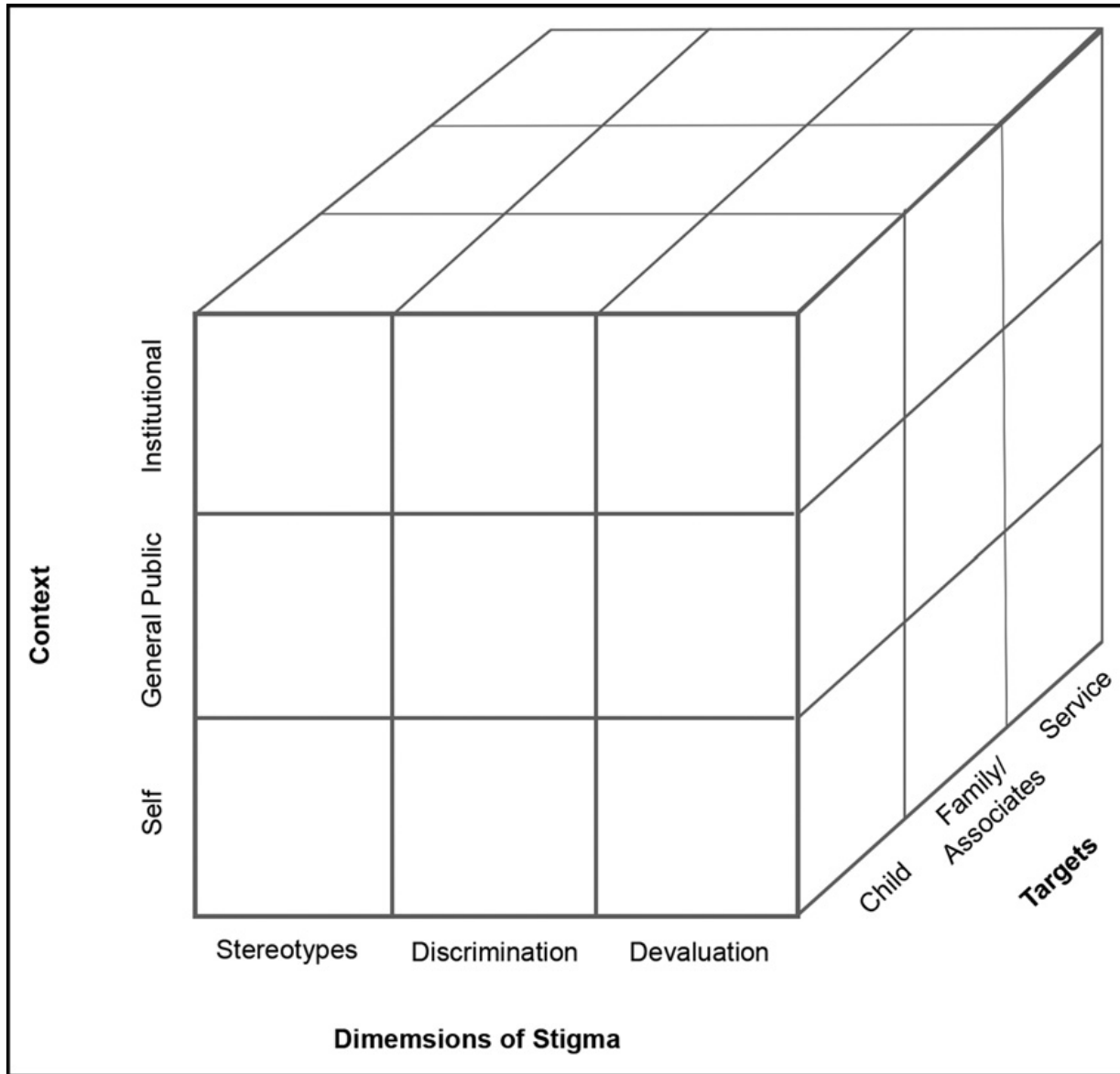
The knowledge base of effective strategies to combat stigma is not yet fully developed. This combined with the absence of standardized tools which are validated across cultures, inconsistent research approaches, methodological flaws in the extant research, and gaps in data all contribute to a gap in the research base. Thus evaluation of stigma reduction programming is important for both tracking the effectiveness of community initiatives and to add to what is known about what works.

Participatory community based research is central to stigma reduction efforts, and evaluation of effectiveness necessitates involving stakeholders in all phases of evaluation as active partners (Corrigan & Shapiro, 2010). One caution is that measures may be skewed by social desirability effects. Attitude measures in particular are at risk of social desirability effects. Corrigan and Shapiro point out that different measures are needed to assess for changes in levels of public stigma, self stigma, courtesy stigma, and other stigma experiences. They also make ten recommendations for measurement of stigma change (see their full paper for further insights into evaluation of stigma reduction programs):

1. Use a Community-Based Participatory Research approach to select measures that represent stakeholder priorities around the goal of stigma change, and consider the social validity of measures.
2. Evaluate stigma change and diversity elements, such as gender, ethnicity, socio-economic factors, etc. Diversity may be an important mediator through which individuals understand mental illness, and how they view others with mental illness.
3. Consider measures of behavior change as these are often prioritized as the most important by stakeholder groups. One avenue is to contrast decreasing discriminatory behavior against increasing affirmative actions.
4. Select measures that reflect the specific interests of targeted and local groups.
5. Choose measures that are less influenced by social desirability.
6. Consider other domains of measurement, including attitudes and emotions, knowledge, and information.
7. Outline how a physiological or informational process may help to better explain stigma change.
8. Develop theory-based models of stigma, which can be particularly important for measures of attitudes and emotions.
9. Measure penetration for population-based anti-stigma programs (such as social marketing efforts).
10. Determine whether awareness has been improved after an anti-stigma program.

Schachter et al (2008) caution that changes in knowledge, attitudes, and stereotypes do not reliably predict behavior change, particularly given the risk of social desirability effects on short-term responses to assessment of attitudes. Thus behavior should be a primary outcome that is measured.

Mukolo et al. (2010), in a review of the stigma of childhood mental disorders, found enough research to develop a conceptual framework composed of dimensions, contexts, and targets of stigma. The dimensions are negative stereotypes, devaluation, and discrimination. The contexts are self stigma, public stigma, and institutional stigma. The targets of stigma are the self or individual (the child), the family, and those who provide services for children, youth and their families. This conceptual framework is a potential outline for evaluation planning (Figure 1, next page).

FIGURE 1 Relationship among child mental disorder stigma dimensions, contexts, and targets (Mukolo et al, 2010)

5. Next steps and other resources

For a selection of publicly available resources and information including toolkits to help in developing stigma reduction programming, see **Appendix A**.

Mental health and mental illness stigma are a major focus of the Mental Health Commission of Canada. Among other recent work, the Commission conducted a scan of stigma reduction programs across Canada and also summarized its intentions to evaluate programs to better identify what is working in Canada. See the *Opening Minds* initiative and associated documents at <http://www.mentalhealthcommission.ca/English/Pages/OpeningMinds.aspx>. Also, see the 2007 foundational report *A Time for Action* at http://www.mentalhealthcommission.ca/SiteCollectionDocuments/Anti-Stigma/TimeforAction_Eng.pdf

As a part of ongoing *Opening Minds* work, the Mental Health Commission of Canada with the World Psychiatric Association Scientific Section on Stigma and Mental Illness is organizing a 3-day conference on stigma reduction. The conference will be June 4-6, 2012 in Ottawa: <http://togetheragainststigma2012.ca/index.php/omas/tas12>

Knowing what works and receiving training on an evidence-informed practice or program is not sufficient to actually achieve the outcomes that previous evaluations indicate are possible. A program that has been shown to improve mental health outcomes for children and youth but that is poorly implemented will not achieve successful outcomes (Fixsen et al, 2005). In order for a program to be evidence-informed, it needs to be applied with fidelity to the design and it needs to be implemented using supportive “drivers” related to staff competency, organizational leadership and organizational capacity. These drivers include assessing and monitoring the outcomes of your practice using evaluation or performance measurement frameworks, which are particularly important when there is insufficient evidence in the literature to guide clinical decisions. Choosing a practice is an initial step toward implementation, but the implementation drivers are essential to ensure that the program reaches appropriate clients, that outcomes are successful and that clinical staff members are successful in their work.

The Ontario Centre of Excellence for Child and Youth Mental Health has a number of resources and services available to support agencies with implementation, evaluation, knowledge mobilization, youth engagement and family engagement. For more information, visit:

<http://www.excellenceforchildandyouth.ca/what-we-do> or check out the Centre’s resource hub at <http://www.excellenceforchildandyouth.ca/resource-hub>.

For general mental health information, including links to resources for families:

<http://www.ementalhealth.ca>

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Appendix A: Publicly available resources

Developer	Resource	Description:	Location
Substance Abuse and Mental Health Services Administration (SAMHSA)	Developing a Stigma Reduction Initiative	Full toolkit with tips and tools to help in planning a stigma-reduction campaign.	SAMHSA Resource Centre: http://stopstigma.samhsa.gov/action/default.aspx . Toolkit at http://store.samhsa.gov/product/SMA06-4176
Centre for Addiction and Mental Health (CAMH)	Talking About Mental Illness: A Guide for Developing an Awareness Program for Youth	Student resource guide that is part of a program designed to increase youth awareness of mental health and reduce stigma.	http://www.camh.net/education/Resources_communities_organizations/TAMI_community/tami_communityall.pdf
Centre for Addiction and Mental Health (CAMH)	Talking About Mental Illness: A Guide for Developing an Awareness Program for Youth	Teacher resource guide that is part of a program designed to increase youth's awareness of mental health and reduce stigma that surround it.	http://www.camh.net/education/Resources_teachers_schools/TAMI/tami_teachersall.pdf
Mood Disorders Society of Canada	Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.	Report examining the state of stigma research and programs since a stigma reducing workshop was held by the Mood Disorders Society of Canada in 2006. Includes information about the perspectives from a variety of mental health professionals and families, with recommended next steps.	http://www.mooodisorderscanada.ca/documents/Advocacy/Stigma_research_and_anti_stigma_programs_Apr1_09.pdf
Mood Disorders Society of Canada	Stigma and discrimination - as expressed by mental health professionals	Research report on stigma as experienced by mental health professionals.	http://www.mooodisorderscanada.ca/documents/Publications/Stigma_and_discrimination_as_expressed_by_MH_Professionals.pdf

Mood Disorders Society of Canada	Stigma: The Hidden Killer	A background paper and literature review covering such topics as negative portrayals of mental illness in the media, self stigma, stigma defined by researchers, consumers and families, why stigma matters among others.	http://www.mooddisorderscanada.ca/documents/Publications/Stigma%20the%20hidden%20killer.pdf
Centre of Knowledge on Healthy Child Development (Offord Centre for Child Studies)	Sticks and Stones: Breaking the stigma of child and youth mental health difficulties through our schools	Overview of stigma and what schools can do to reduce it.	http://www.knowledge.offordcentre.com/component/content/article/73/289-sticks-and-stones-breaking-the-stigma-of-child-and-youth-mental-health-difficulties-through-our-schools-vfc
O'Mara, Mueller, Grypstra, Browne, Akhtar-Danesh, Hoy & Vrkljan, 2009	Does stigma towards mental illness decrease for youth 13-18 years old after participating in school-based Youth Net Hamilton focus groups?	Stigma research study report.	http://www.excellenceforchildand youth.ca/sites/default/files/gai_attach/RG-127_Final_Outcomes_Report.pdf
The Canadian Medical Association, The Canadian Psychiatric Association, The Canadian Paediatric Society, The College of Family Physicians of Canada	A Workshop Dedicated to Ending Stigma and Achieving Parity in Mental Health: A Physician Perspective	A summary of presentations and key emerging themes and recommendations based on this workshop.	http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/Office_Public_Health/MentalHealth/Stigma-Discrimination-Workshop-Report_en.pdf