Scottish Needs Assessment Programme

Schizophrenia

SCOTTISH FORUM FOR PUBLIC HEALTH MEDICINE

69 Oakfield Avenue
Glasgow G12 8QQ
Tel - 0141 330 5607
Fax - 0141 330 3687

Scottish Needs Assessment Programme

Priority Services Network

Schizophrenia

Dr Jacqueline Atkinson — Senior Lecturer in Behavioural Sciences, Department of Public Health, University of Glasgow

Dr Richard Caplan — Consultant Psychiatrist, Southern General Hospital, Glasgow

Dr Cameron Stark — Consultant in Public Health Medicine, Highland Health Board

December 1997

CONTENTS

EXECUTIVE SUMMARY

Schizophrenia is a major mental illness whose management requires coordinated service input from health social work, housing, the voluntary sector and possibly other agencies.

For every 100,000 people each year:

- up to 20 new cases of schizophrenia can be expected
- 300 people would suffer from schizophrenia in the course of a year
- there is up to a four-fold difference in rates depending upon local factors, particularly measures of deprivation and ethnicity

Males have higher rates of hospital admission (60:40 ratio men to women).

There is a consistent excess of individuals suffering from schizophrenia in lower social classes.

10 - 15% of people diagnosed as suffering from schizophrenia eventually commit suicide. The highest risk of suicide is in the first two years following discharge from an acute episode.

Although positive, acute symptoms may cause families distress, it is the negative symptoms which result in social withdrawal, apathy and self-neglect which cause the long-term family conflicts and disruptions.

Community Mental Health Teams have produced a fundamental shift in the delivery of services to patients with schizophrenia in recent years. Their benefits have been demonstrated mainly with respect to increased patient and carer satisfaction.

Services which do not have significant direct involvement from a consultant psychiatrist are likely to be ineffective and tend to drift away from providing services to patients with schizophrenia.

Community services may reduce the overall need for in-patient beds, but there is no evidence that they can eliminate the need for in-patient services.

Services from voluntary organisations should be seen as complementing services provided by the statutory agencies and should be developed in conjunction with them.

Drug treatment remains the most important single aspect of the management of schizophrenia.

All providers should have a local policy for the prescription of neuroleptics in doses higher than those in the British National Formulary.

Local policies and protocols are needed for both the prescribing of the new antipsychotic drugs and for their withdrawal if they prove ineffective in a particular case.

As a proportion of the patients discharged from long stay beds will only have been able to be discharged because of the availability of new antipsychotic drugs, it is suggested that a percentage of the resource transfer to local authorities for the provision of community services should be reallocated to a community drug budget to allow continued prescription of these drugs outside of hospital.

Service commissioners should review further research results, particularly in relation to effectiveness in routine practice, as it becomes available.

Housing is central to supporting patients living in the community. Service commissioners should negotiate more effective arrangements with social work and supported accommodation agencies. This single matter is one of the most important in determining whether a service works or not.

Although further evaluation is required, evidence would seem to suggest that effort spent treating schizophrenia at an early stage can prevent later deterioration in social functioning with a consequent possible reduction in numbers of relapses and greater compliance with treatment.

The role of general practitioners in supporting individual patients may need clarification and shared care protocols may be of benefit.

Education programmes for people with schizophrenia and carers and cognitive therapy for patients offer interesting ways forward and need development within an evaluation framework.

INTRODUCTION

Schizophrenia is a major mental illness, of which the two most commonly recognised symptoms are hallucinations (usually auditory) and delusions. Schizophrenia as currently diagnosed may prove to be an umbrella term for a number of different disorders. One consequence of this is the heterogeneity of the patients who carry this diagnosis, and thus their needs. To meet these needs appropriately (both from the perspective of patients and their families, and commissioners and providers of services) a variety of services and approaches are necessary within a flexible service coming from not only the NHS, but also Social Work, housing and the voluntary sector. There is currently very little available in the private sector in Scotland beyond housing. In discussing issues affecting service planning and provision this report takes account both of the diversity of needs and the diversity of potential providers. This report concentrates on health care commissioning requirements.

An initial draft of this report was circulated to a number of interested individuals and organisations. The consensus of the responses was that social care and housing issues could not be adequately considered in a report of this type. We have therefore confined ourselves to commenting on their importance in mental health care. The other principal comment to emerge from the consultation was that some specialist areas, such as forensic psychiatry and the structure of community mental health services, would be best dealt with separately. They have therefore not been considered in this report in detail but they may be suitable subjects for future SNAP reports.

There are several important Scottish reviews in progress.

1. The Scottish Intercollegiate Guidelines Network (SIGN) is developing a guideline on psychosocial treatments in schizophrenia, which will be available later in 1997.

2. The Scottish Health Purchasing Information Centre (SHPIC) is undertaking work on the role of Community Mental Health Services in schizophrenia, and on the use of newer drugs for schizophrenia. This will again be available in later 1997.

Two other recent reports, ‘Schizophrenia’ (Clinical Standards Advisory Group 1995) and ‘Services for People Affected by Schizophrenia: a good practice statement’ are referred to in the text and summarised in Appendices 1 and 2.

1 SIZE OF THE PROBLEM

Definitions/Description

Schizophrenia is defined as both a clinical entity (e.g. ICD 10, DSM IV) and an individual experience. Although there is overlap between the two they are not necessarily congruent. Schizophrenia is important because it is common and causes chronic long term disability in over half of the people who suffer from it.

Both ICD 10 and DSM IV describe schizophrenia as an illness in which aspects of a person's thinking, perception and personality become distorted. This is primarily a distortion of reality and involves the breakdown of the person's normal mental processes. Thus the individual has difficulty in distinguishing between the 'real world' which is external and objective, and their internal, subjective experiences. It is described in ICD 10 thus:

'The disturbance involves the most basic functions that give the normal person a feeling of individuality, uniqueness and self-direction.'

Schizophrenia is <u>not</u> split personality, a Jekyll and Hyde type character, but the illness can change people. The positive symptoms are those which are most commonly associated with schizophrenia and are those most present in the acute phase of the illness. They can be seen as 'adding' something to the person.

Disturbances to the thought process include the individual experiencing their thoughts/feelings being broadcast to others, or that thoughts are put into, or taken out of, their minds without their control. Disturbances of volition involve the individual feeling controlled by an outside force ('I was made to.....think/feel/act'). Hallucinations are disorders of perception and are most commonly auditory, the 'voices' which give a running commentary or discuss the person between themselves.

Any of this can give rise to explanatory delusions to try to make sense of what is going on (e.g. supernatural forces, enemy agents). A delusion is an unshakeable belief which is culturally inappropriate and may be persistent. It may be culturally/scientifically impossible (e.g. controlled by an alien implant) or more mundane or plausible (e.g. spouse's infidelity, a child is not theirs). They may become grandiose in their thinking, believing themselves to be central to all that is happening and ordinary or insignificant events take an extraordinary personal significance. This may include persecution.

Other perceptual disturbances cause colours and sounds to appear especially vivid or distorted or the person may focus on trivial aspects of objects, situations or concepts which may take over and become more important than the whole. When this happens the person's thinking and speech patterns appear to others to be vague, inconsistent, following a bizarre course and generally obscure. Speech can sound incoherent or irrelevant and made-up words may appear.

Finally, disturbances of movement may occur (which are not attributable to drug side effects) and inappropriate or contradictory expression of emotion.

Individual patients will not experience all these symptoms, thus producing a heterogeneous illness. Some positive symptoms may persist, even when the person is otherwise fairly well, and can cause considerable disruption to their life.

The negative symptoms are more commonly associated with the chronic condition, although they can occur alongside acute, positive symptoms. They represent a 'lack' of normal behaviour. Apathy and loss of motivation show themselves as aimlessness, lack of interest, and what some might label 'laziness'. The person can withdraw and become self-absorbed with slowed speech and emotional blunting. This may lead to social withdrawal and poor social functioning. Although intellectual ability remains unchanged, performance may be affected through problems with memory and poor concentration. It is the negative symptoms which are essentially seen as changing the personality and thus may be more disturbing for the patient, family and friends than the more bizarre positive symptoms.

Incidence

Eaton et al (1988) reviewed 23 incidence studies, including reports from eight WHO sites, and four community studies. The median annual incidence rate in WHO studies was 0.22/1,000 (range 0.16 to 0.42). Dublin and Nottingham both had incidence rates of 0.22/1,000.

The first admission rate for schizophrenia in Scotland declined between 1969 and 1978, and in North-East Scotland between 1969 and 1984 (Eagles and Whalley 1985, Eagles et al 1988). Similar effects have been recorded in other countries (Munk-Jorgensen and Mortensen 1992). This may not be a true decrease in incidence, but rather related to the reduction in psychiatric in-patient facilities, changing diagnostic practices and the methods used to identify incidence (Kendell et al 1993, Munk-Jorgensen and Mortensen 1992).

Prevalence

Table 1
Prevalence Rates of Schizophrenia - Rate/1,000

Source	Diagnostic System	Rate / 1,000
Eaton et al (1988) Review Median lifetime Prevalence Median Point Prevalence	 pre-DSM-III pre-DSM-III	 2.7 3.2
Robins and Regier (1991) Epidemiological Catchment Area Study One year prevalence [1]	DSM-III	10
Levav et al (1993) 6 month prevalence (Israel)	SADS/RDC	7
Kessler et al (1993) U.S. National Comorbidity Survey Clinical Diagnosis	SCID//DSM-III-R	1
Fryers and Wooff (1989) Salford Case Register Point prevalence Average one-year prevalence	-	2.6 3.0

[1] Used lay interviewers: results may not be directly comparable with other studies.
Adapted from Bromet et al 1995.

For the UK population, the results of the Salford Case Register and WHO studies are likely to be the most applicable, and they are used in the remainder of the document.

Expected Incidence and Prevalence

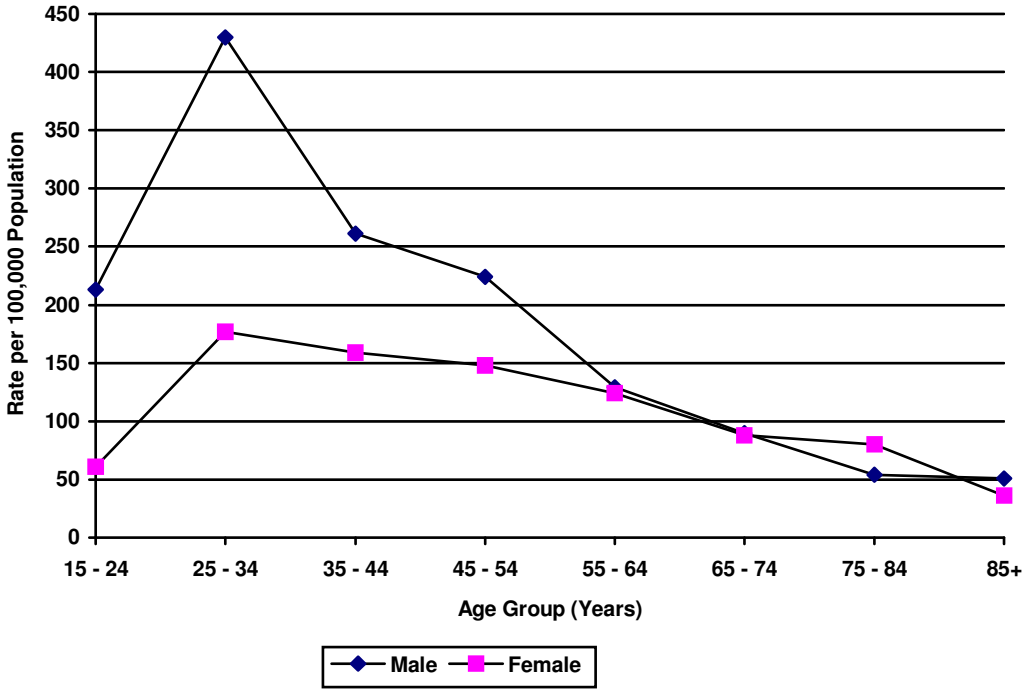
Applied to the total Scottish population structure, these rates would indicate, for every 100,000 people each year:

- up to 20 new cases of schizophrenia can be expected
- 300 people would suffer from schizophrenia in the course of a year
- there is up to a four-fold difference in rates depending upon local factors in the main measures of deprivation and ethnicity (see pages 7 and 8)

The commonly quoted figure of 1 in 100 of the population suffering from schizophrenia refers to life time risk estimates. This includes individuals who have one episode of schizophrenia as well as the majority who have a recurrent condition. The number of individuals who suffer schizophrenia at a particular point in time is far lower than this as shown above.

Age-Specific admission rates for schizophrenia in Scotland 1993 - 94 are shown by gender in Figure 1.

Figure 1: Age-Specific Admission Rates for Schizophrenia Scotland 1993 - 94 By Gender



Quality of Data

Care should be taken in extrapolating directly from locally held data. A study in South Glasgow (Atkinson et al 1994) in the early 1990s traced 868 people with a diagnosis of schizophrenia through Health Board records. When followed up, of these, 10% did not have schizophrenia (in many cases this was an error in data recording rather than a change in diagnosis), 9% had died or moved from the catchment area and a further 9%, although known to exist, were unable to be traced or were of no fixed abode. In addition, the assumption that all people with schizophrenia will be admitted to hospital may no longer be reliable (Cooper et al 1987).

Risk Factors

(i) Age and Gender

Males have higher rates of hospital admission. Although preferential hospital admission could explain some of this difference, it is likely that this is a real difference, with higher rates of illness in men (60:40 ratio men to women).

Age at onset is similar in men and women, and is usually in the early twenties (Beiser et al 1993). Men tend to have a first hospital admission earlier than women, and this may reflect a different clinical course of the illness (Munk-Jorgensen 1985, Jablensky et al 1992).

(ii) Social Class

There is a consistent excess of individuals suffering from schizophrenia in lower social classes. Two main explanations are proposed for this:

(i) A true increase in the risk of schizophrenia, caused by some aspect of the social or physical environment.

(ii) Concentration of people with schizophrenia in deprived areas as a result of their illness, which can reduce their social functioning and wage-earning capacity.

In general, the second theory (social drift) has gained the most support. Service organisation can itself cause "ghettos" of people with severe illness, either by concentrating services in inner city areas, or by preferential housing policies.

As discussed below, birth complications may increase the likelihood of developing schizophrenia, and this and other physical factors could contribute to a true increase in incidence in deprived areas. Schizophrenia is a heterogeneous condition, and it is likely that both explanations play a role in the inverse association with social class. Deprivation Categories (Depcats) identify overall deprivation figures by postcode sector, where Depcat 1 is comparatively affluent and Depcat 7 is deprived. Like all summary figures they have to be interpreted with some caution. Figures 2 and 3 suggest an excess of admissions from deprived areas. Record linkage will identify the role of repeat admissions.

Figure 2
Age-Specific Admission Rates for Schizophrenia Scotland 1993-94 by Deprivation Category of Postcode, Both Sexes

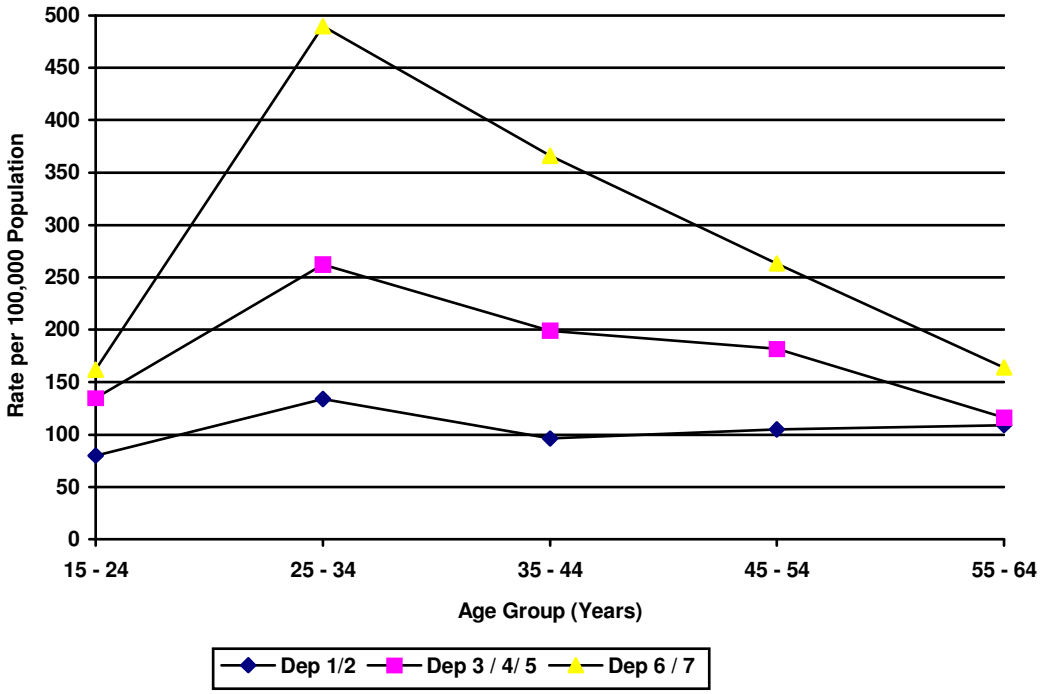
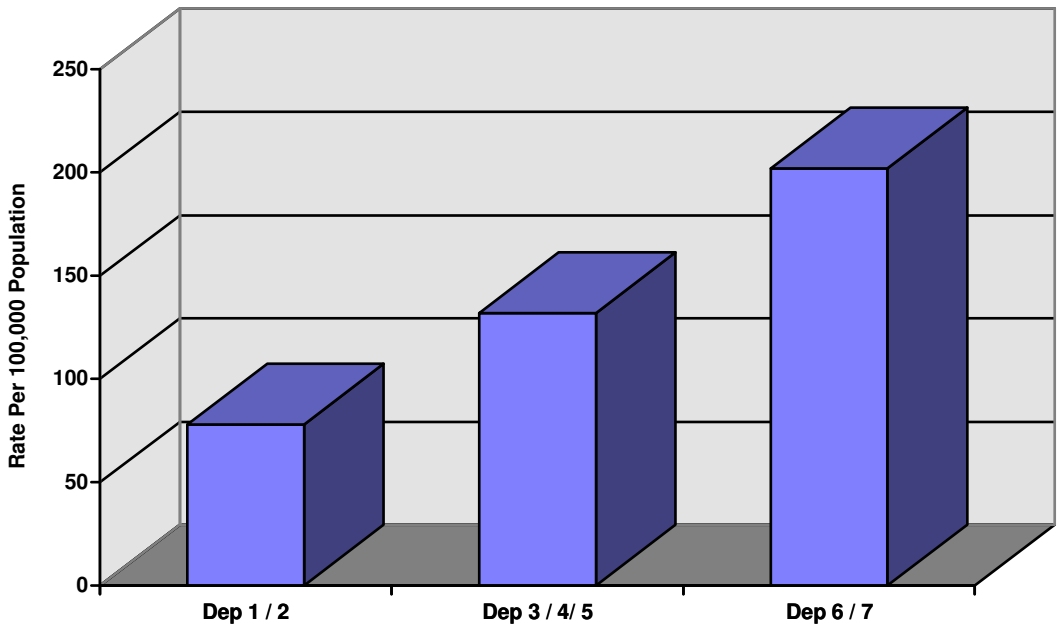


Figure 3
Admissions to Psychiatric Hospitals, Schizophrenia, Scotland 1993-94 by Deprivation Category of Postcode, All Ages



(iii) Ethnicity

Assessment and treatment of people belonging to ethnic minorities requires careful consideration. There are often cultural differences in the presentation of schizophrenia. There are difficulties in providing adequate interpretation services by individuals who understand the issues of mental illness. African-Caribbeans in the UK seem to have an increased incidence of schizophrenia (Harrison et al 1988, Glover 1989). There was much controversy about these findings with allegations of racism, but a prospective study using rigorous methods supported the finding (Harrison et al 1988), while a later study found no evidence of diagnostic differences (Harvey et al 1990). There is evidence of differential referral and admission to hospital (Harrison et al 1984), but the balance of the evidence suggests a real increase in Caribbean immigrants, which is greater in the second generation. This does not seem to be due to altered genetic susceptibility (Sugarman and Craufurd 1994) and may be due to an environmental factor, which may include racism. The prevalence of schizophrenia is no different in rural Nithsdale and inner city Nunhead and Norwood, when only white patients are considered. (McCreadie et al, 1997)

(iv) Genetics/Season of Birth/Pregnancy

a) Genetics

Close relatives of a person suffering from schizophrenia are more likely to develop the disease themselves than are the general population. The risk ranges from 8.5% in the sibling of someone with schizophrenia, to 37% in the child of two parents, both of whom have schizophrenia (Shields 1980). Concordance in identical twins is around 50%, compared to 17% for non-identical twins (Shields 1978). Adoption studies indicate that this risk continues even if the person is adopted away into a different environment, suggesting that this is a true genetic predisposition, rather than some effect of upbringing (Kety et al 1975). The majority of people with schizophrenia have no affected relative, however, so this is no more than a partial explanation.

b) Pregnancy/Season of Birth

There is reasonable evidence of an association between birth complications and an increased incidence of schizophrenia. This evidence is not particularly strong but on balance these complications probably do cause a moderate increase in the risk of an individual developing schizophrenia in adult life. There is also evidence of an increased rate of schizophrenia in people born in the early months of the year (Bromet et al 1995).

(v) Psychosocial Factors

a) The Family

The family as a cause of schizophrenia has long been discredited, but the role of the family in influencing the ongoing illness is of great importance and continued research. The last twenty years have been dominated by the role of high expressed emotion (HEE) in families (first described by Vaughn and Leff 1976) and the role of criticism or over involvement and over protection as patterns of communication in families. High expressed emotion is correlated with increased relapse rates at 9 months especially when there is high face-to-face contact (more than 35 hours per week). This gave rise to the development of family programmes to reduce HEE (Leff

and Vaughn 1985) and thus reduce relapse. Since then a variety of other family interventions have been developed. Reducing face-to-face contact has been studied less. Both are potentially important adjuncts to medication.

b) Life Events

A recent review (Norman & Malla 1993 a,b) concludes that life events are unlikely to be a primary cause of schizophrenia, but that they are correlated with changes in symptoms over time. Thus an exacerbation of symptoms (or acute episode) is more likely to occur a few weeks after a cluster of life events. This ties in with the view that people with schizophrenia tolerate stress poorly.

(vi) Association with substance misuse

Some cases of schizophrenia are associated with illegal drug use. Misuse of amphetamines in particular can produce symptoms indistinguishable from schizophrenia. In some areas, the combination of schizophrenia and illegal drug use can lead to particular problems during treatment and rehabilitation. This is also the case for people who misuse alcohol.

(vii) Stress and the Vulnerability Model

To explain and integrate the variety of aetiological factors in schizophrenia a vulnerability model has been proposed (Zubin & Springs 1977, Nuechterlein & Dawson 1984). This postulates vulnerability to schizophrenia as a relatively permanent biological trait in the individual, which requires psychosocial or environmental stress to exceed the individual's vulnerability threshold to trigger the illness and subsequent episodes. Negative symptoms may be a more or less permanent feature of the condition, with positive symptoms being exacerbated during acute episodes.

Course of Schizophrenia

Specialist mental health services deal with individuals with severe illnesses, and this can lead to an impression of schizophrenia always being a chronic, relapsing illness. When examined epidemiologically, however, some individuals have a complete recovery from schizophrenia.

- 25% recover completely within five years, with no further need for drug treatment
- 50% have symptoms which fluctuate over decades
- 15% have severe, persistent problems
- 10% suffer permanent incapacity (Wing 1994)

Research indicates that most first re-admissions occur within 5 years (Engelhardt et al 1982, Eaton et al 1992, Mason et al 1996).

Effects on Individuals

The impact of the heterogenicity of schizophrenia can be most readily seen when trying to describe the impact of the illness on individuals.

Mortality

10 - 15% of people diagnosed as suffering from schizophrenia eventually commit suicide (Miles 1977, Tsung 1978, Tsung et al 1979, Roy 1982, Wilkinson 1982). The highest risk of suicide is in the first two years following discharge from an acute episode. Mortality as a specific consequence of schizophrenia tends to be hidden if cause of death is recorded as suicide.

The mortality of men and women with schizophrenia is twice that of the general population (Allebeck 1989). The most common causes of death are cardiovascular diseases. While adverse effects of drugs used for the treatment of schizophrenia will explain some of this increase, increased smoking and lack of exercise are also likely to be implicated in this increased mortality. Deliberate self-harm is also increased.

Dangerousness to self and others

Violence is often associated with schizophrenia in the media and in the minds of the public. Although violence is not a symptom of schizophrenia, nor a factor for the majority of patients there is, nevertheless, an association between schizophrenia and violence. One study indicates as many as 20% of patients behaving in a dangerous manner before their first admission. (Humphreys et al, 1992) The public's fear of patients being violent has to be addressed if patients are to live successfully in the community.

More people are, however, a danger to themselves than to others, either through suicide attempts, self-harm or self-neglect. More people in Scotland are on extended leave of absence (i.e. leave of absence longer than six months under the Mental Health Act) for these reasons than because of dangerousness to others.

The assessment of risk in people with schizophrenia is a complex matter. Issues are covered in a recent supplement to the British Journal of Psychiatry (Duggan 1997)

Social functioning and quality of life

For people with a recurring illness and long term, continuing symptoms, quality of life is likely to be low and social functioning poor. This on-going morbidity is in contrast to illnesses such as manic depressive illness where the affected individual usually recovers completely in between episodes of acute illness.

Social competence has a theoretical and practical importance as a mediator of outcome in schizophrenia, including symptom exacerbation, rehospitalisation and future social adjustment (Mueser et al, 1990). Impairment in social functioning is widespread in schizophrenia and may be both a primary impairment as well as a secondary disability (Bellack et al, 1990). Deterioration in interpersonal relationships is part of the syndrome along with withdrawal and impairment in social, personal and work roles (including social and recreational activity, independence and competence in daily living skills). Although these are usually described as residual symptoms, the impact of poverty and poor access to resources should not be overlooked.

Employment

At a time of high national unemployment people with chronic schizophrenia are unlikely to be able to find work, even if they are capable. For many the stresses of a job coupled with negative symptoms make holding down a job impossible. The Scottish First Episode Schizophrenia Study[1] found that only 23% of the group were in open employment five years after diagnosis. This was related to relapse - 69% of those who relapsed in the time period were unemployed, compared to 25% of those who did not relapse (Scottish Schizophrenia Research Group 1992).

Effect on Family and Carers

Community care relies on families to care for people with chronic mental health problems. Traditionally the impact on the family is described in terms of objective and subjective burden with great variation in the relationship between the types of burden (Platt 1985). Families with high subjective burden (emotional and psychological responses such as embarrassment, feelings of stigma, guilt, blame, stress) tend to cope less well, regardless of the level of objective burden (more observable factors including housing and financial problems).

Behaviour directly relating to the illness which families find most difficult to cope with are acute, socially disturbing or embarrassing behaviours and social withdrawal (Creer & Wing 1974, Lefley 1987). Although positive, acute symptoms may cause families distress, it is the negative symptoms which result in social withdrawal, apathy and self-neglect which cause the long-term family conflicts and disruptions. The family may feel they have lost their natural relationship with the individual and may attribute negative symptoms to deficits within the person rather than the illness (Birchwood & Smith 1987).

The Scottish Schizophrenia Research Group study reported on social functioning and psychological distress in relatives of individuals with schizophrenia. Although their follow-up was limited by some relatives declining to participate in later follow-ups, it is the best Scottish information. Relatives showed a trend towards greater social dysfunction than a community sample, and this did not improve over time (Scottish Schizophrenia Study Group 1987, 1992). Oldridge and Hughes (1992) conducted a study of carers of people suffering from long-standing schizophrenia. In this group of 25 carers, 36% were identified as having a significant degree of psychological distress - around twice that which would be expected in the general population. Distress was related to the sufferers' symptoms, being greatest in the relatives of those with negative symptoms of schizophrenia (see description of symptoms on page 2).

[1] This Scottish study followed up 49 individuals who received a clinical diagnosis of schizophrenia, and reported their progress in a series of papers.

2 POLICY AND LEGAL ISSUES

Introduction

In the United States the National Institute of Mental Health (NIMH) provides influential national direction on state programmes. As Turner-Crowson (1993) points out, there is no comparable body in the UK, and policy in this country has been influenced by a range of independent and statutory bodies. In England the Department of Health now expresses clear views that specialist mental health services should target their services on severely mentally ill people. More recently, the new Mental Health (Patients in the Community) Act 1995 and the Care Programme Approach guidance (see below) will also affect the services provided for this client group.

The main Acts of Parliament which shape provision of care and treatment for people with schizophrenia are shown in Table 2.

Table 2
Legislation Relevant to the Care of People with Schizophrenia

National Health Service and Community Care Act 1990	This is the major legislation which introduced community care to Britain. It also reformed the NHS, introducing NHS Trusts and the purchaser/provider split. It modified the *Social Work (Scotland) Act 1968* with respect to the provision of community care.
Mental Health (Scotland) Act 1984	This legislation deals with hospital care and guardianship for people with mental illness and mental handicap. It lays down provision for detaining people with mental illness and mental handicap involuntarily.
Mental Health (Patients in the Community) Act 1995	This introduces powers to manage people with mental illness in the community. It restricts Leave of Absence (available under MHA) to 12 months. It introduces Community Care Orders, which have no power of enforcing treatment, including medication.
Carers (Recognition and Services) Act 1995	This Act entitles carers to an assessment of their own needs. Health and primary care professionals are expected to tell carers about their right to assessment under the Act and then refer them to social work. Assessment should be co-ordinated between social work and health services. Both users' and carers' assessments must be taken into account when planning services.

People may also be admitted to hospital through the Courts and be detained under the Criminal Procedure Act.

Recent Inquiries

One of the major influences on policy are a series of recent inquiries into homicides by people with severe mental health problems (Ritchie et al 1994, Mischon et al 1995, Blom-Cooper et al 1995, Boyd et al 1996, Muijen 1996). These reports identify a number of common failings:

- poor communication between professionals
- lack of multidisciplinary working
- CPA/care plan implementation poor
- staff training and inadequacies
- non-compliance of patients with treatment/care plans
- the effects of racism

In many of these cases there had, in retrospect, been warnings which were not acted upon. There has been recent concern that inquiries have not led to a change in practice and have highlighted attention on events which occur rarely (Eastman 1996). The national inquiry into homicides and suicides (co-ordinated by Appleby) is more likely to inform the process.

In a comment on resources Boyd (1996) also commented that 'very often individual practitioners have not stated their need for more resources and have not put this as a cause for the unfortunate death, but the inquiry has shown that staffing is inadequate or accommodation is unsatisfactory. It is possible that practitioners do not ask for what they construe as being impossible.' One of the reactions to these inquiries has been the Care Programme Approach and its further development.

Care Programme Approach

The aim of the Care Programme Approach is to ensure that individuals with serious long-term mental illnesses or dementia, and complex health and social care needs, receive continuing care and oversight incorporating the most appropriate packages of care to meet their needs. Its objectives are :

- To identify individuals who meet the agreed criteria for inclusion in the programme.

- To design and offer care and support arrangements based on individual need.

- To develop effective systems of multi-agency working to ensure the effective implementation of the Care Programme Approach.

- To establish monitoring systems that allow evaluation, the monitoring of outcomes, the recording of patient feedback and the reporting of unmet needs.

- To ensure that service users are involved in assessments, planning of care packages, and review.

The Care Programme Approach is likely to have a major influence on the future development of mental health services in Scotland. The Care Programme Approach is expected to be fully implemented throughout Scotland during 1997.

A recent Lancet editorial cast doubts on the effectiveness of the Care Programme Approach in meeting its objectives (Lancet 1995).

3 HEALTH CARE SERVICES

This section describes some of the services used by people with schizophrenia. Local needs assessment and flexible response to local circumstances are essential, and the following discussion should not be taken as a shopping list, but rather as an attempt to review the complexity of the support required for sufferers and their families. The nature of some of the service components is discussed in detail in the Effectiveness section.

We emphasise that health care services are only one aspect of care for people with schizophrenia. Social care services and housing are essential components of care. Multi-disciplinary and multi-agency working are vital to the effective delivery of care and each agency has a different role to play in commissioning services for people with schizophrenia. Although for agency and commissioning convenience this is usually seen as the health/social divide, people's problems do not divide so neatly. This is an important point when evaluating services since neither patients nor carers are likely to make a distinction along a health/social care divide.

Primary Care Services

There is considerable scope to support General Practitioners in their care of people with schizophrenia although most GPs have less than 10 people with schizophrenia on their list (Kendrick et al 1994) and some people with schizophrenia are not in touch with any GP (Goldberg and Jackson 1992). The Joint Royal College Working Group (1993) suggests that responsibility should be shared between GPs and psychiatrists - a tripartite care system may be more appropriate by including social work.

The proportion of people with schizophrenia treated by their GP is estimated at 25% in England (King 1992). Historically, more psychiatrists work in primary care in Scotland than England (Pullen & Yellowlees 1988). It would seem inevitable that the workload of GPs will increase as patients are discharged from hospital. A study in South West Thames indicated that people with schizophrenia consult more frequently with their GP than a control population (Kendrick et al 1994). A recent policy decision by a general practitioner subcommittee of the British Medical Association stating that general practitioners should not take on responsibility if a patient is discharged from long stay beds indicates the need for careful and constructive planning in this area.

Burns and Kendrick have written persuasively (Burns et al 1997) about the benefits of close working relationships between psychiatrists and general practitioners for individuals suffering from schizophrenia. Given the higher all cause mortality it may be advisable to institute periodic review of such patients' physical state. Some form of shared care protocol seems sensible.

Community Mental Health Services

Community services for people with severe mental illnesses have been much criticised in recent inquiry reports (see page 15). Community Mental Health Teams (CMHTs), on the balance of the available evidence, can deliver good quality care to people with severe and enduring mental illness. Onyett and Ford (1996) summarise the literature on CMHT effects as follows:

- increased “engagement” (service involvement)
- decreased acute bed use
- increased cost-effectiveness

Onyett and Ford are advocates of CMHTs and numerous caveats need to be applied. Not all teams are effective - Patmore and Weaver’s work (1992), together with the survey conducted by Onyett et al (1994) suggest that the less focused is a team, the less effective it is at dealing with people with severe and enduring illness. Teams are markedly less effective if they are uni-disciplinary. In addition, there are such differences between teams that it is essential to keep in mind that it is not the team *per se* which improves outcome for patients, but rather the care which is co-ordinated and delivered. Establishing a team will, of itself, have no effect on care - it is the quality of care delivered, and the manner in which it is provided, which is all important.

CMHTs have produced a fundamental shift in the delivery of services to patients with schizophrenia in recent years. Their benefits have been demonstrated unequivocally with respect to increased patient and carer satisfaction. Services which have adopted assertive community treatment programmes first developed by Stein and Test (1980) in the USA and replicated by Hoult (1984, 1986) in Australia and Muijen et al (1992) and Burns (1993a,b) in the UK, demonstrate clearly the ability to provide quality services in the community to patients once deemed impossible to discharge from hospital. Home treatment programmes described by Dean and Gadd (1990) and Burns (1993a,b) demonstrate the ability to provide acute treatment to such patients, avoiding the need in some cases for admission to hospital. The development of such services requires careful planning and the involvement of clinicians who feel confident in such an approach and, most importantly, who are equipped with sufficient resources to deliver such a service safely and effectively. Although some services have demonstrated cost savings, the general view is that community services require a similar level of funding to more traditional hospital based services. While we would recommend that commissioners should insist upon community mental health service development we would wish to emphasise strongly that without adequate resources from the outset such developments are likely to have only a limited impact and place considerable strain upon staff and patients. Services which do not have significant direct involvement by a consultant psychiatrist are likely to be ineffective and tend to drift away from providing services to patients with schizophrenia.

Inpatient Services

Community services may reduce the need for inpatient admission, but there is no evidence that they can eliminate the need for in-patient services. The perceived need for in-patient services by consultant psychiatrists is often a matter of tension between clinicians and managers. Clinicians in Scotland may overestimate the numbers of acute beds required once an established community service is in place, but bed reductions should follow from lower bed use, rather than being introduced simultaneously with increases in community services. The relationship between community services and hospital admissions are not clear cut. The introduction of effective community mental health services paradoxically seems to lead to an increase in the number of admissions although the length of stay decreases. The overall effect therefore is to reduce total bed usage. Commissioners should therefore not use admission rates alone as an outcome measure of service effectiveness.

Several factors will affect the volume of in-patient services required. As demonstrated above (Section 1), higher numbers of admissions can be expected from deprived areas. In addition, other service availability will have a direct impact on acute service use - for example, if rehabilitation services are unavailable, acute service use is likely to increase. Use of secure services also affects acute service use.

The effect of rurality and population sparsity on admission patterns has not been explored adequately in Scotland. It is very difficult to provide intensive domiciliary services in rural areas at acceptable cost. It may be that rural areas will have higher rates and longer in-patient stays than would be expected in cities. Research is required in order to test these hypotheses.

Rehabilitation

Rehabilitation services are an important component of psychiatric services and continue to be required and may be provided both through in-patient and day hospital services. These take various forms but focus on teaching social skills and skills of daily living. An example is that developed in California by Liberman (Liberman et al 1993) (see also page 25).

Day Services

There is great confusion about the distinction between day hospitals and day centres. By and large, day hospitals provide treatment packages and should be the responsibility of health services and day centres provide social diversion and social support and should be the responsibility of local authorities and voluntary agencies. There is undoubtedly some overlap but efforts to avoid duplication lead to greater efficiency and better services for patients. Day hospitals should aim for medium term, fairly intensive, multidisciplinary treatment packages for the management of complex cases and to provide rehabilitation. Day centres should focus on longer term support.

Forensic Services

Specialist services are required for forensic patients. All mental health hospital services will have access to an Intensive Psychiatric Care Unit, but use of such a facility for individuals returning from the State Hospital, or being sent to the unit for assessment before being returned to court, will increase utilisation. The provision of adequate local medium secure accommodation will significantly reduce the pressure on acute services and allow more active treatment to take place for those requiring briefer admissions. Services are also required to divert people appropriately from the Criminal Justice system.

4 PERSPECTIVES ON CARE

Health Services

Several recent documents provide professional views on the care of people with schizophrenia. The Clinical Standards Advisory Group has produced a checklist for use in assessing services, including assessment of service specifications and contracting processes (Clinical Standards Advisory Group 1995 a,b). In Scotland, the CRAG/SCOTMEG Working Group on Mental Illness has published a Good Practice Statement on "Services for people affected by schizophrenia" (1995). The CRAG/SCOTMEG document made 29 recommendations. These recommendations are not repeated here, but most are in line with this document. The main additional areas covered by the CRAG/SCOTMEG recommendations are:

- provision of genetic counselling
- availability of guidance on state benefits

See Appendix 2 for discussion of the CRAG document.

Voluntary Organisations

The National Schizophrenia Fellowship (Scotland) is the only voluntary organisation specialising in schizophrenia in Scotland. Although started as a support organisation for carers it now runs services for people with schizophrenia (and other severe mental illness) throughout Scotland. These are primarily drop-in centres but include employment projects, supported accommodation, carer support and an information service. Other voluntary organisations such as Scottish Association for Mental Health (SAMH) and the local Associations for Mental Health (e.g., Glasgow Association for Mental Health, GAMH) are generic and have a more strongly user base. Many of the services they provide are also day care and drop-in centres, befriending, information and advocacy but also include employment and accommodation. The Richmond Fellowship is best known for provision of accommodation.

Services from all voluntary organisations should be seen as complementing services provided by the statutory agencies and should be developed in conjunction with them. Some services, for example, accommodation, may be provided by voluntary organisations instead of statutory agencies, but others, particularly day services and drop-in centres, should not be seen as a substitute for appropriate NHS day services.

Services run by voluntary organisations focus on key features of choice, flexibility, confidentiality and a commitment to involving service users in decisions about how the service is run. Particularly in day services there is an informality which is uncommon in statutory agencies, with open access and little, if any, record keeping on individuals. This, and the services' autonomy and independence from statutory agencies, is valued by service users, some of whom refuse contact with statutory agencies.

Since it seems likely that day services will increasingly be provided by voluntary organisations there is a need for continued financial support for ongoing and new services, which may extend beyond the Mental Illness Specific Grant (MISG). The

recent report from the Social Work Inspectorate for Scotland, *Time Well Spent, (1995)* highlights the need for co-operation between Health Boards and Local Authorities in the planning and provision of day services. The voluntary organisations themselves should probably also take an active part in the planning process. The other responsibility the report highlights for Health Boards is for day services to have a 'quick and ready access to backup services'. Ways of linking the more informal services with appropriate backup must be devised without compromising the aspects of voluntary organisation services valued by users.

5 USER AND CARERS' VIEWS

Involvement

Current policy requires the involvement of users and carers in the development of community care plans. This most commonly happens through local self-help groups and voluntary organisations. Such groups have much to offer but may not represent all views. Widespread consultation is necessary from an early stage. This involves users/carers in drawing up plans to develop new, acceptable approaches to services and their delivery, including their priorities, not merely commenting on policy documents and being involved in audit and evaluation.

It can be difficult for users and carers to take a fully active part in this process when they are in the minority, unused to the formal procedures of the meeting, may have problems in attending meetings due to times and transport costs and are likely to experience stress if they challenge accepted professional/management/bureaucratic views. Users and carers may benefit from:

- training/information on the system and how to function in it
- meetings skills
- support of known professionals/project workers (who attend with them as observers)
- expenses (travel, meals)

Priorities

The main concerns of users/carers are:

- good, accessible information
- appropriate, available housing
- choice and flexibility in day services - through statutory and voluntary agencies
- easy access to (preferably known) services at time of exacerbation of the illness/crisis
- employment /training opportunities.

Users' views

Attitudinal barriers are at the heart of users' views. People with mental health problems want to be listened to, want to be involved, particularly in decision making regarding their treatment and care and want to be taken seriously. Improving the style of interaction between professionals and patients does not require new resources or additional expenditure, but does require a change of approach for many people.

Services which offer flexibility and informality, as provided by the voluntary organisations, are appreciated by many, especially those who are disenchanted with statutory services.

In a recent UK study examining patient and relative satisfaction with hospital services after first admission for a psychotic illness, the lowest satisfaction measures were in relation to time spent talking to patients, privacy on wards, activities for patients and

information about the illness, with only 4% satisfied with information provision (Leavey et al 1997).

Carers' views

For over 20 years the primary concerns of carers have stayed the same. In 1974 the National Schizophrenia Fellowship presented a set of ten demands to the then Secretary of State for Health - the focus being that relatives should be acknowledged and treated as the main carer and to be involved in decision making regarding the care of their ill relative. More recently a new concern has been added - the closure of hospitals, loss of beds and difficulty in getting admission to hospital (Hogman & Pearson 1995). A recent (unpublished) survey by the National Schizophrenia Fellowship (Scotland) of its members indicated that advice and information and home visits were ranked equally as main priorities by members. This was followed by housing, day services and employment. Itemising of other reports simply underlines one finding - although some services have responded, the concerns of carers remain the same twenty years after the 1974 statement. In Leavey's study mentioned above (Leavey et al 1997) only 18% of relatives were satisfied with time spent talking with doctors, and 4% were satisfied with information.

Although there may be some differences in users' and carers' views (and this should be expected, reflecting as it does their different perspective), in most respects their views are similar. They want a service which addresses all aspects of the person's condition and which is not inflexible due to the externally imposed divide between health and social care which in many cases for practical purposes appears false.

Advocacy Services

Advocacy services are usually regarded as an important component of services for people with severe mental health problems. Their local implementation, and decisions such as their place within services or as stand alone services, require careful consideration. Organisations such as the Scottish Association for Mental Health can provide useful advice.

6 EFFECTIVENESS

The literature on the effectiveness of interventions in schizophrenia is extensive. This section does not review this in detail, but rather points out important current issues in relation to service effectiveness.

Drug Treatment

Drug treatment remains the most important single aspect of the management of schizophrenia. The management of schizophrenia was transformed by the introduction of effective drug therapies and most other advances would have been impossible without the underpinning of pharmaceutical treatments.

Anti-psychotic drugs (also known as neuroleptics) control positive symptoms, reduce negative symptoms and reduce relapse. A proportion of people do not respond to these drugs and, although some are helped by newer anti-psychotic agents (discussed below), some are refractory to all current drug therapies (Bentall et al 1996). Many people discontinue their use of anti-psychotic drugs because of adverse effects. Use of depot drug preparations, which are given by intramuscular injection, reduces the rate of relapse.

Adverse effects of anti-psychotic drugs are important but are not discussed in detail here. Other drugs, including anti-depressants, are used in schizophrenia. The following discussion, however, centres on a few important current issues.

High Dose Antipsychotic Drugs

In some cases, for clinical reasons, clinicians use antipsychotic drugs in higher doses than those recommended in the British National Formulary (BNF). High dose levels may be associated with an increased risk of sudden death (see Thompson 1994 for a review). The Royal College of Psychiatrists have produced guidelines for the use of high dose antipsychotics (Thompson 1994) and recommended that all providers should have a local policy for the prescription of neuroleptics in doses higher than those in the BNF.

In addition there is increasing litigation in the United States with respect to tardive dyskinesia, a long term side effect from neuroleptic medication, and more attention should be paid to informing patients before commencing neuroleptics with respect to potential side effects.

New Anti-Psychotic Drugs

Clozapine, although not new, was only reintroduced to the UK market in 1988. It is an anti-psychotic drug which is effective in some individuals with schizophrenia who have not benefited from adequate courses of other drugs (known as treatment resistant schizophrenia). Clozapine may produce serious side effects in about 1% of patients which require blood monitoring. The recent CRAG/SCOTMEG Working Group recommended that all providers should have an explicit policy on treatment with Clozapine (Working Group on Mental Illness 1995).

Other new drugs, such as Risperidone, are now being widely prescribed. These drugs are considerably more expensive than traditional anti-psychotic drugs. Several studies are cited to indicate that these drugs are cost-effective in comparison to

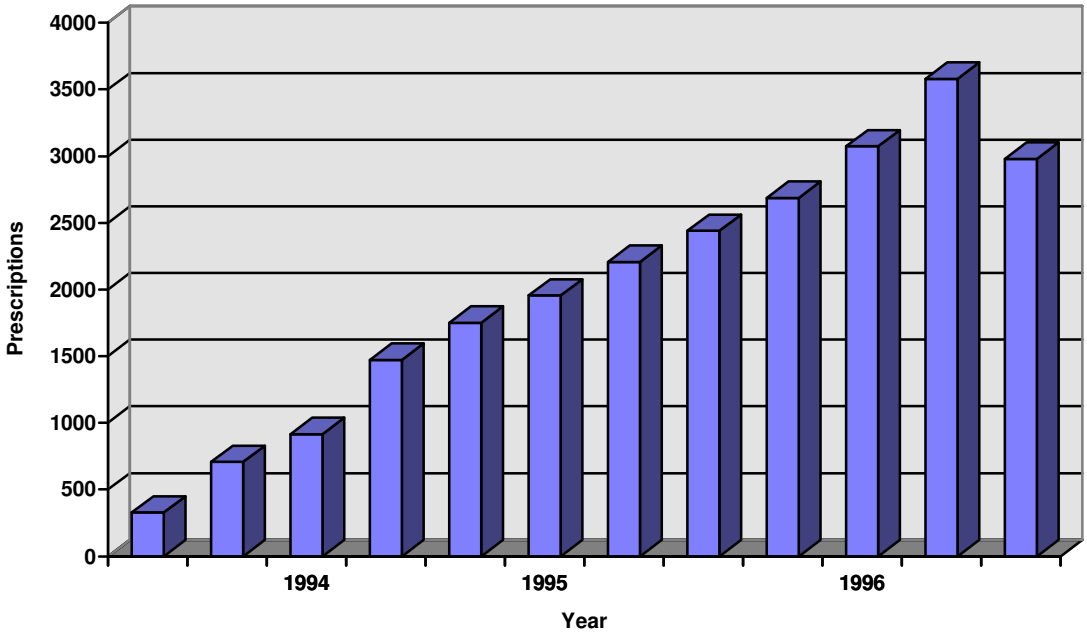
traditional drugs (Davies and Drummond 1993, Addington et al 1993). As Knapp (1996) points out, both these studies had serious limitations including being retrospective and, in the case of the UK work by Davies and Drummond, used American data not obtained by randomisation and used Delphi judgements rather than actual placements and outcomes. An important study by Meltzer et al (1993) suggests markedly decreased bed use and reduction in out-patient costs when Clozapine is used with people who have treatment resistant schizophrenia. This cannot, of course, be readily extrapolated to the use of Clozapine as a drug of first choice in schizophrenia. Drummond and Davies (1996), who undertook the UK work mentioned above, conclude that there is an urgent need for careful studies of pharmacological cost-effectiveness in schizophrenia.

It is important to separate Clozapine from other new anti-psychotics. There is convincing evidence that Clozapine produces improvements in a proportion of individuals whose illness is otherwise resistant to drug treatment. The number of people on Clozapine in Scotland at any one time is small - 640 in mid-1996 (T. Hepburn, Personal Communication). Commissioners can reasonably ask for the criteria recommended by the Working Group on Mental Illness (1995) to be met, and should consider agreeing protocols for withdrawal of Clozapine when it has proved ineffective in a particular case.

The issues in relation to Risperidone and the new drugs Olanzepine and Sertindole are different. Risperidone prescribing and associated costs have increased markedly in Scotland (see below). Olanzepine and Sertindole are licensed specifically to provide treatment for *non*-drug resistant schizophrenia. This pitches it in direct competition with established anti-psychotics. Although cheaper than Clozapine, for example, prescribing is likely to be far higher. If rates were to increase in a similar way to Risperidone, the impact on Scottish prescribing costs would be enormous. Commissioners require further information to assess the value of Risperidone and other new antipsychotics as they become available in routine practice. The SHPIC report, due later this year, will provide some assistance but commissioners will wish to identify local policies and prescribing costs in the interim.

Funding for Clozapine and some of the newer drug treatments in schizophrenia has become a contentious issue with drug costs rising significantly in recent years as a result. With increasing evidence that new drug treatments can improve clinical functioning sufficiently to allow discharge from hospital in cases where treatment had previously failed, there would seem to be every justification for making such treatments available when appropriate. While it certainly is sensible to apply critical reasoning to their prescription, it will become increasingly difficult to justify budget ceilings for their appropriate prescription. We wish to suggest that, as a proportion of patients discharged from long stay beds will only have been able to be discharged because of the availability of such drugs, a percentage of the resource transfer to local authorities for the provision of community services should be reallocated to a community drug budget to allow continued prescription outside of hospital.

Figure 4
Risperidone Prescriptions in Scotland, Primary Care



Source: PRISMS

Table 3
Anti-Psychotic Prescribing in Primary Care, Scotland, July to September 1996

Drug	Items	Cost (£)
Thioridazine	35 462	40 329
Trifluoperazine	5 630	20 309
Chlorpromazine	5 435	10 093
Haloperidol	5 204	31 757
Sulpiride	3 498	69 540
Risperidone	2 980	304 188

Cognitive Therapies

Cognitive-behavioural therapy is a psychological approach which tackles disordered thinking and perception. Used for over 30 years with depression and anxiety it has, in recent years, been developed for people with schizophrenia. The aim of cognitive therapy is to modify apparently fixed beliefs, faulty interpretations and automatic thoughts, through a process of reasoning and reality challenging and by relating them to the continuum of 'normal' experience. In this way fear is reduced and the potential to act on such faulty beliefs may be modified (Kingdon and Turkington 1994).

This procedure is used in conjunction with anti-psychotic medication and may improve compliance as well as developing coping strategies for managing symptoms, including depression associated with schizophrenia. Several treatment variations have developed. Results are encouraging (Tarrier 1993 a, b; Drury et al

1997 a, b; Johnson 1997) and further research projects are in progress. This is an area which may produce valuable treatment options for the future, but even if research results continue to be promising, integration into routine practice may prove difficult (Kavanagh et al 1993). Service commissioners should review further research results, particularly in relation to effectiveness in routine practice, as it becomes available.

Supported Accommodation

Detailed discussion of supported accommodation is outwith the scope of this document. However, the need for this type of accommodation cannot be stressed too much. In order to run an effective service for individuals suffering from schizophrenia one must have immediate access to acute beds. If these are blocked because of difficulties in discharging patients into supported accommodation the acute service can no longer provide its primary responsibility. This can consequently prevent effective community care. Agencies providing supported accommodation often have protracted assessment procedures which can only commence once social work have provided a community care assessment. There are often considerable delays in providing community care assessments and it is not uncommon for patients to wait three or four months from the time that they are ready to be discharged until they are actually discharged. We would suggest that commissioners should negotiate more effective arrangements with social work and supported accommodation agencies. This single matter is one of the most important in determining whether a service works or not.

Early Intervention

There is important work emerging from New Zealand (McGorry et al 1996) and Birmingham (Jackson and Birchwood 1996) about the value of providing intensive early intervention to those presenting with their first episode of schizophrenia. The evidence would seem to suggest that efforts spent treating the illness at an early stage can prevent later deterioration in social functioning with a consequent possible reduction in numbers of relapses and greater compliance with treatment. McGrory and Birchwood both suggest the development of specific early psychosis intervention teams and their work should be followed with interest.

Family Interventions

Family services and interventions can be provided with either the aim of changing outcomes for the patient or for the relatives or carers. Although interventions such as reducing expressed emotion may reduce stress in relatives the main outcome is reduction of relapse for patients (Leff 1985). This is only suitable for families with high expressed emotion, which itself requires sophisticated assessment. Usually conducted by a psychologist or CPN it involves education and developing new ways of family interaction. It can be used in conjunction with medication and has good results with carefully selected families.

Of wider applicability may be the stress management/problem solving approach involving relatives. Again usually carried out by a CPN the focus is on reducing relapse through developing new coping strategies for both patients and relatives, including awareness of prodromal symptoms and management by early medication (Falloon et al 1993).

Little work has been carried out on services whose main beneficiaries are relatives. Support groups and education are important and a feature of relatives demands. On their own they have little impact on patient outcomes but may improve relatives' relationships with services and enable their role as carer (Atkinson and Coia 1995). They are probably best introduced early on and at time of crisis for best uptake. Staff require additional training to undertake this role. Most work to date has been undertaken by CPNs as it fits with their existing responsibilities.

Patient Education

Giving patients information about their illness is part of a number of approaches including cognitive-behavioural therapy. This goes beyond an ad hoc description of the illness and treatment as might be presented at any time to a patient, and is a structured intervention. Understanding and focusing on individual beliefs and explanations for illness is central and may best be approached on an individual basis.

In all trials only a minority of patients (about one-third) have taken up an education intervention alone, although these achieve significant outcomes. This suggests it may best be combined with other social interventions as well as medication. In the United States outcomes have focused on improving compliance with medication (e.g. Kelly & Scott 1990). In contrast, in the British research participants have already been good compliers with medication. Outcome from education groups have shown significant improvements in social functioning and quality of life (Atkinson et al 1996). It is probably best delivered by a trained CPN. Further research developing its use with patients' non-compliance may be warranted in view of the American results. An educational approach to skill acquisition has been developed in the United States by Liberman and his colleagues (e.g. Eckman et al 1992; Liberman et al 1993). Modules covering medication management and a number of life and social skills are presented to patients as part of an individually tailored programme. Significant improvements are reported in skill acquisition and use, including medication compliance.

The effectiveness of all education techniques in NHS settings has not been established and evaluation will be required.

7 RECOMMENDATIONS

Liaison with other Agencies

Although health services are essential in the care of people suffering from schizophrenia, other services such as day services and housing are essential for effective community care. Commissioners should ensure these issues are given high priority in joint planning agreements.

Primary Care

Commissioners should encourage clear lines of communication between primary and secondary care, and should encourage joint Primary/Secondary care audit projects of the care of people with schizophrenia.

Hospital Treatment

In-patient services will continue to be required in the treatment of schizophrenia. Service commissioners should review the balance of in-patient services commissioned. The services required will vary according to need and to the availability of other services, including secure residential places. Health Service planners should not use admission rates alone as an outcome measure of service effectiveness.

Drug Treatments

The available evidence indicates that some newer anti-psychotic drugs offer either increased effectiveness (Clozapine) or fewer short and long term side effects. Providers should agree local guidelines on the introduction and use of new drugs balancing therapeutic value against cost.

Antipsychotic drugs may be used in doses in excess of those recommended in the British National Formulary. Service commissioners should seek evidence that providers adhere to the guidelines produced by the Royal College of Psychiatrists.

Commissioners should consider negotiating with local authorities for a percentage of the resource transfer following closure of hospital beds to be reallocated to a community drug budget to allow continued prescription of mew, more expensive anti-psychotic drugs after discharge from hospital.

Cognitive Therapies and Education

The available research evidence indicates that cognitive therapies and education are likely to have a useful role in the treatment of schizophrenia sufferers. Research studies, in progress at present, should provide further information on efficacy. Effectiveness in local service use has yet to be demonstrated. Where these services are commissioners, commissioners should require participation in research or evaluation.

Community Mental Health Teams

Coordinated CMHTs should be established with significant direct involvement of consultant psychiatrists. Teams should be fully established before any beds are reduced.

Carer Support

Carers who live with relatives with schizophrenia experience considerable psychological morbidity. Commissioners should ensure that service specifications include provision of support, information and advice to carers.

The Care Programme Approach

The Care Programme Approach should increase targeting of services on people with severe and enduring mental illness. Many people with schizophrenia will not be included in the Care Programme Approach, and it is important that their needs are not neglected. Commissioners should encourage service providers to review the needs of all people with schizophrenia, not only those who meet the criteria for the Care Programme Approach.

Supported Accommodation

There is a need for more effective arrangements with social work and supported accommodation agencies over discharge assessments.

8 REFERENCES

Addington D E, Jones B, Bloom D, Chouinard G, Remington G, Allbright P (1993) Reduction of hospital days in chronic schizophrenia patients treated with risperidone in a retrospective study. Clinical Therapeutics 15: 917 - 26.

Allebeck P (1989) Schizophrenia: a life-shortening disease. Schizophrenia Bulletin 15: 81 - 89.

Atkinson J M, Coia D A (1995) Families Coping with Schizophrenia. A Practitioner's Guide to Family Groups. Chichester: Wiley.

Atkinson J M, Coia D A, Gilmour W H (1994) Evaluation of Education Groups for People with Schizophrenia. Report to CSO, Scottish Office.

Atkinson J M, Coia D A, Gilmour W H, Harper J P (1996) The impact of education groups for people with schizophrenia on social functioning and quality of life. British Journal of Psychiatry 168: 199 - 204.

Beiser A, Blanchard J J (1993) Schizophrenia: Psychopathology. In Bellack A, Hersen M (Eds) Psychopathology in Adulthood. Boston, Allyn and Bacon.

Bellack A S, Morrison R L, Wixted J T et al (1990) An analysis of social competence in schizophrenia. British Journal of Psychiatry 156: 809 - 818.

Bentall R P, Day J, Rogers A, Healy D, Stevenson R C (1996) Side effects of neuroleptic medication: assessment and impact on outcome of psychotic disorders. *In* Moscarelli M, Rupp A, Sartorius N (Eds) Handbook of Mental Health Economics and Health Policy, Volume 1, Schizophrenia. London, John Wiley and Sons Ltd.

Birchwood M, Smith J (1987) Schizophrenia and the family. In Orford J (ed) Coping with disorder in the family. Beckenham: Curme Helen.

Birchwood M, Macmillan F, Smith J (1994) Early intervention. In Birchwood M, Tarrier N (eds) Psychological management of schizophrenia. Chichester: Wiley.

Blom-Cooper L, Halley H, Murphy E (1995). The Falling Shadow London: Duckworth.

Boyd W et al 1996. Report of the Confidential Inquiry into Homicides and Suicides by Mentally Ill People. Royal College of Psychiatrists

Bromet E J, Dew M A, Eaton W (1995) Epidemiology of psychosis with special reference to schizophrenia. In Tsuang M T, Tohen M, Zahner G E P (Eds) Textbook in Psychiatric Epidemiology pp 283 - 300. New York, Wiley - Liss.

Burns T, Kendrick T (1997). Primary care of patients with schizophrenia - a search for good practice. British Journal of General Practice 47: 515-520.

Burns T, Beadsmore A, Bhat A V, Oliver A, Mathers C (1993a). A controlled trial of home-based acute psychiatric services. I: Clinical and Social Outcome. British Journal of Psychiatry 163: 49-54.

Burns T, Rafferty J, Beadsmore A, McGuigan S, Dickson M (1993b).A Controlled Trial of Home Based Acute Psychiatric Services. II: Treatment Patterns and Costs. British Journal of Psychiatry 163: 55-61.

Clinical Standards Advisory Group (1995a) Schizophrenia Volume 1. London, HMSO.

Clinical Standards Advisory Group (1995b) Schizophrenia Volume 2. London, HMSO.

Cooper J E, Goodhead D, Craig T, Harris M, Howat J, Korer J (1987) The incidence of schizophrenia in Nottingham. British Journal of Psychiatry 151: 619 - 626.

Creer C, Wing J K (1974) Schizophrenia at Home. Surbiton: National Schizophrenia Fellowship

Davies L M, Drummond M F (1993) Assessment of costs and benefits of drug therapy for treatment resistant schizophrenia in the United Kingdom. British Journal of Psychiatry 162: 38 - 42.

Dean C, Gadd E M (1990). Home Treatment of Acute Psychiatric Illness. British Medical Journal 301: 1021-1023.

Drummond M, Davies L (1996) Economic evaluation of drug therapy for schizophrenia. *In* Moscarelli M, Rupp A, Sartorius N (Eds) Handbook of Mental Health Economics and Health Policy, Volume 1, Schizophrenia. London, John Wiley and Sons Ltd.

Drury V, Birchwood M, Cochrane R, MacMillan F (1997a) Cognitive therapy and recovery from acute psychosis: a controlled trial. I. Impact on psychotic symptoms. British Journal of Psychiatry 169, 593 - 601.

Drury V, Birchwood M, Cochrane R, MacMillan F (1997b) Cognitive therapy and recovery from acute psychosis: a controlled trial. II. Impact on recovery time. British Journal of Psychiatry 169, 602 - 607.

Duggan C (1997) Assessing risk in the mentally disordered. British Journal of Psychiatry 170, supplement 32.

Eagles J M, Whalley L J (1985) Decline in the diagnosis of schizophrenia among first admissions to Scottish mental hospitals from 1969 - 78. British Journal of Psychiatry 146: 151 - 154.

Eagles J M, Hunter D, McCance C (1988) Decline in the diagnosis of schizophrenia among first contacts with psychiatric services in North East Scotland, 1969 - 1984. British Journal of Psychiatry 152: 793 - 798.

Eastman N (1996) Towards an audit of inquiries: Enquiries not inquiries. In Peay J Inquiries after Homicide. London: Duckworth

Eaton W W, Day R, Kramer M (1988) The use of epidemiology for risk factor research in schizophrenia: an overview and methodological critique. In Tsuang M T,

Simpson J C (Eds) Handbook of Schizophrenia. Vol 3. Nosology, Epidemiology and Genetics. pp 169 - 204. Amsterdam, Elsevier Science Publishers B V.

Eaton W W, Mortensen P B, Herrman H et al (1992) Long-term course of hospitalization for schizophrenia: Part 1 risk for rehospitalization. Schizophrenia Bulletin 18: 217 - 228.

Eckman T A, Wirshing W C, Marder S R et al (1992) Techniques for training schizophrenic patients in illness self-management: A controlled trial. American Journal of Psychiatry 149: 1549 - 1555.

Engelhardt D M, Rosen B, Feldman J et al (1982) A 15-year follow-up of 646 schizophrenic outpatients. Schizophrenia Bulletin 8: 493 - 503.

Falloon I R H, Laporta M, Fadden G, Graham Hole V (1993) Managing stress in families. Cognitive and Behavioural Strategies for Enhancing Coping Skills. London: Routledge.

Glover G R (1989) The pattern of psychiatric admissions of Caribbean-born immigrants in London. Social Psychiatry and Psychiatric Epidemiology 25: 49 - 56.

Goldberg D, Jackson G (1992) Interface between primary care and specialist mental health care. British Journal of General Practice 42: 267 - 269.

Harrison G, Ineichen B, Smith J et al (1984) Psychiatric hospital admissions in Bristol. II Social and clinical aspects of compulsory admission. British Journal of Psychiatry 145: 605 - 11.

Harrison G, Owens D, Holton A et al (1988) A prospective study of severe mental disorder in Afro-Carribbean patients. Psychological Medicine 18: 643 - 57.

Harvey I, Williams M, McGuffin P, Toone B K (1990) The functional psychoses in Afro-Carribeans. British Journal of Psychiatry 157: 515 - 22.

Hogman G, Pearson G (1995). The Silent Partners - The needs and experiences of people who care for people with a severe mental illness. Surbiton: NSF.

Hoult J, Reynolds I (1984). Schizophrenia: A Comparative Trial of Community Orientated and Hospital Orientated Psychiatric Care. Acta Psychiatr Scand 69: 359-372.

Hoult J (1986). Community Care of the Acutely Mentally Ill. British Journal of Psychiatry 149: 137-144.

Humphreys M S, Johnstone E C, Macmillan J F, Taylor P J (1992) Dangerous behaviour preceding first admissions for schizophrenia. British Journal of Psychiatry 161: 501 - 505.

Jablensky A, Sartorius N, Ernberg G, Anker M, Korten A, Cooper J E, Day R, Bertelsen A (1992) Schizophrenia: Manifestations, incidence and course in different cultures: a World Health Organisation ten-country study. Psychological Medicine Monograph Supplement 20. Cambridge, Cambridge University Press.

Jackson C, Birchwood M (1996). Early interventions in psychosis: opportunities for secondary prevention. British Journal of Clinical Psychology 35 (4): 487-502.

Johnson D A W. (1997) Peer review of 'cognitive therapy and recovery from acute psychosis'. British Journal of Psychiatry 169: 608 - 609.

Kavanagh D, Clark D, Piatkowska O et al (1993) Application of cognitive-behavioural family intervention for schizophrenia in multidisciplinary teams: what can the matter be? Australian Psychologist 28: 1 - 8.

Kelly G R, Scott J E (1990) Medication compliance and health education among out patients with chronic mental distress. Medical Care 28: 1181 - 1197.

Kendell R E, Malcolm D E, Adams W (1993) The problem of detecting changes in the incidence of schizophrenia British Journal of Psychiatry 162: 212 - 218.

Kendrick T, Burns T, Freeling P, Sibbald B (1994) Provision of care to general practice patients with disabling long-term mental illness: a survey in 16 practices. British Journal of General Practice 44: 301 - 5.

Kessler R, McMonagle K, Shao S, Nelson C, Hughes M, Eshleman S, Wittchen H-U, Kendler K (1993) Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States; Results from the National Comorbidity survey. Archives of General Psychiatry 51: 8 - 19.

Kety S, Rosenthal D, Wender P H, Schulsinger F, Jacobsen B (1975) Mental illness in the biological and adoptive families of adopted individuals who have become schizophrenic. In Genetic research in psychiatry Eds Fieve R R, Rosenthal D, Bull H. John Hopkins University Press, Baltimore.

King M B (1992) Management of schizophrenia - the general practitioner's role. British Journal of General Practice 42: 310 - 11.

Kingdon D G, Turkington D (1994) Preliminary report: the use of cognitive behavioural therapy and normalising rationale in schizophrenia. Journal of Nervous and Mental Disease 179: 207 - 11.

Knapp M (1996) The health economics of schizophrenia treatment. *In* Moscarelli M, Rupp A, Sartorius N (Eds) Handbook of Mental Health Economics and Health Policy, Volume 1, Schizophrenia. London, John Wiley and Sons Ltd.

Krasucki C, McFarlane F (1996) Electrocardiograms, high-dose antipsychotic treatment and College guidelines. Psychiatric Bulletin 20; 6: 326 - 30.

Lancet (1995). Care management: a disastrous mistake (editorial) 345 (8947): 399-401.

Leavey G, King M, Cole E, Hoar A, Johnson-Sabine E. (1997) First-onset psychotic illness: patients' and relatives' satisfaction with services. British Journal of Psychiatry 170: 53 - 57.

Leff J P, Vaughn C E (1985) Expressed Guidance in Families. Its significance for Mental Illness. N.Y.: Guildford Press.

Lefley H P (1987) Ageing parents as care givers of mentally ill adult children: an emerging social problem. Hospital and Community Psychiatry 38: 1063-70

Levav I, Kohn R, Dohrenwend B P, Shrout P E, Schwartz S, Link B G, Naveh G (1993) An epidemiological study of mental disorders in a 10-year cohort of young adults in Israel. Psychological Medicine 23: 691 - 707.

Liberman R P, Wallace C J, Blackwell G, Eckman, T A, Vaccaro J V, Kueknel T G (1993) Innovations in skills training for the seriously mentally ill: The UCLA social and independent living skills modules. Innovations and Research 2: 43 - 60.

McCreadie R G, Leese M, Tilak-Singh D, Loftus L, MacEwan T, Thornicroft G (1997) Nithsdale, Nunhead and Norwood: Similarities and differences in prevalence of schizophrenia and utilisation of services in rural and urban areas. British Journal of Psychiatry 170: 31 - 36.

McGorry PD, EdwardsJ, Mihalopolous C, Harrigan SM, Jackson HJ (1996). EPPIC: an evolving system of early detection and optimal management. Schizophrenia Bulletin 22 (2): 305-326.

Mason P, Harrison G, Glazebrook C, Medley I, Croudace T (1996) The course of schizophrenia over 13 years: a report from the international study on schizophrenia (ISoS) coordinated by the World Health Organisation. British Journal of Psychiatry 169: 580 - 586.

Meltzer H Y, Coia P, Way L et al (1993) Cost effectiveness of clozapine in neuroleptic-resistant schizophrenia. American Journal of Psychiatry 150: 1630 - 38.

Miles P (1977). Conditions predisposing to suicide: a review. Journal of Nervous and Mental Disorders. 164: 231 - 46.

Mischon J et al 1995. The Grey Report. East London and the City Health Authority

Mueser K T, Bellack A S, Morrison R L, Wixted J T (1990) Social competence in schizophrenia: premorbid adjustment, social skill and domains of functioning. Psychiatric Research 24: 51 - 63.

Muijen M (1996) Report of an Independent Review. Southampton Community Health Services NHS Trust and Hampshire Social Services Department

Muijen M, Marks I, Connolly J, Audini B (1992). Home based care and standard hospital care for patients with severe mental illness: a randomised controlled trial. British Medical Journal 304, 749-754.

Munk-Jorgensen P (1985) The schizophrenia diagnosis in Denmark. A register-based investigation. Acta Psychiatrica Scandinavica 72: 266 - 273.

Munk-Jorgensen P, Mortensen P B (1992) Incidence and other aspects of the epidemiology of schizophrenia in Denmark, 1971 - 1987 British Journal of Psychiatry 161: 489 - 495.

Norman R M G, Malla A K (1993a) Stressful life events and schizophrenia. I: Conceptual and methodological issues. British Journal of Psychiatry 162: 161-165

Norman R M G, Malla A K (1993b) Stressful life events and schizophrenia. II: Conceptual and methodological issues. British Journal of Psychiatry 162: 166-174

Nuechterlein K H, Dawson M E (1984) A heuristic vulnerability - stress model of schizophrenic episodes. Schizophrenia Bulletin 10: 300-312

Oldridge M L, Hughes I C T (1992) Psychological well-being in families with a member suffering from schizophrenia. British Journal of Psychiatry 161: 249 - 51.

Onyett S, Heppleston T, Bushnell D (1994) A national survey of community mental health teams. Team structure and process. Journal of Mental Health 3: 175 - 94.

Onyett S, Ford R (1996) Multidisciplinary community teams: where is the wreckage? Journal of Mental Health 5: 1: 47 - 55.

Patmore C, Weaver T (1992) Improving community services for serious mental disorders. Journal of Mental Health 1: 107 - 15.

Platt S (1985) Measuring the burden of psychiatric illness on the family: an evaluation of sane rating scales. Psychological Medicine 15: 383-93

Pullen I M, Yellowlees A (1988) Scottish psychiatrists in primary health care settings: a silent majority. British Journal of Psychiatry 153: 663 - 663.

Ritchie J, Dick D, Lingham R (1994). Report of the Inquiry into the Care and Treatment of Christopher Clunis. London:HMSO

Roy A (1982). Suicide in chronic schizophrenics. British Journal of Psychiatry 141: 171 - 177.

Royal College of General Practitioners (1993). Shared Care of Patients with Mental Health Problems. Report of a Joint Royal College Working Group - Royal College of Psychiatrists and Royal College of General Practitioners. Occasional paper No. 60.

Scottish Schizophrenia Research Group (1987). The Scottish First Episode Schizophrenia Study. IV Psychiatric and social impact on relatives. British Journal of Psychiatry 150: 340 - 344.

Scottish Schizophrenia Research Group (1992). The Scottish First Episode Schizophrenia Study. VIII. Five year follow-up: clinical and psychosocial findings. British Journal of Psychiatry 161: 496 - 500.

Shields J (1978) Genetics. In Schizophrenia: Towards a new synthesis. Ed Wing J K. Academic Press, London.

Shields J (1980) Genetics and mental development. In Scientific Foundations of Developmental Psychiatry. Ed Rutter M. Heinemann Medical, London.

Social Work Inspectorate for Scotland 1995 Time Well Spent. A Report on Day Services for People with Mental Illness. The Scottish Office

Stein L I, Test M A (1980). Alternative to Mental Hospital Treatment. Archive of General Psychiatry 37: 392-412.

Sugarman P A, Craufurd D (1994). Schizophrenia in the Afro-Caribbean community. British Journal of Psychiatry 164: 474 - 80.

Tarrier N, Beckett R, Harwood S, Baker A, Yusupoff L, Ugarteburu I (1993a) A trial of two cognitive-behavioural methods of treating drug-resistant psychotic symptoms in schizophrenia, I, outcome. British Journal of Psychiatry 162: 524 - 32.

Tarrier N, Sharpe L, Beckett R, Harwood S, Baker A, Yusupoff L (1993b) A trial of two cognitive-behavioural methods of treating drug-resistant psychotic symptoms in schizophrenia, II, treatment specific changes in coping and problem-solving. British Journal of Psychiatry 162: 524 - 32.

Thompson C (1994) The use of high-dose antipsychotic medication. British Journal of Psychiatry 164: 448 - 58.

Tsung M T (1978) Suicide in schizophrenics, manics, depressives and surgical controls. Archives of General Psychiatry. 35; 153 - 5.

Tsung M T, Woolson R F, Fleming J A (1979) Long-term outcome of major psychosis. Schizophrenics and affective disorders compared with symptom-free surgical controls. Archives of General Psychiatry 36: 1295 - 1301.

Turner-Crowson J (1993) Reshaping mental health services: implications for Britain of US experience. Research Report 16. London, King's Fund Institute.

Vaughn C E, Leff J P (1976). The influence of family and social factors on the cause of psychiatric illness. British Journal of Psychiatry 129: 125-137

Wilkinson D G (1982) The suicide rate in schizophrenia. British Journal of Psychiatry 140: 138 - 141.

Wing J K (1994) Mental Illness In Stevens A, Raftery J (Eds) Health Care Needs Assessment Vol 2 pp 202 - 304 Oxford, Radcliffe Medical Press.

Working Group on Mental Illness (1995) Services for people affected by schizophrenia: a god practice statement. Edinburgh, CRAG/SCOTMEG.

Zubin J, Springs B (1977) Vulnerability: A new view of schizophrenia. Journal Abnormal Psychology 86: 103-126

APPENDIX 1

Clinical Standards Advisory Group

The Clinical Standards Advisory Group (CSAG) produced a report on services for people with schizophrenia in 1995.

The report includes two volumes;

Volume 1: Reports on a review of services in eleven areas in the UK

Volume 2: Includes a detailed questionnaire for the review of mental health services

CSAG identified 'Key Points' for assessing purchasers and providers:

Box 1: Key Points for Assessing Purchasers

1. **Strategic Plan** - the district has carried out strategy development in conjunction with other key stakeholders to ensure a unified approach

2. **Review and updating of strategic plan** - procedure and timetable for review and update of strategic plan

3. **Population-based needs assessment** - methodology and procedure for population-based needs assessment

4. **Service specification** - a detailed specification including statements of services for people with severe mental illness

5. **Explicit targets and quality standards** - which should be set out in the service specification or contract

6. **Regular contract monitoring meetings** - formal systems set in place for purchasers and providers to meet on a regular basis

7. **Purchasers ensure that providers implement and monitor statutory guidelines** - for CPA, Mental Health Act etc.

Box 2: Key Points for Assessing Providers

1. **Business plan** - that there is a business plan

2. **Service directory** - that there is a service directory

3. **Involvement of clinical staff in contracting** - that there are effective mechanisms for clinicians' views to be communicated directly to the purchasers

4. **Care Programme Approach** - that there is a policy and register for the CPA

5. [**Section 117 of the Mental Health Act** - that there is some form of register and monitoring of individuals subject to the requirements of Section 117 - *not applicable in Scotland*]

6. **Users and Carers actively involved in services** - local organisations should be actively involved in the planning process and the monitoring of quality

7. **Advocacy supported and facilitated** - advocacy schemes or workers, either directly funded or from user groups

8. **Quality of residential accommodation** - the quality of both the physical and social environment

9. **Full range of accessible services** - that there is a full range of services accessible to those with severe mental illness

10. **Specialist practitioners/teams for schizophrenia or severe mental illness**

11. **Audit** - active and routine audits are effective in improving the quality of clinical practices and services

12. **Social Services** - social services' views of local NHS services for those with schizophrenia

13. **Users and Carers** - users' and carers' views of local NHS services for those with schizophrenia

APPENDIX 2

Services for People with Schizophrenia: A Good Practice Statement CRAG/SCOTMEG Working Group on Mental Illness

This document reviews the content of health care services for people suffering from schizophrenia. It includes three relevant appendices:

Contract Standards

Research and Audit: Areas for further Study in Schizophrenia

Training Recommendations

The Contract Standards Appendix, taken with the CSAG document, provides useful suggestions for contract setting, several of which are echoed in this document. The outcomes section (Section 14 in Appendix A of the CRAG Report) suggests numeric measures of outcome. Most of these suggestions are process measures rather than outcomes. Some are difficult to measure (e.g. statistics on sudden death in patients receiving anti-psychotic drugs) and to know how to interpret (e.g. admission and re-admission rates), while others have no clear definition. This should not detract from the value of the report, which contains much of assistance to purchasers and providers in their negotiations.