MEASUREMENT OF THE INCIDENCE OF CHRONIC SEVERE SOCIAL BREAKDOWN SYNDROME

HAS THE DUTCHESS COUNTY SERVICE BEEN ASSOCIATED WITH A DECLINE IN INCIDENCE?

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"Any fool can ask a question; the trick is to ask one that can be answered."[1]

Perhaps the greatest difficulty in the field of psychiatric research lies in "setting meaningful questions and technically satisfactory indicators."[2] The aims of a mental health service are frequently described in such general terms as "improved mental health of the community" but, as MacMahon and Pugh have indicated,[3] this is as useful a concept as "positive genital health" would be to a program of venereal disease control.

Hospital admission or discharge rates are of limited value as indicators of success and failure, since they can be so easily manipulated by administrative measures and their manipulation is sometimes (as in Dutchess County) seen as a *means* of achieving more important goals. Rates of suicide, marriage breakup, crime, and clinic attendance are subject to so many factors which are difficult to control that they are of limited use in the evaluation of a program.

Realistic evaluation requires specific definition in three areas: First, the service or activity to be provided should be described; second, its ultimate objectives must be specified; and, third, the population to be benefited must be defined.

Evaluation research requires, in addition, instruments to determine whether or not the predicted modifications occur in the defined population. It is desirable to apply the same instruments simultaneously to a comparable population which has not had the services that are

being evaluated. Sometimes this is not possible and the population studied must serve as its own control by showing changes over the course of time. Because of the difficulties involved in delimiting comparable populations, the latter method is easier.

THE COUNTY

Dutchess County is located about 90 miles north of New York City, halfway to Albany, and is one of a strip of counties lying between the Hudson River and the Connecticut border. Its population is a mixed urban-suburban and rural one, currently estimated at a trifle over 190,000 by the Office of Biostatistics of the New York State Department of Health.

Nearly 90 per cent of the population of the county resides in a fairly compact area along the river, the traditional line of communication. The railroad and the highway pattern have followed the same Hudson River Valley which provided the earliest transportation route. Most of the population lives within half an hour's drive of the Hudson River State Hospital, which is located in the outskirts of Poughkeepsie, the densest population concentration in the county.

There are other psychiatric facilities in the county. The Harlem Valley State Hospital, with approximately 5,000 patients, lies on the eastern border of the county near the Connecticut line. While it is within the county, most of its patients are not of the county, in that most of them are admitted from Westchester County and New York City. In 1959, Harlem Valley State Hospital received less than 10 per cent of the Dutchess County mental hospital admissions. Its hospital staff are additional resources, especially for some outpatient work in the community.

Near Harlem Valley, also in the eastern part of the county, is the Wassaic State School for the Retarded, with over 4,000 patients. They also carry on some community activities in addition to their inpatient work.

There is an All-Purpose Psychiatric Clinic centered in Poughkeepsie under the auspices of the County Mental Health Society, financed jointly by the county and by the state under the New York State Community Mental Health Services Act. It functions as most such clinics do, and it has all the usual problems and policies, including a lengthy waiting list.

There are four voluntary general hospitals, none of which had any psychiatric beds until one of them began to operate a small unit in October 1962.

The sheltered workshop in Poughkeepsie admits no psychiatric patients at present. There are no municipal hospitals, no county or city hospitals that provide anything equivalent to Bellevue in New York City or Meyer Memorial in Buffalo.

The Hudson River State Hospital currently cares for a little under 5,500 patients. In 1958–59 it admitted 1,543 patients, of whom 453 were Dutchess County residents. This hospital serves a long narrow district of eight counties, stretching from Lake Champlain to the border of New York City.

It is a fairly old hospital, opened in 1871, and is a museum of American asylum architecture, with buildings scattered over a thousand acres, stretching roughly four and one-half miles from one end of the grounds to the other.

The hospital was organized on the traditional American pattern of services filling specialized functions. There was one central reception service to which all new patients were admitted, a tuberculosis service, an infirmary service, a diabetic service, and a specialized building for 750 regressed female patients. Indeed, there even used to be a special building for disturbed and suicidal patients. While that has been largely broken up, the hospital continues to have whole wards and whole buildings designed to take care of one particular behavior classification.

THE SERVICE PROGRAM

The Dutchess County Unit was set up within Hudson River State Hospital in January 1960, to provide a comprehensive and integrated treatment service for the mentally ill of Dutchess County. The concepts underlying this emphasis on decentralized, integrated, small, open and community-centered services providing flexible and continuous care can be traced through a series of Milbank Memorial Fund conferences.[4–14] The participants believed that this type of service represented a needed change from traditional patterns, one which would result in better and more humane care for the psychiatrically ill, improved acceptance of mental illness by families and the community, and the avoidance of adverse effects of institutional residence.

THE GOALS

The main rationale for the unit was summarized as follows by Robert C. Hunt: "While we do not have the knowledge to enable us to prevent the occurrence of serious mental illness, we do have on our hands an enormous burden of disability associated with psychotic mental illnesses."[5] Elsewhere, he emphasized that this disability is only partially intrinsic to the illnesses and that multiple extrinsic factors, originating in traditional cultural attitudes toward the mentally ill, produce further disability. Erving Goffman has vividly described the adverse effects which may result from confinement in a total institution,[15] and D. V. Martin[16] and Russell Barton have offered clear clinical descriptions of the disability known as "institutional neurosis."[17]

The American Public Health Association's (APHA) *Guide to Control Methods for Mental Disorders*[18] groups the secondary effects referred to by Hunt under the heading of "social breakdown syndrome." This syndrome "is one type of mental malfunctioning which occurs in many different chronic mental disorders, particularly schizophrenia, mental retardation, and various organic psychoses . . . it is responsible for a very large part of the institutionalized mentally disordered and for much of the other forms of extreme social disability seen in these illnesses. This form of mental reaction, in the presence of mental disorders, is largely a socially determined reaction pattern which the committee believes can be identified as a major target for community mental health programs today."

The APHA Guide describes the social breakdown syndrome as follows:

> Many mental disorders, particularly the psychoses, both functional and organic, are frequently accompanied by distortions of personality functions which are associated with more or less severe destruction of the affected person's social relationships. These reactions can be viewed as following one of three patterns, (a) withdrawal, (b) anger and hostility, (c) combinations of these two. While we are ignorant regarding some features of this syndrome, clinical experience has shown that the frequency of the syndrome depends upon the social setting and the way in which other people and social institutions, including medical facilities respond to the underlying disorders. . . . The outstanding advances in the control of mental disorders in recent years derive from the gradual recognition that this syndrome can be prevented or modified.

The Dutchess County psychiatric service was explicity intended to reduce the secondary disability associated with mental illness in the

population of the county. This is the setting for the evaluation research: a comprehensive community-oriented unit whose objectives are to provide continuous, flexible psychiatric care for the population of Dutchess County in such a way as to reduce secondary disability among the mentally ill people of that community.

Indices of Success

How should the evaluation of this service be conducted? We have not been concerned with what Hutchinson[19] describes as the intermediate objectives of technique. It has not been part of our function to question whether the Unit provided adequate, comprehensive, flexible, and continuous service. We have been concerned with its ultimate objectives, the reduction of secondary disability.

What are the appropriate bookkeeping measures for such an operation? Hospital admission and discharge rates are not good indicators of achievement. The Unit was specifically planned to encourage free access to the hospital by the community—in contrast to the Worthing Experiment,[20, 21] there was slight emphasis on avoiding hospitalization. Ease of admission or readmission was a stated policy, and this easy admission was to be accompanied by early evaluation, treatment, and return to the community. Early release, even when active symptoms remain, was expected, with easy and informal return to the hospital.

Clearly a unit which facilitates easy return may expect a rising readmission rate, and such factors as increasing community acceptance may result in a rising first admission rate. The percentage of admissions that become cases of long-term hospitalization might be expected to remain static, or even to fall, in spite of no change in the rate with which cases with such an outlook arise in the population of Dutchess County. This could occur because rising admission rates can be expected to include a growing proportion of mild cases with favorable prognosis.

Twelve months' continuous retention is a convenient definition of long-term hospitalization. Since the population served by the Dutchess County Unit has been clearly specified, this population provides the appropriate denominator for computing an annual incidence rate of long-term hospitalization. The incidence of long-term hospitalization per 100,000 population served by the Unit can be used to measure the Unit's achievement. However, even this rate could be manipulated by administrative actions to conceal the presence of chronically deteriorated patients. Repeated short-term discharges may prevent enum-

eration of some of the patients as cases of continuous hospitalization.

A more direct approach to the evaluation of results of the new service is the effect on the incidence and prevalence of severe chronic social breakdown syndrome (SCSBS). Does the function of the unit reduce the incidence and prevalence of severe chronic social breakdown syndrome in the community?

How can we determine the frequency of social breakdown syndrome in the community? Can an operational definition be devised which can be used for case identification in the community and in the hospital? The characteristics of the syndrome have been described in a number of papers and discussions.

THE METHOD

Using these criteria described for identifying a case of severe social breakdown syndrome, we would like to determine the point prevalence of this syndrome in the entire population at risk. However, to question every resident of Dutchess County was beyond our resources. We chose to examine that segment of the population believed to be at greatest risk of developing secondary disability associated with psychiatric illness. It was assumed that almost all those who suffer from severe chronic social breakdown syndrome associated with psychotic disorder at some stage become hospitalized.

It was, therefore, decided to prepare a register of all Dutchess County residents who had sought psychiatric treatment after April 1, 1955 at Hudson River State Hospital, Hudson River State Hospital Day Care Center, the All-Purpose Clinic, Veterans or registered private hospitals. Preliminary studies soon revealed that the yield of cases of severe social breakdown syndrome was small among those currently or formerly hospitalized and virtually nonexistent among those who had received only outpatient services. Also, the characteristics of those using only outpatient services were very different from those hospitalized, with few psychotic patients in the former group, most of whom were still functioning in jobs and maintaining a role in the community.

As a result of preliminary experience, it was believed that a close approximation to the prevalence of severe chronic social breakdown syndrome in the population would be obtained by using hospitalization at any time since April 1955 as a screening device to determine who should be interviewed.

Several decisions were made regarding the method for measuring the prevalence of chronic disability due to mental disorders in the population of Dutchess County. Psychiatric hospitalization since 1955 was to be used as the first screen. Then the level of disability of every person in this group must be appraised at one point in time. But abilities and disabilities are not manifested in a moment of time. An individual's functioning in relation to himself and to his immediate and larger social environment is manifested over a period of days; one cannot appraise the disability of a person who is sleeping. A man who is disturbed and aggressive has moments of rest and tranquility. Variations in functioning under ordinary living conditions are important. A 24-hour appraisal is inadequate since certain work, recreational and social functions do not occur every day; therefore, the concept of a point in time was modified to consist of a week of time—seven consecutive days.

Organizing Data Gathering

To ascertain the level of disability of each individual in a large group during an arbitrarily selected single week would have made demands on personnel which we were unable to meet. Since, however, the week of the individual's life which was to be used to sample his level of functioning or disability was to be arbitrarily chosen, using different weeks for different people would not be expected to affect the results, provided each person's week was randomly assigned.

Since the population to be screened was defined as those individuals who were registered as having been in a psychiatric hospital at some time since 1955, the register was divided into 10 groups. Each individual was allocated to a group on the basis of the terminal digit of his state identification number (or, when this was not available, the first hospital number assigned to him). Each group (10 per cent of the register population) was assigned to a unique five-week period during which each member of the group was to be screened for the presence of severe social breakdown syndrome. The interviewer was instructed to ascertain the patient's level of performance in the seven days prior to the interview.

This method spread the work out in time. Since each interview dealt with the seven days immediately preceding the interview, recall error was reduced, and since the whole register population was included, sampling problems were avoided. The groups were a device to spread the work load randomly.

The resulting point prevalence of severe social breakdown syndrome forms the basis for determining the incidence and prevalence of *chronic* severe social breakdown syndrome (*see* Appendix 1). Any individual identified as exhibiting the severe social breakdown syndrome is re-examined to determine the time of onset of this spisode of disability. Each 10 per cent register group produces its own cases of chronic social breakdown syndrome. Summing up the results from all the groups gives a more reliable estimate of point prevalence and annual incidence rates.

Ideally, these measures would be obtained annually over a number of years and the changes in prevalence and incidence related to the community program. By January 1963 the methods of case ascertainment were developed to an adequate level. Data were gathered during the subsequent 15 months.

Through our follow-up procedures we have identified all cases of severe social breakdown syndrome who were, at the time of their interviews, or became in the 12 months following, examples of chronic severe social breakdown syndrome. For each such case of chronic severe social breakdown syndrome we have identified the year of onset. By "onset" we mean the year in which the individual first met the criteria of severe social breakdown syndrome, whether or not he was in treatment.

FINDINGS

1. At the time of preparing this paper, the five groups scheduled for interviewing between January 1 and June 30, 1963, and the three groups scheduled for interviews from January through March 1964 had been followed sufficiently to enable us to make preliminary estimates regarding the average annual incidence of severe chronic social breakdown syndrome among Dutchess County residents and to provide some evidence as to whether the anticipated decline in annual incidence has, in fact, occurred.

The first five groups scheduled for interview in 1963 provide a direct measurement of the annual incidence during the 12-month period immediately preceding each scheduled interview. For each case of severe social breakdown syndrome found to prevail during the week preceding the interview, data were obtained regarding the time of onset of that episode of severe social breakdown syndrome. If onset was less that 12 months previous, the case was then followed until it had either lasted for over 12 months or had terminated. Cases lasting over 12 months following the onset date were counted as chronic

cases. Consequently *all* cases with onset during the prior 12 months which lasted 12 months or longer theoretically were counted. (Persons who were not interviewed, persons who succeeded in deceiving the interviewers regarding their functioning, and persons who had developed the chronic severe social breakdown syndrome without having been registered as having inpatient psychiatric treatment since 1955 were not ascertained. They remain potential sources of error.)

These five groups yielded 24 cases of *chronic* (over 12 months) severe social breakdown syndrome with onset during the 12-month period prior to the time when each was scheduled for a 1963 interview. These 12-month intervals started as early as January 1, 1962 and as late as June 30, 1963. Since these five groups were presumably not different from the five groups scheduled for interview in the last half of 1963, we may estimate that twice the number of chronic cases, or 48 cases, will emerge from analysis of the whole list of present and former inpatients whose first psychiatric contact occurred between 16 and 64 years of age. Since the estimated population aged 16 to 65 years of age in the study area is about 100,000, we conclude that the annual incidence of chronic severe social breakdown syndrome was in the neighborhood of 48 per 100,000 in 1962.

The annual incidence in the previous two years was not measured directly, since 1963 was the first year for which the register population was interviewed. At the time of interview in 1963 these same five groups yielded 21 chronic cases with an onset in the calendar year 1960 and 20 cases with onset in 1961.

From these remnants of the chronic cases starting during 1960 and 1961 it is possible to estimate the number of new cases which arose in those two years, if certain assumptions are made.

Some episodes of chronic severe social breakdown syndrome must terminate in their second and third year of existence. Some cases die, some recover, some may even migrate out of the population. In order for 21 cases with onset in 1960 to remain, a larger number of episodes of one year's duration must have started in 1960, for each one found in 1963 had lasted two and one-half to three and one-half years. Those with onset in 1961 had lasted one and one-half to two and one-half years at the time they were found.

An estimate of the rate at which chronic cases terminate can be derived from data for cases prevailing in the three groups interviewed from January to March 1963. The status of these cases is available through March 1965.

These three groups in 1963 showed 14 cases from 1960, 11 cases from 1961, and 13 cases from the 12-month periods preceding the 1963 interviews. A year later six cases remained from 1960, eight remained from 1961, and seven remained from 1962. Thus, during this 12-month period 17 of 38 prevailing cases terminated. (At least four of these recovered and most of the rest had died in the interval.) Of the 15 cases still prevailing in 1964 with onsets in 1961 and in the 12-month periods preceding the 1963 interviews, 11 were still prevailing in 1965. In the same three groups, 11 cases had onset of chronic episodes in the 12 months preceding their 1964 interviews (onset in 1963). Of these, at least seven had terminated within a year after finishing the first 12 months' continuous low-level functioning.

From these data one can infer that about a third of the chronic cases terminate within a year after becoming chronic, and that over a two-year period their number is about halved.

Since 21 and 20 cases with onset in 1960 and 1961, respectively, remained at interview January through June, 1963 for the five groups, the number starting chronic episodes in those years must have been considerably higher, at least 30 and perhaps 40–45 in each year. Consequently, the 24 new cases observed with onset in the 12 months prior to the 1963 interview dates were at least matched in 1960 and 1961, and are more likely to have been exceeded by one-third or more, even twice as many.

2. On comparing the admission figures during the period April 1960 to March 1962 (Patton's Table 2) with the diagnostic categories of the 62 chronic severe social breakdown syndrome cases prevailing in 1964 (three 10 per cent groups), some interesting suggestions emerged.

Fourteen per cent of the patients admitted to the hospital were diagnosed as psychoneurotic, yet none of these was retained continuously in the hospital for more than 12 months and no case of CSSBS was found in this diagnostic category. Affective psychosis accounted for 9.4 per cent of admissions, and only 3 per cent of these experienced 12 months continuous hospitalization, accounting for 2 per cent of all those who had such experience. Affective disorders accounted for 4.8 per cent.

On the other hand, schizophrenia accounts for 10.7 per cent of all admissions; 5 per cent of these patients experience a 12-month episode of hospitalization, making up 4.3 per cent of those who did so. Despite this low retention rate, schizophrenia accounts for 40 per cent of those who become cases of chronic severe social breakdown syndrome.

First, cases of recent incidence should be well represented in current prevalence, while cases with onset in earlier years would tend to be less well represented because some will have recovered, some will have emigrated, and some will have died. The population listed in the county register increases every year because of rising mental hospital admission rates. Consequently the probablity of a case of chronic severe social breakdown being missed because of absence from the register is presumed to be decreasing.

Second, since the number of chronic severe social breakdown syndrome cases found by this procedure is exceeded by the number of people scheduled for interview but not interviewed, it is possible that newer cases avoid interviews more successfully than long-standing cases. From what knowledge we have about the uninterviewed cases, we do not believe that this has occurred but the possibility cannot be eliminated.

Third, the assumptions made about termination rates (compounded of recoveries and deaths) derive from experiences in the later years of the project. It could be that recovery rates have improved and that, in fact, there were not so many new cases arising in 1960 and 1961 as we have estimated.

Fourth, a small proportion of cases has required the exercise of judgment in assigning a time of onset to the episode from the available evidence, and a smaller proportion has required judgment because the evidence available described an individual whose functioning was very close to the specified boundary line. It is conceivable that a systematic bias toward assigning earlier years of onset or toward accepting a case as severe if its onset was earlier has entered into these judgments, despite earnest efforts to eliminate any need for such judgments and our impression that no such bias existed.

The evidence that the Dutchess County Service Program development corresponded in time with a decline in incidence of severe social breakdown syndrome does not provide proof that this service development actually produced a lower incidence of this serious condition. It is possible that a general secular trend is occurring throughout the

country and that the demonstration services simply coincided with this falling incidence. Judgments on this possibility will vary, but further evidence on which to base such a judgment will depend on obtaining comparable evidence regarding the incidence of chronic severe social breakdown syndrome in other populations, preferably similar populations with quantitatively adequate services not organized in the integrated fashion used in Dutchess County.

Fifth, diagnostic groups at admission to hospital show different risks of subsequently developing SCSBS, and these risks do not correspond to the risks of becoming long-term hospital cases. It is of particular interest to note that schizophrenic cases account for less than half the SCSBS cases, organic psychoses accounting for about one-fourth, and the other cases arising from other miscellaneous diagnostic groups. These results indicate that further analysis of the data in terms of relative risks of different diagnostic, age, and sex groups, and in people who came to the hospital from different parts of the county would be productive.

CONCLUSIONS

1. The Dutchess County Service expected to reduce the rate at which new cases of certain forms of long-term severe social deterioration would occur as a result of severe mental disorders.

2. This objective was translated into researchable terms by setting up criteria for ascertaining the prevalence and incidence of chronic severe social breakdown syndrome.

3. The evidence suggests that the annual incidence of this condition in non-geriatric adult patients stood at about 50 per 100,000 toward the end of 1962, and that it had been higher in 1960 and 1961, perhaps as much as twice as high.

4. Technical weaknesses in the studies could conceivably have produced these findings, but it is believed that they reflect a true decline in incidence during the demonstration project.

5. It is possible that the declining incidence of chronic severe social breakdown syndrome would have occurred without the demonstration services.

6. Further data and data analysis will make it possible to provide incidence measurements of greater precision.

7. Evidence regarding a widespread downward secular trend in the incidence of such disorders can come only from investigations in other populations.

REFERENCES

[1] Lemkau, Paul V., and Pasamanick, Benjamin, Problems of Mental Health Programs, *American Journal of Orthopsychiatry,* 27, 55–58, 1957.

[2] Morris, Jeremy N., USES OF EPIDEMIOLOGY, Edinburgh and London, E. S. Livingstone Ltd., 1964 (2nd Edition).

[3] MacMahon, Brian, Pugh, Thomas F., and Hutchinson, George G., Principles in the Evaluation of Community Mental Health Programs, *American Journal of Public Health,* 51, 963–968, July, 1961.

[4] AN APPROACH TO THE PREVENTION OF DISABILITY FROM CHRONIC PSYCHOSES: The Open Hospital within the Community, Proceedings of the 34th Annual Conference of the Milbank Memorial Fund, 1957, Part I.

[5] Hunt, Robert C., Ingredients of a Rehabilitation Program, in AN APPROACH TO THE PREVENTION OF DISABILITY FROM CHRONIC PSYCHOSES, *Op. cit.,* pp. 9–21.

[6] CAUSES OF MENTAL DISORDERS, A Review of Epidemiological Knowledge, 1959. Proceedings of a Round Table held at Arden House, Harriman, N.Y., Milbank Memorial Fund, 1961.

[7] DECENTRALIZATION OF PSYCHIATRIC SERVICES AND CONTINUITY OF CARE, Proceedings of the 38th Annual Conference of the Milbank Memorial Fund, 1961. Milbank Memorial Fund, 1962.

[8] THE ELEMENTS OF A COMMUNITY MENTAL HEALTH PROGRAM, Papers presented at the 1955 Annual Conference of the Milbank Memorial Fund. Milbank Memorial Fund, 1956.

[9] INTERRELATIONS BETWEEN THE SOCIAL ENVIRONMENT AND PSYCHIATRIC DISORDERS, Papers presented at the 29th Conference of the Milbank Memorial Fund. Milbank Memorial Fund, 1953.

[10] MENTAL HOSPITALS JOIN THE COMMUNITY, Proceedings of a Round Table and of a Workshop at the 39th Annual Conference of the Milbank Memorial Fund, 1962. *The Milbank Memorial Fund Quarterly,* Vol. XLII, No. 3, July, 1964, Part II.

[11] PLANNING EVALUATIONS OF MENTAL HEALTH PROGRAMS, Proceedings of the 34th Annual Conference of the Milbank Memorial Fund, 1953, Part II.

[12] PROGRAM FOR COMMUNITY MENTAL HEALTH, Proceedings of the 33rd Annual Conference of the Milbank Memorial Fund, 1957.

[13] PROGRESS AND PROBLEMS OF COMMUNITY MENTAL HEALTH SERVICES, Proceedings of the 35th Annual Conference of the Milbank Memorial Fund, 1959, Part I.

[14] STEPS IN THE DEVELOPMENT OF INTEGRATED PSYCHIATRIC SERVICES, Proceedings of the 36th Annual Conference of the Milbank Memorial Fund, 1960.

[15] Goffman, Erving, ASYLUMS, New York, Doubleday & Company, Inc., 1961.

[16] Martin, D. V., Institutionalisation, *Lancet,* 2, 1188, 1955.

[17] Barton, Russell, INSTITUTIONAL NEUROSIS, Bristol, J. Wright and Sons, 1959.

[18] Program Area Committee on Mental Health, American Public Health Association: A GUIDE TO CONTROL METHODS FOR MENTAL DISORDERS, New York, The American Public Health Association, Inc., 1961.

[19] Hutchinson, George B., Evaluation of Preventive Services, *Journal of Chronic Diseases,* 2, 497–508, May, 1960.

[20] Carse, Joshua, A District Mental Health Service, The Worthing Experiment, *Lancet,* 1, 39, January 4, 1958.

[21] Sainsbury, Peter, and Grad, Jacqueline, THE BURDEN ON THE COMMUNITY, London, Oxford University Press, 1962.

[22] Kay, D. W. K., Beamish, P., and Roth, M., Old Age Mental Disorders in Newcastle upon Tyne; Part II. A Study of Possible Social and Medical Causes, *British Journal of Psychiatry,* 110, 668–682, 1964.

[23] ———, Sociological Review Monograph No. 5, University of Keele, 1962.

[24] Mental Health Research Unit, New York State Department of Mental Hygiene, A MENTAL HEALTH SURVEY OF OLDER PEOPLE, Utica, N.Y., State Hospital Press, 1961.

APPENDIX

SOME DETAILS OF THE DUTCHESS COUNTY REGISTER AND SAMPLING PROCEDURES

1. The Initial List

In October 1959 the Hudson River State Hospital census of patients was scrutinized for Dutchess County residents and an entry in the register was made for each person found. Those who were in the chronic services and a set of matched controls formed the basis of the cohort study, which is discussed in another paper.

2. Subsequent Hospitalizations

The hospital admissions and discharges from April 1, 1955 to January 1, 1960 were searched for patients discharged to a Dutchess County address or who gave a Dutchess County address on admission. Since early in 1960 admission and transaction records were made on all Dutchess County residents. The same three steps were taken at Harlem Valley State Hospital and these entries, too, became part of the register. The Veterans Administration hospital near Peekskill receives the bulk of Dutchess County residents using Veterans Administration facilities. County residents as of January 1, 1960 were listed, and all subsequent admissions and discharges of Dutchess County patients were reported to the register.

One county general hospital, St. Francis Hospital, opened a 16-bed psychiatric unit on October 9, 1962 and up to March 31, 1964 admitted *190* patients of whom *86* were already known to the register. These patients were, on the whole, less psychiatrically ill than those admitted to the state hospital, were more often admitted for purposes of investigation, and were more often short-stay patients.

The Day Care Center of Hudson River State Hospital was established in 1956 as a pilot project by the Department of Mental Hygiene and was intended to offer day treatment facilities to patients whose illness was of such severity that admission to the hospital would be the alternative. Admissions of Dutchess County residents were gleaned from the records of this center and were entered in the register on an ongoing basis.

It is known that very few county residents are admitted to private institutions and most of those who are go to a state licensed hospital in an ad-

joining county. Relationships with this hospital and its staff were good but our approach to follow-up this group has been cautious. We propose to review the number involved when these are reported to us by the state.

A small number of Dutchess County residents are admitted, for a variety of reasons, to other state hospitals. Arrangements were made for such patients to be reported to us, but technical difficulties have delayed this. At present we do not know about such patients if they were never in Hudson River State Hospital or Harlem Valley State Hospital.

3. Outpatients

Finally, the termination records of the local All-Purpose Clinic were added to the register beginning on January 1, 1963. The diagnostic categories and demographic characteristics of this group of patients were very different from those of other sources reporting to the register. Their patients were younger and were largely functioning in their job roles in the community. We were advised by clinic staff that psychotic patients were almost invariably referred to the state hospital for admission. These reporting sources then made up the Register of Dutchess County patients under psychiatric care since April 1, 1955. Only patients exclusively under the care of private practitioners were omitted, and we have good reason to believe that these do not constitute a high risk group for the development of social breakdown syndrome. Our early field trials produced few examples of the syndrome among former patients in the community and none among those who had never experienced hospitalization. In view of this finding and of the marked differences in the populations involved, it was decided to omit from the interview program those patients whose only contact was with the All-Purpose Clinic or a private physician.

The meticulous attention to detail required to maintain this register, with the constant need to correct inconsistent reports and to detect the multifarious ways in which errors can arise make considerable demands upon staff.

In our experience a single master file is essential to the operation, as is the need for precise definition of terms and standards.

4. Residence

Definition of population presents some problems. For registration purposes we have taken the actual county boundaries but definition of some people's residence presents other problems. Hospital and clinic records often assign individuals of doubtful residence to the place where their journey to the hospital began. Street addresses of police stations, jails, transient accommodations, or general hospitals can be deceptive and the records of individuals assigned to such addresses have to be examined to determine their true residential status. In making rules it has been assumed that everyone in the United States is either a resident of some county or is a transient with no residence.

Students, people with multiple residences, people in familial limbo, and institutional residents present problems of definition. In cases where ambiguities arise we take the view that residence is where the patient believes his home is, and that this is usually a place where he has continuing emotional ties and would go if he became ill or otherwise unable to care for himself.

Clearly the transient population is of considerable importance in planning community facilities but this segment of the population is unlikely to be modified by long-term preventive measures based on the stable resident community.

5. "Simple Alcoholism"

A special group within the community and one containing a high transient population is made up of those admitted to the hospital with a primary diagnosis of chronic alcoholism or psychosis due to alcohol. The Dutchess County Unit offers no special treatment for this group of patients and the clinical staff believe that within the framework of the Unit these alcoholics are not likely to benefit from the services available and that deterioration in such patients would not be prevented by the Unit. These patients are, therefore, not interviewed unless there is a record of associated organic psychosis or of another psychiatric diagnosis. Registration of all alcoholic patients is, however, maintained.

6. Children

The Dutchess County Unit has no provision for children under the age of 16 years; consequently such patients were registered but not interviewed until after they reached the age of 16.

The register's master file contains the standard statistical record from the hospital or clinic and some additional information obtained from the medical record. The file contains the names of relatives and friends who are aware that the patient has had psychiatric treatment, since it is important that our interviewers have some contacts which might help them to trace a patient without inadvertently revealing the psychiatric contact to anyone not already aware of the fact. Information on associated conditions which may complicate the interview such as deafness, language barriers, etc., are also noted.

7. Drawing a Group for Interviewing

The register is broken into ten random 10 per cent groups on the basis of the terminal digit of the first register contact record number. Each person is assigned to one and only one of these groups. The term "group" is used here to avoid the implication of sampling with its problems of error and bias. The division into groups is a device to spread the work load, and while each group can be regarded as a sample, the research design calls for consideration of all ten groups—the whole register population.

When a group is drawn, eligibility of each individual for interview is then considered. Patients who have died or emigrated from the county are excluded. Deaths were identified by daily checking of obituary columns in the local press, notifications from the public health department, and other sources in the community. Emigration from the area was usually established following an attempt to contact the former patient but sometimes the local press and community contacts provided this information. Tracing transients is difficult. Those whose tenuous roots are in the county can sometimes be interviewed in freight yards or transient accommodations. Patients still in the hospital and those with a family home in the county present little difficulty. But the interviewing force was severely taxed to trace others who were not at the address given on their admission sheet. This "not located" group consituted a sizable segment of our early field trials, and it became clear that the group used up a large proportion of interviewer time.

One segment of the register in which time could be saved without serious loss of information were individuals whose first psychiatric contact occurred after they had reached the age of 65 years. It was determined in field trials that the incidence of severe social breakdown syndrome was high enough in this group to obtain an adequate measure from a 50 per cent sample of them. Many ascertained as examples of the syndrome were manifesting terminal or irreversible organic change. Furthermore, there was good reason to believe from a number of studies (Kay, et al.[22, 23] Gruenberg[24]) that only a small proportion of elderly people with chronic severe social breakdown syndrome would have had a psychiatric contact. The data gathered on this group, therefore, are of less value.

Finally, we had to consider the situation in the eastern townships of the county. The four easternmost townships contain 12 per cent of the population and are cut off from the main mass of the county by a range of high, thinly populated hills. These townships are largely rural farm country. The main employers are Wassaic State School and Harlem Valley State Hospital. Residents here tend to seek many services in nearby Connecticut, and the psychiatrically ill mainly use Harlem Valley State Hospital, hence they would rarely get the benefits of the Dutchess County Unit at Hudson River State Hospital. Difficulties in traveling, the scattered small communities involved, and the fact that the people in these townships were not exposed to the effects which might be generated by the Dutchess County program led to a redefinition of the population to be studied. The population of these townships could be clearly defined and excluded from all Dutchess County census statistics. We decided that the time involved in seeking out cases in these distant parts of the county could be more usefully employed in attempting to reduce the group of former patients listed as "not located."

In summary, all patients who were residents of, or homeless transients in, Dutchess County and who sought psychiatric treatment from other than a private practitioner were entered in the Dutchess County Register.

Those registered but not interviewed were:

1. patients whose only contact was with the All-Purpose Clinic (out-patient);

2. those whose admission was due to "simple alcoholism";

3. anyone under the age of 16 years at time of interview;

4. those who had emigrated from the county or died at time of interview;

5. those in alternate groups who were over 65 years of age at time of first psychiatric contact; and

6. residents of the eastern townships.

These exclusions were made on the grounds of relevance, and the geriatric group was excluded on the ground of economy of effort, in the belief that it would not significantly reduce the precision of the resulting measurements.

Those patients whose only admission was to a private hospital, including St. Francis Hospital or other state hospitals, were also omitted from the interviewing program because of delay in development of reporting procedures.

8. Tracing Unlocated People

Those individuals who could not be traced in the community, even after checking with relatives and friends who had visited the patient in the hospital, were subjected to a routine tracing procedure. The city directories and telephone directories of the county provided some addresses. A special interviewer made inquiries through local agencies including the County Health Department, the Welfare Department, the Salvation Army, and other less well-defined contacts. Local post offices were checked for forwarding addresses. Through the courtesy of the late Commissioner, Paul H. Hoch and of Mr. Robert Patton, the Department of Mental Hygiene records were scrutinized. Since New York State continues to submit the psychiatrically ill to the indignity of placing their fingerprints on record at the Criminal Identification Bureau, use was made of this to trace recent arrest records on the patient.

9. The Interviewing

Just before each five-week interview period the appropriate 10 per cent group was drawn from the register and the exclusions outlined above were made. The last known location of each individual to be interviewed was then established and interviews allocated to interviewers accordingly.

Information on patients who were in the hospital was collected on 21 shift schedules covering seven days. The nurse or attendant most concerned with each patient completed a questionnaire at the end of each shift. In 1964, three groups were evaluated by using the patient himself as the prime informant and a questionnaire identical to that used for patients in the community.

Former patients were interviewed in their homes by a public health nurse from the County Health Department, a member of the Visiting Nurse Service of Poughkeepsie, or one of our special interviewers. The latter were mainly staff of the Public Health Department or of the hospital who were willing to undertake evening or week-end work on an overtime basis.

Patients still in family care homes or on convalescent care were usually interviewed by the hospital social worker responsible for their supervision.

All of the personnel involved in data collection were given both verbal and written instructions on the use of the questionnaire. In addition, regular sessions were arranged for general discussion of interviewing techniques and similar problems, and members of the research staff were always available for consultation.

Patients located in other institutions were interviewed there, unless they had ceased to be county residents.

Despite these procedures, there remained some patients who simply could not be traced after they left the hospital.

The interviews in the community were always conducted with the former patient unless the patient was unable to communicate, in which case someone in close daily contact was used as informant. The questionnaire was addressed to the interviewer who was required to inquire into each area of behavior. There was no standard interview method. Each interviewer had to use his or her own judgment in approaching any particular individual or any particular question.

10. Prevalence and Incidence Measurements

Thus in each group, that is, each 10 per cent group of the register, each individual was assigned a grade of 0, 1, 2, 3, 4, or 5. Those with a score of 0 through 3 were regarded as examples of severe social breakdown syndrome. Their records were examined to determine the date of onset of this disability, and if these records proved inadequate, the patient or those caring for him were reinterviewed in order to obtain this additional information. A case which had, at the time of interview, already been at the severe social breakdown syndrome grade for 12 months or more was labeled "chronic severe social breakdown syndrome." Cases with onset within the previous 12 months were followed to termination of the epsiode ("acute") or until the duration exceeded one year ("chronic").

The "point prevalence" measure obtained by examining each of these groups was thus a "point" of one week's duration. The particular week was not the same for each individual.

An annual incidence of chronic severe social breakdown syndrome was measured for each 10 per cent group, since at the point of pickup each case of severe social breakdown syndrome was sorted as "acute" or "chronic," and each case with onset during the prior 12 months was identified. This

annual incidence, however, did not correspond to a particular calendar year. These measurements led to estimates of the "1963" incidence derived from cases of chronic social breakdown syndrome identified in 1964 but which began at varying times in the period 1962–1963; the "1964" incidence cases similarly originated in the period 1963–1964. Chronic cases identified in 1963, that had been continuously disabled since 1962, were allocated to the calendar year in which their disability began.