DOCH II Final Report:

Measuring Stigma to assess the impact of an anti-stigma intervention targeted to adolescents

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Abstract:

Individuals with mental illnesses represent one of the most highly stigmatized populations. Stigmatizing attitudes are widespread in the general public, and these create a discriminatory environment that limits the opportunities of people with mental illness. Anti-stigma interventions aim to reduce this discrimination and status loss and improve social justice for people with mental illness. Workman Arts (WA) is currently designing an anti-stigma intervention called the Youth Film Program. The Program is targeted at high school students. It consists of a collection of short films meant to stimulate interest in issues facing the mental illness community followed by a panel discussion about those issues. In order to eventually evaluate the effectiveness of the Program at decreasing stigmatizing attitudes in the adolescent population, I generated a review of the literature looking at the different tools that are available to measure the success of anti-stigma programs in this population. I identified 5 studies that made use of 4 different stigma measures: Knowledge Test, Social Distance Scale, Attribution Questionnaire and Public Stigma Scale. Each of these tests measure stigma by targeting a specific construct of the stigmatization concept. All of the tests successfully detected statistically significant changes in stigmatizing attitudes post-intervention. Based on the theory behind each of the tests and by comparing their utilities and limitations, I am able to recommend which tests should be including in WA's program evaluation.

Keywords: Mental Health, Stigmatization, Adolescents

Individuals with mental illnesses represent a highly stigmatized population. Discrimination or the expression of devaluing statements against mentally ill persons have been observed in employers[1], mental healthcare workers[2], prospective landlords[3], the families of patients with mental illness[4] and the general public. [5, 6] Public stigmatizing attitudes have a devastating impact on the mental illness community. They act as an obstacle to the achievement of important life goals by limiting the opportunities available to people with mental illness. These attitudes negatively impact an individual's ability to acquire and maintain gainful employment[1, 7] and to secure comfortable living accomodations.[3, 8] Perception of social stigma by individuals diagnosed with mental illness correlates with decreased self-esteem[9]. Fear of being stigmatized promotes withdrawal as a coping mechanism resulting in social impairment. [10] Furthermore, stigmatization adversely affects the health and wellbeing of people diagnosed with mental illness, acting as a barrier to recovery. The World Health Organization called stigma one of the greatest obstacles in treating mental illness.[11] Social stigma discourages people from acknowledging their own mental illness and is associated with an unwillingness to seek treatment[12]. Of the 1 in 4 Canadians that will suffer from a mental illness in their lives, only 1 in 3 of them will actually seek medical help.[11] The degree of perceived stigmatization is also associated with non-adherence to psychiatric medications[12] and the severity of mental illness.[10]

Despite a large body of research in this field, the concepts of stigma and stigmatization are not fully understood. Though many studies have targeted the prevalence, consequences and causes of stigma, there is no universally agreed upon definition of the terms – they vary between publications and are rarely explicitly defined.[13] One of the earliest and most frequently cited definitions of stigma was proposed by Goffman *et.al*, who call stigma "an attribute that is deeply discrediting" which reduces anyone bearing that attribute from a "whole and usual person to a

tainted, discounted one." Examples of different stigmas include mental illness, drug addiction, criminal backgrounds, ethnic groups, obesity and HIV infection. Goffman's definition suggests a reason why individuals bearing these stigmas are often subjected to discriminatory behaviors from society. For instance, if someone has been discounted as a tainted individual in the eyes of an employer, they will likely have difficulty being hired by this employer. The concept of stigmatization was expanded upon by Jones who used the term "mark" to denote any human difference deemed by society to be deviant. Stigma occurs when individuals bearing a mark are linked to undesirable characteristics that may discredit them. According to Jones, the attribution of negative characteristics, or stereotypes, are a means by which individuals in society can justify their negative feelings towards the marked population. This role stereotypes play in justifying pre-existing attitudes may explain why they are difficult to challenge through anti-stigma interventions. One of the most destructive stereotypes attributed the mental illness community is that of dangerousness – the misguided belief that people with mental illness cannot control their actions and are a threat to society.

Following the attribution of stereotypes to marked populations, an exclusionary situation develops. There is a separation between "us", the majority, and "them", the marked population. This separation is not physical but rather linguistic. Society creates and reinforces the separation by creating specific labels for the marked population. For instance, "crazy", "mental" and "psycho" are three of the most common terms used by adolescents to refer to people with mental illness, and these are examples of labels. In addition to excluding the marked population, labels also facilitate the attribution of stereotypes. According to Link *et al.*, "when people are labeled, set apart, and linked to undesirable characteristics a rationale is constructed for devaluing, rejecting and excluding them."[13] Thus, stereotypes and labels provide the cognitive framework

to bring about and justify discrimination, the behavioral outcome of negative attitudes which robs people of equal opportunity. Individual discrimination occurs when one individual discriminates against another individual while structural discrimination occurs beyond direct person-to-person discrimination and relates to social institutions. An example of the former is a landlord who rejects an apartment candidate because of mental illness, and the latter, decreased allocation of funds towards research and treatment of mental illness compared to other conditions. Another result of stereotypes and labeling is status loss wherein stigmatized individuals are placed lower on the social hierarchy.

Anti-stigma interventions aim to reduce this discrimination and status loss. According to Corrigan *et al.*, the three categories of approaches to challenge public stigma are protest, education and contact.[14] Protest efforts attempt to reduce stigmatization by portraying it as morally unjust. Though useful at challenging institutional discrimination, these campaigns are not effective at challenging individual discrimination. By asking individuals to stop discriminating against people with mental illness without actually challenging the underlying beliefs leading to that discrimination, protest campaigns may actually increase stigmatizing attitudes in the public. Education interventions aim to decrease discrimination by replacing stereotypes with factual knowledge about mental illness. These can reach large audiences and have been shown to be effective at lowering stigmatizing attitudes. Contact with a person with mental illness is the most effective way to challenge stigmatization.[14] By allowing people to interact with a member of the stigmatized population, contact interventions seek to break down the psychological division between “us” and “them” that is reinforced by labels. Thus, while protest challenges the outcome of stigmatization (discrimination and status loss), education and contact challenge the cognitive processes leading to that outcome (stereotypes and labeling).

Workman Arts is currently developing an anti-stigma intervention that combines the two most effective means of lowering stigmatizing attitudes: education and contact. This intervention, entitled the Youth Film Program, is being designed to decrease the stigmatizing attitudes of high school students. The program will feature a collection of short documentary or fiction films in which people with various mental illnesses are shown directly or discussed by others. These films will be followed by a panel discussion lead by a psychiatrist and a WA member with mental illness. The idea is that the films will generate interest in some of the general issues faced by people with mental illness so that these same issues can be discussed in the panel discussion. Though the film program is not yet complete, WA hopes to represent several mental illnesses including depression, bipolar disorder, schizophrenia, anxiety and alcoholism. Two prominent stereotypes about mental illness will be of particular focus in the Film Program: dangerousness, the belief that people with a mental illness have lost self-control and engage in violent behavior; and personal responsibility, the belief that mental illness is a consequence of preventable behaviors. Adolescents are an excellent target for anti-stigma interventions such as this. They are easily accessible through school and already possess stigmatizing attitudes[15]. Furthermore, several anti-stigma interventions have been shown to be effective at lowering stigmatizing attitudes in the short-term in this population[15-19].

The purpose of my research with WA is to help this agency answer the question:

Will Workman Arts' Youth Film Program effectively decrease stigmatizing attitudes in adolescents?

As the film program is incomplete and I could not test the question directly within the DOCH timeline, my project has been to conduct a literature review looking at the different tools

available for measuring changes in stigmatizing attitudes due to an intervention. The Youth Film Program targets adolescents so I limited my search to interventions that specifically target this population.

I was able to identify 5 studies:

Chan JYN, Mak WWS, Law LSC. Combining education and video-based contact to reduce stigma of mental illness: "The Same or Not the Same" anti-stigma program for secondary schools in Hong Kong. Social Science & Medicine 2009;68:1521-6.

Pinfold V, Toulmin H, Thornicroft G, Huxley P, Farmer P, Graham T. Reducing psychiatric stigma and discrimination: evaluation of educational interventions in UK secondary schools. Br J Psychiatry 2003;182:342-6.

B. Schulze. Crazy? So what! Effects of a school project on students' attitudes towards people with schizophrenia. Acta Psychiatrica Scandinavica 2003;107:142-50.

Stuart H. Reaching out to high school youth: the effectiveness of a video-based antistigma program. Can J Psychiatry 2006;51:647-53.

Watson AC, Otey E, Westbrook AL, et al. Changing middle schoolers' attitudes about mental illness through education. Schizophr Bull 2004;30:563-72.

Each of these studies aims to evaluate changes in stigmatizing attitudes after an anti-stigma intervention. Though specific details about each intervention were not given, I have categorized them according to Corrigan's 3 types of anti-stigma. Chan, Pinfold, Schulze and Stuart all evaluated education and contact programs, whereas Watson evaluated an education-only program. The contact interventions can be further subdivided into live-contact (Pinfold and

Schulze) and video-contact (Chan and Stuart). Unfortunately, none of these interventions is directly comparable to Workman Arts' program which features education and both subdivisions of contact.

Measuring Social Stigma:

Much like the definition of stigma itself, there is no standardized test for assessing stigmatizing attitudes. Stigma is a multi-faceted concept and it cannot be measured directly. Instead, we measure information related to the key constructs in the stigmatization concept. In each of the abovementioned studies, students were asked to fill out a survey one week before and one week after an anti-stigma intervention. The pre-test and post-test questionnaires were then compared for statistically significant differences in the answers to the questions. Within these five studies, I identified four types of measures of stigmatization: the knowledge test, social distance scale, attribution questionnaire and public stigma scale.

Knowledge Test:

The knowledge test was the most frequently used of the four measures. This test consists of a series of true or false statements about mental illness. The respondent is given the option of selecting "true", "false" or "unsure". Example questions from the studies include:

1. Individuals who have a family member with a mental illness are more likely to have a mental illness themselves. (T)
2. Most people with mental illness can do normal things like go to school or work at a job (T)
3. People with schizophrenia are likely to be violent (F)
4. Mental health problems are caused by stress (F)

Students can respond to these statements correctly or incorrectly. Pre- and post-test answers are compared. The role of the knowledge test is to specifically measure changes in knowledge following an intervention. Because the statements used in these tests are often linked to stereotypes, the knowledge test allows us to assess the effectiveness of an intervention at challenging these stereotypes. The example questions above deal with stereotypes of personal responsibility (1-4), dangerousness (3) and the belief that people with mental illness are a burden on society (2). If an intervention increases the number of correct answers relating to these questions, this is an indication that the stereotypes have been challenged, one of the ways in which stigmatizing attitudes can be reduced.

The knowledge test was used in all five of the reviewed studies. This makes sense given that the interventions all had an educational component. This test was able to demonstrate statistically significant increase in knowledge following the interventions. However, social desirability bias represents a limitation to the knowledge test. Social desirability bias refers to people's tendency to answer questionnaires based on the values of society instead of their own values. For instance, in question 3 above, someone may believe that people with schizophrenia are violent but may not select "True" because they do not want to appear unenlightened. This is especially likely to occur in the post-test as the anti-stigma intervention will recently have presented these values to students. Also, because the pre- and post- knowledge tests are identical, respondents have the potential to learn from the pre-test in order to answer correctly during the post-test. Both these limitations could result in an overestimate of the effectiveness of an intervention at challenging misinformation. However, this could be accounted for with a control group. Another limitation is that the test is not standardized. It varies from study to study, so we cannot actually compare the results for different interventions with one another.

Social Distance Scale:

The social distance scale was used in 4 of the 5 reviewed studies. It consists of a series of hypothetical situations involving contact with someone with mental illness, where the respondent is asked to accept or decline the contact. These situations represent a range of degrees of closeness, such that the respondent's answers are used to predict closeness of association that the respondent will allow. This self-reported closeness of association is referred to as social distance. Example questions include:

1. I would be afraid to talk to someone who has had a mental illness
2. I would not be upset or disturbed to be in the same class with someone who has had mental illness
3. I could imagine making friends with someone who has had a mental illness
4. I would feel embarrassed or ashamed if my friends knew that someone in my family had a mental illness

The respondent is asked to rate these questions in terms of "Agree", "Disagree" or "Unsure". Agreement with questions 1 and 4 would indicate a relatively high social distance, whereas agreement with questions 2 and 3 would indicate a relatively low social distance. Social distance is a way to measure the division of "us" and "them" that occurs in stigmatization and is used to infer discriminatory behavior: particularly avoidance.

The social distance scale has excellent internal-consistency ranging from 0.75 to >0.90.[13] The scale also shows good construct validity. Studies have demonstrated that older persons, people of low educational levels, people who have never met someone with mental illness and people who believe in the danger stereotype of mental illness all provide increased social

distance measures.[13] In other words, the tool is validated because social distance measured in these groups correlates with the expected social distance. An advantage of the social distance scale is that it is among the most widely used tests for measuring stigmatizing attitudes. [13] However, it is not standardized. The questions used in this scale vary from test to test and are designed to reflect realistic situations that could be faced by the research's target population. Schulze used a focus group of adolescents to create their 12 point social distance scale. Of the 12 questions, they included the 4 mentioned above because these questions were used extensively by the World Psychiatric Association (WPA) to evaluate previous anti-stigma campaigns (unpublished) and would allow for the comparison of results. Chan used the same social distance questionnaire as Schulze but omitted question 4 (above) because they felt it was a stronger measure of emotional response than social distance. Stuart used the 4 standard WPA questions and 3 additional items from Schulze's social distance questionnaire. Pinfold only used the 4 WPA questions. All 4 studies identified a statistically significant reduction in social distance post-intervention.

Like the knowledge test, the social distance scale is also subject to social desirability bias. This would most likely contribute to an underestimation of the true social distance in a population. Furthermore, it cannot be used to infer specific behavioral responses. While self-reported social distance is a measure of the division between "us" and "them", one may not assume that increasing or decreasing social distance will impact discriminatory behavior. If the goal of an intervention is to target a specific behavior, changes in the incidence of that behavior must be measured directly.

Attribution Questionnaire:

The attribution questionnaire was only used in one of the reviewed papers. This questionnaire is based on the attribution theory model of stigmatization.[14] According to this theory, "the target's perceived responsibility for the stigmatizing circumstance predicts either anger or punishing actions (if believed to be controllable) or pity and helping behaviors toward the target (if believed to be uncontrollable)"[16]. In other words, when someone witnesses unexpected behavior, they explain that behavior to themselves with an attribution which may be external (uncontrollable) or internal (controllable), and this attribution will predict the emotional and behavioral outcomes. Take the example of an individual who sees a man with mental illness talking to himself. An example of an external attribution is the realization that this person likely has a mental illness that renders this behavior beyond their control. An example of an internal attribution is the belief that this man is unpredictable, that he has relinquished control to his mental illness and that, consequently, he might be dangerous. While the former attribution would lead to pity and helping behavior, the latter could lead to fear, anger, avoidance and punishment. The attribution questionnaire was designed to measure stigmatizing attitudes through key constructs in the attribution model of stigmatization. Watson *et al.* designed a modified version of the attribution questionnaire specifically targeted to adolescents. It begins with a vignette describing a fictional new student with mental illness. Students were then asked to score 8 items on a 7 point scale of disagree to agree.

1. The new student is not dangerous. (Danger)
2. I feel sorry for the new student. (Pity)
3. The new student should be locked away in a mental hospital. (Segregation)
4. I will try to stay away from the new student. (Avoidance)

5. It is not the student's fault he or she has a mental illness. (Responsibility)
6. The new student makes me angry. (Anger)
7. I would help the new student. (Help)
8. I am scared of the new student. (Fear)

The particular constructs being measured are listed in brackets next to each question. The utility of this test is that it provides information about two very important stereotypes (dangerousness and personal responsibility) and allows for a wide spectrum of behavioral intention to be assessed. While the social distance scale is used to predict the behavior outcome of avoidance, the attribution questionnaire lets respondents rank three types of behavioral intention: pity, avoidance and segregation. This information could provide more specific insight into how propensity towards different types of behaviors is being modified by an intervention.

The attribution questionnaire shows strong construct validity. Individuals who perceive uncontrollability are more likely to perform helping behaviors, whereas perception of uncontrollability is related to avoidance, segregation and decreased real-world helping behaviors.[13] However, it may be limited in its sensitivity. While Watson *et al.* were able to demonstrate that their intervention was successful in decreasing belief in the stereotypes named above, the pre-test and post-test attribution questionnaires did not show a statistically significant difference in overall stigmatizing attitudes. Consequently, they identified a subgroup of students with high pre-test stigmatizing attitudes (one standard deviation above the mean) and were able to demonstrate a statistically significant decrease in stigmatizing attitudes post-test within this group. Identifying data is required for this type of manipulation of results.

The attribution questionnaire is a commonly used measure of stigma but not in adolescents, meaning that it would be difficult to compare the results of different studies conducted on this population. It is also subject to social desirability bias.

Public Stigma Scale:

The public stigma scale is designed to assess stigmatizing attitudes in individuals according to 3 categories: affective, cognitive and behavioral. Respondents rate 12 items on a 6-point Likert scale ranging from "strongly disagree" to "strongly agree". Examples of these statements include:

1. People with schizophrenia are repulsive. (Affective)
2. People with schizophrenia are a burden to society. (Cognitive)
3. When you meet someone with schizophrenia, it is best to avoid him/her. (Behavioral)

By comparing the overall pre-test and post-test answers, the Public Stigma Scale can be used to assess if an intervention lowered stigmatizing attitudes. The flexibility of this test lies in its categorization. Specifically comparing differences within the 3 categories provides information about how each of these categories of stigmatization is being affected by an intervention. These results may help guide future modifications of the intervention. Like the Attribution Questionnaire, the Public Stigma Scale also measure provides information about a broader range of behavioral intention than the Social Distance Scale. Chan *et al.* were able to identify statistically significant changes in stigmatizing attitudes using this measure. The results of the Public Stigma Scale had good internal consistency – they identified Cronbach's-α scores of 0.85 and 0.88 in the pre-test and post-test respectively.

Validity for the Public Stigma Scale was established in a population of 941 adults in Hong Kong. Unfortunately, the details of this study were not available for review because they were never published. Furthermore, the test was written in Chinese and only the above 3 questions were translated and published in the English version of the Chan *et al.* manuscript. While an English version of the test may exist, I believe Dr. Jenny Chan would need to be contacted directly in order to access it. The infrequency with which this test has been used (I only saw it in this one publication) would preclude the comparison of results for different anti-stigma campaigns. As with the other measures, social desirability bias is also a limitation.

Recommendations:

Within the 5 studies that assess changing stigmatizing attitudes following an anti-stigma intervention, 4 different measures were used: Knowledge Test, Social Distance Scale, Attribution Questionnaire and Public Stigma Scale. All 5 of these studies including a Knowledge Test, and I recommend that WA also include this test in their future research. It is a useful means of measuring changing in knowledge following an intervention and also provides information about how belief in specific stereotypes is affected. Because WA Film Program is likely to be less didactic than the reviewed interventions which were mostly classroom-based, the focus of the questions in this test should relate to the specific stereotypes that WA is attempting to challenge. One such stereotype which was not tested in any of the reviewed Knowledge Tests was the belief that people with mental illness are brilliant or geniuses, so a question about this should be included in the questionnaire. Because the film program is not complete, I cannot make specific recommendations about the Knowledge Test questions that should be used. However, because the Youth Film Program intends to discuss mental health issues relevant to many different types of mental illness, I believe the questionnaire should test the stereotypes specific to each of these

mental illnesses. I do not think that asking general question about "people with mental illness" (Pinfold), "people with mental illness" and depression (Watson) or exclusively asking about schizophrenia (Chan, Schulze, Stuart) would provide enough insight into the range of stereotypes being challenged by the program. Therefore, I recommend that WA create a specific Knowledge Test asking questions about all the relevant mental illness and their stereotypes that will be discussed in the program.

The Social Distance Scale is a tried and true measure of the division between "us" and "them" that occurs in stigmatizing situations. The test has been extensively used, and was able to demonstrate statistically significant changes in stigmatizing attitudes in 4 of the reviewed studies. I recommend its inclusion in the WA questionnaire. The questionnaire should include the 4 social distance questions listed above because they have been used extensively by the World Psychiatric Association to measure a number of anti-stigma campaigns. I also recommend using the other social distance questions designed by Schulze *et al.* in their adolescent focus group. However, these questions may need to be modified because they specifically ask about schizophrenia. They could be modified to ask about any specific mental illness, or "people with mental illness" in general. I did not see any cases in the literature where different specific mental illnesses were assessed in the same test, so I would not recommend creating a modified social distance questionnaire asking about multiple mental illnesses unless the term "people with mental illness" is used. If WA would like to determine changes in stigmatizing attitudes towards multiple mental illnesses, they should repeat the social distance questions for each mental illness.

The Attribution Questionnaire and Public Stigma Scale each provide useful information about a wider range of behavioral outcomes than the Social Distance Scale. However, these tests

have limitations. The Attribution Questionnaire was only able to find statistically significant differences in attitudes post-intervention within a subset of students that expressed high stigmatizing attitudes in the pre-test. This date manipulation requires identifying data from the respondents, and I believe that this is unnecessary and will likely complicate getting ethics approval for the study. For this reason, I do not recommend its use. The Public Stigma Scale was effective and did not require identifying data, but I was only able to find one example of its use in the literature and there may not be an available English translation of the questions. Unless this test is translated and the English version validated in a new publication, I do not recommend using the Public Stigma Scale.

I will remain in contact with WA. Once the Film Program has been completed, I will meet with Lisa about her specific goals for evaluating the program and I will use this information to create an appropriate questionnaire. It is my hope that a IT2 student in DOCH will then continue the research. Lisa has also expressed interest in having someone evaluate an existing anti-stigma intervention, the WA "Edward the Crazy Man" play, and I believe this could also be done by another student using a slightly modified but similar questionnaire.

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