AN OVERVIEW OF THE ISSUES AND SERVICES RELATED TO CHRONIC MENTAL ILLNESS

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Table of Contents

Executive Summary.....i

Background.....1

Literature Review.....2

Case Studies.....5

Interviews with Agency Professionals.....11

Conclusions.....16

Future Directions.....17

Executive Summary

This report explores the issue of chronic mental illness as it affects residents of selected public housing in the city of Minneapolis. This is the last of three reports focusing on issues which emerged over two years of experience with nursing students in a High Rise Project of the University of Minnesota School of Nursing, initiated in 1984. The project is a joint effort between the city of Minneapolis and the School of Nursing through the Center for Urban and Regional Affairs. It is based on a reciprocal arrangement in which residents receive health services and students receive educational credits leading to a baccalaureate degree in nursing.

The three reports explored issues which emerged as repeated concerns of the high rise residents: 1) Transitional Housing Options for Low-Income Elderly; 2) Chemical Abuse Among Elderly; and 3) Mental Health Services to Residents of High Rises. The central purpose of the reports is educational: to facilitate student understanding of major societal concerns related to quality of life for residents of public high rises and to describe the access, organization and delivery of services in these areas.

Chronic mental illness has broad and specific health and societal implications. The shift over the last two decades from institutional to community based care has profoundly affected the American mental health system. The deinstitutionalization process that began in the 1960s has been plagued by the absence of a planned, coordinated, and systematic approach. Even with improved treatment outcomes through pharmacological and psychological interventions, the lack of sustained followup and support into the community has compromised the effectiveness of services. Funding for these types of community programs has not stabilized.

While the findings of the investigators exhibit the availability of multiple services for chronically mentally ill persons in Hennepin County, access and utilization continue to be problematic. The current structure which locates formal provider services at sites distantly removed from the client tends to create an access barrier. This report suggests locating services in the context of the residents' living situation for the following reasons: 1) A commitment to service availability within the social setting would constitute a more responsive approach to service access. 2) Professionals located on-site can become aware of naturally occurring social networks which provide informal support important to improved functional ability. 3) Heightened contextual awareness, resulting from presence in the social setting, facilitates individualization of interventions to include relevant critical elements such as age, culture, education and economic resources.

The case studies of individual clients presented in this report are permeated with feelings of uncertainty and fear regarding their ability to maintain an independent living status. These people are often stigmatized by myths of helplessness and hopelessness. Coping with the ordinary demands of life is difficult for these residents. There are strong dependency needs which are financial, emotional, and social in nature. Social integration may be further complicated by such things as unpredictable behavior, inappropriate communication patterns and personal grooming problems.

The findings of this report reveal the complexity of the issue of chronic mental illness, both at a societal and an individual level. It is anticipated that this report will facilitate student-faculty discussion and promote sensitivity to the needs of this population.

The project faculty wish to thank the high-rise residents and staff persons who participated in this study. Also, we are grateful to Tom Anding, the Associate Director of the Center for Urban and Regional Affairs, for his invaluable assistance in planning for these reports.

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An Overview of the Issues and Services Related to Chronic Mental Illness

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Background

More than two decades have passed since President Kennedy's historic 1963 message to Congress about the need to redirect and intensify this nation's commitment to the mentally ill. Subsequent legislation contained two goals: 1) the treatment and rehabilitation of the mentally ill within the community and 2) the promotion of mental health in general.

In the ensuing years, numerous strategies aimed at prevention and treatment of mental illness have emerged. Psychiatric conditions long considered to be chronically dysfunctional have yielded to pharmacological, social, and/or psychological interventions. The American mental health system has been profoundly altered as the locus of care shifted from large distant state hospitals to smaller mental health centers located in the midst of dense populations. However, there is evidence that the problems encountered by the mentally ill may have been exacerbated in the shift from the institution to the community. Maintaining a supportive network of mental health services in the community has been jeopardized by continuing funding problems and an ongoing lack of public understanding regarding the problems of the mentally ill. (Stein and Test, 1978).

The range of services that chronically mentally ill (CMI)* persons may at times need is broad and includes assistance with socialization, medication, and finances. These services may or may not be available in the community at any given time. Efforts at follow-up and support must

*Chronically mentally ill will subsequently be referred to as CMI for the remainder of this report.

be sustained to prevent lost human potential. A large number of CMI persons live in community residential facilities not geared specifically to deal with their problems. The accessibility of needed services is a central issue. Even when services exist, negotiating a connection to the system is complex because the services are removed from the everyday living situation of individuals (Lamb and Peterson, 1983). This report examines the connection between need and service availability, within four Minneapolis high-rise settings.

Literature Review

The term chronically mentally ill refers to persons who, by reason of severe and persistent mental disorder, experience serious functional limitations in aspects of daily living such as personal relations, living arrangements, and employment. They tend also to have problems with thinking, perception, attention, mood, and affect. These persons may or may not have previous histories of institutionalization.

About two million CMI persons live in the United States. Ninety-three percent of them now live in the community (Bachrach, 1983). Research shows that chronically mentally ill persons tend to live in smaller networks, to have a greater proportion of their energies consumed in kin relations, to have intensely negative or ambivalent kin relationships, to have fewer social roles with higher density, and to have few long- term relationships except with kin. There is very little multi-dimensionality or reciprocity in these relationships (Cutler, 1983). It follows that knowledge of these characteristic social variables and limited social networks would be highly useful in providing any meaningful intervention for this population.

Environmental variables found to be important in influencing successful adjustment to a community residence include its size, the atmosphere of social support and involvement, neighbor response, and the amount of stimulation and expressed emotion (Test, 1981). Many CMI persons lack the financial resources and/or the instrumental skills to meet their basic needs such as adequate food, clothing, shelter, and health care. Supplemental social security income (SSI) and Medicaid or Medicare are the most common forms of special financial assistance available to this population. However, there are problems with this type of assistance. For example, not only do social attitudes regarding public assistance place recipients into an ambiguous situation, the income received may not meet basic physical needs. Problems with aid include disincentives for work, stigmatizing effects of mental illness, and insufficient income to ensure acceptable quality of life with adequate health and mental health care (Test, 1981).

Goals for successful treatment of CMI persons go beyond decreased hospitalization and reduction of symptoms. The goal of integration into the community includes ensuring a decent standard of living as well as optimizing social and role functioning (Test, 1981).

The usefulness of certain psychotropic medications in the reduction of symptoms and the prevention of relapse is well documented. However, these drugs do not always improve social functioning and frequently have uncomfortable and sometimes toxic side effects. Monitoring individual response to these prescribed drugs is essential to ensure their accurate use in the lowest therapeutic dosage (Test, 1981). Medication management is still a major roadblock to successful maintenance of clients in the community (Mirabi, 1984). Serious effort should be made

to assist CMI persons to understand their own medications and their role in managing their illnesses.

To provide effective assistance, a public mental health system must have a comprehensive range of services to meet multiple needs within a variety of living arrangements. To be relevant, the service should address issues of culture, socioeconomic status, and age. They need to be accessible and not overly restrictive of individual freedom (Mirabi, 1984).

The chronically mentally ill may need assistance to make a connection with the system of formal care and the informal support network of family, neighbors, and friends. Such assistance must take into account potential limitations in this network. Family involvement may range from active assistance to total abandonment. The long term nature of the illness discourages consistent involvement by neighbors and friends. In the formal delivery system, mental health professionals are often more accustomed to working in a centralized location than in residences not specifically designed for CMI clients (Test, 1981). One unanswered question remains: Who is the most appropriate person to assist with the connection to these services?

The literature supports the position that services specific to this group must be available on an ongoing basis. Numerous studies have shown that without services and monitoring, positive progress is easily lost, resulting in recidivism and loss of gains in social functioning (Stein & Test, 1978). Concepts of "cure" need to be exchanged for ones connoting long-term disabilities requiring possibly lifelong supports. These clients have unique characteristics and needs requiring a particular approach to intervention (Test, 1981). In order to

facilitate our understanding of the ideas presented in the literature and how they apply to individuals in the local setting, three interviews of high-rise residents were undertaken. Summaries of these interviews follow.

Case Studies

Art and Anna*

Art is a 69 year old white male and Anna is a 67 year old white female. They have been married for over ten years. They were married one month after her release from a state hospital. They met and dated there for 19 years. Anna entered a state hospital at age 24 for schizophrenia and had insulin shock therapy shortly after arriving at the hospital. Art was released from the state hospital twenty nine years after admission, one year prior to Anna's release. During the ten years since his release, he has worked in a sheltered workshop, has lived in a halfway house, and most recently has been residing in the high rise for several years. The couple currently has no active family involvement in their lives, but they do return to the state hospital for vacations in order to visit friends and acquaintances.

The day of the interview with this couple, there was confusion in the apartment. Although an appointment had been made, the interview was complicated by the presence of other agency personnel and questions being raised about movement to a more supervised living situation. This caused dissension between the couple because Anna did not want to move

*Names have been changed to protect confidentiality.

and leave her two best friends while Art wanted to move as he did not feel safe in the high rise. He described having a knife held at his throat in the elevator and attempts by younger men in the complex to seduce his wife. He worried too because they had often found their apartment door open after being gone and remembered having carefully locked the door before leaving.

Art felt that the social worker was a nice man and very helpful, if one could ever get to see him. He felt that there were way too many people needing help for one man to handle part time. He was pleased about the interactions with the nurses that he saw in the building. He felt the high rise resident council meetings were useless, because there was no power to change anything.

Anna told me that she was on five medications. She named and sorted her medications from a common container. She set up a day's supply and explained what she should take and when. Both utilized their own private and separate physicians. She made sure I knew that it was not a psychiatrist, but a general practitioner that prescribed psychotropic medications. She had a prior history of overdose and suicide attempts. On one occasion she experienced seizures and was hospitalized after not taking medication. Instead, she had been selling her medication to another resident in the high rise. She described occasional hallucinations, but indicated she had control over them.

The following problems were identified in this couple's management of their daily living situation. Frequently, the couple was not at the apartment when the home health aide came. Access by service providers was further complicated by the couple's reluctance to share their phone number or have their name listed on the building directory at the

entrance to the building. There is question regarding accuracy of taking medications and abusive fights between the couple necessitating outside intervention.

Paul

Paul, a 66 year old white man, felt the high rise apartment complex was a palace. Previously he had lived in a two room apartment on Hennepin and Lake with his mother, who was now in a nursing home. He walked every day to see her there.

Paul described his lonely life and his depression. He saw getting out of the apartment complex everyday as what kept him going. He described at length the visits to his mother, the isolation in the nursing home, his extensive planning of his social activities by reading the Senior Pages published by Senior Resources, his fear of not managing his money according to government guidelines and the possibility of getting in trouble with the government.

He too felt it was necessary to handle any complaints about actions in the building himself, that there was no one he could depend on, that it took two months for someone to fix the clogged sink and one month to get a new window shade that did not fit. He refused to raise or lower the shades for fear one would break.

He felt very positive about the counseling he had received about SSI from the Mental Health Center downtown, even though he thought the center should be in a nicer building, so it would not depress one to go there. He felt that the social worker in the building was good, but inaccessible because too many people needed to see him. It made him feel unimportant and left out. He did indicate that he knew exactly

where in the Hennepin County system to call if he was really having difficulties.

The apartment was cluttered and messy; he kept apologizing for this and repeatedly told me that the "expensive" cleaning lady from Allied Health Maintenance was coming that afternoon to "clean up the place." He avoided social gatherings in the apartment lobby area because of the "gossipy nature of the people." He made repeated references to being alone in the world and fear of mismanaging his money and "getting into trouble with the government."

Sam and Bertha

Sam and Bertha are a married couple, ages 56 and 65 respectively. They live in a one bedroom apartment and are very proud of the possessions they have been able to acquire on time through their Sears charge account and the catalogue. Both individuals were married prior to this marriage, which occurred in 1970. They met through answering a mail order ad. Sam went to Madison from Minneapolis to meet Bertha and they were married 5 weeks later.

Bertha has 4 children from a previous marriage. Her first episode of psychosis was in 1957. She spent months in a state hospital after that first illness. When she returned home, her previous husband would not allow her to take any medications and soon she was ill again. After the next hospital admission, her children were taken away and her husband did not want her. She admits that without medication she could not care for her children. She lived with a boyfriend for a while, who would also not allow her to take medication. She said finally her

father took her home to live with him and made sure that she received her medication. During this time, she met Sam.

After their marriage, they moved to Minneapolis, where Sam worked as a dishwasher until he retired. Both describe periodic episodes of Bertha getting sick and having to go to the hospital where she received shock treatments and/or medication. The nurses there told him how to give Bertha the medicine and instructed him to take care of Bertha. He considers that his most important task in life. They take the bus wherever they want to go. Bertha sees a psychiatrist and a nurse at a community center on a regular basis for counseling, receives her Haldol injection, and instruction on medication management. She is presently on many medications, indicates that she feels pretty good, and is not having depression and/or problems with hallucinations. They both felt confident about their ability to contact mental health professionals if needed. Both understand Bertha's necessity to consistently take her medication to be able to function, and the need to get help from the mental health nurse at the clinic or hospital if some complication arises.

Sam and Bertha desire to move back to Madison as their dream and to "get out of the terror of living here." When pressed for an explanation about this, both relayed Bertha's experience of being assaulted in an upstairs apartment, the couple's reluctance to press charges for fear of further recrimination, and Sam's difficulty in getting along with the other tenants. He seems only to see his side and chooses to withdraw from social interaction as the way to cope. Bertha has decided that she will not always stay home because of Sam's difficulty with people, and attends building social events she chooses.

Both Sam and Bertha like to talk at the same time with Sam attempting to monopolize the conversation with a louder voice. Careful communication was necessary to complete an interview that yielded the impressions of both individuals. It is obvious that this couple has positive regard for each other and depends tremendously on each other.

Interviews with Agency Professionals

Mary Huggins - Hennepin County Mental Health Program Specialist

Hennepin County has 40 programs, of which 20 are administered directly through Hennepin County and twenty are contracted with other agencies.

One can enter the Hennepin County mental health system by committment, voluntarily, or by referral. One is then assigned a case manager. The case loads are high and if a voluntary client refuses service, the case is closed. Hennepin County has 1500 people in its program with 32 or fewer people to do services; this means at least 60-person case loads which is very heavy. It is frequently difficult to locate clients because of geographical mobility.

Hennepin County has interagency agreements with Senior Resources, a social service agency providing case management for those clients 60 years and older, living independently in the high rises. The social workers seem to be overwhelmed with the needs of the CMI population in these settings.

Nursing plays a small role in community mental health in Hennepin County. There are four nurses employed at the Mental Health Centers, two at Circle F, one at Day Treatment and one at West Suburban. Ms. Huggins, based on her experience with mental health nurses in Chicago's Cook County, respects the expertise of nurses and wishes her budget allowed her to employ more.

Betty Ortman, R.N. - Nursing Support Services

(This is representative of a private agency which is contracted for service through county preadmission screening.)

Nursing Support Services provides home care for personal care and housekeeping. This agency is a part of Allied Health Maintenance which also provides child care, technical services, medical receptionists, dental hygienists, physical therapists, occupational therapists, and homemaking. The services of this agency are usually hired privately, for a flat fee or a sliding fee scale.

Referral is through pre-admission screening, a Hennepin County project that provides home care to persons 65 and over to keep them out of nursing home situations. Pre-admission screening sets the fee rate that Nursing Support Services can charge Hennepin County residents.

The screener meets with clients every six months. The Nursing Support Services RN visits the client home every 2 months and calls the client on the alternate month. A home care aide provides care in the home to one case study client 2 times/week. She fills out an activity sheet and phones the case manager RN if there are any problems or new developments. A homemaker cannot do any personal care, only light housekeeping. A home health aide/homemaker is a certified nursing assistant and may provide basic physical care..

Patti Manion, R.N., Clinical Supervisor - Metropolitan Visiting Nurse Association

The Metropolitan Visiting Nurse Association is a public health nursing agency serving the city of Minneapolis and suburbs which provides generalized care including health promotion and care of the ill

and disabled in the home. (They serve residents in the high rises.) Very few CMI persons are referred to MVNA. Many CMI persons are in board and care facilities in south Minneapolis and are usually seen only for medication compliance or Prolixin injections. Ms. Manion feels there are a lot of mental health problems that remain unattended and the difficulty comes with reimbursement policies. MVNA is reimbursed from third party payors for a category of "sick and disabled". This means health care resources must pay for medically diagnosed conditions e.g. diabetes. Therefore, if a CMI person also has a medical diagnosis, they could be seen by this agency. It is MVNA's hope that more of the current needs of the CMI population will be documented by the nursing students in the high rise apartment complexes.

The MVNA can now intervene through the Life Enhancement Program, offered by the University Minnesota nursing students and by referral to MVNA nurses by U of M students. Depression has been clearly identified as a significant problem in the high rises. If a client becomes or expresses suicidal comments, a referral is made to a Mental Health Center and then a home visit can be made. The nurses see many residents having trouble coping with daily concerns and direct their efforts in obtaining more services for these residents.

The MVNA employs mental health nurses who may see clients for mental health needs, but generally only on a short-time basis due to lack of third-party reimbursement for that type of care. Both Medicare and Medical Assistance only provide reimbursement for clients with a psychiatric diagnosis who are under the care of a psychiatrist and who are taking medication. Therefore the MVNA mental health nurse is more involved in promotion of mental health and really does not do

psychiatric nursing except under the brief circumstances outlined above. If the nurses do see a client for a short time, the only reasonable goal is to link the client up with some other medical care provider or referral to available reimbursable care. There is a need to provide more comprehensive nursing service to the CMI population.

An additional problem of providing nursing service to a general CMI population is MVNA's funding priority given to high risk parenting problems. This priority competes with the chronically mentally ill population's need for services because of staffing limitations. To further complicate nursing service to the CMI population, health promotion follow up cannot be provided to CMI individuals without a physician's order. Also, help offered is often rejected by prospective clients because of the nature of the illness or lack of trust in professionals. It has been pointed out by public health nurses that psychiatrists are difficult to communicate with because they cannot share information or will not return calls. Confidentiality and conflicting treatment goals among different disciplines are also issues.

Joe Ingram - Social Worker for Senior Resources in the High-Rise Apartment

To live in a high rise, the clients must be able to live independently with supportive services, as necessary. In one building there are 137 individuals over 60 and 146 under 60. At this time, J. Ingram is contracted to give direct service only to the over-60 clients and to provide information and referral for those individuals under-60, but without direct service. However, that is unrealistic, as many of

the under 60 and those who are CMI also need assistance. (Since these interviews were completed, Hennepin County has made a social worker available to residents under 60 in this building.) Many of these individuals have been abandoned by their families. Individuals are supposed to be screened before entering the high rise apartments for criminal and psychiatric histories. However, many people refuse to reveal their histories. Often the way a worker learns of any history is after deleterious behavior is exhibited. Only at this point is a worker notified or a referral made to the mental health section for a worker and some followup. J. Ingram works frequently with the housing service representative.

Many of the older inhabitants do not see the younger CMI individuals as disabled. They are fearful and just do not come out of their apartments, especially the old and frail. J. Ingram cannot technically counsel or treat the younger CMI's. However, other residents drop into his office and will pass on information and complaints. He states that U of M nursing students are an invaluable source of information as they provide him with selective information that can allow him to help people. They make assessments, have case conferences, and make recommendations. He feels the students view the residents wholistically, spend time with them, and find out about their medication and their problems and concerns. The nurses also obtain some referrals through informal networks in the building. This naturally encourages nurses to be invited into the apartments where the social workers have limited access except by invitation. During crisis, invitation is not the usual mode of behavior. According to J. Ingram,

one of the most important problems regarding the CMI population is that of medication compliance.

J. Ingram explains that he continues to encourage group activities that will address common interests. Attendance is sporadic and he considers it a success if three people attend. He feels it would be helpful if there was a mechanism available for more follow-up after hospitalization, more release of information that will directly affect someone's adjustment and survival in independent living situations, and some way of tracking an individual's psychiatrist. This would save time and duplication of effort in time of crisis.

In the high rise setting, current policy dictates that housing is not authorized to get more information regarding background and past problems that would affect eligibility to live in a high rise setting. Considering the nature of the issues and problems that arise, a social worker contracted to provide service 2-3 days a week only to those 60 and over is not adequately meeting the needs of the total resident community.

Conclusions

The exploration of the issue of chronic mental illness in a selected high rise population yielded information indicating that the structures to serve the chronically mentally ill population in the public high rise buildings were generally available in Hennepin County. However, a gap exists regarding access to these services for individuals who live in independent, unsupervised residences. Systematic follow-up for chronically mentally ill individuals within these high rise buildings is necessary.

Increased involvement of CMI individuals in the community life of the high rises may help reduce isolation and fear. Linkages of formal and informal social support systems where information can be exchanged seems crucial to this successful integration of the CMI population into public high rise residences.

Future Directions

This report points to the need for a systematic follow-up form of care for chronically mentally ill individuals. Less clear is who is the most appropriate type of personnel to provide this care? A coordinator of care is usually required; an individual or team who can indefinitely be the client's contact to the formal and informal systems of care. It may be that existing support systems (e.g. families, friends, neighbors) are the most appropriate coordinators of care. The dominant role of professionals in these situations would be in recognizing the inherent strain on natural helping relationships for the CMI population and providing support to these caregivers. In other situations, a professional coordinator may be the most appropriate. Essential to the continuity of care is a decision-making and planning process which incorporates all members of the client's network.

Optimal functioning for the chronically mentally ill may connote long term disabilities requiring lifelong supports. The treatment goals may be maintaining current strengths rather than curing disabilities. Goals must be individualized, realistic and provide for network supports to be activated when necessary. Future research needs to address whether mental health professionals actually accept maintenance as a treatment goal and whether they systematically incorporate network

supports into treatment plans. Another issue that needs to be addressed is the relationship of confidentiality and the need for information in a crisis situation.

The educational directions for students related to the CMI population are numerous. Because of their frequent on-site availability, nursing students are in a unique position to interact with residents in the high rise. Nursing students possess knowledge of both physical and emotional behavioral variables and can assist residents and families in decision making regarding appropriate treatment possibilities and living situations. It is our belief that students of nursing require direct experience with chronically mentally ill persons in order to understand the multiple factors that influence behavior. Hopefully, attitudes stigmatizing the mentally ill can be reduced through this experience. Students can be assisted to assume a stronger advocacy role for these individuals. Students conduct programs within the high rise environment sensitizing residents to a variety of individual needs with the goal of integrating the chronically mentally ill population into the community setting. On a social policy level, students can participate in political strategies aimed at program initiatives necessary for social change relevant to this population. These experiences, we believe, are vital in achieving both educational and service objectives.

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