

Raising Mental Health Literacy

Introduction:

In the United States we may be more familiar with the concept of mental health advocacy groups working to reduce the *stigma* attached to mental health problems and illnesses. In Australia, and other countries that have implemented early intervention programs, the phraseology used is *mental health literacy*. So what is the difference and why might this difference be making a difference in changing people's attitudes?

Let's begin with definitions. Mental health literacy derives from the concept of "health literacy" which has been defined as the ability to gain access to, understand, and use information in ways that promote and maintain good health. An Australian psychiatrist, Anthony Jorm, coined the phrase mental health literacy in 1997 and used it to refer to knowledge and beliefs about mental disorders that aid in their recognition, management, or prevention. According to Jorm, "mental health literacy includes the ability to recognize specific disorders; knowledge of how to seek mental health information; knowledge of risk factors and causes, knowledge of self treatment and/or professional help available; and attitudes that promote recognition and appropriate help-seeking."

In some respects this is a different concept than "stigma-busting". To start with, stigma has been defined as a mark of shameful difference or a personal attribute that is deeply discrediting. Therefore, "stigma-busting", in regards to mental illness, attempts to take action to rid our culture and communities of messages and images that label and characterize individuals with a diagnosis of mental illness in a negative, inaccurate, or discriminatory manner. As one can imagine, "stigma-busting" can be personalized and thus carry an angry edge to its message. Although some stigmatizing images are blatantly discriminatory, others are a product of ignorance or insensitivity.

Although both methods function to educate the public about mental health problems and illnesses – raising mental health literacy is pro-active, whereas "stigma-busting" is reactive. In addition, strategies to raise mental health literacy do not get "personalized". These campaigns strictly work to raise awareness so that people can identify problems and get the help they need. The following brief report highlights two examples of early intervention campaigns that use the strategy of raising mental health literacy – and demonstrate effectiveness.

It is important to note that at this time, the US is lacking any empirical research evidence to show that certain mental health literacy campaigns have been effective. Just at the beginning of September, 2001 – NIH hosted an international conference to discuss how the international research community should empirically study how to raise mental health literacy effectively. NIH stressed this because the stigma attached to mental health problems and disorders leads to an extraordinary economic burden. In fact, depression alone is ranked second only to heart disease in magnitude of disease burden in established market economics. Among mental illnesses in general, schizophrenia ranks second in magnitude of disease burden next to unipolar depression. Thus it makes clear sense that something significant must be done in order to raise

mental health literacy and finds effective ways to educate the American public. In light of this evidence, let's take a look at what other countries have done that has been effective.

A Message That Works – Physical Health/Mental Health Connection – Evidence of Effectiveness:

TIPS –

Jorm argues in his 1997 article, that attempts to raise mental health literacy must be made to the public – but particularly made to the healthcare system. The strategy is a form of health promotion which researchers argue is the most effective when incorporating multi-level strategies including individuals, families, neighborhoods, schools, work places, and communities in addition to including use of the media (Green and Kreuter, 1991 and Redman et al., 1990). Health promotion studies show that effective strategies include both the use of the media as well as community awareness raising. Relying on just the media or just community education is simply not as effective. In short, the strategy must be one with multiple access points, i.e. through the media, health services, schools, and the work place (US Department of Health and Human Services, 1994). For the researchers who designed the TIPS education and awareness campaign, their methods of reducing the stigma of mental illness was to completely bombard targeted groups with multiple different tactics. As we will see, this aggressive approach proved effective.

The study began on January 1, 1997 in the Norwegian town of Rogaland. This community has a population of roughly 370,000 inhabitants, among who 95% Caucasian, 60% are urban living, and 30% are educated beyond the 13 years of obligatory public schooling (Johannessen et al., in press). This is the site that would receive the elaborate education campaign efforts aimed at raising mental health literacy. General target populations include the public (patients, families, and friends), health care professionals, and schools (teachers, counselors, and students). The goal of the information campaign is to inform about mental disorders in general and the early signs of serious psychiatric disorders in particular. The program tries to change the help-seeking behaviors of the population. The focus is on the positive outcomes of receiving help and possible recovery. Researchers felt that the message of recovery would be a strong tactic to reduce the stigma connected to both mental disorders and the profession of psychiatry. The campaign also stresses the importance of treatment for psychiatric disorders as being just as important as treatment for somatic disorders. The following are the specific tactics designed to target particular populations in Rogaland County.

The General Population: In January of 1997 all households received a 12-page brochure with general information about the TIPS project. The program's motto read: "Psychiatric disorders have at least one thing in common with other disorders; the chance of getting well is better when treatment is started as soon as possible"(Johannessen et al., 14:in press). This message is directed at fighting the stigma of mental disorders that states that mental illness cannot be equated to the legitimacy of other somatic illnesses or disorders. This is the same strategy used in many of the national programs we have had here in the US. Included in the brochure was general information on psychiatric disorders and psychosis with a symptom checklist signifying grades of severity, and how to contact the detection team. The detection team is the TIPS project's mobile outreach service. This service is also part of the larger research question that is examining

effective methods of getting people who are symptomatic into early treatment. For our purposes we will focus on how the detection team also performs duties of community education. For example, they are the group of individuals who outreach to community members in local forums. Members of the detection team include psychiatrists, psychologists, psychiatric nurses and social workers.

Information was further dispersed through the local mass media (radio, TV, and newspapers). This included free editorial coverage as well as paid advertisements and other public relations strategies such as playing dramatic informational shorts before the screening of films at the local movie house. A marketing company distributed items like postcards, car stickers, and T-shirts at movie theatres, restaurants, and other popular public gatherings eight times over a two-year period. Public meetings were held on a regular basis – including free lectures. Additional tactics include educational booklets issued in co-operation with a publishing company that specializes in psychiatric literature. A theme series of “myth and reality” whole-page newspaper advertisements that attacked stigmatizing images of mental illness, such as images from the movie “One Flew Over The Cuckoo’s Nest” ran over the two-year course. In this case the stigmatizing image is counterpoised to a non-frightening or realistic image of individuals with mental disorders such as a young person meeting with her psychiatrist or images of members of the detection team working in the community.

Health Professionals: This target population was especially trained by educational programs tailored for general practitioners, psychiatric nurses and other professionals that worked in the general health system. The reason for this is because individuals suffering from psychiatric symptoms often see their general physician initially, and unfortunately GPs often do not make the right diagnosis promptly or do not refer the patient for psychiatric assessment. Other researchers have argued that one of the reasons for this is because GPs often do not want to stigmatized their client by giving them the “label” of a mental disorder unless the patient is nearing the crisis level, particularly if the diagnosis is schizophrenia (McGlashan, in press). TIPS researchers decided that it was very important that these professionals be educated at detecting mental disorders. In addition, these professionals were also educated about mental disorders within the recovery model. Open discussions were encouraged as part of the 3-4 hour training seminar for the above groups. The GPs remained updated with “newsletter updates” throughout the years as well as any preliminary results about the study. These efforts were made to illustrate that healthcare, whether it is for somatic or mental disorders, is all part of the same service community.

Schools: All High Schools were visited 2 times per semester (4 times per year) by the Detection Team. Separate educational programs were designed for students, teachers, and counselors, with counselors receiving the most amount of training. They supplied the educational materials to the schools that consisted of a movie, overheads and brochures. The key to TIPS success, researchers believe, is the way in which public relation efforts were coordinated. For example, a full-page ad in the local paper was addressed just to secondary school aged kids and noted that they would be learning about the “school of life”(referring to the tough mental health issues that life consists of) at school in the next week, and they did. Information enhanced one another through different mediums at similar times. For example, one ad pictured a prestigious school official, stressing the importance of early detection. That same day of the newspaper ad, all

pupils received a brochure that detailed the warning signs of psychosis and mental disorders. The brochure then offered the TIPS number for advice, more information, or help. The same ad and brochure still-photos ran before movies in the next few weeks. Overall, this tactic works to continuously repeat the same message in a number of different of places but all within a matter of a few days or weeks – effectively bombarding the target population with information.

Results: Was Stigma Reduced?

In order to measure the effectiveness of their efforts, researchers conducted opinion polls that measured public attitudes and opinions about mental disorders and the professions of psychiatry and psychology. Polls were conducted in the experimental site, Rogaland, as well as two other Norwegian counties (Oslo and Telemark) for comparison in 1996, before any education or anti-stigma efforts were executed. The results were similar for all three Norwegian counties. Polls were later conducted in 1998, 1999, and 2000 after the launching the educational campaign in Rogaland in 1997. In 1996, roughly two-thirds of respondents stated they had some knowledge about schizophrenia but after 3 years of the campaign, the proportion of people with knowledge about psychosis and severe psychiatric disorder rose to nearly 90% (Johannessen et al., 18: in press). Respondents noted that their primary sources of knowledge about schizophrenia and mental disorders came from media sources such as newspapers, radio, and TV. This is why the TIPS project invested heavy financial resources in this area. Several questions in the poll addressed stigmatizing and negative attitudes, illustrating that education reduced stigmatizing attitudes significantly three years later. For example, there was a 20% reduction in those who believed that recovery was not at all possible with schizophrenia and there was a 10% increase in those who think that schizophrenia is treatable (Johannessen et al., 19:in press). Other notable changes made in the public's attitude include an increase in recognizing that severe mental disorders are not the fault of the individual. For example, in 1996, 66% of respondents felt that the individual was not at fault for the disorder but by 2000, 76% felt this way (Johannessen et al., in press).

A second major area of concern that researchers were hoping to change was the help-seeking patterns of individuals in order to assure that treatment is made available as soon as possible. In the early segment of the study thus far, many calls to the DT were anonymous and this pattern fell off dramatically throughout the three years. Researchers conclude that the lack of wishing to remain anonymous was the result of effective tactics to reduce the stigma of seeking treatment for psychiatric disorders (Larsen et al., 2000). Another significant finding was an increase in the number of referrals that the DT received. In 1997, after less than one year of the TIPS program, there were 361 total calls to the detection team. By 1999 the number of calls had risen to 1,226 (Johannessen et al., 2000). The largest source of referrals remained GPs and others from the health care sector but this source did decrease from the 1996 rate, illustrating that referrals sources were broadening throughout the target populations.

Summary: Important Strategies to Remember –

The TIPS project highlights some effective strategies to raise mental health literacy that can be adapted at the national, state, or even local level. **First, the campaign's message makes more than one statement. It states that mental illnesses or disorders are just as important as somatic illnesses; hence seeking early treatment enhances recovery.** With this message the target groups learn that receiving treatment for mental disorders is not inferior to seeking

treatment for somatic illnesses, recovery is possible, and treatment should be sought because it is effective. This message dispels one of the strongest held beliefs about mental illness, that is, that there are no effective treatments or positive outcomes. Although campaigns that are currently underway in the US also stress the equality between mental illness and somatic illness – the focus is different. Some US campaigns, such as NAMI’s current Campaign to End Discrimination, focus on qualifying mental disorders as somatic disorders in order to gain equal legitimacy and thus reduce stigma. **Although TIPS also stresses the equal importance of mental illness and somatic illness, there is no mentioning of biological aspects or processes in the educational material that discusses mental disorders.** Instead posters make a statement such as “psychiatric disorders have at least one thing in common with other diseases – the chance for a good cure is better when treatment is started as soon as possible.” Another example of a poster statement is “psychiatric disorders are like other diseases; it is easier to help if you have knowledge about the symptoms.” It is evident from these examples that qualifying a mental disorder as a biological process is not necessary in order to make it equal to a somatic disorders. This is a tactic that might work more effectively than educational campaigns that just focus on teaching psychiatric conceptualizations of different mental disorders.

In addition, the TIPS campaign message also makes a strong argument for seeking early treatment. Currently the mental health community is trying hard to advocate for early detection. TIPS message encourages this by stating that there is no reason why a person with symptoms of a mental disorder should wait until a crisis occurs to seek help. People with infections do not wait to seek treatment until they have gangrene, why should a symptomatic person wait until they are suicidal to seek help for their condition.

A second important strategy that seems to be a key to this project’s success is the combination of community outreach in conjunction with media exposure. Now it is one thing for target populations to be exposed to messages that raise mental health literacy through media sources, but for the message to be fully explained through lectures or forums in the workplace and classroom has a different effect. As the research shows, most people learn about mental disorders from media sources, but many populations in this study received more than just media information. The advertisements were followed up by lectures and seminars to target audiences, solidifying the message. What can be learned from this is that the general public can be reached through media venues and then target audiences can be sought through community education that is more aggressive. For example, if an area is having a “NIBMY-problem” the community outreach should take place in at local churches, parks, workplaces, or even town meetings. The same message these folks see in the media should be what they hear from lectures or see on posters in the bus station. The key is repetition among many different forums.

PEPP – London, Ontario

PEPP is a community-based treatment program for first-episode patients and their families. Information about PEPP is distributed through a public awareness model that uses an additional tactic of not labeling a “psychotic episode” as a long-term condition. The main objective of PEPP is to provide early assessment and phase specific treatment of psychotic disorders in individuals who have either never been treated before or have received no more than one month of total treatment. The strategy here is to keep the patient who seeks help or treatment from being

labeled a “mental patient”. The idea is that treatment will be sought because an adolescent, his or her family, or even referring general practitioners will be more willing to accept that treatment is being sought for an “episode” rather than a debilitating disease. The stigma is not attached to the individual seeking treatment.

The PEPP program has released some preliminary results after two years of being up and running. Early case detection is similar to TIPS but certainly not as extensive. The catchment area of London, Ontario ranges around a population of 390,000 and is mostly urban. When the program began back in 1997, funding was limited to only \$5000 and pamphlets and information about PEPP were disseminated to family physicians and other health care workers until further and more extensive funding could be acquired. By February of 2000 enough funds had been established, (about 25 to 30 thousand dollars), to execute an assertive-community based detection phase that focused on a massive distribution of educational materials through multiple media sources, much like the TIPS project. The goal was to use as many effective methods as feasible in order to inform both the public and any other possible referral sources about the early signs of psychosis, as well as, information about PEPP and getting treatment. Additional funds were even raised by family groups that became involved with PEPP in earlier years and wanted to increase and support the future and more expansive goals of the program. Ideas on how to make the posters, pamphlets, and the messages contained within them effective were established through involving consumers (patients and their families) from the project’s conception. Over 10,000 pamphlets and posters were sent to venues such as public and university libraries, pharmacies, high school and college campuses, physician and walk-in clinics, shopping malls, churches, and all social service agency buildings. Further strategies to reach the general public include bus advertisements, press releases, interviews with local TV news programs, radio interviews, commercials, desk calendars, and a website. Funding to partake in these activities was further contributed by forging partnerships with community businesses. In addition, the PEPP team worked to establish referral sources through school-based counseling services in both high schools and colleges (Schotlen, 2000).

The assertive-outreach approach implemented in early 2000 so far has demonstrated significant improvements in the number of individuals referred to PEPP. Increases came from the non-health sector such as through community services and self/friend/or family referrals although the primary source of referrals continues to come from the inpatient hospital unit. The median DUP also decreased substantially from the 1997 length of a mean of 25.6 weeks to 12.9 weeks in 2000. Unfortunately, unlike TIPS, the PEPP program did not conduct polling data in order to evaluate if their “message” and “methods” of raising mental health literacy were effective in increasing the knowledge level of the public and healthcare community. Despite this, researchers at PEPP expressed confidence that the increases in referrals demonstrate that their campaign efforts have raised the mental health literacy level of the general public and the healthcare community. 2002 will mark a year in which one-year (2001) results from the mental health literacy campaign will be analyzed in order to evaluate the effectiveness.

Summary:

Although the US lacks it’s own form of data to illustrate which strategies are effective in increasing mental literacy – the leading national health research organization, NIH, is calling on Americans to do just that – find out what works in the US. If we wanted to adapt the TIPS or

PEPP model in order to test applicability (EPPIC in Australia is doing this currently), what kinds of challenges are we likely to face? First, and most importantly, campaign messages must be able to address the vast cultural differences we share as Californians. Different cultures not only hold different views about mental health problems – but different values about accessing care. Some may believe the proper place to seek treatment is within their place of worship or family network. This issue must be addressed with depth and commitment or the campaign is likely to fail. Second, involving the larger medical community of primary care doctors is absolutely critical, not only because most individuals are more comfortable seeking treatment from their primary doctors initially, but also because most medical insurance providers require carriers to receive a referral from their primary doctor before specialized services, such as mental health services, can be sought. Finally, there is the challenge of expense. A campaign that is 3 to 5 years in duration and practices the techniques of multiple access points and heavy repetition can be costly, up to 1 dollar per year per person. But the COMPASS project, from EPPIC, feels it can accomplish the same goal as TIPS using half as much funding. Whether this is possible remains to be seen, as COMPASS has just been launched in the summer of 2001.

Despite these obstacles – it is apparent that these strategies have been successful – thus worth a shot in California for any organization, agency, or group of interested individuals ready to meet the challenge.