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School of Occupational Therapy

Promoting Humanness: Occupation-Based Programming and Advocacy in a State Psychiatric Hospital

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May, 2019



A capstone project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy.

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A Capstone Project Entitled

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Abstract

Problem: A need for increased promotion of humanness among people with mental health concerns is prevalent in both the medical and societal realms. Stigma surrounding mental illness from both health professionals and the greater outside community provides challenges to those living with mental illnesses.

Program: Two programs were developed to address this problem: 1) An occupation-based program focused on volunteerism with social skill and self-care components was implemented on two youth units at a state psychiatric hospital and 2) A narrative-medicine based anti-stigma campaign including a sustainable resource to promote empathy was created and presented to staff at a state psychiatric hospital. Both programs were created to promote the humanness of each patient at the site, increasing their quality of life through meaningful occupation and empathetic staff.

Outcomes: Youth participants learned and implemented social skills and self-care strategies, attempted new leisure skills, and completed volunteer projects for local community organizations allowing them to feel more connected to their community. Participants noted a desire to continue at least one leisure pursuit introduced in group as well as volunteer again with at least one community organization in the future. Following the anti-stigma campaign presentation to hospital staff, there was an average of a 0.45 point change on a 10 point Likert scale regarding ability to understand and empathize with patients. Additionally, staff identified an average of 1.35 mindsets/biases they wanted to improve and created an action plan with an average of 2.58 ways they planned to work to increase their empathy.

Background and Literature Review

Participation in meaningful occupation is critical to each unique individual so that they may lead a life of value. The Value in Meaningful Occupation (VaIMO) theory explains that a meaningful life full of value is deeply intertwined with the participation in meaningful occupation on the micro, meso, and macro levels (Persson, Erlandsson, Eklund, & Iwarsson, 2001). In this theory, micro level occupation includes actions and operations which, combined, allow us to participate in a meaningful occupation. The meso level occupation includes the meaningful occupation itself as well as daily patterns of occupation which give life its meaning. Macro level occupation is then viewed as an entire life made up by one's meaningful occupations (Persson et al., 2001). In essence, the micro facilitates the meso which creates the macro.

In the VaIMO theory, one sees actions and operations, even something as small as the ability to attend to craft directions in a school setting, can ultimately impact one's entire life (Persson et al., 2001). By addressing occupations and, within them, client factors and performance skills necessary for participation, an entire lifetime of meaningful occupation and value can be addressed.

Occupational therapy interventions have the potential to improve occupational performance and wellbeing in people with a wide range of mental health diagnoses (Ikiugu, Nissen, Bellar, Maassen, & Van Peursem, 2017). In fact, Lipskaya-Velikovsky, Kotler, & Krupa (2016) explicitly state that, "participation in meaningful occupations is an important component of recovery in mental illness, and recovery is a focus of mental health service delivery internationally" (pg. 4). This heavily supports the incorporation of occupation-based interventions and activities into the daily lives of people in an inpatient mental health setting as

researchers in this study suggest occupational engagement and participation aid in recovery, a goal of inpatient mental health settings around the world (Lipskaya-Velikovsky, et al., 2016).

Specifically, researchers found that there is strong evidence to support the use of ADL, IADL, and social participation interventions as well as moderate evidence to support the use of leisure, and rest/sleep interventions among mental health service consumers (D'Amico, Jaffe, & Gardner, 2018). In addition, researchers have found evidence to support the use of Tier I (universal), II (targeted), and III (intensive) occupation and activity based interventions with youth who have a mental illness, are aggressive, have been rejected, have learning disabilities, or are generally at risk in order to improve social skills, self-management, and coping mechanisms (Arbesman, Bazyk, & Nochajski, 2013).

Furthermore, researchers have found that increased engagement in structured activities is inversely related to incidence of depression in youth with disabilities (Berg, Medrano, Acharya, Lynch, & Msall, 2018) suggesting the mental health of vulnerable youth benefits when meaningful occupation is more central to their lives. This concept is supported by Larivière, et al. (2015), who also found participation in meaningful occupations as well as being a part of healthy relationships were critical factors in mental health recovery. This is crucial for occupational therapy practitioners to understand in order for programs to be made that encourage engagement in meaningful occupation to address the mental health of the youth populations they serve.

Patient intervention, however, is not the only skill-set occupational therapy practitioners have which can address the betterment of the lives of people in inpatient psychiatric facilities. Occupational therapists can also address stigma and biases surrounding care of those with mental illnesses through a holistic understanding of care. Stigma related to mental illness can decrease a person's likelihood to participate in treatment, leading to decreased self-esteem and decreased

social opportunities (Corrigan, 2004). This means stigma can directly impact a person's ability to participate in meaningful occupations. While it is likely many staff members working in this setting have a passion for caring for those with mental illnesses, researchers have found that, at times, professionals working in health-care, when compared to those in the general public, report more negative feelings towards people with mental illness (Thornicroft, et al., 2016).

Elaborating on this finding, researchers also found 119 patients from 16 acute psychiatric units felt the nursing staff they interacted with on an almost constant basis were unfriendly and did not understand or attempt to empathize with them during their time admitted, ultimately leading to feelings of being undervalued (Stewart, Burrow, Duckworth, Dhillon, Fife, Kelly, ... & Wright, S. 2015). The staff members at these facilities interact with people working through recovery on a daily basis. In order to positively affect the quality of life and wellbeing of patients in psychiatric settings most fully, it is crucial to address any negative or incorrect stereotypes, stigmas, biases, or general indifference the people who interact with mental health consumers may have. This is where the holistic perspective of occupational therapists has a role to play.

Researchers have found there is evidence of long term benefits, beyond four weeks post-intervention, of mental health related anti-stigma interventions including decreasing attitudes of stigma towards the population in addition to general increase in knowledge regarding the anti-stigma topic (Mehta, et al., 2015). Ke, Lai, Sun, Yang, Wang, & Austin (2015) found even a one-hour anti-stigma intervention related to mental illness decreased the participants' stigma scale score by 23%, of which a 21% decrease was maintained at one month post-intervention. This provides hope for future anti-stigma interventions in increasing the quality of life of mental health consumers through the decrease in attitudes of stigma in the people they interact with on a daily basis.

Screening and Evaluation

In order to further inform program development, a screening and evaluation process took place through the form of a needs assessment. The evaluation process, “consists of the formal and informal collection of useful information...from multiple sources” (Christiansen & Matuska, 2011, pg. 46). Asher (2014) states there are several forms of data collection, or information sources, to consider when conducting an occupation-based assessment: history, survey, experiment, observation, questionnaire or interview, and measurement. The needs assessment completed was multifaceted and consisted of three of the methods listed previously: observation, interviews, and surveys. This screening and evaluation process was developed to allow for the programs created as a result of their finding to be as client-centered and holistic as possible.

Observation. Part One of the needs assessment consisted of a week-long observation of youth programs, focusing on youth behavior and interactions among peers, current programming at the site, and staff interactions with youth. From this process, the observer received insight on several factors impacting the youth and their experience while hospitalized at the site. Youth relationships with peers were at times strained, likely due to the constant closeness in proximity they face on a daily basis. Currently, the largest of three total youth units has only five patients. These youth wake up together, go to school together, eat together, and spend their free time together. They experience the effects of one another’s behaviors throughout the day and, at times, have little patience for another’s struggles. Despite this, the youth, in other moments, show empathy and help one another through difficult situations.

The current programming for the youth, lead largely by the recreational therapists outside of school hours, allows the patients time to play and interact with each other in a less stressful environment. The majority of youth at the site appear to enjoy the recreational therapy activities.

When discussing their favorite parts of the current programming and groups, they noted things including, “learning to control our actions,” “fun stuff,” “physical activity,” and, “activities with other [youth] units.”

Additionally, while many staff members have positive interactions with the youth at the site, several staff members’ words and actions sometimes reflected frustration, impatience, and exhaustion related to working with the youth, specifically during their moments of maladaptive behavior. While these feelings are understandable, it is unreasonable to speak and act in a way that reflects those, as these youth are hospitalized as a result of a mental illness or illnesses which often times lend themselves to these difficult behaviors. This was perhaps the most problematic observation.

Interviews. Part Two of the needs assessment involved interviewing both youth patients and staff members. Both youth and staff member interviews were largely focused on gaining insight into programming desires. When asked what they wish they could learn more about while at the site, youth stated, “staying out of people’s space,” “coping skills,” “art,” and, “how to stop self-harming.” Their favorite things to do ranged from, “being caring,” to, “sleeping,” to “exploring abandoned houses.” When asked what group they would create at the site if given the chance, they explained they wanted, “craft group,” “babysitting group,” painting group,” “karate group,” “crocheting group,” (Youth patients, personal communication, January 23, 2019; January 25, 2019) and more.

Staff members were asked about what they felt the youth’s greatest daily need was throughout hospitalization. Responses included, “consistency in their schedules...discipline and consequences,” and “knowing how to entertain themselves during downtime” (F. Bunch & K. Yamasaki, personal communication, January 23, 2019). When asked what they feel holds the

youth at the site back from living safely and appropriately in the community, staff responded by saying, “Placement availability (group homes, step down facilities, or foster homes)” and “They don’t get to have the typical things they would have outside of here- crayons, a variety of clothing...we’ve fallen into a habit of, if one person gets put on precautions and can’t have it, then no one can have it.” Additionally, when asked what they wish they could provide for the youth, staff members responded, “Especially for the girls - but across the board - transitional care,” “even just getting to help them do daily things like brush their hair,” and, “Exercise, staying active, more activities during non-school days and weekends” (F. Bunch & K. Yamasaki, personal communication, January 23, 2019). With the high and varying needs of the youth hospitalized at the site, in addition to the lack of time and resources of the staff, many needs go unmet, despite best efforts.

In addition to interviews surrounding programming, an informal interview was conducted with a director of one of the site departments. In this interview, the director stated that some staff members have challenges related to stigmatizing the patients they work with due to the nature of the diagnoses that brought them to the hospital (E. Clampitt, personal communication, March 28, 2018; January 7, 2019). This was echoed in the aforementioned negative staff-to-patient interactions noted in the Observation section.

Scholars have noted this is not an uncommon problem related to mental health conditions. Brown & Stroffel (2011) explain much of mental health stigma has to do with people placing blame on the person who has the diagnosis (Brown & Stroffel, 2011). This is very much in contrast to the majority of diagnoses one sees in healthcare. This stigma can be detrimental to the recovery process (Brown & Stroffel, 2011). In order to promote recovery, especially in a

hospital setting, it must be a priority to eliminate the stigma surrounding mental health diagnoses.

Occupation-based survey. Part Three of the needs assessment was a survey (see Appendix A) focused on better understanding the occupational challenges faced by the youth on site. A total of 16 staff members working with all three youth units responded to the survey. These staff members included nursing staff, support staff, psychologists, recreational therapists, social workers, and dieticians. Below are the results of the survey:

Occupation	Prevalence	Significance
Bathing/Showering	8	0
Grooming	11	3
Functional Mobility	2	0
Dressing	3	0
Safety and Emergency Maintenance	3	0
Health Management and Maintenance/Coping Skills	14	1
Rest/Coping Skills	13	6
Sleep Preparation	4	2
Sleep Participation	2	1
Formal Education Participation	11	2
Informal Education Participation	8	1
Volunteer Participation	10	2
Play/Leisure Exploration	9	1
Play/Leisure Participation	7	3
Social Participation (Community)	9	1
Social Participation (Family)	6	0
Social Participation (Peer/Friend)	13	10

Prevalence refers to the number of respondents who reported the occupation as a challenge for the youth with whom they work. Significance refers to the number of respondents who reported the occupation as a top concern in need of being addressed for the youth with whom they work. Respondents were able to mark three occupations as a top need. Note, not all respondents noted significance of need on their surveys.

From the data above, the program developer discovered that the top occupational challenges related to prevalence of the challenge were: 1) Health Management and Maintenance including coping skills (88% of respondents), 2) Social participation - Peer/Friend (81%), 3) Grooming and Formal Education (69%), 4) Volunteer Participation (62%), and 5) Play/Leisure Exploration and Social Participation - Community (56%). Regarding significance of challenge, the rankings were as follows: 1) Social Participation - Peer/Friend (83% of respondents), 2) Rest including coping skills (50%), 3) Social Participation - Community and Grooming (25%), 4) Volunteer Participation, Sleep Preparation, and Formal Education Participation (17%), and 5) Health Management and Maintenance including coping skills, Sleep Participation, Informal Education participation, and Social Participation - Community (8%).

Needs assessment analysis and relation to previous studies. The needs assessment yielded a wide range of meaningful results displaying a variety of challenges related to experiences of youth and mental health patients in general at this site. Challenges included difficulty performing meaningful occupations and interpersonal barriers regarding peer-to-peer as well as patient-to-staff interactions. These results are not surprising as social participation, community participation, ADLs, and coping and self-efficacy are all areas occupational therapists focus on when working in a pediatric setting whether with young children or adolescents (Case-Smith & O'Brien, 2015). This is critical to understand when creating a program to address youth's needs in any setting.

In order to address these multifaceted challenges, it is important to create a group surrounding an occupation that involves many of these concepts. A volunteerism group can address peer and community social skills, leisure exploration, and healthy coping. Researchers, after coming to understand the many benefits of volunteerism, provided the Volunteering-in-Place (VIP) program to residents of an assisted living facility, all of whom had mild cognitive impairment (Klinedinst & Resnick, 2016). The participants of this program were found to have increased participation in the meaningful activity of volunteerism, greater feelings of purpose, and heightened quality of life as a result (Klinedinst & Resnick, 2016).

These researchers also noted the challenge of finding volunteer opportunities for their population due to lack of transportation and health problems in addition to challenges related to finding projects that were meaningful to the participant while also allowing for success during the allotted volunteering time (Klinedinst & Resnick, 2016). This is important to note, as challenges related to health conditions and allowance for success should be taken into account in all groups focused on volunteerism.

In another study, researchers working with youth and young adults with disabilities found participation in volunteerism increased their feelings of human capital related to coping and self-confidence, social skills, and community involvement (Lindsay, 2016). In a study with a population of youth with mental health problems, a population not unlike the population of this needs assessment, researchers had similar findings including volunteerism as a way for youth to give back to their community and relate to those around them (Leavey, 2009). Additionally, volunteerism allowed these youth to take the focus off of their own challenges and look towards helping others (Leavey, 2009).

In addition, it is noteworthy that mental health related stigma must be addressed in order to more effectively improve the quality of life of the patients at this site. Addressing these negative biases and stereotypes will allow for decreased stress and frustration as a result of greater understanding of the patients, their diagnoses, and their unique needs. This need for the addressing of stigma within mental health staff is supported by the literature. Thornicroft, et al. (2016) echoed this finding, explaining health-care professionals tend to report a more stigmatized view of the patients they work with than do the general public. Researchers also found these negative perspectives amongst health-care workers are often outwardly portrayed in negative emotions, such as unfriendliness and unempathetic tendencies, towards patients (Stewart, et al., 2015).

Researchers studied the efficacy of an anti-stigma program presented to high school students. A one-hour mental health anti-stigma program was presented to high school students and found to have positively affected their views in relation to those with mental health diagnoses even up to a month following the one-hour intervention (Ke, et al., 2015). This supports the need for such a program to be presented to the staff members at this site.

Intervention Implementation

Interventions implemented to improve quality of life for the patients at the state hospital included a volunteerism-based group for two of the three youth units and a narrative medicine inspired anti-stigma campaign which was disseminated to hospital staff members. In order to incorporate more of the concerns found from the needs assessment, social skill and self-care components were incorporated into the volunteerism group at the start of each session.

Youth volunteer group. The youth volunteer group titled WE CARE (Working Everyday to Create And Relate to Everyone) took place over six weeks. Twelve sessions of one

hour each were spread out over those six weeks with one session occurring on the Thursday of each week and another occurring on the Saturday of each week. Each week, the group was given a volunteer project to complete. Thursday groups started out with a social skill discussion. Saturday groups began with a self-care discussion. At the start of each group, the participants discussed how they used the previous session's skill. The weeks followed the same basic schedule (see Appendix B).

Volunteer projects included painting thank you cards for the hospital staff, making dog toys for a local shelter, and trying their hands at modified needlepoint projects to create decorations to be given to a local pay-what-you-can baby boutique. Social skills discussed included conversation skills, appropriate dressing, and resolving conflict. Self-care skills, called "healthy habits" in the group setting, included personal hygiene, sleep preparations/routines, and healthy coping. A full schedule can be found in Appendix C.

Anti-stigma campaign. In order to address the stigma issues observed in the staff towards mental illness, a narrative medicine inspired anti-stigma campaign titled, "Promoting Humanness" was created. 17 patients in the hospital were asked the following three questions: 1) What is the best thing about you? 2) What do you wish people knew about you? and 3) What is your greatest hope? Patients participated in the interviews voluntarily following an explanation of the interviewee's anonymity in addition to the purpose of the interviews and how they would be used. Interviewees expressed a desire to use their story to decrease the stigma surrounding mental illness. Interviewee's responses were de-identified and placed into a presentation alongside artwork created by Toby Allen in his collection entitled "Real Monsters" (Allen, 2019).

The presentation was then disseminated to staff members who participated in the presentation on a voluntary basis. Following the presentation, each participant was given a packet of anti-stigma resources including books and movies on mental health and illnesses, podcasts discussing mental illness, organizations supporting a decrease in stigma surrounding mental illness, and more. Participants were encouraged to fill out a personal anti-stigma plan outlining steps they would take to decrease their biases surrounding mental illness and fight stigma. See Appendix D for this resource and anti-stigma plan guide. Each staff participant was given a pre and posttest (Appendix G) in order to assess the immediate effectiveness of the anti-stigma campaign and resource.

Leadership

Due to the various mental health diagnoses represented in the volunteer group in addition to their behavior typical of youth, a directive approach to leadership was maintained throughout the six weeks. The group leader planned all group activities, prepared activities prior to the session's start when necessary for safety reasons, and provided thorough verbal instructions, visual demonstrations, and feedback as appropriate. This leadership style allowed the group to remain on task and goal-focused despite symptoms and/or general temperament that interfered with attention, focus, comprehension, and overall ability to complete group discussions, activities, and projects. Towards the end of the group, leadership style was, at times, transitioned to a more facilitative style. While the group leader continued to provide group projects, some more advanced participants began assisting their peers with projects they understood well. The group leader's patience, even temperament, encouragement, and determination to empower participants and see them succeed were all key to creating and maintaining this group. These

leadership skills were present at the start of the group, however developed, strengthened, and matured over the overall course of the group.

Staff Development

Both the program development and advocacy interventions address staff development. Firstly, the program development portion in the form of an occupation-based group for the youth allowed staff who assisted with the sessions and/or works with the youth daily to see the creation, implementation, and outcomes of an occupation based group. This allowed the staff to open their minds to new programming concepts which were not in the forefronts of their minds do to the absence of occupational therapy in their specific hospital. Additionally, this opened their eyes to the value of meaningful occupation as a form of therapy and mode to recovery in tandem with the rest of their skilled care.

Additionally, the advocacy intervention, in the form of a narrative medicine based mental health anti-stigma campaign, promoted staff development in various critical ways. Firstly, the presentation of this campaign, in addition to the eventual use of resources given as a part of the campaign, was designed to increase empathy and understanding of the people they work with daily. Secondly, this campaign empowered them to create a personalized plan to decrease negative biases they may have, whether in their daily lives or which interfere with their work. Lastly, this program allowed staff to discuss the challenges of mental health stigma, specifically in their work, and collaborate with each other to increase the quality of life of those whom they work with on a daily basis through advocacy them.

Discontinuation and Outcomes

Continuous quality improvement. The concepts of continuous quality improvement (CQI) were incorporated into the program development for the youth volunteerism group

primarily through verbal feedback. CQI began at the start of the development process via a thorough needs assessment completed to gain a more thorough understanding of the needs of the population being served. The needs assessment was completed by several professionals from a variety of disciplines in order to incorporate a multidisciplinary viewpoint in order to develop a program that met the needs of the patients as holistically as possible.

Following the start of the youth volunteerism group, each session allowed for natural feedback in reference to progress towards group goals. For example, each session the group members would discuss how they were or were not able to implement the previous session's social skill of the week or healthy habit of the week. After hearing this feedback, future sessions were adjusted based upon the participants' demonstrated abilities to comprehend and implement concepts. Additionally, recreational therapists, the head of the rehabilitation department, and psychiatric technicians were also in attendance in various volunteer group sessions. This allowed for observation of how they assisted different participants based upon their extensive prior work with each individual patient. Verbal feedback was also always welcomed, and, on occasion, given by recreational therapists consistently involved in the group.

Overall, this CQI process allowed for achievement of group goals (Appendix E) as well as a higher quality of group sessions which allowed participants to express themselves, learn new leisure skills, interact socially, learn positive coping skills, and gain a greater sense of connection to their community.

Youth programming. The youth volunteer group took place over six weeks with sessions taking place twice a week for a total of 12 sessions. The group had 8 total participants with an average of 3 attending each session. Due to many participants struggling with transitions secondary to various psychiatric diagnoses, the discontinuation of group was discussed starting

at the eighth session. This allowed for the participants to prepare mentally for the discontinuation of the group. Additionally, this allowed for participants who had inconsistent attendance to be aware of the groups impending conclusion. During the start of the final session, group members were shown pictures of their volunteer projects being delivered and/or used in their respective community settings. This allowed for them to see their contributions in a more concrete manner. This sparked discussion regarding what organizations they would like to continue helping or start volunteering with in the future upon discharge.

All four goals outlined in Appendix E were met at the expected level (GAS 0). The majority of patients in attendance implemented four out of six total social skills discussed during the six Thursday groups. Additionally, the majority of patients in attendance implemented three out of five total healthy habits of the week focused on self-care. The implementation of these skills was demonstrated via each participant discussing a concrete example of when, in the previous days, they had used the skill(s).

All group participants who had not been discharged prior to the completion of the group verbalized a desire to incorporate at least one leisure skill learned through the various volunteer projects into their daily lives in the future and/or upon discharge. Furthermore, all group participants who had not been discharged prior to the completion of the group verbalized a desire to work further via volunteering with at least one of the community organizations supported by the group's projects.

Anti-stigma campaign. The mental health anti-stigma campaign was presented to staff on five separate occasions over the course of two weeks, with staff making additional requests for the presenter to return to the site for additional trainings and present at events outside the site. A total of 40 staff members of various professions attended the sessions. The presentation was

narrative medicine focused incorporating de-identified patient interview responses to questions regarding their hopes and life goals, artwork which personalizes and de-stigmatizes several psychiatric diagnoses, and a resource including books, short stories, artwork, television shows, movies, and organizations which aim to accurately portray mental illnesses and decrease stigma surrounding various mental health concerns. Prior to the conclusion of the presentation, each participant was encouraged to fill out a personal anti-stigma plan outlining how they plan to continue their personal involvement in decreasing stigma. See Appendix D.

Goal 1 outlined in Appendix F was met at the expected level of outcome (GAS 0), Goal 2 was met at a somewhat less than expected level of outcome (GAS -1), and Goal 3 was met at a somewhat more than expected level (GAS +1). This means that following attendance at the presentation, there was an average of a 0.45 point change on a 10 point Likert scale regarding ability to understand and empathize with patients. Additionally, staff in attendance identified an average of 1.35 mindsets/biases they wanted to improve and created an action plan with an average of 2.58 ways they planned to work to increase their empathy.

Response to Societal Needs

Community involvement. Participants were exposed to a variety of community organizations throughout the group. These organizations included a hospital, homeless shelter, animal shelter, adult day center, and a local pay-what-you-can baby boutique for mother's lacking resources. These organizations were all local, allowing for participants to gain a stronger sense of connection to their community. Volunteerism generally has been found to increase sense of community connection (Lindsay, 2016; Leavey, 2009). Additionally, this community involvement allows participants to focus on others rather than themselves (Leavey, 2009).

These concepts were brought up throughout the previously discussed needs assessment. Several staff members from a variety of disciplines noted greater community participation would benefit the youth at this site. By incorporating regular discussion and service related to outside community organizations, that mission was accomplished.

Positive Coping. Regardless of mental health status, every individual needs coping skills in order to handle life's stresses and struggles. It is especially important for these coping skills to be positive, as opposed to maladaptive behaviors such as using drugs, drinking alcohol, self-harming, or problematic internet use (Lee, Chung, Song, Lee, Kim, Shin,...Kim, 2018). Often times, these maladaptive coping mechanisms are seen in people admitted to psychiatric hospitals (Lee, et al., 2018; Hare, 2017). It is especially important to foster positive coping skills for youth in this setting.

Volunteerism has been shown to act as a positive way to cope with various life challenges (Lindsay, 2016). This concept was discussed intermittently throughout the group, and participants were receptive to the concepts. One participant who was often quiet during session discussion spontaneously discussed wanting to help organizations such as homeless shelters prior to the group discussing a homeless shelter as one of the group's community partners.

Decreasing stigma. There is a societal need for a decrease in stigma regarding mental illness and those who live with mental health conditions. This stigma hurts both the people who are being stigmatized as well as those who hold these hurtful thoughts. Most clearly, people who are stigmatized are often treated as lesser, looked down on, and not given as many opportunities. Additionally, society, who drives these negative thoughts, in turn misses out on bright, innovative, fun, loving, passionate people and their unique and necessary ideas.

Researchers have found that even, and especially, hospital staff holds stigma towards people living with mental illness (Thornicroft, et al., 2016). This can, and does, affect their medical care and quality of life. In addition, stigma can actually decrease a person's willingness to seek help for their condition in the first place (Corrigan, 2004), causing a potential decrease in safety of the person with the mental illness in addition to those around them.

The creation and dissemination of an anti-stigma campaign regarding mental illness addressed this societal need within the hospital setting. The anti-stigma campaign, which can be disseminated continuously after the completion of the initial presentation, consists of a presentation and a resource. This program is sustainable in two ways: 1) The presentation and resources will be given to the site to disseminate as they see fit to staff throughout the future and 2) The resource given to each participant allows them to continue increasing their understanding and empathy even after the one hour presentation.

Overall Learning

Communication with patients. Communication with patients was critical throughout this process. This process began prior to the initial needs assessment through observation of and participation in various groups in which the youth were already regularly participating. This communication allowed for the group leader to build rapport and implement therapeutic use of self prior to the initiation of the volunteerism group and anti-stigma campaign interviews. This process continued more formally in the form of a needs assessment which involved interviews with patients. This communication allowed for the group developer to get a better understanding of the goals and desires of the potential participants as well as helped the future participants feel more involved in the planning process. A sense of ownership in the group's concepts fostered a stronger desire to attend and participate in groups. Communication with participants continued

on throughout the group and following its discontinuation due to a therapeutic relationship having been formed and grown.

Additionally, further patient communication was sought out for the creation of the narrative medicine based anti-stigma campaign. Patients were given the opportunity to share some of their story, hopes, and goals with staff in a non-threatening manner in the form of de-identified interview responses. This communication was also enhanced by therapeutic use of self. Participants were generally, though not exclusively, more inclined to share details of their lives with the interviewer when they had encountered the interviewer in previous, less formal settings.

Communication with families. Communication with families occurred on a semi-regular basis during monthly treatment team meetings. These typically occurred with the group participants' family phoned in to the meeting via a conference call. These communications were brief, but informative. The group developer/leader gave a description of the group and its objectives and then reviewed their child's attendance and participation in the group. The group leader then made sure to end on a positive note to encourage the families. These positives included instances when their child assisting another participant, unprompted, who was struggling with the project or when their child said something insightful during group discussion.

Communication with health professionals. Communication with health professionals occurred continuously throughout the program development and advocacy process. Communication occurred informally on a daily basis as well as formally via the aforementioned needs assessment. Communication most frequently occurred with recreational therapists as they allowed the group to take place under their program model and schedule. Recreational therapists and behavioral health recovery attendants attended groups and assisted as needed. Regular and

frequent communication occurred with various professionals including psychiatrists, psychologists, dieticians, pharmacists, social workers, and nursing staff during staff meetings and treatment team meetings. All staff communication aided in the development and modification of group goals and modifications as well as patient updates.

Communication with community organizations. Communication with community organizations occurred prior to delivery of projects in some cases and at the time of delivery in all instances. All community organizations were eager to accept the donated projects and gift them to the people or animals they serve. Community organizations were informed that a local group of youth handmade all projects and learned about their organizations. The volunteers and employees at the organizations were visibly grateful for the projects delivered to them and verbalized an eagerness to see those they serve enjoying the gifts.

Since the participants themselves could not personally deliver the projects, community organizations and/or those they serve who were willing were photographed with the projects to show the group participants. This allowed for community organizations to show their thankfulness to those who made the projects as well as allowed the participants to see more concretely the impact they had on their local community.

Leadership and advocacy. Throughout this process, leadership has been demonstrated most directly throughout youth program development and implementation. As noted in the previous section on leadership, a directive approach was maintained throughout the majority of the sessions which transitioned into a mix of directive and facilitative depending upon those who were in attendance during a particular session.

Leadership was also demonstrated throughout the advocacy portion of this process. Leadership skills including initiative and self-directed behaviors were used to compile

information for the anti-stigma campaign from the patients as well as from various resources. A facilitative approach was used when presenting the anti-stigma campaign to the staff in addition to facilitating discussion surrounding anti-stigma plans and staff's thoughts related to mental health stigma.

Advocacy was woven throughout both the program development and implementation as well as the creation of the anti-stigma campaign. Advocacy during program development was perhaps demonstrated most clearly in including potential participants in the needs assessment process. This showed both the patients and the staff members that the patients' opinions and goals were critical in developing their new program. Establishing this concept is essential to promoting the humanness of each individual being served by the hospital staff. Advocacy for each individual was noted in the program developer going to each treatment team and advocating for the participation of each individual referred to the group.

In addition to advocacy in program development, advocacy can clearly be seen in every step of the anti-stigma campaign development. This campaign was created, in and of itself, to advocate for patients. This campaign was designed to promote seeing the humanness in each individual regardless of background, behavior, or diagnosis. By incorporating a discussion explicitly discussing stigma regarding mental illness into the workplace, a more open, and hopefully kinder, environment was demonstrated and put into action for the benefit of everyone involved.

Promoting Humanness through Occupational Therapy

Throughout this entire process outlined above, advocacy for others has taken place via the promotion of humanness through occupational therapy. Occupational therapy allows people to be themselves in as unhindered a manner as possible. Participation in meaningful occupations

promotes the humanness in everyone. Through the volunteerism group for youth as well as the presenting of the narrative medicine based anti-stigma campaign regarding mental health, this message was clearly communicated to all involved as well as all observers of the process.

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Appendix A

Youth Needs Assessment

Thank you for taking the time to help make an occupation-based program that best fits the needs of the patients here at LCH. Please put an X next to any of the occupations (daily tasks) you notice come as a challenge to the patients with which you work. Feel free to elaborate if you feel that would be beneficial...more detail is great! Following the completion of the checklist, please fill in the three blanks with the top three tasks on the list you feel most need to be addressed. Again, thank you for your help!

Activities of Daily Living (ADLs)

- ☐ Bathing/showering
- ☐ Grooming (brushing teeth, fixing hair, etc.)
- ☐ Functional mobility (making their way from one place to another)
- ☐ Dressing
- ☐ Other: _____

Instrumental Activities of Daily Living (IADLs)

- ☐ Safety and emergency maintenance
- ☐ Health management and maintenance (including coping skills)
- ☐ Other: _____

Rest/Sleep

- ☐ Rest (relaxation, coping skills, etc.)
- ☐ Sleep preparation (bedtime routines, etc.)
- ☐ Sleep participation
- ☐ Other: _____

Education/Work

- ☐ Formal education participation (school day, homework)
- ☐ Informal education participation (instruction/training in other identified areas of interest)
- ☐ Volunteer participation (including awareness of the needs of others and a desire to help others)
- ☐ Other: _____

Play/Leisure

- ☐ Play/leisure exploration (identifying interests)
- ☐ Play/leisure participation
- ☐ Other: _____

Social Participation

- ☐ Within the community
- ☐ Within the family

- ð With peers/friends
- ð Other: _____

Top Needs to be Addressed:

- 1) _____
- 2) _____
- 3) _____

Additional Comments:

Appendix B

WE CARE General Session Outline

Thursday Sessions

- Warm Up: Healthy Habit of the Week Review (if applicable)
- Social Skill of the Week Introduction and Discussion/Activity
- Introduction of Project and Supported Community Organization
- Project Work
- Wrap Up: Social Skill of the Week Challenge, Questions

Saturday Sessions

- Warm Up: Social Skill of the Week Review
- Healthy Habit of the Week Introduction and Discussion/Activity
- Review of Project and Community Organization
- Project Work
- Wrap Up: Health Habit of the Week Challenge, Questions

Appendix C

WE CARE Schedule and Contents

Week 1: Painting/Bubble Painting Thank You Cards for Hospital Staff

- Session 1
 - Social Skill of the Week: Conversation Skills
- Session 2
 - Healthy Habit of the Week: Personal Hygiene

Week 2: No-Sew Sock Bunnies for Local Women and Children's Homeless Shelter

- Session 3
 - Social Skill of the Week: Personal Space/Boundaries
- Session 4
 - Healthy Habit of the Week: Sleep Preparation/Routines

Week 3: Homemade Braided Dog Toys for Local Animal Shelter

- Session 5
 - Social Skill of the Week: Appropriate Dressing
- Session 6
 - Healthy Habit of the Week: Healthy Coping and Volunteering as a Coping Skill

Week 4: No-Sew Heart Pillows for Local Adult Day Center

- Session 7
 - Social Skill of the Week: Appropriate Asking
- Session 8
 - Healthy Habit of the Week: Table Manners

Week 5 & 6: Needlepoint Decorations for Local Pay-What-You-Can Baby Boutique

- Session 9
 - Social Skill of the Week: Resolving Conflict
- Session 10
 - Healthy Habit of the Week: Healthy Snacking
- Session 11
 - Social Skill of the Week: Active Listening
- Session 12
 - Group Review and Wrap-Up

Resources

Promoting Humanness An Anti-Stigma Campaign



istockphoto.com

How can I help?

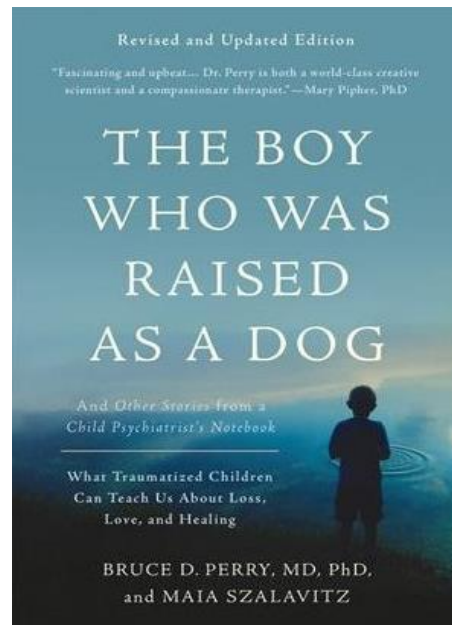
Now that you're fired up about **promoting the humanness of all people** regardless of background, behavior, or diagnosis, you're on the right track to helping end the stigma surrounding mental health diagnoses. Seeing people with mental health diagnoses as just that - *people* - is just the beginning. But how do you keep this momentum going? I'm glad you asked! Here are some resources that may help you in your quest to end the stigma.

Books and Short Stories about People Living With Mental Health Diagnoses

Books

- **Girl, Interrupted** by Susanna Kaysen
 - Mental Health Topics: borderline personality disorder, psychiatric hospital
- **All the Bright Places** by Jennifer Niven
 - Mental Health Topics: bipolar disorder, suicide, peer support
- **Turtles All the Way Down** by John Green
 - Mental Health Topics: anxiety, OCD
- **It's Kind of a Funny Story** by Ned Vizzini
 - Mental Health Topics: major depressive disorder, insomnia, psychiatric hospital
- **Under Rose-Tainted Skies** by Louise Gornall
 - Mental Health Topics: Agoraphobia, OCD, peer and family support
- **Made You Up** by Francesca Zappia
 - Mental Health Topics: schizophrenia, peer support
- **A Child Called It** by Dave Pelzer
 - Mental Health Topics: child abuse, recovery, resilience
- **Perks of Being a Wallflower** by Stephen Chbosky
 - Mental Health Topics: PTSD, anxiety, depression
- **One Flew Over the Cuckoo's Nest** by Ken Kesey
 - Mental Health Topics: various mental illnesses, psychiatric hospital
- **Speak** by Laurie Anderson
 - Mental Health Topics: sexual assault/rape, depression, seeking help
- **An Unquiet Mind** by Kay Jamison
 - Mental Health Topics: bipolar disorder, mood disorders
- **Brain on Fire** by Susannah Cahalan
 - Mental Health Topics: anti-NMDA receptor encephalitis (autoimmune disease which attacks the brain)
- **The Bell Jar** by Sylvia Plath
 - Mental Health Topics: schizophrenia, ECT

- **A Million Little Pieces** by James Frey
 - Mental Health Topics: addiction, recovery
 - **The Reason I Jump** by Naoki Higashida
 - Mental Health Topics: Autism spectrum disorder, empathy
 - **The Boy Who Was Raised as a Dog** by Bruce D. Perry (MD, PhD) and Maia Szalavitz
 - Mental Health Topics: Childhood trauma, PTSD, ADHD, depression
- Find more at: [goodreads.com/list/tag/mental-illness](https://www.goodreads.com/list/tag/mental-illness) **and** [bookriot.com/2018/10/02/ya-books-about-mental-illness/](https://www.bookriot.com/2018/10/02/ya-books-about-mental-illness/)



Short Stories

- **The Yellow Wallpaper** by Charlotte Perkins Gilman
 - Mental Health Topics: depression, anxiety, stigma/lack of understanding
- **The Tell-Tale Heart** by Edgar Allan Poe
 - Mental Health Topics: schizophrenia, paranoia
- **Jumper Down** by Don Shea
 - Mental Health Topics: suicide, empathy
- **The Man Who Did Not Smile** by Yasunari Kawabata
 - Mental Health Topics: mental illness, psychiatric hospitals, happy endings
- **Trying to Save Piggy Sneed** by John Irving
 - Mental Health Topics: intellectual disability, lack of empathy
- **A Clean, Well-Lighted Place** by Ernest Hemingway
 - Mental Health Topics: loneliness, depression, support
- Find more at: shortstoryguide.com



TV Shows, Movies, and Documentaries about Mental Illness

TV Shows

- **One Day at a Time** (Netflix)
 - Mental Health Topics: PTSD, addiction, recovery
- **This Is Us** (NBC)
 - Mental Health Topics: anxiety, addiction, recovery
- **Jane the Virgin** (Netflix)
 - Mental Health Topics: mental illness, addiction, grief, panic attacks
- **9-1-1** (Fox)
 - Mental Health Topics: mental health of a first responder
- **MOM** (CBS)
 - Mental Health Topics: family and peer support, sobriety

Movies

- **Loving Vincent** (Hulu)
 - Mental Health Topics: mental illness and compassion
- **Being Charlie** (Netflix)
 - Mental Health Topics: addiction and family support
- **The Spectacular Now** (Netflix)
 - Mental Health Topics: substance use among young adults
- **Captain Fantastic** (Amazon Prime)
 - Mental Health Topics: bipolar disorder and addiction
- **Megan Leavey** (Amazon Prime)
 - Mental Health Topics: resilience of veterans and military families
- **The Dark Horse** (Amazon Prime)
 - Mental Health Topics: bipolar disorder, family support, recovery
- **To the Bone** (Netflix)
 - Mental Health Topics: eating disorders, support, group home

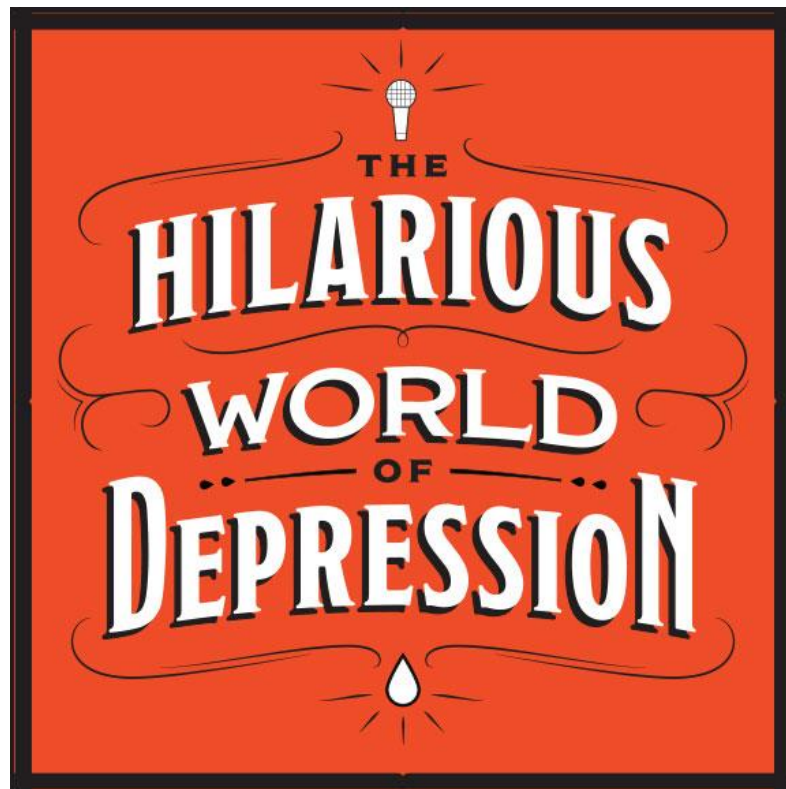
Documentaries

- **Heroin(e)** (Netflix)
 - Mental Health Topics: addiction, community support
 - **Don't Call Me Crazy** (Netflix)
 - Mental Health Topics: eating disorders, self harm, depression, psychiatric hospital
 - **Simply Complicated** (YouTube)
 - Mental Health Topics: eating disorders, suicide, depression
 - **The Anonymous People** (Netflix)
 - Mental Health: addiction, shame, recovery
- Find more at: communot.aota.org



Media Provoking Empathy and Understanding

- **Real Monsters** by Toby Allen
 - Purpose: To make mental illnesses more easily understood, decrease stigma, start a conversation about mental health
 - Website: zestydoesthings.com/realmonsters
- **The Hilarious World of Depression** Podcast
 - Purpose: To talk about depression in a de-stigmatizing and honest way
- **ADHD ReWired** Podcast
 - Purpose: To talk about ADHD and its effects on daily life in a down-to-earth and realistic way
- **MakeItOK.org** Anti-Stigma Campaign and Pledge
 - Purpose: To reduce the stigma of mental illness



Organizations to Support

- **National Alliance on Mental Illness (NAMI)**
 - Purpose: inform the public about mental illness, support those living with a mental illness
 - NAMI Greater Indianapolis
 - Address: 911 East 86th St, Suite 70, Indianapolis, IN 46240
 - Phone Number: (317) 257-7517
 - Email: info@namiindy.org
 - Website: namiindy.org
- **Mental Health America**
 - Purpose: promote mental health for all Americans, understand mental health as a “critical part of wellness,” advocate for those living with mental illnesses
 - Website: mentalhealthamerica.net
- **American Foundation for Suicide Prevention (AFSP)**
 - Purpose: inform the public about suicide, decrease stigma surrounding suicide, provide support
 - AFSP Indiana
 - Address: 14350 Mundy Dr., Suite 800-199, Noblesville, IN 46060
 - Website: afsp.org
- **Project ;**
 - Purpose: “help reduce the incidents of suicide in the world through connected community and greater access to information and resources”
 - Website: projectsemicolon.com
- **Man Therapy**
 - Purpose: “help [men] with any problem that life sends their way, something to set them straight on the realities of suicide and mental health, and in the end, a tool to help put a stop to the suicide deaths of so many of our men”
 - Website: mantherapy.org

Resources to Know and Understand



Text HELLO to 741-741

CRISIS TEXT LINE |

A free, 24/7 text line for people in crisis.

My Anti-Stigma Plan

One thing I will do **today** to increase my understanding of lived experiences of people who have mental health diagnoses:

1. _____

Two things I will do **this week** to increase my understanding of lived experiences of people who have mental health diagnoses:

1. _____

2. _____

Two things I will do **this year** to increase my understanding of lived experiences of people who have mental health diagnoses:

1. _____

2. _____

My #1 Anti-Stigma Goal for 2019

Appendix E

	Goal 1: Participants will increase their understanding and use of appropriate social skills as evidenced by participant reporting (with specific example) use of “Social Skill of the Week” during at least 4/6 weeks (majority of entire eligible group).	Goal 2: Participants will increase their understanding and use of age appropriate hygiene and grooming as evidenced by participant reporting (with specific example) use of “Healthy Habit of the Week” during at least 3/5 weeks (majority of entire eligible group).	Goal 3: Participants will demonstrate an investment into community organization(s) by verbalizing an understanding and interest in a minimum of one community organization supported by the group’s projects (majority of entire eligible group).	Goal 4: Participants will participate in effective leisure exploration as evidenced by verbalizing a minimum of one new leisure interests gained through participation in the group (majority of entire eligible group).
<i>Timeline</i>	12 Group sessions between February 4 – March 15, 2019	12 Group sessions between February 4 – March 15, 2019	12 Group sessions between February 4 – March 15, 2019	12 Group sessions between February 4 – March 15, 2019
<i>Much Less than Expected (-2)</i>	Participants reported (with specific example) use of “Social Skill of the Week” during 2/6 weeks.	Participants reported (with specific example) use of “Healthy Habit of the Week” during 1/5 weeks.	Participants identified neither an understanding nor interest in 1 community organization.	Participants verbalized decreased leisure interest following the completion of the group.
<i>Somewhat Less than Expected (-1)</i>	Participants reported (with specific example) use of “Social Skill of the Week” during 3/6 weeks.	Participants reported (with specific example) use of “Healthy Habit of the Week” during 2/5 weeks.	Participants identified an understanding, but not interest, in 1 community organization.	Participants verbalized no new leisure interest following the completion of the group.
<i>Expected Level of Outcome (0)</i>	Participants reported (with specific example) use of “Social Skill of the Week” during 4/6 weeks.	Participants reported (with specific example) use of “Healthy Habit of the Week” during 3/5 weeks.	Participants identified an understanding and interest in 1 community organization.	Participants verbalized 1 new leisure interest following the completion of the group.

<i>Somewhat More than Expected (+1)</i>	Participants reported (with specific example) use of “Social Skill of the Week” during 5/6 weeks.	Participants reported (with specific example) use of “Healthy Habit of the Week” during a 4/5 weeks.	Participants identified an understanding and interest in 2 community organizations.	Participants verbalized 2 new leisure interests following the completion of the group.
<i>Much More than Expected (+2)</i>	Participants reported (with specific example) use of “Social Skill of the Week” during 6/6 weeks.	Participants reported (with specific example) use of “Healthy Habit of the Week” during 5/5 weeks.	Participants identified an understanding and interest in 3+ community organizations.	Participants verbalized 3+ new leisure interests following the completion of the group.

Appendix F

	Goal 1: Staff attending anti-stigma program will have an increased understanding of and empathy for patients they work with on a daily basis as demonstrated by a change of 1 point on a 10 point scale addressing the topic (average of all participants).	Goal 2: Staff attending anti-stigma program will have an increased understanding of biases they have towards people with various mental illnesses as evidenced by identifying a minimum of two mindsets they will work to improve (average of all participants).	Goal 3: Staff attending anti-stigma program will feel better equipped to empathize with people who have various mental illnesses as evidenced by identifying 2 ways they will work to decrease mental health related stigma (average of all participants).
<i>Timeline</i>	30 minute program between April 2 – April 12, 2019	30 minute program between April 2 – April 12, 2019	30 minute program between April 2 – April 12, 2019
<i>Much Less than Expected (-2)</i>	Participants reported a change of 0 pts on a scale determining understanding and empathy.	Participants identified 0 stigmatized or biased based mindsets they will work to improve.	Participants identified 0 ways they will work to increase their empathy.
<i>Somewhat Less than Expected (-1)</i>	Participants reported a change of 0.1-0.9 pts on a scale determining understanding and empathy.	Participants identified 0.1-1.9 stigmatized or biased based mindset they will work to improve.	Participants identified 0.1-1.9 way they will work to increase their empathy.
<i>Expected Level of Outcome (0)</i>	Participants reported a change of 1 pt on a scale determining understanding and empathy.	Participants identified 2 stigmatized or biased based mindsets they will work to improve.	Participants identified 2 ways they will work to increase their empathy.

<i>Somewhat More than Expected (+1)</i>	Participants reported a change of 1.1-1.9 pts on a scale determining understanding and empathy.	Participants identified 2.1-3.9 stigmatized or biased based mindsets they will work to improve.	Participants identified 2.1-3.9 ways they will work to increase their empathy.
<i>Much More than Expected (+2)</i>	Participants reported a change of 2+ pts on a scale determining understanding and empathy.	Participants identified 4+ stigmatized or biased based mindsets they will work to improve.	Participants identified 4+ ways they will work to increase their empathy.

Appendix G

Pre/Post Test

Promoting Humanness An Anti-Stigma Campaign

Pre-Test (please circle or write your answers)

I understand, and can empathize with, the patients I work with on daily basis.

Strongly Disagree			Neutral				Strongly Agree		
1	2	3	4	5	6	7	8	9	10

Do you feel you have negative biases related to mental health diagnoses and/or the people who have those diagnoses?

Yes

No



Post-Test (please circle or write your answers)

I understand, and can empathize with, the patients I work with on daily basis.

Strongly Disagree				Neutral		Strongly Agree			
1	2	3	4	5	6	7	8	9	10

What are two negative mindsets/biases you will seek to improve upon in the coming weeks? (No judgement here!)

1. _____
2. _____

Please name at least two ways you will work to decrease your negative biases/increase your ability to be empathetic. (This can be from your Anti-Stigma Plan).

1. _____
2. _____
3. _____
4. _____

