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Mental Health Policy and Services in Tampa, Florida

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
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Department of Anthropology
College of Arts and Sciences
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Mental Health Services in Tampa, Florida

Shelly Yankovsky

ABSTRACT

During the summer of 2004 I interned with the Mental Health Association of Greater Tampa Bay (MHA), a local affiliate of the National Mental Health Association. My time spent with the MHA became a gateway into the world of mental health. In the course of fulfilling my duties, I developed a particular interest in understanding the services that are available to persons, especially adults seeking treatment/services for mental illness. Through the MHA I was introduced to a wide range of people who have some link to mental health services, including psychiatrists, therapists, policy makers, and lawyers. This thesis utilizes an anthropological perspective to review the mental health policies, services, and provider networks available in the Tampa Bay region.

My findings reflect the views of providers of or advocates for mental health services. This thesis is therefore presented as a necessary baseline and prelude to a more comprehensive study of consumer/client responses to the system. My data suggests that mental health services in Florida provide only a patchwork of services: there are not enough professional service providers to handle the actual patient load. Providers of mental health services who serve the uninsured are particularly overburdened. The largest barrier to providing treatment is underfunding, relative to the actual cost of services. Treatment is also impacted by the stigma attached to seeking mental health services.

Chapter One

Research Setting

The Mental Health Association of Greater Tampa Bay (MHA), a local affiliate of the National Mental Health Association was established in 1952. It is a non-profit organization whose members volunteer their time. During my internship the staff consisted of two people, three including myself. The current president has been striving to find an organization to partner with in order to build a stronger foundation for the MHA to work from. The president of the MHA works with a Social Worker at the University of South Florida. Both volunteer their time with the MHA in addition to their day jobs. Currently, the MHA does not occupy a physical space. For the duration of my internship, however, I worked out of the USF department of Psychiatry. The MHA's mission is:

“To educate, inform, dispel the stigma related to seeking assistance for mental/emotional difficulties and support improvements and advances in the area of mental health care” (MHA 2004a).

Currently, the MHA's most prominent project is the “Campaign for America's Mental Health”. This is an on-going National project with the goal of raising awareness about mental health through education. This has been done by partnering with “local healthcare providers through educational presentations, information distribution, screenings and other education/advocacy activities” (MHA 2004). During my internship with the MHA I participated and/or observed many MHA activities. In particular, I have

attended a seminar for training police officers to better recognize/understand the mentally ill while on the job. This was a week long seminar that brings in lecturers from the community to teach the class on differing topics relating to mental health/mental illness. Additionally, the officers, as part of their training also tour some of the local mental health facilities. I also participated/attended a health fair celebrating “Older American Month”. This health fair took place in Tampa at an apartment complex for older Americans. The health fair was preceded by a presentation. The presenters talked about Medicare, about Prescription Drug Discount Cards, and about the spending power of older Americans. Throughout my internship I participated in three conference calls, all of which included a phone seminar. The first conference call seminar was about aging and mental illness. The speaker was from the “Alliance for Aging Research”, and the second speaker was from the “National Council on Aging”. The second conference call seminar was about childhood depression. The speaker was a doctor from Vermont. He talked about issues surrounding children and mental illness. The third conference call seminar was about screening for mental health. This was in preparation for National Depression Screening Day which was to take place on October 7th 2004. I also attended/participated in three health fairs; the first was at the above mentioned “Older American Month” celebration. The second was at a local YMCA. There were approximately seven to nine vendors all lined up in the hallways of the YMCA. The third health fair was in Sun City Center; however, here we mostly did mental health/memory screenings. At all of the health fairs we passed out literature from the National Mental Health Association on topics pertaining to mental health/mental illness. I also attended a FACT Advisory Committee Board meeting, a Baker Act Committee Meeting, and a staff meeting at the

USF Psychiatry Dept. The FACT Advisory Committee Board meeting included ten people representing varied positions in the community. Many issues were discussed most of which revolved around the activities of the FACT (Florida Assertive Community Treatment) program. The Baker Act Committee Meeting is a monthly meeting. When I attended, there were twenty people present representing different programs and organizations that all have some involvement with persons that have been Baker Acted or could be Baker Acted (Involuntarily or Voluntary committed). These different programs and organizations all report their monthly statistics. The staff meeting at the dept of Psychiatry included approximately eight people from the department. They discussed patient presentations, histories, diagnosis, test results and brief patient biographies.

In addition to these experiences I had various duties while interning with the MHA. These included updating the Mental Health Association's web log. This log is a way for the National Mental Health Association to keep up with how the local MHA is fulfilling its proposed goal to raise awareness within the Tampa Bay community. I was also a representative for the MHA, particularly during health fairs. I assisted the organizers of the forums, lectures, workshops, etc. that the MHA presented. I communicated with the NMHA in order to place orders for necessary pamphlets, literature, etc. I also helped research the community for additional venue options. I contacted organizations that invited us to participate in health fairs, and so forth.

While I interned with the MHA of Greater Tampa Bay my anthropological goal was to familiarize myself with issues specific to mental health. This investigation combined with recent commercials, news articles and reports about mental health that are more and more common in the media today lead me to focus on mental health services in

particular. I kept thinking - how do people know where to go? How do they get connected with mental health services in the first place? As an anthropologist fieldwork was the immediate and appropriate choice to understand these questions. Fieldwork allowed me to use methods that would enable me to understand the services available in a way that originated from my experiences and would invite positive change. I could have just looked in the phonebook or the internet and compiled a list. However, this kind of research would not have allowed me to observe just how dynamic the topic of mental health is in Tampa. I wanted to know, in addition to the general workings of the MHA:

- What kinds of services are available (primarily to adults)?

To understand this question, however, I needed to “demystify” the social relations that underpin the availability of these services. To understand the current availability of services I wanted to use a political economic approach. This entailed understanding the history of mental health and mental health services particularly policy and legislation. Additionally, understanding the barriers to treatment and how this affects services.

My research methods were qualitative. I used my eyes and ears as my primary mode for data collection (LeCompte 1999:2). In addition to participant-observation, the remaining research/data was gathered through semi-structured interviews, literature reviews, public documents, pamphlets, and so forth.

Chapter Two

Research Problem

There is and has always been significant stigma surrounding the concept of mental illness. Stigma and misunderstanding play a large role in issues of mental health care. For example the National Mental Health Association (NMHA) conducted a national survey in the 1990's to see what Americans knew about clinical depression. The results were very interesting and made the case that there was widespread misunderstanding when it came to mental health.

- 51% said they or a family member had suffered from clinical depression
- 43% believed that depression was a personal weakness
- 54% did not believe that depression was a health problem
- 34% said that if they had depression, they would handle it on their own
- 60% said they knew little or nothing about clinical depression” (NMHA 2004a).

The National Mental Health Association states in one of its pamphlets that according to the Surgeon General, “one in every five Americans experiences a mental illness each year” (NMHA 2004b). This situation is linked to crime rates, as well as to higher welfare costs, direct treatment costs and lowered productivity. According to the same report, the direct costs of mental health services in the United States in 1996 totaled \$69.0 billion, and the indirect costs of mental illness were estimated in 1990 at \$78.6 billion. The Committee on Health Care for Homeless People at the Institute of Medicine

states that “The major mental illnesses, principally schizophrenia and the affective disorders (bipolar and major depressive disorders)... can cause a level of disability and impaired social functioning in some people that, in the absence of adequate treatment and support, may lead to homelessness, which will then exacerbate these conditions” (Institute of Medicine 1998:51).

Because mental illness is so prevalent and at the same time so misunderstood by the public in general, and because of its huge impact on the workforce of the U.S., I believe it is a topic worth exploring. In particular, we need to develop a greater understanding of mental health services at the local level, and how policy and legislation at the State and Federal level affect those services. Unfortunately, there is currently no directory that explicitly describes to the public what to do or where to go or what to expect when faced with a mental illness. During the course of my internship I have worked side-by-side with the Mental Health Association of Greater Tampa Bay, a local affiliate of the National Mental Health Association. It is through my involvement with the Association that I have become familiar with the issues that surround mental health and mental health services. These issues were addressed by clarifying the way the system is ideally supposed to work, particularly for adult clients. My main research questions were:

- What factors are most likely to become barriers to accessing mental health services?
- How can those factors be explained in terms of the history and current status of policy and legislation?

Through this line of questioning I hope to uncover how such problems as stigma, mental illness, treatment options, policy, and legislation interweave and overlap.

Chapter Three

Methods

My goals while interning with the Mental Health Association of Greater Tampa Bay were to gain a working understanding of the history and current status of mental health services in Tampa. I intended to explore the services available for those who suffer from a mental illness, and investigate the historical legacy and current atmosphere of mental health issues.

During the internship I worked on a project called “Campaign for America’s Mental Health.” This is an ongoing nationwide project; however, each affiliate has its own set of goals particular to the local issues which it concentrates on. The campaign’s main goal is to disseminate information regarding mental illness to the public; the local MHA in Tampa chose to do this by presenting and participating in various venues to get the message across, such as workshops, lectures, health fairs, and other informational forums. For example, at a particular health fair many vendors set up booths with their information about particular topics. While the vendors were setting up in the parking lot of an apartment complex for seniors, inside people were gathering together to listen to the speakers who had been invited to talk about elder issues. The Mayor sent a representative to speak on behalf of the city, there were people from the Tampa Housing Authority, as well as county officials. Media were present and video cameras captured the event. The event was begun by wishing happy birthday to a resident of the complex

who had turned 102 years old on this day. They awarded her a plaque and roses. The speakers talked about various topics pertaining to older American issues. They talked about the “Medicare Improvement Act”, they talked about the new Prescription Drug Discount Cards – warning the residents that there would be a lot of marketing and to take your time in considering your options. This lasted about an hour, however, about half way through I, along with the other MHA member, whom I will call Sandy, made our way out to the parking lot to set up our table. There were two rows with about 40 tables in the parking lot – It was very hot outside and luckily the table reserved for us was under a tree. The vendors there were from various places, for example there was a doctor’s office there taking people’s blood pressure, there was an ombudsman (advocate for residents of nursing homes and long-term care facilities), one table was set up with a display showing what cholesterol does to your blood vessels, and also had a replica of what five pounds of fat looks like! As the speakers ended people began to trickle outside. However, in addition to the health fair, the festivities also included a Bar-B-Q which was set up on the adjacent corner to where the health fair was located. The majority of people went to the Bar-B-Q after listening to the speakers. Most of the vendors brought things to give away. For example, they would have literature to hand out in addition to trinkets, such as pencils, pens, cups, refrigerator magnets, and so forth. The vendors appeared to have two reasons for being there, first to distribute their information and advertise, secondly, to make contacts with the other vendors. The MHA did the same, literature about different mental illnesses and ways to seek treatment were distributed and depression screenings were offered. Unfortunately, we had no trinkets to hand out, only our literature. Additionally, we had very few people come by our table; the majority of

those who did were other vendors. One of these vendors invited us to another health fair – which we did later attend. The reactions from the people when we offered them Mental Health literature when they visited our table included comments such as: “I don’t need that!” to “Oh! Let me take some of these – I have friends who could use this information”. The actual pamphlets that we had to pass out were very limited. The pamphlets provided general information such as signs and symptoms of depression, signs of depression particular to women, to African Americans, etc. They also included a phone number to the National Mental Health Association. My concern however, was that even this information was too little and was not locally oriented. After about an hour the vendors started to pack up and head over to the tent where the Bar-B-Q was being served. We did the same.

It was at events such as these that I was introduced to a wide range of people who have some link to mental health services, such as: psychiatrists, therapists, policy makers and lawyers. All of my informants were indirectly met in this fashion.

As for my research methods, I did participant-observation and observation. I kept a detailed journal of my observations and activities during my internship. I sought semi-structured interviews with informants that I met while with the MHA. These interviews have provided the bulk of my data. From my own observations I have gathered a sense of how mental health services work and from this knowledge based my questions on. The purpose of my interviews was to enable me to understand the service provider’s perspective. My research did not require any testing materials; however I did use a digital tape recorder when conducting interviews. My interviews were kept to a maximum of an hour. I was able to collect 6 interviews, three women and three men. I

only interviewed those who have knowledge relating to mental health issues. I interviewed one legislator, two psychiatrists, one social worker, an advocate, and a community educator. I have protected the privacy of my informants by using pseudonyms. I have included in the appendix my IRB application which discusses the particulars of my research. I have also included in the appendix my interview questions. The topics covered during the interviews addressed information that is already of a public nature. I focused on the structure of mental health systems and mental illness in general, not to specific case histories of people suffering from a mental illness.

My research methods were qualitative. Qualitative research “uses the researcher’s eyes and ears as the primary modes for data collection” (LeCompte and Schensul1999:2). In addition, this kind of research depends on “systematic observation in the field by interviewing and carefully recording what is seen and heard, as well as how things are done, while learning the meanings that people attribute to what they make and do” (LeCompte and Schensul 1999: 2). It is important to note that qualitative research should be done in natural settings, where the researcher does not “manipulate or create the settings or situations in which responses to interventions are solicited, obtained, or measured” (LeCompte 1999:10). It is also important to note that I was an active participant in my research. I did not simply sit on the sidelines and observe. I became an advocate and helped the MHA with their goal of raising awareness of mental health. These activities provided the bulk of my research methods. However, the remaining research/data was gathered through literature reviews, public documents, pamphlets, and so forth.

Chapter Four

Literature Review

Currently, mental illness is defined as a treatable disease – however it was not always defined as such. The National Mental Health Associations (NMHA) describes it as causing “mild to severe disturbances in thought and/or behavior, resulting in an inability to cope with life’s ordinary demands and routines”(NMHA 2004). They state that there are “more than 200 classified forms of mental illness”, such as “depression, bipolar disorder, dementia, schizophrenia and anxiety disorders” (NMHA 2004). Symptoms that are associated with these may include: “changes in mood, personality, personal habits and/or social withdrawal” (NMHA 2004). The causes of mental illnesses vary from - reactions to environmental stresses, genetic factors, biochemical imbalances, or a combination of these. They liken mental illness to diseases such as cancer or diabetes in that they “are often physical as well as emotional and psychological” (NMHA 2004). However, as I will later discuss, the accepted definitions of what mental illness is and what the appropriate treatment should be are complex issues.

Political Economy

In my attempt to understand the dynamics of mental health services I have employed a political economic approach. Political economy, as an analytic tool within anthropology has the ability to “include macroanalytic questions about the effects of

international politics and the world capitalist system” (Morgan 1984:131). In addition, it is critical and employs a historical perspective. This orientation is a way of explaining phenomena in relation to the socio-economic environment. However, historically, anthropological use of the political economy paradigm has been critiqued as relying too heavily on dependency theory (this approach focuses on the unequal relationship between developed and underdeveloped countries), and not incorporating micro-level analysis (Morgan 1984:). Lynn Morgan writes about the three predominant theoretical perspectives that are commonly used by anthropologists who look at the political economy of health. The first of these is “orthodox Marxist approaches” (Morgan 1984:131), they typically see health and its relations as directly resulting from “capitalist socioeconomic formation” (Morgan 1984:133). They tend to discuss “medical knowledge as ideology” (Morgan 1984:133), and “draw attention to the interplay between social class formation and the power of the postindustrial nation-state” (Morgan 1984:133). This perspective has been influential in understanding the “evolution of the medical-industrial complex” (Morgan 1984:133), and “aspects of doctor-patient relations” (Morgan 1984:133).

The second theory of anthropological political economists is called “cultural critiques of medicine” (Morgan 1984:131). They “argue that medicine supports and replicates the status quo by keeping women and minorities subordinate” (Morgan 1984:133). It is similar to the Orthodox Marxists’ in that they both look at individuals within “the context of unequal power relations based on gender, race, and socioeconomic status” (Morgan 1984:133). However, they are often criticized for not using terms such as “class formation” (Morgan 1984:133) to explain these inequalities (Morgan 1984:133).

The third theoretical stance is that of “dependency theories or world systems theory” (Morgan 1984:131). This perspective focuses on “the unequal relationship between developed and underdeveloped countries” (Morgan 1984:134). Disease, poverty and underdevelopment are described as being the result of “imperialism, colonialism, and capitalist penetration” (Morgan 1984:134). This approach, she says, should not be taken for granted because “there are whole sets of national and international health problems which might be better understood as interrelated problems of exploitation between core capitalist (industrialized) nations and peripheral (underdeveloped)nations” (Morgan 1984:139). However, it is this theory that many medical anthropologists have given the most attention to, and it is the overuse of this theory that is often criticized. Morgan states that dependency theorists “emphasized economic determinism over social relations” (Morgan 1984:134), they also “define capitalism by reference to the market” (Morgan 1984:139), this definition is not enough because one aspect is left out – that “production for profit via exchange can only be considered capitalist if accompanied by specific social relation, namely a system of free wage labour, where labour power is a commodity” (Morgan 1984:140). Most importantly, however, Morgan states that if “capitalism and medicine were defined within the realm of *production*, [instead of the market] a political economy of health would cease treating medicine as a commodity to be exchanged and sold through market systems...the focus would veer from econocentric models...to socially centered models that emphasize social class, the professionalization of medicine, competition between health-care providers, and the dialectic relationship between sociopolitical structure and medical systems” (Morgan 1984:141). In other words, instead of focusing so much on macro analysis, a more encompassing political

economy of health would include micro analysis as well. In addition, for a definition of capitalism to be thorough what must not be left out is that there is one segment of the population (that population which is at the mercy of those who control the means of production), “whose labor power is a commodity” (Morgan 1984:140), and provides a surplus to those in control.

In my own analysis I hope to pull from the “Orthodox Marxist approach” and the “Cultural Critiques of Medicine approach”.

Mental Health Services/Community Mental Health

Before the 1970’s people with mental illnesses were housed in state institutions and hospitals. After the 1970’s there was a shift in care for these people from institutions to the community. However, as NAMI states, “adequate funding has not followed people released from hospitals into the community. This failure produced several consequences: increased homelessness – at least 22,500 homeless Floridians have a mental illness, and increased criminalization of people with mental illness – at least 23 percent of adults in local jails suffer from mental illness. Currently, Florida has about 121 state-supported, community programs serving 54,000 Floridians with mental illness” (NAMI 2000:6). Housing in Florida is also a problem – “none of the housing alternatives is adequately or consistently available” (NAMI 2000:8). Those housing alternatives being: “supervised residential treatment facilities, supervised apartments, client-owned housing, independent living with HUD – subsidized assistance and assisted living facilities with mental health overlays” (NAMI 2000:8).

Levin et. al. state that before deinstitutionalization state hospitals provided their consumers with things such as food, clothing, education, etc. (2004:81). After deinstitutionalization people with mental illnesses had to rely on separate delivery systems in order to find housing, education and so forth. However, much of these delivery systems are funded by different places most of which are not specifically designed for the cyclic needs of those with mental illnesses (2004:81). Additionally they are driven by the demands of the bureaucracies that fund them (2004:81). Therefore Levin et. al. state that “The interaction between the design of service delivery system and their funding is important in understanding both the shortcomings and the successes of state mental health systems”(2004:81).

The Mental Health Association’s web site states that the “first point of entry for many patients with depression and anxiety disorders is the primary care setting” (The MHA of Greater Tampa Bay). However, even though they can help to detect mental illness, and do often treat their patients with prescription drugs such as Prozac, from my observations much of this treatment goes unmonitored and unlegislated. Furthermore, there are no numbers or statistics available representing those that seek mental health services from private doctors, so any picture of mental health will need to take this into consideration. Health Management Organizations (HMO’s) have been steadily growing, “...by the end of 1995, more than 60% of Americans belonged to some form of managed health care plan” (Durham 1998:495). These HMO companies could possibly have better data than other areas of the health care system, unfortunately, there are many reasons why this data is of “undocumented quality” (Durham 1998:496). First of all they tend to limit

access to their databases, and the data collected is not standardized. Additionally there is a high turnover rate of decision makers within these companies (Durham 1998: 496-497).

It is the Community Mental Health Centers (CMHC) where the uninsured public finds treatment. It is also here that much of mental health legislation has been focused and developed and because these facilities receive State and Federal funding they are required to keep statistical data in order to continue to receive funding.

The CMHC movement was first enacted into legislation during the Kennedy administration in 1963 (Kenig 1986: 96; Department of Family and Children Services 2004; 30). However, the elements which created the conditions for the enactment started much earlier. As Kenig describes: on the one hand the movement “was part of a larger revolution of social responsibility” (1986:54), and on the other it was an “extension of current professional ideology with modified goals, tactics and technologies over that part of society from which it has been hitherto alienated; [which] legitimates a two-class system of mental health treatment in this country – self-actualization for the rich, rehabilitation for the poor” (1986:54). In other words, at the time of its inception the country was feeling a moral obligation to help people, including all the patients who were being mistreated, neglected and abused within the mental health hospitals and asylums. This shift from state institutions to local mental health facilities was possible primarily because of advances in the areas of medications for the treatment of mental illness. (Department of Family and Children Services 2004: 36). With medications, the mentally ill no longer needed to be locked away. Before this advancement state hospitals were mini-cities, whose purpose was to protect the public from those with mental illness (Department of Family and Children services 2004: 36). Florida’s first civil mental

hospital was opened in 1876 in Chattahoochee, Florida (Department of Family and Children Services 2004:30). In 1946 G. Pierce Woods Hospital was opened in Arcadia, in the 1950's two other hospitals opened in MacClenny and Pembroke Pines (Department of Family and Children Services 2004:30). With the passing of the CMHC's Act in 1963 federal funding would now be available to help Florida, along with the rest of the country to develop community based systems of care (Department of Family and Children Services 2004: 30). At first, the new Federal funding flowed directly to the CMHC's, however, in 1970, "Part IV of Chapter 394, Florida Statutes, the Community Mental Health Act, was enacted to establish a methodology for the distribution of federal funds through the state agency rather than directly to the CMHC and clinics (Department of Family and Children Services 2004: 31-32). Not long after this change, funds were directed to district offices and then allocated to mental health boards through contracts, the boards then contracted for services with the community providers (Department of Family and Children Services 2004: 32). With the 1980's came the Reagan Administration and the end of Federal funding and the beginning of Medicaid and HMO's.

The CMHC movement can be described in three phases. Kenig describes Phase one as starting in the 1930's with the theory of "public health psychiatry" (1986:58). This theory borrowed themes from public health views, particularly, "individual vulnerability to illness, environmental characteristics which promoted or undercut the spread of illness, and agents of illness" (1986:60). For the most part then, it was public health advocates who were expanding on these ideas, while psychiatrists and psychologists were still working with the "legacy of the asylum" (1986:60) and

contemplating Freud (1986:60). In 1946, the “National Institute of Mental Health”(1986:61) was created. This was important since it recognized a larger service market for public health services, which had previously been focused on the military (World War II veterans), and in addition marked an increase in “federal intervention into the general service market” (1986:61). The NIMH’s first director was an advocate of the public health approach to psychiatry (1986:61). He particularly felt that services should include “prevention, outpatient services, geographically responsible care, community involvement, and rational planning” (1986:61). It is these same principles which later became important to the evolution of the CMHC movement. In 1950, all the federal organizations merged (the National Committee, the National Mental Health Foundation, and the Psychiatry Foundation) to form the “National Association for Mental Health” (1986:61). So in the 1950’s there emerged a monopoly on mental health, where a few federal administrators were writing the mental health policy and were “being supported by social science research which explored the relationship between factors and mental illness” (1986:62). Not only were they a small group, but they were also lay people and social scientists (as opposed to psychiatrists), this is important to note because they influenced the direction in which mental health services were thought about, and they influenced the direction of psychiatric theory in general. In 1955 Congress mandated a “Mental Health Study Act” (1986:63). This study suggested that “community based clinics be linked to hospitals in order to decentralize and to improve care” (1986:64). At this time the majority of the costs for mental illness treatment were being paid for by individual states (1986:64). As a result of the study, in 1963 President Kennedy sent a message to Congress supporting the NIMH’s study recommendations of community

mental health centers (1986:66). The same year it was enacted into Congress. It was called the “CMHC Act” (1986:69), and it was to be federally sponsored.

A number of important factors need to be considered at this point. First of all, psychiatric training in the 1960’s “included very little in the way of social science of “community” psychiatry since the medicalization of treatment and theory had long since become dominant in psychiatry” (1986:70). However, it was this very field that was charged with the new centers... “center directors, by law, had to be psychiatrists” (1986:70). So psychiatry had to move forward into this new orientation towards mental health or be surpassed by non-psychiatric therapists (1986:70).

The CMHC’s were required to fulfill five basic services: “in-patient care, out-patient care, emergency care, partial hospitalization, and consultation and education” (1986:71). Centers were “mandated to be geographically responsible to catchment areas, areas defined to include between 75,000 and 200,000 persons” (1986:71). In addition, they were to target special needs groups, such as: “low income areas, chronic unemployed, substandard housing, alcoholism, drug abuse, crime and delinquency, as well as ... the mentally handicapped, the aged and children” (1986:71).

In her analysis of the first phase of the CMHC movement, Kenig states that the CMHC was a “major vehicle for extending the monopoly dominated, mental health service market at State expense, in doing so, the movement was fulfilling the State functions of heightened accumulation and legitimation” (1986:72). In addition, during the 1960’s it was used as a vehicle for “urban black unrest” (1986:72), when “massive health, welfare and urban development expenditures were used as an alternative form of reaction and control” (1986:73). Monies were being poured into local programs that

were to help the poor, but in addition were seen as ““program patronage” in return for black votes” (1986:73). “CMHC monies were federal social investments which reaped privatized profits for the monopoly sector” (1986:73).

The second phase of the CMHC was marked by conflict. Civil rights, anti-war protests, counter-culture movements, feminist activity, and national liberation movements worldwide were present during this phase (1986:73). CMHC directors had to find other sources of funding during this period. Kenig states that of all the problems faced by the CMHC, many could be “traced to the clash between the promise of innovation... and the reality of traditional psychiatric care delivered in CMHC’s. Social problems were not defined as “treatable” within this psychiatric tradition” (1986:75). In addition, because the “community psychiatry” was not very popular within the discipline of psychiatry, clinics were not finding it easy to find psychiatric staff... so the demand was growing faster than the supply (1986:75). At this point in the history of the CMHC, Kenig states that the public health psychiatry faction and the other schools of psychiatry were set off against one another (1986:76). However, the State function of “accumulation for the privatized psychiatric market and legitimation for middle-class values” (1986:76) continued to be fulfilled (1986:76). Kenig states also that there was an increase in prescription drug use. “From 1961 until 1972 there was an increase of 100 percent or more in manufacturers’ sales ... including the three largest types, i.e., central nervous system drugs, anti-infectives, and the category that included contraceptives” (1986:77). Also Valium and Librium became very popular (1986:77). By 1971, the CMHC saw “rates of care episodes” rise to 15 percent (from 0 in 1960), that was over 600,000 care episodes (1986:77). Kenig states that the “CMHC’s history cannot be separated from the

history of Medicaid, Medicare, and Supplemental Security Income (SSI) legislation” (1986:77). It is here that that the shift of patients from state hospital to other sites (such as CMHC’s) began, “frequently with little care or oversight” (1986:77). Because of the tremendous “increase in federal funding and market expansion” there came “great complexity and fragmentation in the political and economic interests within the CMHC movement” (1986:78). It was during this time that the mental health market was expanding, and the division of labor became more complicated (1986:79). Kenig describes that in the early 1970’s the “CMHC’s were much more heavily dependent on non-psychiatric staff than on psychiatrists” (1986:79). These non-psychiatric staff (50%) held less than a B.A. degree (1986:79), while “psychiatrists and other M.D.s accounted jointly for slightly over 7 percent of those positions” (1986:79). For the most part, “psychiatrists were, by and large, well-paid white males. Social workers and nurses were paid considerably less, and were usually women, white or minority” (1986:79). Another important factor to consider here is what was happening in the mental health market - even though the cost of mental illness treatment had been socialized (1986:79), most of the profits were “fed back to the monopoly sector which included drug and related industries, and high paid administrators and psychiatrists” (1986:79). The federal government now had to worry about “inflation and recession” (1986:80). As a result “the change from expansion of federal expenditure, including CMHC’s, to consolidation and rationalization of expenditures amounted to a change from regulating civil disorder to regulating the increased labor market” (1986:80).

During the third phase of the community health movement, Kenig states that “accountability” (1986:80) sums up what was on everyone’s mind. There was an

extreme shift between 1955 and 1975, the number of “in-patients” went from “77 percent in the mid 1950’s to overwhelmingly out-patient, 72 percent by the 1970’s” (1986:81). She states that at this time Nixon wanted to dismantle the mental health care funding programs (1986:81). In 1971 a report was sent to Congress – “The Community Mental Health Centers Program – Improvement Needed in Management” (1986:81). This report laid out issues found within the CMHC’s. Those people who were against CMHC’s took this data as an opportunity to charge that “the programs were really attempts at State social control” (1986:82). It was in 1974, that after falling under the scrutiny of Congress that the CMHC’s had tacked onto them “increased mandatory services including services for the elderly, children, consultation to courts and to other agencies, follow-up care, and halfway houses” (1986:83). For the CMHC’s the 1970’s was a time of increased federal money for improvement. In 1971, Florida passed the Florida Mental Health Act, otherwise known as the Baker Act – this provided standards for involuntary admissions to state treatment facilities, and stressed the concept of the least restrictive environment and due process for persons being committed (Department of Family and Children Services 2004: 31).

It was during the Carter administration, however, that “the CMHC movement was brought into its final years” (Kenig 1986:85). Rosalyn Carter, the president’s wife “was appointed Honorary Chairperson of the Commission [President’s Commission on Mental Health], and her interest in mental health services was an important element in this effort” (1986:85). From her work was a new piece of federal legislation, “the Mental Health Systems Act” (1986:85). The difference between this and the CMHC’s Act was the funding, - “rather than funding direct federal funding, the Systems Act called for

turning monies back to states for distribution through individual state departments of mental health” (1986:85). In the 1980’s under the Reagan Administration the programs were all “lumped into block grants with numerous other social programs and was eventually forgotten in the rush to save whatever federal monies could be saved for such programs” (1986:85). This led to a push for alternative funding which was found in Medicaid Community Mental Health Services (Department of Family and Children Services 2004: 32). A consequence of this is that “public mental health systems and providers must piece together funding from dozens of disparate and uncoordinated funding streams, including Medicaid, Medicare, and private health insurance, federal, state, and local grants and contracts, and support from private foundations (Levin, et. al. 2004:78). Because of the piecing together of different funding sources, each of which have different restrictions and limits of reimbursements for certain services, the providers were able to drive program development and system design (Levin, et. al. 2004:79). For example, “Medicare and private insurance plans favor institution-based settings over community-based services and include significant limits on reimbursements for both inpatient and outpatient mental health care (Levin, et. al. 2004:79). This has some effect on mental health agencies ability to focus on priority services and populations (Levin, et. al. 2004:79).

Cutler, Bevilacqua, and McFarland describe 1981 to 1992 as “the decade of Medicaid” (2003:392). This is also the beginning of the HMO’s or Health Maintenance Organizations. The HMO’s created a special category called “behavioral health”. This term refers to mental health and substance abuse simultaneously. The name was created by “private sector managed care companies to reflect joint responsibility for two

segments of the treatment system that have usually been separated” (Durham 1998:494). Managed care organizations were attractive because they claimed to be able to cut costs. This was achieved by, for example instead of employing psychiatrists they employed social workers, and instead of authorizing a stay in an inpatient facility or hospitalization they would refer the individual to an outpatient service. Additionally they reduce costs by lowering the number of hospital admissions and reducing the length of inpatient stays” (Durham 1998: 498-499). Durham calls for more research into “cost, quality, access, satisfaction, and functional outcomes associated with managed mental health care” (Durham 1998: 493). Because of the phasing out of federal support mental health centers gradually had to increase their fees and reduce staff and services (Cutler, et. al.2003:392). As a result, the centers used waiting lists to help deal with the growing numbers of consumers. This has also affected the quality of the services, which has continued to decline (Kenig 2003:393). However, the CMHC’s did find alternate routes for funding – they were able to use Medicaid, “which allowed for a 60/40 to 70/30 match, federal to state depending on poverty level...this proved to be a much bigger cash cow than CMHC/block grant money especially for the high poverty states” (Kenig 2003:393). “Medicaid funding now accounts for over half of all state expenditures for the publicly-funded mental health system (Department of Family and Children Services 2004: 32). Cutler, Bevilacqua, and McFarland note here a “deprofessionalization” of mental health systems in general. They state that between 1970-1975 “psychiatrists were leaving CMHCs and were being replaced by other sorts of mental health workers” (2003:394).

Cutler, Bevilacqua, and McFarland call 1992-2002 the “decade of managed care” (2003: 394). During this time period to the present hospitals had to either raise the rates

of care to their private patients or decide not to care for the poor, because neither Medicare or Medicaid pay for the total cost of care. So, “in order to remain financially solvent they had to learn to collect third-party payments from insurance companies, Medicare, and Medicaid” (Kenig 2003:394). However, there were extreme restrictions in regards to income placed on patients in order to qualify for public welfare. As a result of this privatized public system “people had to lie to obtain eligibility or be a part of an estimated 40 million people who have no health coverage at all” (2003:394). Cutler, Bevilacqua, and McFarland describe the American service system as having “a peculiar maze of entitlement programs and eligibility requirements” (2003:394), and “mental health coverage is almost always limited in some way” (2003:395). In the 1990’s there was a growing trend for “managed care Medicaid wavers in the public sector” (2003:395). The authors discuss how managed care for many states was a disaster, “managed care seemed like another panacea that would over night solve a lot of problems while at the same time make money for the stockholders” (2003:396). The authors sum up their article by discussing the growing numbers of non-psychiatrists in the mental health clinics and state that “Critical issues, quality of care, and so on, get lost in the shuffle as business oriented administrators are hired to replace social workers and psychologists to try to turn these public clinics into profit-making operations” (2003:396).

Chapter Five

Results

As I have stated previously, I collected interviews from various people who have some relationship with mental health services in Tampa Florida. I constructed a set of interview questions that were used with each informant. These questions were devised using the knowledge I had gathered about mental health services, focusing on what I was most interested in investigating further. However, because my interviews were only semi-structured I asked additional questions when possible. I have placed my interview questions as well as my transcription key in the appendix. My informants all have different vested interests concerning mental health services and come from a variety of fields. While my informants do not represent all the possible perspectives on mental health services, they do offer much insight into the issues of mental health services from the service provider point of view. I interviewed one legislator, two psychiatrists, one social worker (LCSW), an advocate, and a community educator. I will now briefly introduce my informants.

Tim works for a local crisis center; this crisis center provides a 211 telephone hotline amongst various other hotline related services. His role as an educator is to provide community education and education within his agency.

Mark is head of consultation psychiatry at one of the local hospitals in Tampa, in addition to many other positions that he fills. He sees patients “who are on the more

acute end of the spectrum... people who are post suicide”. He is for the most part in charge of all psychiatric services including the inpatient unit and the emergency room of one of the local hospitals.

Paul is an advocate and president of a local affiliate non-profit mental health organization. His and the organization’s goal is to follow legislation and try to understand how it impacts access to services... “to advocate and to educate”. Additionally, he works at one of the local Community Mental Health Centers and he works in collaboration with the local police departments to help with the training of officers to better understand persons with mental illness, how to effectively recognize and deal with the mentally ill while on the job.

Brianna is a social worker. She works with families and particularly older patients and their families, helping them to understand the causes of the disorder and the disease process, presentation of the illness and some effective treatment strategies. She provides information about new interventions, how to support themselves in the community and connects them with others who are struggling with the same kinds of issues.

Louise is a recently retired state legislator and sits on the board of one of the local Community Mental Health Centers. She has a great interest in children’s mental health, and even though retired she still plays a role in the public policy arena and has been a leader in mental health reform.

Jane is a psychiatrist and a professor. Additionally, she is a medical review officer; assessing professionals that have been suspected of substance abuse/mental

illness. She has worked extensively on addictive and co-occurring disorders in addition to many other activities.

My informants represent varied positions within mental health systems of care. It must be understood that each individual is working and/or representing different agendas. Their positions and experiences play a part in how each of my informants sees the mental health care system working, and play a large role in their understanding of the system and its associated issues.

Defining Mental Illness

In the U.S. our Western folk taxonomy tells us that there is a distinct difference between the mind and the body, that they are separate entities. Non-western theories usually recognize that one's mental health is linked to one's physical health and vice versa. These definitions and taxonomies of illness and disease are cultural constructs, varying from culture to culture. In the U.S. we generally define a disease as something that is scientifically identified and caused by a bacterium, virus, fungus, parasite, or other pathogen (Kottak 2000: 590). Whereas an illness is "a condition of poor health perceived or felt by an individual (Kottak 2000:590). In this sense an illness is viewed as non legitimate, not as important or significant as a disease since it is not scientifically identifiable. This seems to be the case for the way mental illnesses have been viewed in the U.S. It is no wonder that mental illnesses are so stigmatized. This view of mental illnesses can be clearly seen throughout our society, from the way we talk about mental illness, from the lack of parity in our Insurance coverage of mental illness, to the limited availability of funding for mental health services.

Anthropologists have long critiqued western treatments of illness. One such critique is that Mental Health Practitioners usually treat the symptoms instead of looking for the causes (Kottak 2000:596). “Traditional curers often succeed with health problems that biomedicine classifies as psychosomatic (not a disease, therefore not an illness) and dismiss as not requiring treatment – despite the feelings of the ill patient (Kottak 2000:596). There is a direct link between the notions of what a disease vs. an illness is and the way we treat them. Recently, there have been advancements made in this area, although most of these advancements have not been enacted into policy. For example, historically, treatment for mental illnesses focused on the individual, excluding the family. However, much research has been done showing that including the family provides more positive outcomes. This notion is referred to as “family-driven systems of care” (Stoep 2001:41). "Family-centered approaches posit the family as the unity of service and optimal family functioning as the desired outcome"(Hinden 2002:13). "The achievement of basic family needs is essential, and reflected in outcomes like securing stable housing or employment, and achieving access to health care or childcare. Enhanced social networks and family supports would be relevant outcomes in most programs"(Hinden 2002:14).

The Western way of dealing with mental illness is just one of many however. In *Culture and Depression*, a collection of articles edited by Arthur Kleinman and Byron Good, Charles Keyes wrote an article about Depression. He used a case study from rural Thailand of prolonged grief to illustrate the dynamics of the social aspects of suffering, showing “the interplay of risk factors and resources that either create or prevent depressive disorder” (1985:19). He then posed the question as to whether biomedicine’s

treatment of depression is appropriate for dealing with this type of illness (1985:20). He illustrated his point by talking about death as a catalyst for depression. He states: “In traditional societies, the grief experienced at death of a significant other is worked through by means of a cultural process whereby a standardized set of texts – funerary rituals and memorial rites – literally “make meaning” of the loss” (1985:159). He makes the difference here between religious texts and texts employed by psychoanalysts. The religious text is a “spiritual meaning”, a “teleology”, and the psychoanalyst text is an “archaeology” of meaning, the “primordial” meaning of the unconscious made conscious (1985:159). “The most effective work of culture, (Ricoeur 1970, esp. pp. 459ff.) is one that moves dialectically between these two types of meaning” (1985:159). He poses the idea that maybe depression is becoming popular simply because of the disappearance of “more traditional works of culture that have served at least as well as either preventive or redressive treatments” (1985:169).

While Depression is only one of many mental illnesses, I believe that his point is an appropriate one, are we wasting our money on psychotropic medications to treat the symptoms of depression, or would we be better served seeking out the causes of the illness. It is an interesting question ... do people who suffer from depression really just need time and rituals. Or would this not work unless the rituals were performed using “sacred” texts, as Keyes describes it.

I believe that more research needs to be put into alternative treatment options for Americans; however consumers of mental health services face many barriers before they ever begin treatment. My informants listed a whole host of things: cost of services and medications, available funding, awareness of mental health and services available,

stigma, transportation, hours of operation, wait times, insurance coverage/parity.

Interestingly enough even though my informants were from varied disciplines and had different interests many of their answers to the question of barriers were similar.

Tim stated that cost to the consumer was a large barrier...

“Cost, it is expensive to go to counseling... for marriage counseling ... especially if they don’t have insurance”...

He also talks about the cost issue from the provider’s prospective...

“... how do we [talking about service providers] afford to send a counselor to a service center in three different parts of the county to hold these support groups and then where’s the space were going to hold them and do we have to pay to rent a space and working out all those kind of things can be pretty complicated also. So the barriers of cost and the barriers of what’s available”

Tim also cited that awareness was a major concern ...

“...that’s part of the whole awareness problem of all kinds of mental health issues in any community ... if people are more aware of mental health issues they can do some of the work of understanding and becoming aware and recognizing what resources are out there before they have to rely on the community service”.

Another barrier that Tim mentioned was that of getting funding passed through legislation for mental health services...

“...then I guess the other barrier is that um the legislators are not you know putting as much funding into mental health services as some of the other services which might make some of those barriers to the service organizations easier to do to have funding to have more you know support group counselors or more locations available ...things like that... and that’s one of the issues” ... “term being used a lot is parity.. that there ought to be parity between what mental health services get funded for and what other kinds of services get funding for, um and that also is still an awareness issue making the legislators aware, making the people in the communities aware so that they are telling their local representatives “this is what we want... this is what we want you to vote for, to work toward”. And the community doesn’t often realize how difficult it is unless they have first hand experience of trying to get mental health services”

Lastly, Tim states that transportation and hours of operation and stigma all tie into being barriers as well...

“It can be transportation for people, it can be financial, it can be hours of operation, and of course there’s the other barrier of people feeling there’s a stigma to them if they are seeking mental health services”

Mark states that funding is the greatest barrier regarding mental health services...

“The state of Florida is stingy in regards to many things and they just do not um adequately fund the mental health centers”... “It’s all about funding, and if you had more people [service providers] you’d have more time and there would be less of a wait time. But funding’s not there and a lot of times in a lot of cities what instigates um change is tragedy...we’ve been fortunate not to have that”

He also cites the extreme wait times that people face before they can get in to see someone....

“...there’s a huge wait, there’s a long waiting period. I actually had patients that have waited 4 to 5 to 6 months. Now understanding that the natural history of depression is that it lasts an average of 8 months for every depressive episode...”

He then talks about cost of medications...

“Cost of medications, cost of ... you know the best medication isn’t gonna work if you don’t take it cause you can’t afford it.”

Paul, when asked what he felt were the greatest barriers to mental health services described the way people conceptualize mental illness as being a barrier.

“The understanding that it’s not cured... that’s it’s managed... or that it’s yea... you manage your mental illness the way you manage diabetes. You don’t cure diabetes you only manage it ... you live with it

This leads to another problem that is directly related to people’s ability to pay for mental health services... Paul states that because mental illnesses are thought of the same way as

physical illnesses, people think that it is curable, and therefore insurance companies give you very little time to become stabilized.

“Because you can’t just stop in the private sector with your care because the illness doesn’t allow you to just get cured ... the illness is only managed and when you get into private sector the insurance companies won’t approve enough visits to maintain or manage your mental illness only the public sector will”

Paul also mentions other barriers to treatment later in the interview...

“Wait list... overburdened public system, no resources – can’t afford private, once you can’t afford private... which is the first barrier then it’s overburdened system .. that causes wait lists and the illness doesn’t allow you to meander through the system”... “and access to care would be another, they just don’t have access to ...not enough public agencies or enough public money.”

Brianna states that insurance coverage, not knowing where to go and stigma are huge barriers to mental health services.

“insurance coverage... or having no coverage at all... I think those are the biggest barriers and people don’t know where to go. They don’t know where to go when I tell people in the community that” ... “medicare covers family therapy ... they look at me like I have three heads ... nobody’s ever told them that”... “And then of course the other thing of course is the stigma of seeking treatment for mental health issues.”

Louise states that one of the greatest barriers is not knowing where to go to get help, and also limited funding available for people in need.

“Probably the greatest barriers are.. I think there are a couple of them, one of them is access to care. When people have problems, they don’t really know where to go, ... access, I think the other is limited amount of dollars that are available for people in care which means that a lot of people out there that don’t get services, unless you are able to pay privately.”

Jane states that one of the greatest barriers regarding mental health services is that of education and having knowledge about the resources available. She also mentions stigma as a barrier.

“One of them is just education and knowledge about the resources that are available, two I think it’s sort of, it’s not an acceptance of doing therapy and ...you know it’s ok to do therapy and ... people have ... it’s not like other cities, it’s much more a, it’s a very social pretense, much more pretense than I dreamed there ever was. Um and it’s [talking about mental health system] also very new and so people are dusting off these new images, of themselves...”

From these issues talked about by my informants I noticed that they could be split into two groups. The first group could be called stigma or prejudice; the remaining issues would fit under the heading of structure. Additionally, the two groups were related, because our shared understanding about what mental illness is and means has over time lead to the structural defects of the mental health system. This point was made stronger when I asked my informants why they think stigma is so prevalent; they all mentioned history.

Tim felt that the prevalence of stigma was due in part to history and how the mentally ill were treated in the past.

“The way mental health services have been looked at decades ago were that people with the most severe mental illnesses were institutionalized in some state hospital somewhere kept away from the general public, and even people with physical disabilities it was often the case where there were sheltered workshops, and you know places to help with their unique needs but it wasn’t keeping them in the mainstream um society so that concept kind of kept it out of the awareness of a lot people so it was something that they didn’t understand and didn’t know and so the things your unaware of can be scary to the general public and if they don’t understand it then there not gonna vote for things to assist those areas. There are certainly a little less stigma with young people to seek services.”

Tim states that a barrier to overcoming stigma is the fact that we have scientifically separated out the mental from the physical, and that we should not have done this because the two are inseparable.

“maybe that’s one of the big barriers - that we have created this field called ‘mental health’ when in reality you can’t separate that from physical health it is part of a ... we get callers to our hotline who are in the midst of a panic attack and their heart is racing and they can’t catch their breath and their scared and their so worried about it and our approach is to talk them through... ask them how they got through the last time they had a panic attack ... ask them to take some deep breaths and calm and what makes them calm and what can they do... exercise, listen to music, and remind them of those things because in the midst of that panic attack ... it is a physical reaction and the brain chemistry and the thought pattern are connected with that physical reaction.”

Mark relates history to the prevalence of stigma also. He calls upon the image of the psychiatrist with patches on his elbows. He says that it is getting better now that psychiatry is not so “psycho dynamic” and is becoming more “medicalized”.

“I think the uh the view of the psychiatrist with patches on their elbows, probably on the couch, people think that’s sort of weird and the old viewpoint of the psycho dynamic nature of psychiatric care, and you know what?... There is a place in the field for that... but there are people who understand that this is the decade of the brain...I think as psychiatry gets more medicalized and people understand that um this is not something that’s due to weakness it due to problems... neurotransmitters and it becomes a lot easier to accept um treatment...”

Mark also says that people see mental health care as never ending and are therefore reluctant about seeking treatment.

“I think people tend to see psychiatric care as never ending. And liken hypertension that can get better with exercise and weight loss and such ... depression can get better...let’s just say someone comes in and they’re depressed...um, they say “I’m 25 ... I’m going to be seeing a psychiatrist for 50 more years”, ... “people need to understand that medications are not meant forever...”

Mark states that increasing awareness is necessary to overcoming stigma.

“But increasing awareness is nice and also um...who ever has the bouncing ball... these are your nerve transmitters...(talking about Zoloft commercials). I think that’s a nice layman’s understanding of depression. Whenever they run a series of those ads, people come in and say you know what I have all symptoms and need the medicine that makes my nuero ... my brain better”.

Paul feels that the best way to overcome stigma is by getting the media involved, because they were the ones that have created the stigma in the first place.

“um just two years ago there was um... give you an example there was a .. it was around Christmas time... there was a ... fire in the state mental hospital in New Jersey and the headline read .. “Nuts roasting over an Open Fire”... in the paper. That’s what it said. So, um that was two years ago ... so you think that the country’s come a long way but it hasn’t so it still needs to be overcome and the biggest barrier is the media ... because they created it.. and they can undo it, if they so choose, but uh that doesn’t sell papers and that doesn’t sell sponsors for TV’s or movies. It’s going to be tough.”

Paul also feels that because diagnoses are variable instead of definitive, like a broken bone, and this helps prorogate stigma.

“The diagnosis is uh done by practitioners and each practitioner has their own guidelines and what they see...one practitioner might see it as paranoid schizophrenic, another practitioner might see the same person and say it’s schizo affective. They just have different criteria they use to diagnosis people. That’s another reason for the stigma, is that it’s not finite, it’s not an exact science, and there’s a lot to be left open for interpretation... that’s what fuels some of the stigma too. Cause it’s not that definitive... and it can’t be cured ...which also adds to it not being definitive and because it can’t be cured it’s open-ended and anything that’s open-ended confuses the public. A broken bone will mend and there’s specific ways to have that mend; public don’t understand why can’t you mend the brain.. if you can mend the bone.”

Brianna feels that stigma is so prevalent due to the historical roots of mental illness just as Mark and Paul did. People, especially the elderly are scared of mental illness because historically, people were locked away in institutions.

“I think particularly in this population, in the elderly population what they understand mental illness to be is being locked away in a crazy house... ok... you have to remember that there were state institutions where crazy people would be put away for their entire life. And people’s ideal of quote, unquote crazy people could realistically been perhaps a young mother that suffered post-partum depression before any body knew what that was... went into a psychotic episode and maybe they locked her away for the rest of her life... took her kids away and you know... she could be sitting in.. could have been sitting in a state for years

and years and years ... or it could be somebody who's truly criminally insane that's in an institution ... but I don't think that's the case, I think most of the elderly know that people who have mental health problems were considered crazy and if you considered crazy then you could be locked away sometimes for your entire life".

Brianna also feels however, that mental illness is tolerated better in younger generations.

"... I do think that it's a little, it's a little better understood, no not better understood.. I think it's a little better tolerated because they don't have that specific experience... you know I think it's more that we there's more that's in the media whether it be medication advertisement, whether it be advertisement in magazines that we might read... whether it be training in school. I think it's a little more palatable to people who might be under 50 or 60 years of age... than for the folks that are over those ages."

Brianna feels that we can overcome stigma through education.

"...education, educating people that these are disease processes and disorders just like hypertension, just like high cholesterol, just like thyroid problems ... I think if we could um figure out a very good way to normalize things for people who experience these problems..."

Louise talks about history as well and about her own perceptions of mental illness while growing up.

I just remember when I was growing up... mental health is like a deep dark secret you know it's like ... hide it in the closet, shut the door and don't let it out. You know and if it doesn't hurt anybody no one will ever find out. I think it's just... stigma is always going to be there. People don't want to be perceived as crazy because it affects their ability to maintain... to have a job, their ability to be productive in our society... it's just important ..."

Louise feels, just like everyone else however that the perceptions of mental illness is changing. She feels that parents and pediatricians are making more of an effort to acknowledge the mental health of their children and patients.

"...but I do think that stigma is changing. Parents are acknowledging the special needs of their children. XX that's why children's mental health is becoming such a major issue. I think that the demand in children's mental health is incredible. And when the parents go to the pediatrician now that's almost like the entry

level... if that pediatrician knows how to diagnosis an emotional issue or if the parent knows something most pediatricians don't know where to send a child. They don't, so... that's an area where I think ...XX... can make an impact... at that front end with the children.

Louise feels that education is needed to overcome stigma. Additionally, she feels that if the insurance companies would recognize mental illness that it would help to reduce stigma.

Well, get more people like Terry Bradshaw out there doing dinners and things and telling people it's not that XX He's perfectly normal now...people still admire him, all he does is pop a pill every day to help him."... "And I think one of the other things is if um... if the insurance ... I think insurance should cover mental health. It all starts also with the insurance coverage and that's another reason... a barrier, another barrier... huge, is the insurance coverage. If insurance companies would recognize mental health as a health issue...it would help people in the stigma side and also the access.

Jane talks about the service providers and their lack of vision and even their lack of understanding regarding the systems of mental health care. She also feels that there are not enough social workers and psychologists out providing care. That people, or service providers are isolated from one another.

"Here in Tampa everybody sort of seems set to sort of do their own thing in their own little world and ... let's don't rock it. Very sort of... for this city old southern, were just going do it this way and that's cool and" ... "I think there's people in the city and the Tampa Bay area that have been here forever... and sort of ground roots people XXX that are past their prime. Old ideas that have been forever and they have no more ... you know people get burned out after awhile, sometimes and ... or they're going towards retirement and they just don't see... why rock the boat? Or just the quality of care" ... "you have to have a strong basis of education like your counselors and your social workers and this is not a community that has a whole lot of social workers out there that are visible ... and I mean therapy social workers, you know people who are out , and psychologists, this is a very spread out um, place. And like in XX you know you see all these advertisements for social workers and I referred to social workers, and I worked with a psychologist and could do med management for her, um but it's different, here it's like people are sort of ... isolated."

Stigma is propagated not just by our definitions and taxonomies but also by our tendency to lump things together. You would never hear a legislator asking for money to fund a bi-polar clinic. Mental illnesses are usually lumped together, even I am doing so. This is very misleading, not only because of the differences between these illnesses, but also because of the causes. No one is really certain why some individuals are more resilient than others and no one is really certain what the causes of mental illnesses are, there are theories; they range from being biological and therefore hereditary, to resulting from the environment, or a combination of the both.

Mark feels that grouping all mental illnesses together does help to propagate stigma.

“I think it’s easy to stigmatize mental illness because ... now essentially what you do then is you lump everybody”... “it’s a very large brush to paint everybody with and I think it’s easier to dismiss people ... you say “There just the mentally ill” but when you break it down you say hey .. they’re suffering from an anxiety disorder.. that’s reasonable... oh they’re suffering from depression that’s reasonable too. But it’s easier to ignore a whole group than people in specific... it’s easier to distance yourself from a mental ill... because you don’t want to hang out with the mentally ill. But um it’s easier to distance yourself and then ignore them in the legislative process”

Paul states that lumping mental illnesses together does fuel stigma. He explains that people are lumped into the heading ‘mental illness’ because every practitioner has their own guidelines for diagnosing someone, so that one person might be diagnosed differently depending on the doctor they see.

“The diagnosis is uh done by practitioners and each practitioner has their own guidelines and what they see...one practitioner might see it as paranoid schizophrenic, another practitioner might see the same person and say its schizo affective. They just have different criteria they use to diagnosis people. That’s another reason for the stigma, is that it’s not finite, it’s not an exact science, and there’s a lot to be left open for interpretation... that’s what fuels some of the stigma too.”

Brianna feels that just separating out mental from medical illness does damage.

“Well.. I think just the fact that it’s a mental illness instead of a medical illness because it’s a separation. Is it a medical illness? “No it’s a MENTAL ILLNESS!”...you know it’s almost like it’s less accepted... “oh their psychiatric!”, you know .. “Oh that’s the psychiatric population!” whereas you wouldn’t do that with “Oh, there hypertensive!”. You know or “Oh, they’ve got cancer!”. You know there are disorders, these are disease processes for some people that can certinately impact and interfere with people’s lives on a lot greater level, I think, than something like hypertension, high cholesterol, you know.”

Louise feels that people not only lump all mental illnesses together, but that they also use terms such as ‘bi-polar’, or ‘depression’ too loosely.

“People have no clue what a bi-polar is... they use the phrase loosely, manic depressive they use it loosely, hey I just, there is a girl who” ... “I was five minutes late for an appointment with her and she lashed out at my staff ... It was the worst experience they’ve ever had in my whole eight years and she just stormed out of the office... five minutes and I called to say I was on my way you know no big deal and then she did it again to somebody else and everybody’s saying there’s something wrong with her... she’s got to be bi-polar, manic depressive, people use these terms, they don’t know what there talking about. They’re trying to diagnosis somebody without really knowing what their issues are... and it could just be an emotional imbalance, hormones or something, who knows.

Jane gives a few examples about how the words you choose to describe someone’s mental illness can affect the way you see that person and the repercussions it might have for the individual.

“Yea, I think there’s a lot negativity, in the general lay people, it’s like saying somebody’s a junkie, for having chemical dependency while it brings up a different connotation in your head if you say “O that person’s a junkie”, you know, “That person’s a wino” vs. saying “yea, that person has a problem with alcohol”, it’s the same thing for mental health. If I say “You’re a mental patient”... which a lot of people say it’s like, think of the connotations it brings XX vs. you know saying you have a biological disorder that’s going on and you know it’s a disease just like diabetes or heart disease or anything else.”

So after years of stigma and prejudice towards those who suffer from a mental illness, and even towards the idea of mental illness, we have a system in place in Tampa Florida to help those who are seeking treatment.

Structure of Mental Health System

The way we think about mental illness is reflected in the way we treat mental illness. The Department of Children and Families state plan defines mental health services as “therapeutic interventions and activities that help to eliminate, reduce or manage symptoms of distress for persons who have severe emotional distress or a mental illness” (2004: 37). They state that there are three primary mental health services in Florida that can be delivered in different settings, such as a “crisis stabilization unit, residential facilities, mental health treatment facilities, individual homes, community support services, clubhouses, drop-in centers and other community settings” (2004:38).

These three services are:

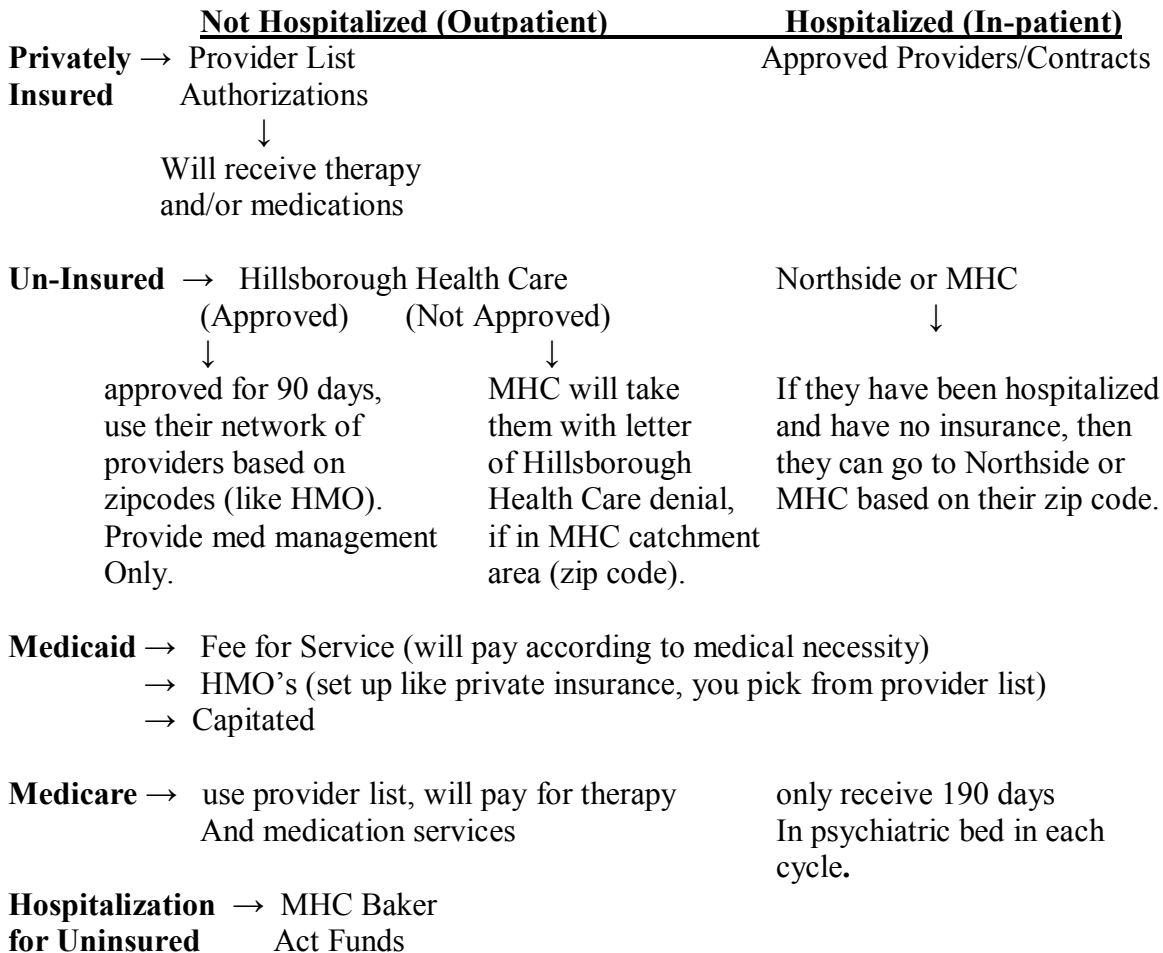
- Treatment services such as psychiatric medications and supportive psychotherapies intended to reduce or improve the symptoms of severe distress or mental illness;
- Rehabilitative services that are intended to reduce or eliminate the disability associated with mental illness. These services may include assessment of personal goals and strengths, readiness preparations, specific skill training, and assistance in designing environments that help individuals maximize their functioning and community participation; and
- Case management services that are intended to assist individuals in obtaining the formal and informal resources needed.” (2004:38).

This same report also states that 2.4 percent of persons over the age of 18 in Florida have severe and persistent mental illness. (2004: 48). They state that in 2002-2003 approximately half (54 percent) of those with severe and persistent mental illnesses

accessed some type of service. (2004:48). Of the total number of individuals served over the past six years there has been a steady “decline in dollars spent per person served...suggesting a reduction over time in the ability of the system to sufficiently meet the needs of persons seeking services” (2004:49). “The total state budget for mental health services in 2002-2003 was 363,429,263. Out of this figure emergency stabilization and residential care services accounted for more than 50 percent of the budget. (2004: 58) So Florida is spending over half of the total budget getting consumers stable by providing emergency stabilization.

The services available for an individual seeking treatment for a mental illness all hinge on questions such as: How are you going to pay? or Do you have insurance? The next question will be regarding the level of care needed, ex. Outpatient, inpatient, or hospitalization. I have put together a diagram of how mental health services in Tampa work or flow (Fig. 1). Funding Source of the individual is read on the left. The type of care is labeled on the top. For instance, a privately insured individual would choose from their provider list for authorization to seek treatment at an outpatient facility, or would get in-patient treatment from a facility that the insurance company has a contract with.

Figure 1. Diagram of how mental health services in Tampa Florida work.



- If you have private insurance you would be seen by a physician or psychiatrist on your insurance's provider list. The physician would either prescribe you medications him or herself, or refer you to a psychiatrist or a therapist. If your needs are more severe and you need to be hospitalized then you could go to a private hospital that your insurance provider has authorized. Once you have stabilized at an inpatient facility – they would refer you back to an outpatient facility/provider.
- If you are Un-insured you would be urged to apply for Hillsborough county Health care. If you are approved it would be for 90 days at a time. You would go to a provider in their network based on the zip code that you reside. If you are not approved, with a written letter of the denial by Hillsborough Health care Mental Health Care Inc. (MHC) will take you if you live in MHC's catchment area (determined by zip code). If you do not, then you have run out of options. However, if this is the case, your only hope then is to pay out of pocket or if your case becomes severe enough and you are hospitalized then MHC and Northside are required to take you.

- If you have Medicaid it is like having an HMO, you would follow the provider list. There is also something called Straight Medicaid or Fee for service – here there are fewer limits for services.
 - If you have Medicare you are only allotted 190 days for inpatient psychiatric care.
-

This system is by no means perfect and by no means understood by all; health providers or consumers, and is by no means set in stone. The current state of mental health services has been evolving over the years. Robert Wilton describes the shifts as “bold experiments and seismic shifts away from [the] traditional welfare states toward ‘workfare’ programs that impose mandatory work requirements for people who receive benefits” (2003:2). After these new requirements were enacted assistance was also frozen or reduced. The underlying premise behind these policy changes is that once these benefits are taken away people would be forced out of welfare dependency and become independent on their own. This premise is also present in our current political administration; President George Bush has used the term “ownership society” to sell his social security reforms. These conservative notions have had an impact and will continue to have an impact on conceptions of mental illness and services for mental health. The idea of less assistance is in direct contradiction to what has been proven affective for those who suffer from mental illness.

I asked my informants to describe the different ways that an individual might enter into care for mental health services. Tim stated that one way people might get linked up to services is through the 211 telephone hotline. The hotline is setup so that when someone calls in the person taking the call can search through a database and refer the caller to services in their area.

“...[the] database has about 1500 resources... and we couldn't put those all on a card or a book and that would just be so enormous that it would be hard for people just to go through that it would be like another phone book”... “Well we'd hope that people's first step would go to 211, gee I heard that you have information about community services I think that this is you know my problem, where can I go to get help? Um, I don't know that enough of the community realizes that they can use that service for that, I think what they would do if they had that something hopefully they would call a doctor, a clinic, a emergency room, and say you know I think have this mental illness how do I deal with it. And that place could refer them to some organization that could do an intake and assessment for them. But yea that's the problem, we think that 211 will grow in time to be as well know as 911.”

Mark described how people find their way into mental health systems the same way most of my informants described it, by separating out the insured from the uninsured. He says that most people seem to come through primary care physicians, however the uninsured usually go through the community mental health centers and the remaining go through the emergency rooms or the crisis centers.

“I can do that in two ways, I can do that ...insured and noninsured. An insured person I go see my family doctor and I say...”you know what... I'm feeling lousy... let's just say I'm depressed... um you see your family doctor and say “you know what you can try this medication or we can or we can get you hooked up and see a psychiatrist, and you do it all through the insurance company. Very easy and um it's usually done within a week to 10 days. Sometimes even the same day or the next day.”... “The uninsured person calls every psychiatrist in town and gets seen by nobody. Unless they can bring cash along. Um, then they will either go to ...they will either call um the crisis center, or they will call one of the .. they can call the county and ask what their catchment area is and which free mental health center ... let's just say it's Northside which is over here on Bruce B. Downs. Um, and then they'll be triaged, they'll be assigned a time to come in for a full evaluation where they'll be seen by a psychiatrist and treated or not treated depending on what the psychiatrists recommendations are. Um, that's somebody who can wait. If I develop ... I'm schizophrenic and I'm new to town and I have no money and my family and I need to be seen right away... um the emergency room becomes an amazing primary care clinic at that point as well. Either because they have no place else to go or because the wait to get into the community mental health centers was too long and their out of medication etc., or because they didn't get treatment and now they've decompensated and now they've done something or they're out of control and they're with police escort or

there because they intended to harm themselves then they come see me [in the E.R.].”

Mark brings up this topic again elsewhere in the interview. Here he talks about the over-utilization of the primary care doctor for psychotropic medications as a precursor to entering the systems of mental health.

“More antidepressants are written by primary care doctors than by psychiatrists and a lot of times the patients come into um the system because they over utilize the primary care doctor”... “the doctor figures out there is nothing wrong here organically that’s when you know they either refer or they try to treat on their own. Usually the primary care will give it a shot...I’d say a good half of patients come through our primary care brethren. And the other half, 35, 40 % come through just because they ... something psychiatric wrong with them and they seek help through their insurance companies, whatever, um, and another 10% come because they come through me [through the E.R.]”

Paul also describes entrance into mental health services by breaking down the choices for the insured and the uninsured, or as he calls it “private”, vs. “public”.

“if he can afford to go pick a doctor or psychiatrist that will be recommended to him if he asks somebody for a recommendation. Or he might call the American Psychiatric Association and say ... can you recommend um ... or he may just look in the yellow pages and pick someone geographically close to him.. to where he lives. Um , if he can’t afford a private physician then he’s limited to just where the public facilities are and those are the mental health centers.

Paul then describes what options one has when seeking out services.

“The private psychiatrist would or the public psychiatrist would determine whether he’s sick enough to be hospitalized.”... “He could [also] go to the E.R... and they would then uh refer him... if he can’t afford that hospital and he doesn’t have insurance they would refer him to a public mental health center or if he was sick enough he could be baker acted in the E.R. and transported to a public hospital... if he’s sick enough... if he’s not sick enough he would be referred out to a mental health center and then he would ask for an appointment. And he, depending on how sick he is he may get an immediate appointment or it might take two weeks ... that’s public. If he has insurance then he can get the treatment as soon as possible.”

Brianna describes people seeking services by the level of severity of their symptoms.

She talks about the crisis center, going to a doctor, talking to a friend, seeing something on TV, etc.

“Well I think it can happen in a number of different ways. A person could seek services at a crisis level, ok, somebody’s gone off the deep end there starting to shoot themselves, they’ve taken their children hostage, you know those kinds of things a crisis situation where um the sheriff’s office is called in ... um certainly that ‘s probably one of the most difficult times to intervene because it’s in the crisis situation. And at the other end of the continuum is the people who have on going problems and talk about it with... maybe even talk about it with one other person, but don’t really know how to access services... how would they go about accessing services? If the people that their talking to have any kind of similar experiences they might say.. “oh, well why don’t you talk to your doctor about it”. They might go to their doctor about it, their doctor may or may not listen in their eight minutes that they have to spend with that patient. May put them on medication, may or may not tell them what to expect from the medication. May or may not realize that the medication needs to be optimized, may or may not ask all those questions about the signs and symptoms of depression. Um, an individual might get involved in the jail setting, might have had to do with their arrest. Maybe their was domestic violence, maybe their was substance abuse, maybe they were running naked down the street because they were in a manic episode. You know there could be anything in between any of those situations ... could be a person who sees something on TV that talks about Northside Mental Health or Mental Health care Inc. or they could be riding by a bus, riding on a bus down 22nd street and notice that it’s there. I don’t think that we do a particularly good job of telling people how to get some kind of assistance. I think it’s um by hit or miss honestly. So I don’t know that there’s any typical way that somebody gets involved in the system. I think there’s a number of ways to enter the system. And some are probably more successful than others.”

Louise describes the different ways to enter into services for mental health care as “silos”, or “gatekeepers”. Because she is a legislator she has spent time working towards this issue. In particular she talks about getting Hillsborough County hooked up into one gatekeeper so that people don’t get turned away from services providers unnecessarily.

“Well, um and what I try to do is make this consistent throughout the state, cause here in Hillsborough it is a lot better than it is throughout the state, eight years ago we tried the prepaid mental health... well behavioral health, managed care... we tried managed care behavioral health uh plan here in Hillsborough and it really has worked out very well. Because it gives us a central gatekeeper, central Florida Behavioral Health Care, Central Florida Behavioral Network. Um there the gatekeeper, all these providers are hooked into that so when somebody walks

in their front door they can get to the right person for services, and we don't have that. Right now we have silos throughout the state. People can go to one, they may not be able to treat them so then they have to jump over to another silo and ... without somebody truly accepting them, first hand and trying to get them to the appropriate service and we did do the bill and took candidates statewide this year so I'm hoping in a couple of years we can say that there is a better system for people to access services.

S: When you say silo what do you mean exactly?

L: Providers and the mental health service providers so it's you know you may have a community mental health center, you may have a physician clinic, you know different providers, somebody going in for primary care says to the doctor ...I've been feeling very depressed the past couple of months that doctor prescribes Valium, you know...XXX.. without really assessing the individual, you know referring... you see how dangerous it starts to get. Now you know a couple of two or three months the person gets hooked on Valium, hey that really works, can I get some more...sure, and that's how the cycle starts. Without really getting assessed.

Jane describes how there are not many services available in the first place to choose from.

She states that existing services are scattered and do not work together enough.

“I don't know that there is a whole lot of mental health services here, not like a lot of other places. Florida really has a dearth of ...things, um ... with mental health or even co-occurring. X there's some agencies, but you know if you look at mental health X you have the mental health clinic over here which takes in people... X three month waiting list to get people in to do psychotherapy you have Northside and you have Lee Davis to see their psychiatrist or you can go to the Tampa General E.R., where you may wait for days, you know , one of the E.R.'s but that's not great services, it's not staffed by psychiatrists, I mean a psychiatrist comes out and does a consult, like USF's one for Tampa General E.R., but you know X do consults there, it's just the worst of the worst, you know your baker acted and waiting a bed, then you've got the crisis, you've got Bay Life. You've got mental health inc. , and then I guess the crisis center, that's different I think, I mean I know it's different than mental health cause we send people ?? Baylife. It's very scattered and none of them seem to work together a whole lot.

The picture that is laid out by my informants is that the Primary Care Physician is the starting point for many who complain of mental health issues. The Physician will either choose to medicate the consumer himself or depending on the severity of

symptoms could refer the consumer to a psychiatrist, counseling, to the E.R., to the crisis center, etc. Therefore as my informants stated, care can begin and end with the physician, or they can refer the consumer out to a specialist.

My informants also listed the Emergency Room as a starting point, but also as an option if the consumer is in crisis. Usually you would go there when your symptoms become more severe... a crisis; you have or are thinking of hurting yourself or others and go yourself or are brought by police. Many people who end up here might already be seeking treatment for their mental health, or they may not be. From the emergency room you would be transported to the Crisis Center (formerly called BayLife) or you might go to one of the different hospitals who have a psychiatric ward - this decision would be based on your insurance, or your lack of insurance.

My informants also listed the crisis center as a starting point; you might call the crisis hotline or voluntarily or involuntarily be Baker Acted. You would spend 48 hours minimum at the crisis center (formerly called BayLife, which is apart of Mental Health Inc.) being assessed. After 48 hours and if you are stable you will be referred for after care services at a CMHC or, if you can afford it, a private doctor.

My informants also listed the Community Mental Health Center as a starting point. Generally, you would seek services at a CMHC if you are uninsured or have Medicaid/Medicare. However, you might also seek services here if your insurance has run out (which does happen since they only give you so many days/sessions to overcome your illness). CMHC's charge their consumers on a sliding -fee scale basis. You can make an appointment with a CMHC to be assessed; however it might take months before you can be seen.

A social organization such as a church usually provides services themselves such as shelters, food, clothing and counseling. So one might actually start here whether they are a member of the church or not. However, most require that you attend church services in exchange for help. This kind of help many times requires a referral. Additionally, their programs rely on contributions from people/organizations... etc... so their funding is limited and unpredictable.

One might have friends or family members who have knowledge of mental illness and might recommend a doctor or just help to push someone in the right direction towards seeking treatment. They might even play the role of advocate for them. One might also see a magazine ad or television ad for depression, for prescription drug ads, or see a commercial for a psychiatrist or one of the Community Mental Health Centers, etc... and decide to reach out and seek treatment. This might be initiated by making phone calls and setting up an appointment.

The Barriers

This system sounds great, but in reality there are many problems, barriers, overlaps and gaps that confuse the consumers and the professionals. This is further confounded by the stigma that is attached to seeking mental health services. My informants listed many issues regarding barriers that individuals find when seeking out mental health services. Tim, throughout his interview stressed that one of the biggest problems that people face when trying to access services is lack of education and awareness about services. He feels that there are many issues out there that people need help with. For example,

“Everybody knows that if you have a fire, a police need, you call 911, but what if your grandmother has Alzheimer’s and forgot to pay her rent and is going to be evicted. Who do you call?”

Mark gives an account of what happens when you have insurance and when you have no insurance.

“Now, life’s a lot easier if you have insurance, um I can call up any doctor and say “you take Blue Cross Blue Shield? And he says, come on in, and they’ll have a cup of coffee waiting for me. Um, for our uninsured populous it’s a much different, it’s a much different idea. Here we have what’s called the different catchment areas, there are different mental health centers that are available, like Northside, there’s MHC, and they have different parts of the county that they care for. Panos center out in Plant City, ... um it’s sort of a sliding scale, but usually people are unfunded, but there’s a huge wait, there’s a long waiting period. I actually had patients that have waited 4 to 5 to 6 months. Now understanding that the natural history of depression is that it lasts an average of 8 months for every depressive episode... wait a couple of weeks and then you get your XX six months down the line... then your pretty much done with it anyway... well in some cases. Still the fact is that it’s an inordinate wait time.

Mark talks about primary care physicians as “gatekeepers” because they are usually the ones to decide if they can treat you or if you require the assistance of a psychiatrist.

“...your choice is you can go see XX... your gatekeeper... the gatekeeper decides whether to medicate you himself... or refer you to therapy or refer you to a psychiatrist for either therapy or medications. It’s one of those things. More than likely they’ll try to medicate you first unless there’s a possibility that you might be bi-polar. People with bi-polar disorder are much more changeling to treat because as opposed to depression ...XX You get people’s levels up .. XX.. bipolar you have to keep bipolar you have to keep them down too. So there’s a little more art to it. So if the person is possibly bi-polar or psychotic or has been treated a bunch of times before unsuccessfully that’s probably a call for a referral.”

Paul talks about how your resources directly affect the quality of services that you are able to attain. He says the determining question is “can the private sector be compensated for this?”

“.. does your insurance pay for it?. Can the private sector be compensated for this? Whether it’s you personally... out of your pocket or whether it’s your insurance. If the answer’s no to those two questions then it’s the public sector

[where you would find services]. But the services are still the same ... your either outpatient or inpatient and it's uh if it's outpatient do you need the assisted living or can you live independently? And it would be the same question for the private sector. They also have halfway houses for people who are being discharged from the hospital and they would go to a uh assisted living facility. And there's private ALF's [assisted living facility] and public ALF's. It's a lesser restrictive setting than the hospital ... then after the ALF then you go to independent... and from there you go to outpatient.

Paul also talks about the difference in how insurance companies handle mental health from physical health and how this affects one's treatment.

“... private insurance companies don't pay for it the same way they pay for it the same way they pay for physical illnesses.”

S: “So like 30 years ago they would have paid for it?”

R: “No”

S: “ok, see that's what I was thinking.”

R: “They would pay for it but not in the same scale that they pay for physical illness. And that's why they call it.. that's why you hear parity.. what their saying is ... don't make us pay more because we have a mental illness than we do for a physical illness... and they do now, private insurance companies make your co-pays higher... if you have a mental illness... all except congress.. they voted themselves a nice package four years ago. And that's what the rest of the public wants they want the same coverage that congress has ...because Congress doesn't... the insurance they have doesn't discriminate in coverage from physical illness or mental illness. There're all the same.”

This results in people who are insured having to go to the public sector once their insurance runs out for mental health (behavioral health) coverage. I asked Paul whether he felt that the majority of people seek treatment in the public or the private sector and this was his response.

“...after their resources dry up then they end up in the public. So, I don't know how that breaks down because the private sector doesn't keep statistics... so I don't know. The public sector does because they have to for their funding. There's enough private physicians out there so there's plenty of people that are supporting the private system.”

Brianna responds to barriers regarding mental health by talking about how there are services available, but no one is aware of them.

“...people have the services and through a lack of education about what kinds of services are available and a lack of understanding they don't access the services. Other folks don't have the services, they don't have anyway to access them, they don't have insurance or they don't have coverage or the co-payments are too high or they don't know where to go... to start with.”

Brianna also talks about health insurance and parity, just as Paul mentioned.

“Why should an individual, we talked about parity when we met with um ... earlier, Why should mental health co-pays be more than a regular doctor's office visit? Why should they be limited? Are you going to limit somebody that has hypertension? “Oh, your suppose to be over your mental illness in 10 sessions”? Where does that come from?”

Louise mentions the fact that in Tampa there are limited services for children. This is particularly important because she feels that early intervention could prevent problems later.

“Parents are acknowledging the special needs of their children .XX that's why children's mental health is becoming such a major issue. I think that the demand in children's mental health is incredible. I'm personally pushing it and I know the new secretary of the department of children and family ... and he knows that it's been grossly under funded... so... XX the school districts play a minor role in this issue because teachers interact with these kids along during the day in their classroom”... “I think across the board, everyone that comes into contact with.. spends a lot of time with small children, pediatricians are one teachers are another. There should defiantly be... I think it would be a benefit to everybody if somewhere the in-service for teachers could incorporate identifying emotional problems with children, and not ... there's a fine line here, we do not want teachers prescribing mental health drugs, we do not... cause I did a bill against that... but allow them how to handle the situations in their classrooms without thinking negatively...”

Jane talks about how many people get treated for mental health issues through their primary care physicians. She questions whether the treatment given is appropriate.

“... and I think there's also an issue that you know as time's gone on more and more family practitioners have treated ... there may be a lot of mental health

services being treated, say Depression and biological conditions treated that we don't know about. Because their treated by family doctors and internists, and so they never got to see us, but how appropriately they are treated is another question. I don't think they probably get the right dosage on that occasion. I think there's way too many XX... so these people are thinking they are getting services out there, and they are of some type, but how totally appropriate they are is another question."

Jane feels that in addition to all the barriers surrounding mental health and services provided, people are getting hooked on the notion that a pill will make it all better. She feels that pills are not a cure all.

"I think some of it is, you know part of the worlds' XX living through pharmacology now and I'm not sure everybody... a pill won't solve everything, you know ... I think that they drug companies would have you believe that a pill will solve everything, and then you get these people that have been on ten different anti-depressants and they'll say nothing worked, just maybe worked for a while, well if you look at their luck it may be that they got better for a while because they got a job for awhile or money or things were going better with their relationship and then you know they got divorced and they got worse, well ... you know the anti-depressant wasn't what was going on it was the underlying current of everything else in your life.

Jane goes on to explain her point in greater detail and describes how medications can help someone with depression, anxiety disorders, etc... and how medications can only do so much towards what is going on in someone's life.

Well, I really don't think the pill will solve everything, I think it's for some XX yea, you have a strictly biological depression or anxiety disorder and you can take this medication and I'm not anti medicine, but you can take this medication and you'll be right back to where you always were, and you don't need psychotherapy. But there's so much other craziness going on that a pill's not going to solve and that is not being addressed.

S: My understanding is that it does get you back to where you were before, but then you get back into the world and you get hit with those problems again and so it just sort of...

J: Well, if your constantly running around after your husband trying to clean up and take care of and he's constantly yelling at you and you get biological depressed, well that's great I can give you a pill that will get you back to where

you were, but are you really going to feel ok if your constantly going home everyday after work to a husband who yells at you or beats you or .. and you don't feel like you can leave because you've got five kids and you know your working, you know you live in a nice house and you got two mortgages, two car payments, you don't want to give that lifestyle up ... "Are you going to feel really good?" "NO, probably not." "Is a pill going to help that?" "No, only a certain portion will it help"... and all the rest of that, unless you do some changing and some work in terms of psychotherapy and we know there's certain types of psychotherapy that work just as well as medications many times .. you know truly the two of them work best together. Particularly for biological depression, which is ..."

Jane's answers made me wonder about the nature of mental illness, and about the theories concerning the origins of mental illness.

S: So is it then that there are things other than biological depression ... I've always been led to believe that even if it is onset by something else [from the environment] then it is still a biological ...

J: oh, yea... I talk about nerve X symptoms, if you have nerve X symptoms, that part of your depression I can fix with a pill. That's the biological part of it... What are those things?... well, if you eat too much or eat too little, have no energy or have too much anxiety, can't sleep, sleep too much... I can probably fix some of those. Of those I can XX them to some extent... but you come home and you feel sad and your crying all the time because your husband gets drunk every night and beats you ... there is no pill that's going to fix that. But your going to feel sad and come home every night and cry.

S: Does that getting beat from your husband, or these kinds of situations... does that change the chemistry in your brain?

J: We don't know... but it probably certainly does. But, and I give you the antidepressant so I fix that part of it, but you still feel sad, or you may have all sorts of feelings about things, I mean how you grew up and how you respond to the world, you may be a very sensitive person and so somebody looks you, you may misinterpret that they don't like you when it's really has nothing to do with you ... you know your looking down the street at something, that... but who you are as a person and what experiences you've had dictate how you interpret the world in and of itself. So... you know it's like Road rage, you know people have ... why do we have road rage now, we didn't have road rage 20 years ago. But, there's a lot of factors I think that go in ... craziness of the world, but I can't fix road rage with a pill."

Directly related to these barriers that one might run into when seeking mental health services is the topic of legislation relating to mental health. I asked my informants if they could think of any specific legislation that was or is particularly important.

Tim mentioned the topic of “parity” here. Parity in general “requires insurers that provide mental health coverage to offer benefits at the same level as the benefits provided for medical and surgical coverage”

<http://www.nmha.org/federal/parity/partiyfactsheet.cfm>. Tim states:

“...and that’s one of the issues that um... term being used a lot is parity...that there ought to be parity between what mental health services get funded for and what other kinds of services get funding for, um and that also is still an awareness issue making the legislators aware, making the people in the communities aware”

Mark answers this question by talking about the Baker Act, a piece of legislation that was enacted into legislation in 1971 in Florida, named after Maxine Baker, a Florida legislator. It provides “a reasonable process for involuntarily committing those whose conduct made them dangerous to themselves or others”

(<http://www.psychlaws.org/GeneralResources/article77.htm>, 2002). He states:

“...you know not all people bad mouth the Baker Act all day long ... “Oh, the baker act’s terrible ... it’s abused” But understand the important thing about the baker act. The Baker Act is for 72 hours no more no less ... So there are some states that have no involuntary ... laws out west where things are based on the frontier and personal freedoms they don’t have baker act laws ...so if your psychotic and if your suicidal... I can’t stop you .. ok.. um that’s not good. Most states have something that’s close to a baker act law Georgia does, Alabama does ... but they have different names, but the same general idea. But you know the thing is if someone comes in ... they might have been suicidal ... you think there suicidal and you baker act them and you find out you were wrong you cost them a day or two in the hospital if your right you saved their lives. So I actually appreciate the Baker Act it’s a lot of oversight Where the problem comes in is when it’s used for dementia, because you can have... because baker act can be used for people who are disorganized, or can’t care for themselves and that’s sort

of where most of the problems have actually happened with it in the state of Florida. The problem with nursing home people being Baker Acted ... but you know what people of good intention if their wrong it cost them the most three days if their right it keeps them alive. So I appreciate the Baker Act, cause it makes our job to keep people healthy and safe easier, and that's a good thing."

Paul talks about the recent privatization of mental health services, which used to be publicly funded. He states that the change was made to cut Medicaid costs, however, this has had repercussions - such as the effectiveness of the treatment that is now available. Additionally, he describes how the HMO's work and how it affects the patient.

P: Well the most recent one is the HMO's being given behavioral health...

S: That's for Medicaid right?.. or is that everyone?

P: Everyone. That your now going to have HMO companies... be included in giving services to um mental health, behavioral health. Before they were carved out. The only people that were in HMO's were people with physical illnesses, now mentally ill are going to be having to go into HMO's.

S: I guess I don't really understand the history of that.

P: Health Maintenance Organization.. that's what it stands for, and they're private, so they're profit driven. So when your profit driven your not always going to do what's right for the patient... because your profit driven and you don't want patients to absorb your resources and your profits so HMO's what ... what's the most efficient treatment of service isn't always the most effective. And that's what mental illness is all about. It's not effective ... and the most efficient treatment isn't always the most effective. HMO's are saying they are efficient and they leave off the effective part off it. So if you need 8 more visits .. well better analogy would be ... Maternity HMO going to somebody for maternity needs that you have and you have a problem in delivery ... HMO says you have a day in the hospital and your going home but you go home and you hemorrhage or you have complications ... when in fact the standard practice for that particular problem is 4 days in the hospital ... HMO says "I don't care.. your going home". ... more effective.. I mean more efficient ... so your going home.. you got problems come back to the hospital. So and that where preauthorization comes in ... they want to send somebody home... the doctor says this person can't go home... there not ready to go home whether it's pregnancy or heart attack or whatever.. there not ready to go home ... Well, were giving you three days in the hospital if you need 7 you just come back.

S: Will they pay for it if they come back?

P: If they have prior authorization. Prior authorization might take two days, three days"... "Physical Illnesses have been HMO... not mental... but public... now the public is going to have to do HMO.. for mental illness.

S: and that was something that was enacted in congress.

R: yea... and it is to curb Medicaid costs... that's why they're doing it... they admit they're doing it. The costs are too extravagant. Therefore they want to cut costs. The way you do that is you have a company that manages care... not a publicly run facility because there's not the most efficient. They maybe more effective ... but you're not the most efficient person or agency is not always the most effective.

S: So with HMO's that means you're going to go to a private physician ..."

P: "No, you'll go to that public facility... that public facility's going to be managed by HMO company. .. and that HMO company's going to dictate to that public facility how many visits these mental patients can have and how many admissions these mental patients can have ... it's not based on what they need, it's based on what the HMO will approve.

Brianna also talks about the way HMO's cover mental health, and how they just don't adequately cover medical costs incurred for mental health.

"...this is a medical problem [talking about mental illness], ok... it's not to be carved out separate from the medical problem. You know it's not any stretch to figure out that mental problems, mental illnesses lead to an increase in medical illnesses. You put your money on the front end and treat what's going on .. it's not going to be so expensive in the back end."

Brianna also talks about the privatization of mental health services and the impact this has on accessing services.

"I think anytime there's services that are available in the community and they have funding that's federal I think there's always gonna be the push for privatization because just like when I worked in the jails, there's a lot of jails in Florida that are privatized because the privatization firms come in and say "We can do your services for less per unit per person"... of course when they get in and start doing it, they're not able to do it any better than the individuals who are already doing it... pretty much with a lot less money. We've seen that in the state with adoptions, we've seen that in the state with um, protective services, we've seen that with jails, and that leads me to believe that we wouldn't be very successful doing it with privatized mental health services."

Louise, being a legislator, feels that she would have liked funding to increase more than it has and she is happy that children's mental health is becoming a priority.

“I’ve increased the funding for mental health every year ... um not as much as I’d like to and this year I think the Department of Children and Families are making children’s’ mental health their number one funding priority. So I’m very, very happy about that ...and I hope that works out.”... “Well there’s schools of thought that the legislation I’ve done some people think it’s gonna kill the system, providers that are out there trying to do services and on the other hand there’s another school of thought and the thought that I have that it’s gonna help because there’s a lot of drug over utilization in the mental health and we’ve proved it. And there is people are getting drugs, there not getting cures, there not getting successful end to their past, or some resolution to their difficulty in life they just go in to these mental health centers they get their drugs... whether they need them or not and I think a lot of our money has gone to that ...and that’s why I’m a big proponent of the behavioral health network , because I think if the providers work together and the client gets access to the best place for services, you know everybody’s gonna win.”

Jane mentions the Baker Act. She feels that far too many providers are able to Baker Act and this has consequences.

“Well I think if I’m looking in Florida, I think it’s very hard you know, it’s a two edged sword, you know looking at whether how easy is it to commit or Baker Act somebody and particularly for... you can’t seem to keep people here very long if there having difficulty and it’s, it’s ...they can sort of walk out the door easily, you can Baker Act and a lot of people can Baker Act, which couldn’t happen like in Louisiana, but yea people turn around and get out very rapidly, which has a good point to it, but also and there’s a process that seems very onerous to sort of get all these different... keeping people there. It’s even more of a onerous long term thing for substance abuse. Somebody may come in and look ... you know, it takes forever to get them there and you know to me mental health and substance abuse are all sort of all one big huge entity...”

Because the Baker Act had been mentioned several times I wanted to know - when someone is Baker Acted where they typically go and what determines that.

Mark gives in response to this question a brief description of what happens when someone is Baker Acted and some of the issues related to the procedure.

“There’s a thing called unit 50, sort of the Baker Act transport van and it’s a white van with heavily tinted windows that spends all night shuttling patients that are Baker Acted from Emergency Rooms or Doctor’s Offices to inpatient facilities.

I understand that uh the Baker Act gives you, provides for an evaluation on an inpatient basis and you know if there's a visit whether it's an adult or child the nursing staff and the staff on the medical units are not really... have the specialty training to do good psychiatric evaluations... these patients to them are just people who they have to watch more closely and so there not really welcomed with opened arms. On a psychiatric unit, not only are you evaluated by the physician, by the medical students but you are also evaluated by the nursing staff and by the occupational therapist and that way everyone has an idea of what were looking for, is the patient suicidal?... what are their complaints now and um you have a much more, much richer understanding of what's going on when you have more than one viewpoint."

Paul defined for me what a Baker Act is, and additionally, what a Marchment Act is.

S: How would you define the Baker Act.

R: How to define a baker act? Someone that is a danger to themselves or others. Or suffering from substance abuse...

S: So they don't necessarily have to have a mental illness?

R: Well.. yea..

R: No, No, No, to be baker acted no you could have a situational crisis on your hands where you have no history of mental illness, but you are a danger to yourself or someone else and you would be baker acted. So you don't have to have a mental illness. It's all based on your immediate behavior... that's being witnessed by either law enforcement or a clinician.. if your substance abuse then you're a marchment.

S: What is the marchment act?

R: that's the equivalent of a baker act only it's substance abuse. Baker Act is mental illness and marchment act is substance abuse.

Jane says that she believes that many people go to Tampa General, especially if they were picked up of the street, or if someone is a veteran they might go the V.A. hospital, however it is probably insurance that would determine where someone would be taken if they were Baker Acted.

That's a good question, I'm not sure I know the right answer. It probably also has to do with insurance... ok we think that a lot of folks that are picked up off the street are going to go to Tampa General. You know if you're a veteran I think you can say you're a veteran and you could end up over at the V.A. I don't know what the difference is between say Tampa General and say Bay Care[I believe she is referring to the crisis center, formerly known as Bay Life].

S: Would a police officer come and pick a Baker Act person up?

J: I think so, I've not worked in the E.R. ... so I haven't really learned the system yet, because occasionally I've used them in the clinic and I know we've called the X police and they come over and then they transport them, and they certainly treat them like criminals, which is you know one of the things that Paul's [one of my informants] been trying to get together with, uh, to get a better humane system in place so the people who are mentally ill um ... who have problems, who are doing things that are interpreted as really dangerous, you know they can be helped and not shot."

Additionally, I asked my informants about the networks between providers in Tampa, whether they existed and if they felt they were adequate. Tim stated that his organization has in the past teamed up with other local organizations. In some ways however, the 211 hotline that Tim works with is a network within itself. Other organizations can call the hotline or go online to <http://www.211@yourfingertips.org> and access their database and find other programs and agencies that they might otherwise not know of. So in this way they themselves help to bring the community of mental health services together.

"We do occasionally get some collaborative efforts we had one a year or so ago with the children's board ... and they put up some billboards about a parenting line that we were answering the calls for and so that was advertising 211 that they wanted to do to get their parenting line.. um... information out to the community... but we were the parenting line so it helped us too so it was a combination of two organizations."

Brianna stated that there is some communication between providers, for example at the FCOMHA conference and monthly meetings at the crisis center. However, she states that there is not enough and that the lack of networking is due to everyone competing for the same money.

"The FCOMHA conference, the Florida Council on Optimum Mental Health and Aging, that is something that is done through Florida Mental Health Association, excuse me, Florida Mental Health Institute, here at the campus at USF.

We have the meetings that are monthly over at the crisis center where individuals get together those are actually seniors and law enforcement together, but that also is a round table that brings together a lot of the people that are involved in mental health in the area, kind of like a networking meeting.

There's things like the tampa bay manic depressive society.

S: Do you think there's enough networking between??

B: NO, no I don't. I think that's there's certainly a good attempt at that but you have to remember that a lot of the reason that there's difficulty in securing excellent networking is that people are competing for the same money. There's not much money that's out there, but there's a lot of people competing for the same money. So just like you heard earlier... you know here is a project that he's gone forward and funded and the organization that he's working with has already yanked three of his eleven position and has already instituted an 11 percent overhead before the doors are even open. So, people have to have money to serve the massive number of people that come through the doors. So there's extreme competition for that little pot of money."

Louise feels that there is a network that exists and networks are continuing to develop, however, one important network in particular is not currently publicized in Hillsborough County.

"Well there is here in Hillsborough and they are developing around the state now, so um central behavioral health network is one"... "We do not publicize the central Florida behavioral network in this area. I mean we should that should be the first and foremost you know kind of like the 911 of mental health."

Jane feels that there is a network in Tampa, particularly, however, for substance abuse.

"There's a forum for actually co-occurring [disorders] that goes on and I've done a couple of those meetings from DACCO. Substance abuse places that get together, so it would be DACCO and it would be ACTS, um, USF's FMHI involved, um XX they were doing some studies in terms of co-occurring and trying to get co-occurring services into the substance abuse area. I don't know who else goes to those meetings."

Brianna's story

Brianna told a story during her interview that describes how misunderstanding and stigma regarding mental illness can affect people in such a profound way. Her story

describes how a person's life can quickly spiral out of control. This story also makes evident how socioeconomic factors play into the quality of treatment a person can access.

“I had a young woman that came in here who in fact I was just talking to and she was gainfully employed, suffered what sounds like um a fairly significant depressive episode, went on medical leave came back and whatever the situation might be she is no longer working. She is on unemployment compensation, she's been resistant to medications, which certainly is not her fault by any means, ok ... she's actively sought treatment, she's what would be considered a frequent flyer, a regular customer here, um, but because an employer could not, or did not understand how to tolerate or deal with somebody who had a mental health issue she lost her job... was fired. So now we've got the legal system tied up because she feels as though she was unfairly let go and that might very well be the case, the legal system is tied up the mental health system is of course burdened by her continued need for services, um she would have probably continued to need services anyway, however now she's gonna need them more because she's got a situation that's kind of kicked everything into high gear. Then you've got somebody that's on unemployment compensation that's burdening the financial system whereas they could have been gainfully working and doing what they need to be doing in ... so I think one action begets a whole lot of other actions in the mental health arena and I have to wonder what impact it's had on her family financially and just her own quality of life, her own outlook on life, and her feelings of worth. You know because she was in tears, she was just describing that scenario to me. And I asked her if she had applied for disability, social security disability and she looked at me with these tears in her eyes and said ... “I hope that I don't need something the rest of my life ... I want to work”. So I think that there's lots of people like her I don't think that she's the exception, but I wonder how many people we shove into boxes that don't need to be there that with some support, education and maybe some accommodations just like any other medical disability... that we'd have some pretty gainfully employed people and pretty functionally less impaired individuals.”

Unfortunately, as I have found through my participant observation as well, this type of scenario is quiet common. This woman whom she had spoke to did not lose her job because she had a mental illness - that is illegal; she lost her job because of the stigmatization of mental illnesses. This story shows that even if you have insurance the systems of mental health put people only an inch away from a crisis, with just the smallest disaster or bad luck being the catalyst for a crisis – and trip to an in-patient

facility or worse. Insurance companies only give so many days for the insured to “stabilize” after which they will no longer pay for treatment. If the insured is “drug resistant” like the person that Brianna spoke with, the insured would eventually run out of authorization from her insurance and have to pay out of pocket for her treatment, or go to a CMHC – where she would face all the barriers that my informants have spoken of repeatedly. The problem here is not mental illness – the problem is how we define mental illness, which has determined how we treat mental illness. Philippe Bourgois wrote in his book “In Search of Respect: Selling Crack in El Barrio” about inner city poverty and substance abuse in East Harlem. His words describing why “policy initiatives, or even short-term political reforms” have not been able to “remedy the plight of the poor in the U.S. urban centers” (318), also describe why these tactics have not been able to remedy mental illness. Those words being: : “Racism and class segregation in the United States are shaped in too complex a mesh of political-economic structural forces, historical legacies, cultural imperatives, and individual actions to be susceptible to simple solutions” (318).

Unfortunately, we do not know the exact causes of mental illness. They range from biological to environmental to a combination of the two. However, as one’s physical health declines, so does one’s mental health and vice versa. Thus one’s socioeconomic standing should be in direct relationship to one’s mental and physical health. However, as we have seen from Brianna’s story it is much more complicated. The woman in the story had a stable income before her depressive episode (which could have been brought on by anything... death of a significant other, etc). However, the events that unfolded afterwards have put her in a position where she might have to live

off of disability payments and Medicaid, etc. Her socioeconomic standing was directly affected by her mental health. Even if she is able to sue her employer, how much of a blow to her financial security, self esteem, and quality of life has this crisis cost her? Just as Phillippe Bourgois also writes "...the U.S. common sense, which blames victims for their failures and offers only individualistic psychologically rooted solutions to structural contradictions has to be confronted and changed" (325).

Chapter Six

Conclusions and Recommendations

The statistics I mentioned at the beginning of this thesis do not address why there is such a prevalence of mental illness within the U.S. These statistics also do not address why so many people go undiagnosed until they are in a crisis situation. Finally, they also do not address the extreme structural oppression and poverty faced by so many Americans and the link this has with mental illness. However, I believe that if you look at the way we define mental illness and the way we treat mental illness - a direct link can be seen. We need to move forward together and redefine mental illness. Even within my informants answers I could see multiple definitions of mental illness as well as multiple views as to the appropriate methods for treatment. The *recovery* movement has become a concept that Levin, et. al. claim “has provided a simple yet powerful vision and framework that consumers and other stakeholders have used to begin the process of transforming mental health systems in the United States” (2004:88-89). The goals of recovery have been evolving through organizations such as NMHA and NAMI (2004:91). Levin, et. al. state that “In order to achieve this objective [of recovery], a transformation of how those with mental disorders, their families, mental health professionals and society view mental illness is required” (2004:89). Unfortunately, what changes, and how these changes should be made in order to transform mental health systems are not agreed on by all who follow the movement (2004:92).

It seems obvious to me that much of the policy geared towards poverty and mental illness are only short-term. This can be seen in the treatment of mental illness, Florida spent over half of its mental health budget on emergency stabilization in 2002-2003 - so half the budget goes just for stabilizing people after a crisis. How much money would we save if these people hadn't gotten so far along as to feel that they, or someone else felt that they needed crisis stabilization. Taking Prozac might help the severely depressed woman who has suffered trauma from being beaten by her husband; however, when she stabilizes and goes back to her husband her problem has not been solved. Just as Philippe Bourgois writes about inner-city poverty and the prevalence of substance abuse, "drugs are not the root of the problems...they are the epiphenomenon expression of deeper, structural dilemmas" (2003:319). These issues, however, beget another issue – why is there so much poverty. Again, Philippe Bourgois writes – "the restructuring of the world by multinational corporations, finance capital, and digital electronic technology, as well as the exhaustion of social democratic models for public sector intervention on behalf of the poor, have escalated inequalities around class, ethnicity, and gender" (2003:319). Mental Health in Tampa, and the U.S. I believe suffers the same condition as inner-city poverty and the prevalence of substance abuse. The prevalence of mental illness is not the problem it is the way mental illness is defined and treated that is the problem.

From the questions that I did ask my informants, much uniformity was displayed in the answers given regarding mental health services in Tampa. Cost, under funded programs, lack of insurance or inadequate coverage from insurance, stigma and lack of awareness of the services that do exist all together form a nearly impenetrable barrier.

There is a large gap in mental health services – this gap is primarily a result of inadequate funding – which affects cost, availability, quality and quantity of services. On the other side of this, however, is stigma – a result of misunderstanding and a fuel for the structural problems within mental health services. There are programs in place to help serve those with mental illness however; there is little funding available for these programs. What funding is available in turn drives the mental health services that are focused upon. Additionally, much of the community of mental health providers and advocates agree that we should be working toward *recovery*, however, there is no consensus on how that should be achieved. Some advocates and practitioners feel that there is a new weapon in the battle against stigma – taking the blame away from the individual and putting it on the chemical processes within the brain. But I wonder if this in the long run will create greater problems by allowing society to rely too heavily on prescription drugs and “medicate” their problems. Additionally, this view is one of the controversies within the *recovery* movement. The biomedical definition that mental illnesses are physical disorders of the brain is not embraced by all (Levin, et. al. 2004:95). Some feel that this definition “damages consumers’ self concept, diminishes hope, impairs their ability to have a collaborative relationship with providers, and actually increases stigma” (Levin, et. al. 2004:95).

Those who experience mental illness must “face a society that often reacts to these symptoms with fear and discrimination, a culture that traditionally has not respected their rights and has limited their opportunities, and a mental health system that at times has undermined the very healing it attempts to promote” (Levin et. al. 2004:88). The de-

stigmatization of mental illnesses I believe can only occur if we re-define what it means to have an illness and how we treat these illnesses.

In the latest Report on Mental Health from the Surgeon General (1999), a slightly new definition of what mental illness is was given:

“diagnosable conditions that impair thinking, feeling and behavior, and interfere with a person’s capacity to be productive and enjoy fulfilling relationships.”

Instead of calling them illnesses, the Surgeon General calls them conditions. He also proposed that we view mental illnesses and physical illness as being one in the same and that treatment is effective when it is taken as seriously as other health conditions (Department of Children and Families 2004: 34). This is a step in the right direction, a step towards legitimizing mental illnesses. We must continue to reconstruct our folk taxonomies and definitions of illness and disease.

In the mean time, the local community of mental health care services in Tampa, I believe would be better served if there was a greater push for mental health education. From my observations and from what my informants stressed repeatedly is that people are uneducated when it comes to understanding mental illness. People are unaware of signs and symptoms, treatment options and so forth. However, even if they do recognize that there is a problem, it is a mystery as to where to go to seek help, or how the system of mental health works in the first place. It seems logical that if we were able to educate everyone from pediatricians, lawyers, mothers, fathers, the grocery store clerk, to Judge Judy that maybe the stigma would begin to dissipate. One of my informants (Tim) felt very positive about the effects of education; he feels that a change is already taking place, especially with younger people.

“The concept of mental health service giving a citizen a stigma of having something wrong with them is changing, there’s more awareness out there, and one of the things we find is I think younger people teenagers, um young adults probably don’t see it as quite a big a stigma because a lot of these issues around things like, um emergency pregnancy crisis services, rape crisis support, date rape issues, substance abuse issues... teens and young adults have been seeing those issues dealt with on a regular basis on television and the movies, in their schools...”

During the course of my research I have tried to capture the perspective of providers and advocates regarding mental health services, however there are very important voices that are missing from my research - those of the consumers. In order to truly understand the socio-economics of mental illness it will be necessary to continue this line of research into mental health services from the perspective of the consumers. I also believe that a more thorough examination of the psychiatric tradition and how that relates to the political economic context is needed. In addition, an anthropological comparison of different ways of dealing with mental illness, and how those might work for the American public is also needed. The fact that most of my informants described how mental health services in Tampa work by describing two categories – those who have insurance and those who do not makes the point that funding is what drives the choices that are available to individuals. This is a serious issue and needs to be addressed. I anticipate being able to continue studying these topics through future research.

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<http://www.nmha.org/federal/parity/partiyfactsheet.cfm>.
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In *Social Science and Medicine*, 58(1): 25-39

Appendices

Appendix A Transcription Key

Transcription Key

S: Shelly (interviewer)

T: Tim

M: Mark

P: Paul

B: Brianna

L: Louise

J: Jane

XX – inaudible word

... pause

Appendix B Interview Questions

Interview Questions

How would you describe your role within the system of mental health... or within the systems of mental health care?

How do you fit into the larger picture of mental health? Long-term goals, etc..

What are the greatest barriers in regards to mental health services and treatment?

What about stigma as a barrier?

Why is stigma so prevalent?

What is the greatest barrier in regards to overcoming stigma?

I have noticed that many times when people refer to mental illness they do not necessarily specify any particular illness.. (depression, bi-polar, etc.). Do you think that this does damage? Do you think it is ok to not specify which mental illness?

My overall goal is to put mental health services and care within Florida into perspective... within Tampa can you describe all the levels of care that an individual (specifically an adult) might enter into mental health services. For instance; primary care physician, hospital, etc.. In other words, where and how do people receive treatment?

What kinds of issues are specific to all these levels... in other words what are the barriers that individuals might find when seeking out mental health services? Ex. Funding, ability to seek disability payments... transportation.. etc..

Can you think of any specific legislation that is particularly important in regards to mental health services and treatment?

Ex. Involuntary outpatient? 4 misdemeanors..

Does any kind of network exist between providers of mental health services... for example, can you call mental health inc. and readily talk about issues, etc..

When someone is Baker Acted – where do they typically go.. a CMHC.. or to a hospital.. or does that depend on the insurance?

For IRB Staff only:
IRB #: _____
Subjects
 New Study
 Revision of _____

Application for Initial Review
Social & Behavioral Research Involving Human

Institutional Review Board
University of South Florida
OHRP Federalwide Assurance: FWA00001669

1. Principal Investigator

[Shelly Yankovsky] **PI** **Student**
Degree: _____ **SS#:** _____ **E-Mail:** jupiterin@hotmail.com
Phone(s): _____ **Fax:** _____
Address: _____

USF College and Department: College of Arts and Sciences, Department of Anthropology

If not USF, indicate Institutional Affiliation:

Co-Principal Investigator / Faculty Advisor **Not Applicable**

[Dr. Michael Angrosino] **Co-PI** **Faculty Advisor**
Degree: Ph.D. **SS#:** _____ **E-Mail:** angrosin@cas.usf.edu
Phone(s): 813-974-0786 **Fax:** _____
Address: _____

USF College and Department: College of Arts and Sciences, Department of Anthropology

If not USF, indicate Institutional Affiliation:

2. Contact Shelly Yankovsky

E-Mail: _____
Phone(s): _____ **Fax:** _____
Address: _____

3. Protocol Information

Study Title: De-Mystification of Mental Health Policy and Services Using an Anthropological Approach

Additional Title(s):

Sponsors / Sources of Funding: N/A

Anticipated beginning date of study: 10/1/04 Anticipated ending date of study: 12/1/04

4. Sites Involved

4.1 Please indicate the number of sites or locations where you plan to collect data and/or implement your research procedures: My observations will take place at approximately 10 sites within Florida. For example, when the MHA does a workshop to train law enforcement on how to recognize and deal with persons with mental illness - the location of the training will be up to the police department.

Appendix C (Continued)

- 4.2 Please mark all of the sites where you plan to collect data or implement your research procedures and attach copies of letters of approval/support if required. Sites that are USF Affiliates (column 2) require letters of approval from the appropriate facility's review committee. For non-affiliated sites (column 3), a letter of support is required. For information about what to include in a letter of support, please refer to the information guide for "Off-Site Research" on our web site at http://www.research.usf.edu/cs/irb_docs/off-siteresearch.doc.**

Appendix C (Continued)

USF Sites:

- FMHI
- College of Arts & Sciences
- College of Business
- College of Education
- College of Public Health
- [Other - Please list]

Affiliated Sites:

- All Children's Hospital – FWA 00000977
- Bay Pines VA Hospital – FWA 00001906
- J. A. Haley VA Hospital – FWA 00000505
- Moffitt Cancer Center – FWA 00001464
- Shriners Hospital – FWA 00001441
- Tampa General Hospital – FWA 00001442

Non-Affiliated Sites

- Health Department
 - DCF Agencies/Clinics
 - [Other - MHA of Greater-Tampa Bay]
 - Tampa Bay
 - [Other - Please list]
 - [Other - Please list]
-

5. Research Plan

5.1 Please briefly state the objectives and/or the hypotheses of your proposed project:

To explore the services available for those who suffer from a mental illness within Florida, specifically Tampa. To explore the historical legacy of mental health issues and legislation within Florida, and what that legacy is today. The historical legacy being local, state and to some extent Federal policy as it pertains to mental illness. It is important to note that I will not ask questions about patients - all data gathered will be of a public nature. In other words, I will not ask personal or private questions regarding staff or patients.

5.2 Please briefly describe any previous literature, research, etc. that provides a rationale or reason for conducting this study: Before the 1970's people with mental illnesses were housed in state institutions and hospitals. After the 1970's there was a shift in care for these people from institutions to the community. However, as NAMI states, "adequate funding has not followed people released from hospitals into the community. This failure produced several consequences: increased homelessness – at least 22,500 homeless Floridians have a mental illness, and increased criminalization of people with mental illness – at least 23 percent of adults in local jails suffer from mental illness. Currently, Florida has about 121 state-supported, community programs serving 54,000 Floridians with mental illness" (NAMI 2000:6). Housing in Florida is also a problem – "none of the housing alternatives is adequately or consistently available" (NAMI 2000:8). Those housing alternatives being: "supervised residential treatment facilities, supervised apartments, client-owned housing, independent living with HUD – subsidized assistance and assisted living facilities with mental health overlays" (NAMI 2000:8).

The Mental Health Association's web site states that the "first point of entry for many patients with depression and anxiety disorders is the primary care setting" (The MHA of Greater Tampa Bay). However, even though they can help to detect mental illness, and do often times treat their patients with prescription drugs such as Prozac, little data has been gathered about this population, in other words it would appear to be unmonitored and unlegislated. It is the Community Mental Health Centers where the uninsured public finds treatment. It is also here that much of mental health legislation has been focused and developed.

Appendix C (Continued)

Sylvia Kenig has studied the CMHC movement framing her analysis through “the sociology of applied knowledge”. This theoretical perspective argues that “the products of intellectuals are significantly limited and shaped by the economic and political atmosphere within which their works are created” (Kenig 1986:4). In other words, it is not knowledge that responds to the intellectual activity of scientists, but rather that the intellectual activity is limited by the economic and political spheres which they are apart of. This idea can be traced back to Marx’s famous words: “life is not determined by consciousness, but consciousness by life”. This theoretical perspective is relevant because the way mental illness is thought of and cared for today did not magically appear, and in order to understand the current state of mental health we must understand this political/economic lineage. Kenig’s main goal was to demonstrate that “the applications of the intellectual products of social scientists are influenced by the political economic context in which those products are applied” (Kenig 1986:1)... by using the CMHC movement as a case study. Within her analysis she looks at the larger political economic forces which social psychiatry developed. On the one hand the movement “was part of a larger revolution of social responsibility” (Kenig 1986:54), and on the other it was an “extension of current professional ideology with modified goals, tactics and technologies over that part of society from which it has been hitherto alienated; [which] legitimates a two-class system of mental health treatment in this country – self-actualization for the rich, rehabilitation for the poor” (Kenig 1986:54).

Because mental illness is so prevalent, and because of its huge impact on the workforce of the U.S., I believe it is worth exploring what resources, what systems of care are available to combat it. If you or someone you know suffers from a mental illness where do you go? What do you do? What is the historical legacy of mental health issues and legislation, and what is that status today?

5.3 Please describe your plan for carrying out this project (A through D):

A. Identify the type of design (e.g., experimental, correlational, survey, qualitative):

Qualitative

Appendix C (Continued)

B. Briefly describe the procedures that you will use to collect information (e.g., interviews, experiments, focus groups, review of records). Clearly indicate which procedures, if any, are new and might increase risks to participants. Indicate whether deception will be involved.

I will use Participant-Observation, Observation, Semi-structured Interviews, archival records - such as census data, Mental Health pamphlets, etc.. all data gathered will be of a public nature, in other words I will not access private records of individuals. I will not be using focus groups or experiments. My observations have taken place mostly at health fairs, seminars, committie meetings, etc. In particular, I have observed what takes place at the various functions that the MHA has participated in. For, example: how people react to the MHA literature, how the MHA members interact and represent themselves in the community and with consumers, and so forth. Lastly, I have observed the general workings/procedures of a non-profit organization. These observations have been noted in a journal. My interviews, however, are still forthcoming. Once I have IRB approval I will collect at least 10 interviews from respondets such as: disability lawyers, thearapists, doctors, etc. No deception will be involved.

C. Briefly describe any testing materials and equipment you will use. Clearly indicate which, if any, are new and might increase risks to participants. Attach copies of all scales, survey instruments, questionnaires, interview scripts, etc.

I will be using open-ended interviews to be administered to therapists, physicians, disability lawyers, etc.. I have attached copies of my interview script.

D. Please estimate, if applicable:

- 1. The total time needed for each participant to take part in the study:**
one hour
- 2. The total number of contacts/visits:** one contact
- 3. The time needed for each contact/visit:** one hour

6. Participant Recruitment

- 6.1 How many participants (records or data sets) do you anticipate using for your study?** 10
- 6.2 What is the anticipated age range of participants?** 18-65 years old
- 6.3 Populations involved**

Appendix C (Continued)

- A. **Normal Volunteers** (non-incarcerated individuals between 18 and 65 years of age who are able to read and fully understand the informed consent form written in standard English. Adults who are not fluent in English, or who have cognitive or mental disabilities, or educational disadvantages that would prevent them from fully understanding an informed consent form are not considered normal volunteers.)
- B. **Existing data, such as secondary data, public records, or information gathered for non-research related reasons.**
- C. **Other Populations - please check all that apply:**
- Children (<18)** **Elderly Persons (>65)** **Pregnant Women**
- Prisoners** **Juvenile Offenders**
- Other (e.g., secondary data, other populations):** [Please specify]
- D. **Persons who may be unable to understand informed consent – Check all that apply:**
- Acute/severe mental/cognitive disabilities – Describe:**
- Likelihood to develop acute/severe mental/cognitive disabilities - Describe:**
- A sedated/traumatized/crisis state – Describe:**
- Persons who do not understand English fluently. Please attach translated Informed Consent documents for each language population. The PI will be responsible for ensuring the accuracy of each translation.**
- E. **Persons with social, economic, or educational disadvantages – Describe:**
- F. **Persons receiving genetic testing or genetic counseling**

Appendix C (Continued)

- 6.4 Please describe the inclusion criteria (the characteristics of the people/records who will be included in your study, e.g., physical/mental/health status, gender, occupation, diagnosis).**

I will only interview those who have knowledge relating to mental health issues, for example: legislators, disability lawyers, professors. No patients/consumers will be interviewed.

- 6.5 Please describe the exclusion criteria (the characteristics of the people/records who are not eligible to participate in your study, e.g., physical/mental/health status, gender, occupation, diagnosis) and explain why these persons/records will be excluded.**

Those who have no knowledge of mental health issues will not be interviewed. My interviews will only come from those who provide mental health services, not from those seeking services.

- 6.6 Please describe the steps you will implement to recruit participants. Please attach copies of recruiting materials, e.g., flyers, brochures, advertisements.**

I will approach informants that I met while at health fairs, seminars, committee meetings, etc. and ask their permission to interview. In addition to approaching possible informants I will also make contacts through my internship supervisors - these contacts would be possible informants. My internship supervisor will give me the information so that I may contact these informants on my own. Upon contact I will explain my research interests and ask their permission to interview. I will not produce any recruiting materials.

- 6.7 Would the process of identification or recruitment of participants put them at risk (e.g., disclosure of private or potentially embarrassing information)?**

No.

Yes. Please describe the steps for ensuring that the privacy of potential participants and participant's information is not invaded and that the participant's privacy is maintained during their identification and recruitment.

Appendix C (Continued)

6.8 Will financial compensation or other incentives be offered to investigators, research staff, or others for the identification, recruitment, and/or enrollment of participants?

Please Note: It is unlawful for any health care provider to offer, pay, solicit, or receive remuneration for the referral of a patient. Florida Statutes: 456.054

- No.**
 Yes. Please describe:

6.9 Will financial compensation or other incentives for participation be offered?

- No.**
 Yes. Please describe the compensation that will be offered to participants for their time in the study and the schedule for payment of this compensation. Please address how payment will be disbursed should a participant choose to withdraw from your study. Payment cannot be based on completing the study but rather should be paid in full or pro-rated on the time the participant volunteered his/her participation.

6.10 Will participants incur costs because of their participation (e.g., travel costs, time away from work, purchase of special materials, etc.)?

- No.**
 Yes. Please describe those costs and explain, if applicable, how those costs will be reimbursed:
-

7. Anticipated Risks and Benefits

DHHS defines minimal risk as “the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.”

7.1 Based on the definition above, what is your estimate of the level of risk to participants? Please check the appropriate box (A, B, C, or D) and provide the information requested:

A. Minimal risk.

Please briefly explain why you believe this is a minimal risk study:

I will only interview people about information that is already of a public nature, for example I would be interested in statistical information regarding types of insurance, how many people suffer from a mental illness, etc. I would also be interested in their general impressions about mental health services. I would ask them questions that anyone could ask - questions that are not private.

B. Greater than minimal risk and the study presents the prospect of direct benefit to the participant.

1. Please describe the risks, including any risk to confidentiality, and the specific steps that you will take to minimize each:

2. Please describe the direct benefits that the participants can be expected to gain from participation (other than financial compensation or other incentives):

C. Greater than minimal risk and the study presents no prospect of direct benefit to the participant, but will likely yield generalizable knowledge about the study topic.

1. Please describe the risks, including any risk to confidentiality, and the specific steps that you will take to minimize each:

2. Please describe how society and/or the field of study can be expected to benefit from the generalizable knowledge obtained in this study:

D. Greater than minimal risk and the study would otherwise be unapprovable, but presents an opportunity to understand, prevent, or alleviate a serious problem affecting people's health or welfare.

- 1. Please describe the risks, including any risk to confidentiality, and the specific steps that you will take to minimize each:**
- 2. Please describe how this project presents an opportunity to understand, prevent, or alleviate a serious problem affecting people's health or welfare:**

8. Informed Consent Process

8.1 Please check the appropriate box (A, B, or C) and provide the information requested:

A. Informed consent will be obtained.

If a study involves greater than minimal risk, informed consent must be obtained.

Written informed consent is required if the participants can be identified, even in minimal risk studies. Parental permission must be obtained in order to enroll a minor (e.g., a person under the age of 18) in research. Assent from the minor is also required. Written documentation of that assent (an assent form) is required for children 12 or older. Children 7 to 12 should be given the opportunity for assent and their agreement should be noted in the research record.

- 1. Please describe the informed consent / parental consent / child assent process, including how informed consent will be documented:**

I will approach potential participants and explain the nature of the research. I will ask if they are willing to participate, make an appointment for a future interview . At that meeting they will be given a copy of the informed consent and asked to sign, they will keep a copy for their records

- 2. Go to Section 8.2.**

Appendix C (Continued)

Waivers of informed consent

An investigator can request a waiver of the informed consent process for minimal risk studies in which participants can be identified. Waivers are only granted when they meet certain federally mandated criteria and when obtaining consent would be impractical or would compromise the wellbeing of the subjects. In cases where documentation of informed consent is waived, the IRB may still require that the participant be provided a written statement explaining the study.

- B. A waiver of written documentation of informed consent is requested. Please provide the information requested in Question D.**

The investigator must read or provide the consent form to the participant, but the participant's signature would not be required on the consent form (examples: some Internet or phone surveys or when signing the form might have some negative consequence for the participant).

- C. A waiver of the informed consent process is requested. Please provide the information requested in Question D.**

The investigator would not be required to obtain the participant's informed consent at all (examples: when a researcher is conducting secondary data analysis and the participants cannot be located or when requiring informed consent might have some negative consequence for the participant). The IRB will grant such waivers only when there are compelling reasons for doing so.

- D. If a waiver is being requested, please provide the complete information requested for each question below (1, 2, and 3). Where applicable, please attach supporting documentation (e.g., information sheet or letter explaining the study to participants).**

- 1. Explain why the research could not practicably be carried out without the waiver.**

- 2. Explain how the requested waiver of informed consent will affect the rights and welfare of the participants.**

- 3. Will pertinent information be provided to participants later?**
 Yes. Please attach examples.
 No. Please explain why not.

- 8.2 Federal regulations require informed consent documents to include certain elements.**

Appendix C (Continued)

The elements are described in *Required Elements of Informed Consent* located on the Research Compliance web site at <http://www.research.usf.edu/cs/requiredelements.htm>. The USF *Adult Informed Consent Template* contains these elements and is available in the *IRB Forms and Templates* section of the Research Compliance web site at <http://www.research.usf.edu/cs/>.

Will you be omitting or changing any of the elements required for informed consent?

- No.**
 Yes. Please describe each change and explain why this is being done:

8.3 Will one or more of the populations listed in Question 6.3.C, D, or E be included as participants?

- No.**
 Yes.

If subject populations may be vulnerable to coercion or unable to give valid informed consent, additional safeguards should be included as appropriate, e.g., participant assent, parental permission, consent by legally authorized representative, advance directive, independent monitors, waiting periods, and continuing assessment of capacity to give valid consent.

Please describe what additional procedures will be used to safeguard that:

A. Subjects understand the consent process.

B. Subjects are participating voluntarily.

9. Data and Safety Monitoring

9.1 Describe the early stopping criteria (how you will decide to withdraw a subject or stop the study if there is evidence that an individual has reached an unreasonable level of discomfort or that participants may be placed at greater risk or deprived of benefit if the study continues):

A. For individual subjects:

If the informant becomes uncomfortable, or no longer wishes to be interviewed - then we will stop.

Appendix C (Continued)

B. For the study:

I will stop the study altogether if I find that I have placed any participants in great risk.

- 9.2 If your proposed research is the first time this type of intervention has been used in humans (Phase I) or if the research is trying to answer how safe and effective the research intervention might be (Phase II) and this is an NIH-funded study, you are required to have a formal, written plan to monitor the integrity of the data and the safety of the participants.

Does the sponsor of this study require a formal plan for data and safety monitoring?

- No. Please go to Section 10.**
- Yes. Please check the appropriate box (A or B) and provide the requested information:**
- A. This is an NIH funded study. Please attach a copy of the data and safety monitoring plan.**
 - B. This study is not NIH funded, but is required to have a plan for data and safety monitoring. Please describe your plan, including:**
 1. **How participant safety will be monitored**
 2. **How data integrity will be monitored**
 3. **Who will do the monitoring (e.g., the PI or the monitoring board)**
 4. **The frequency of monitoring**
 5. **How adverse events will be reported to the IRB and other applicable agencies/sponsors.**

- 9.3 If your proposed research intervention is externally funded and involves greater than minimal risk and you are trying to determine which level of intervention is most effective (Phase III) or how effective the intervention is when compared to standard therapy in a large population (Phase IV), you may be required to have a Data and Safety Monitoring Board/Committee (DSMB) to monitor data integrity and participant safety.

Does the sponsor of this study require a DSMB?

- No. Please go to Section 10.**
- Yes. Please provide the following information (A and B):**
- A. Is this an NIH or pharmaceutically recognized DSMB?**
 - Yes.**
 - No.**

B. Please describe how the DSMB findings will be reported to the PI and the IRB:

10. Privacy and Confidentiality

10.1 Please describe how the data (including informed consent documents) will be kept confidential during collection, analysis, and storage?

For example, describe the media and documents in which the data will be recorded, how and where they will be stored; how long they will be kept, how they will be destroyed.

I have kept a daily log/journal of my observations using pseudonyms (I will keep a separate key to the journal -using an alphanumeric code) I will avoid the inclusion of information that can identify the respondent, etc. All interviews will be taped only with the participants' permission and all materials will be kept under key in a locked cabinet and only I will have access to those records. I will keep all data for no less than three (3) years, whereby I will then destroy all data by shredding.

10.2 Do you plan to share the confidential data with anyone other than members of your research group?

- No.**
 Yes. Please provide the following information (A and B):

A. Please describe who this will be and under what circumstances this will occur:

B. Please explain how subjects will be informed that this data will be shared:

10.3 Will the participants be providing private, identifiable information about individuals other than themselves (e.g., family, friends):

- No.**
 Yes. Please describe who these other individuals are and how the privacy/confidentiality of these individuals will be protected (in some instances, it may be necessary to obtain informed consent from such individuals):
-

11. Disclosure of Investigator Interests

The USF *Policies and Procedures Manual* states that “any University employee who is responsible for the design, conduct, or reporting of a sponsored research project which is conducted under the auspices of the University must disclose financial or other interests that are, or may be perceived to be, related to the project.”

Significant financial or other interests, as defined in USF’s *Policies and Procedures Manual*, may include (but are not limited to) the following:

1. Income (e.g., salary, fees, honoraria, reimbursements, dividends, or other payments or considerations) which exceed \$10,000 per year when aggregated for the investigator and the investigator’s spouse and dependent children
2. Equity interests (e.g., stock, stock options, or other ownership interests) exceeding 5% interest when aggregated for the investigator and the investigator’s spouse and dependent children
3. A position (e.g., director, officer, partner, trustee, or member of the board of directors)
4. Intellectual property rights (e.g., patents, copyrights, or royalties)

11.1 Do you or any of the study personnel have significant financial or other interests that are related to this project or that may be perceived to be related to this project?

- No. Please go to Section 12.**
 Yes. Please explain briefly:

11.2 Has this (potential) conflict of interest been reviewed by USF’s Independent Substantive Review Committee (ISRC) or your institution’s conflict of interest review committee?

- No.**
 Yes.

11.3 Has a plan to manage this (potential) conflict of interest been approved by the ISRC or your institution’s conflict of interest review committee?

- No. IRB review may not proceed until a plan has been approved.**
 Yes. Please attach a copy of the approved plan.

11.4 Will subjects/participants be informed about the (potential) conflict of interest?

- No. Please explain why they won’t be informed:**
- Yes. Please explain how they will be informed:**

12. Other Key Personnel

12.1 Is this study being conducted in conjunction with the Veterans Administration?

- No. Please go to Section 13.**
- Yes. Please complete Question 12.2.**

12.2 Please list all key personnel in the table below. Do not include the PI/Co-PI's listed in Section 13.

“Key personnel” are those individuals who have contact with subjects or subjects’ private, identifiable information for research purposes.

All key personnel must certify the following:

- a. I acknowledge my responsibilities in the conduct of this research study.**
- b. I agree to follow the procedures for the conduct of this study as described in this IRB approved application.**
- c. I agree to uphold the rights and welfare of all study subjects.**

Name	Job Title	Responsibilities in this Study	Authorized to Obtain Consent? (yes* / no)	Date began service on this protocol	Date left service on this protocol	Met Human Subjects Education requirements? (yes / no)	Signature

***All personnel who are authorized to obtain informed consent must be listed on the consent documents**

13. Principal Investigator's Statement of Assurance

This application, which describes my proposed investigation involving human subjects, was prepared in accordance with the policies of University of South Florida (USF) and its affiliates for the protection of human subjects participating in research.

I certify that I have read and will conduct this study in accordance with the terms of *The Belmont Report*, the *USF Federalwide Assurance – FWA00001669*, and all relevant affiliate assurances.

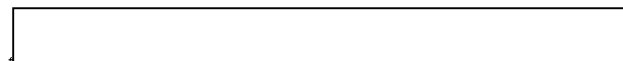
I understand USF's policies concerning research involving human subjects and I agree to:

- a. **Obtain the voluntary informed consent of subjects (or of subjects' legally authorized representatives), in a language that is understandable to them, to the extent required by federal regulations and by the determinations of the IRB.**
- b. **Report to the IRB any serious or unexpected adverse events or unanticipated problems within the appropriate reporting period (submit an *Adverse Events Report*).**
- c. **Cooperate with the IRB in the timely continuing review of this project (submit research progress reports via an *Application for Continuing/Final Review*).**
- d. **Obtain prior approval from the IRB before implementing changes in the approved research protocol or approved informed consent document (submit a *Modification Request Form*).**
- e. **Maintain informed consent documents and progress reports as required by institutional and federal policies (for more information, see the Research Compliance web site at www.research.usf.edu/cs/).**
- f. **Accept the responsibility for the conduct and supervision of this research and the protection of human subjects as required by state and federal law and regulation, and as documented in all applicable Federalwide Assurances and USF policies and procedures.**

Appendix C (Continued)

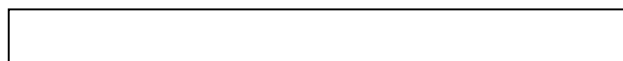
g. Ensure that research staff and students have been trained and are qualified to conduct this research and to protect human subjects. I agree to provide supervision to research staff and students that will ensure the protection of human subjects. I will keep records that prove that these requirements have been met.

h. Allow site visits for evaluation and monitoring by the FDA, the DHHS, the USF Division of Research Compliance, and the USF IRBs.



**Signature of Principal Investigator
(or Student Investigator)**

8/25/04
Date



**Signature of Co-Principal Investigator (if applicable)
(or Faculty Advisor)**

8-27-04
Date

Appendix C (Continued)

14. Signature Requirements

Study Title: De-Mystification of Mental Health Policy and Services using an Anthropological Approach

Principal Investigator: Shelly Yankovsky

14.1 Approval of Scientific or Scholarly Review

Scientific or scholarly review must be conducted by a member of the Principal Investigator's department or centrally by an affiliate's research administration branch.

I certify that this study application and protocol have been reviewed for scientific or scholarly merit and meet departmental/affiliate standards.

Signature of Scientific or Scholarly Reviewer

Sep. 10. 2004

Date

Print or Type Name:

Department/Affiliate:

Anthropology

14.2 Approval of Department Chairperson

I certify that this study application and protocol have been reviewed and meet departmental standards and that this principal investigator has the appropriate expertise to conduct this research.

Signature of Department Chairperson

9/15/04

Date

Print or Type Name:

Department:

Anthropology