defunct in America. Behind the apparent childishness and quaintness of the Southern Negro (that American identity) there was always despair and rage, open enough now for all to see. Seen with the eyes of the seventies, it is a long, sentimental Mark Twain passage.

We could not predict from these pages, the historical necessity of the rise of the Black Panthers, of the Civil Rights Movement, of riots, massacres by State police, the bankruptcy of the American liberal attitude, the despair of the American Negro turning towards revolution.

In other words, the endless discussion of 'mind-stuff', the ghost-in-the-machine, the generalised person who 'contains' and categorises periods of history, cannot in fact exist in the here and now of actual history. Nothing in Erikson's schemes allows for the positive acts of men who change history now. They are only seen as patients lying on couches, mixing facts with fantasies, passively responding to events.

In a study of the kibbutzim in Israel I met no one who could recognise themselves and their 'identity' as described by Bruno Bettelheim in his book *The Children of the Dream*, particularly where Bettelheim uses Erikson's way of describing adolescence.

When I saw the film *Klute* in Hampstead, I was particularly struck when one of the characters in the film, making a confession, said something like, 'It was a couple of years ago, I had this crisis of identity...'. The Hampstead audience laughed. It sounded so slick, false, fashionable. If he had said, 'I was depressed' or 'anxious' or 'had had a breakdown', this audience would have sympathised and not responded with derision.

**Same kinds of people**

Across the graves of all the wars, our 'national' problem is to see we are all the same kinds of people on either side of frontiers. Depressive anxiety, feelings of persecution, de-personalization, the loss of a sense of reality, are common to all races. They are not 'fashionable' experiences. They are yet commonplace.

I would agree that the schizoid have problems with identity. Touchy, uncertain, seeing the world as split into the good and the bad, making others feel their feelings, the schizoid deny that all this is their problem. Let us not agree with them that it is ours. We are nearly drowning in our psychiatric terms without all that too.
The impact of schizophrenia on an ordinary family is just as shattering as any natural disaster—extreme reactions from members of the family are to be expected. To talk of co-existing with the illness is an 'obscenity' yet proper social provision is still totally lacking.

Relatives seldom have the chance to share what little they may have learnt with professional workers. Still less, of course, are they in a position to make their voices heard by the central policy-makers and administrators of the health and social services. They are unorganised, shy of publicity and some are rather broken by their experiences.

In the past year, during which I have had contact of some sort with over 300 families of schizophrenics, it has been depressing to find how many able and knowledgeable relatives there are—some in influential positions—who shrink away from any public involvement with the condition.

It is not that they reject their schizophrenic relative. They will make ample provision and they may contribute generously to a research fund. But they cannot bear the thought of the condition itself, the intolerable fact. So far as social action is concerned, they would rather 'leave things to the professionals'. But this is not really enough if, as I believe, there is a specific contribution to the common stock of knowledge about the management of schizophrenia, and social arrangements for dealing with it, which relatives are qualified to make.

Social progress, as we know, is not always a straight-line advance. Usually some penalty has to be paid for every step, and the question (often pushed under the carpet until dragged out by later historians) is who, at any given time, is paying the penalty. The new drugs and attitudes towards treating mental illnesses which came in during the fifties have been amply and rightly praised. But the penalty?

Well, I suggest that the penalty for the mass discharges of chronic schizophrenics from mental hospitals which began to show in the statistics from 1954 onwards—those deceptively pleasing statistics—has been paid mainly by inadequate and overworked

Based on a paper delivered at the MIND/NAMH conference 'Focus on schizophrenia' at the Middlesex Hospital, September 21st, 1971

Trying to contain a schizophrenic member within the family home is so disruptive of normal life that it is almost like demolishing the home from the inside.
local authority services, and — above all — by the relatives.

With hindsight it is easy to see that no adequate steps were taken to expand community services step by step with mental hospital run-down, and that it really was not sufficient hopefully to get some patients on to a stabilising dosage and then turn them loose on unhelped relatives or on nobody and nothing, as happened in many areas and still happens.

The more ruthless policies for removing what was called ‘the silt’ from hospitals were not humane nor even rational. But they were believed in, with the force of a general idea, and they saved the Treasury money. We have it on the authority of Professor J. K. Wing that somebody highly-placed even advised the Minister that schizophrenics were not really ‘handicapped’, nor ‘disabled’, just ‘ill’.* So the GPs, or the relatives, or somebody, could cope.

And what, on a national scale, was done to enable the relatives to cope? I think you know the answer to that, and why the slogan ‘community care’ has come to have, for many families, the sound simply of a con trick.

The chips on my shoulder will now be apparent. But the weariness and bitterness of the relatives is touched with an awareness that many professional workers are also having to cope with impossible burdens. The difference between us, of course, is that the families are ‘emotionally involved’ as the dreadful jargon puts it, and cannot escape from their involvement.

Watching someone fragment

At one level of this involvement there is nothing to be said about schizophrenia except that it is an obscenity, and that to talk of ‘living’ with it, of having to watch someone one loves fragment, and to know that, although the pieces may never be put together in this world, none the less one must devise means for putting a bright, optimistic, forward-looking face on things is also an obscenity. At the infinitely lower level of comprehension from the relatives’ point of view — that of intellect — there are the puzzles of causation, what is ‘schizophrenia’, how does it come about? The analysis and dissection of schizophrenics has the status of a growth industry. I hope I personally retain an open mind about causation. If disturbed parental personalities are to blame, or faulty intra-familial patterns of communications, oedipal rivalries, mystifications of sexual or personal identity, if only for triggering something which could otherwise have stayed dormant, for

* Address in Mental Health Week 1970

heaven’s sake let’s have it proved, and the sooner the better.

But I do note that most studies of families are — inevitably — made after the event. The observer was not there when the catastrophe struck or before. He did not observe the family before the diagnosis was made, nor during the period — perhaps of years — in which the condition was presumably incubating. His evidence about this period is always indirect and often hearsay. So I have some scepticism about the validity of working backwards and deducing from the family pattern, as observed at point B in time, what the pattern was like at point A, and then going on to discover in the hypothetical point A pattern explanations for the schizophrenia.

Ludicrous inferences

As a no-doubt crude simile, some of these generalisations read to me as though a party of sociologists, on visiting a town devastated by an earthquake, were to conclude from watching the dashed survivors that a state of apathy, confusion, indecision and feeble bickering was quite ordinary, that this was their normal social pattern, and that this, in turn, had been primarily responsible for the earthquake. I hope this is not too much of a parody but some of the inferences drawn from post facto case studies seem almost as ludicrous.

A lot of very clever people, it seems to me, are constantly overlooking the obvious: that the impact of schizophrenia on the most ordinary family can be as shattering as that of a natural cataclysm, and that many extreme reactions are probably normal and even to be expected. In the schizophrenias of slow onset particularly, families may be ‘living with schizophrenia’ in the words of my title and making innumerable adaptations to it — good or bad, but all modifying any ordinary family pattern — before they or anybody else knows that they are, in fact, ‘living with schizophrenia’.

I can hear some of you thinking, ‘But he is begging the question, what is a “normal” family’. Very well, may I briefly outline what could happen if the blow struck any of you? (May I add that I have received several letters from psychiatrists with schizophrenic children and I cannot say that in tone or account of experiences these letters are markedly different from the others.) Would you try please — though I know it is impossible — to put out of your minds anything that you know professionally. Imagine yourselves to be butchers, bakers, candlestick-makers, politicians, priests — anything you like — knowing no more about
mental illness than what you have gathered from a chance newspaper article or from some TV programme.

One of your adolescent children begins to behave oddly. At first he just moons about. But many adolescents moon about. He or she takes to lying on the bed, presumably day-dreaming. He or she becomes moody, bad-tempered, slovenly, ‘difficult’. But many adolescents day-dream and are moody or difficult.

To you, as a sensible parent, such behaviour is well within the limits of the normal growing-up process and no attention is paid to it. He or she will ‘grow out of it’, you say. But time goes on and he or she does not grow out of it. A crisis occurs when some wild display of aggression, truancy, or merely bizarre behaviour, drives you to seek expert help.

Blessed are you if at this point you get a firm diagnosis; twice blessed (one is almost tempted to say) if there is an acute and unmistakeable schizophrenic episode and rapid hospitalisation.

But often you will get no firm opinion about your son or daughter and a period of months or years begins – mercifully you have no pre-vision of it – punctuated by spells in and out of hospital, hopes raised and dashed, vague reports that he or she is suffering from ‘neurosis’, a ‘severe depression of adolescence’, or that she is ‘a seriously disturbed girl’ – as though you cannot see that for yourself.

Is anyone being honest with you? Do they know, and are not aying? Or does nobody know? And within the fog of uncertainty, disputes in the family grow and fester. Grandpa says the boy must be got away from home; he needs work in the open air – there is a cousin in Canada who might take him. Or perhaps you have a brother-in-law who presses on you somebody in Zurich – or was it Vienna? – who did wonders for that nephew of a friend of his.

Meanwhile your home, in an atmosphere of simulated normality, a determined show of ordinary living, is rapidly becoming preoccupied by the sick member: the ups and downs of his moods, his unpredictable vagaries of behaviour.

Reactions of brothers and sisters may differ widely and their resentment may be deep if the sick one is not handled according to the ideas of each: affectionate concern; or alternatively, jealousy over the attention he is getting; irritation at the sufferer’s ‘laziness’ or ‘selfishness’; rejection; guilt for past teasing or bullying (shadowing the omnipresent and inescapable parental guilt); refusal to accept that he is ill at all, but only ‘being himself’, ‘doing his own thing’, that it is not he or she but ‘society’ which is ‘all wrong’ – ‘What he needs is to get away from those damned hospitals and live among normal people’.

About the last reaction, what else can one expect? After all, they – the brothers and sisters – you – the butcher or baker – and I – are all exposed to the total climate of our time in which the individual’s madness has become a paradigm for a mad society and in which to many it is a perfectly valid question whether the fantasy world of schizophrenia is not less insane than the so-called real world of Vietnam, race hatreds, and the hydrogen bomb (or the images of these, and all the rest of the phantasmagoria projected by the mass media on the individual’s consciousness).

Opposite pressures, reflecting the ambivalencies of your situation, will be exerted on you by the fears of social embarrassment and ‘stigma’, both in the post diagnosis stage and earlier.

There are the material anxieties: how is the disabled one to be given a livelihood? None of these fears is irrational or imaginary. Try finding a sympathetic employer for your schizophrenic. Try getting digs where the landlady will not quickly make some excuse for getting rid of him. Try just listening in the background as he or she is floundering in front of some social security clerk who suspects he is work-shy or fiddling his ‘benefit’.

Protests from neighbours

As regards stigma, your family has to live in the world as it is – a world in which the popular press and TV ‘image’ of a schizophrenic is mostly of a rapist or child-murderer, in which a hostel cannot be established in a ‘better class’ district without protests from the neighbours that their wives and daughters won’t be safe. (Useless for families of schizophrenics to reflect that their poor, frightened lad wouldn’t hurt a fly.)

The recurrent little social dilemmas. ‘What nice children you have, Mrs. So-and-So. And what does your other daughter do? She is a great deal at home, isn’t she?’ And the swift calculation whether to evade, or whether the questioner is sufficiently intelligent and sympathetic to be told the truth or part of the truth.

Do not be surprised, therefore, if your family, with the abnormalities of its home-life, shrinks from introducing too many fresh outsiders into the home. (To be thereupon typecast by the investigator with the clipboard as: ‘Introverted family which finds social contacts difficult’.)

Some members of your family may never accept the diagnosis and will quarrel with the parent who tries to implement it. You then have a divided and part alienated family on your hands, if you haven’t one
already—to say nothing of the cases where once happily married parents are themselves driven apart because one rejects or partially rejects, which the other cannot forgive.

The sheer disruptive power of schizophrenia over a family is fully intelligible only to those who have been through it. But a few of the worst effects, could, I think, be avoided if the medical problem of communicating with the family were tackled at an earlier stage, and firmly. And not only with the parents, but with all the family who matter, collectively. I do not know how this is to be done, only that it ought to be done.

As it is, I am sometimes tempted to think, from my own experience and that of others, that the mystifications in hospital communications (medical and administrative) might almost have been deliberately devised for creating dread, uncertainty and discrimination among relatives.

Too many of us, in what begins as a search for the facts and clear guidance, have found ourselves in a Kafka-like world where even the hospital corridors seem to whisper, 'don't ask', where nobody knows or perhaps everyone knows but nobody will say: passed on from one shadowy functionary to another and back again—'Didn't you ask the doctor that?', or 'Mental breakdown is only a label, you know', looking at you with a bright stare or a glance from behind half-open lids to see how you are taking it, how disturbed you are; the strange platitudes—'treat her as normally as possible' or 'we shall have to see how things go, won't we?'

Job done sketchily

Must it be like this? I can understand the doctor who says, 'I can't spare the time from my clinical work. I must leave someone else to put the families in the picture.' I can understand consultants deputing the job to others. But I cannot understand the job being done sketchily or the impression being conveyed, subtly or crudely, that almost everything the families really want answers to, including vital questions of management, are something for some inferior kitchen-and-scullery end of the hospital in which the doctors are not much interested—and then not even keeping these, in practice essential, departments properly informed.

I am not greatly impressed by the 'lack of time' excuse when to put the relatives fully in the picture may be important for the patient's chances of not occupying a bed in that hospital again. But my concern here is only to suggest that mystification may begin not in the home but in hospitals, and is inflicted not by the relatives on each other but by hospital doctors and officers on the relatives.

I feel that far more research ought to be done on the psychology of communication with the relatives of the mentally ill. Are all the obfuscations, ambiguities and
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Mending

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Published
Dr. Lawton
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really necessary?

I had hard evidence about all this. I suspect
the middle class and educated
counselling
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in

Dr. Lawton Tonge suggests in his book, *The
Mending of Minds*, that 'the psychiatrist needs to

* Published by Darwen Finlayson at £1.75

protect himself from his own feelings', that he shies
away from communicating a diagnosis of schizo-
phrenia as a physician does from one of cancer. Dr.
Tonge admits that if he is not careful, 'the patient,
the family and the psychiatrist . . . are all involved in

system of which the keynotes are inconsistency,
confusion and evasion', but he is not clear himself why,
as he puts it, the psychiatrist is 'tempted to play the

same game'.

A quite different form of non-communication is, I
fear, practised on relatives by doctors and social
workers alike, indeed by town halls, ministries,
official bodies – the lot. They may tell the schizo-

phrenic something but they omit to inform the
relatives. Some of them may assume (why?) that he
himself will tell his relatives.

Bits of buff paper

I wonder how many schizophrenics are walking the
streets at this moment with screwed-up bits of buff
paper in their pockets (or how many have been thrown
away) – communications from town halls, hospitals,
Government departments and so on, or with some
oral message which is supposed to have entered their
heads, on matters important to their well-being, of
which parents, wives, brothers know nothing.

This has little connection with problems of a
'divided service'. It is wrapped up with basic attitudes
to schizophrenia and schizophrenics, deriving from a
mixture of the legal position and professional codes,

neither wholly appropriate to the case. Either (the
general fiction goes) the person is ill enough to be
under a compulsory order, or he is a fully responsible
adult with whom we, the authorities, can deal
directly, not needing to inform anyone else.

In reality and in common sense, he is neither, but a
mentally-handicapped person in need of care and

protection, probably by a team. But if the team is to
include the relatives, and especially if some relative is
in practice the 'long-stop' guardian, they should surely
be kept in the picture at every point. I can scarcely
over-emphasise the importance of this, or the muddles
and confusions caused by neglecting it.

May I in conclusion mention two practical improve-
ments the need for which to me stand out in this vast
field. The first might cost little new Treasury money:
the second, I fear, a great deal.

First, there is the need for a really adequate

counselling service for relatives at all stages of their
confrontation with the condition, integrating every
aspect: psychiatric, familial, social.
Second (and this takes me back to where I started), there is the making good of the most glaring deficiency in the post-1950 arrangements. Starting with the fifties, the accent has been on rehabilitation and ‘living in the community’. Plans, as I said earlier, were geared (and largely still are geared) to the belief that de-institutionalising the chronic schizophrenic would in itself have such a therapeutic effect, in conjunction with hostels and day-hospitals, that long-term care would hardly be necessary. This assumption has proved to be unfounded.

Under the carpet

I would have thought the evidence is now overwhelming that a hard core of chronics require, and will go on requiring, long-stay sheltered environments. Which do not exist – not even on paper. Most hospital doctors, and every warden of a transitional hostel, can speak of cases which they are forced to discharge but which they know are almost bound to deteriorate without some permanent shelter. Here is a problem that cannot indefinitely be pushed under the carpet – or back on the family.

For what is ‘the family’ in this connection? Chiefly, I have suggested, an administrative fiction enabling legislators and administrators to pretend – or even believe – that the burdens their policies lay on individuals are being carried by wider shoulders than is in fact the case. But the administrative fiction is also a nostalgic folk memory of the former extended family, which is the ‘ghost in the machine’.

When I hear somebody complaining irritably in the press that hospitals get cluttered up with people having their babies in them, or dying in a protracted way, I reflect that the speaker is not really living in 1972. He is lost in a folk memory of rambling farm-houses in Thomas Hardy country replete with uncles, aunts, cousins and chimney corners for the aged or disabled. He is not looking at the 1972 reality of a nuclear family occupying a ‘semi’, or a boxy little flat, in some industrial conurbation, with the fit members out all day.

And it is through the same romantic haze that Whitehall, when it suits its book, can discover the remarkable virtues of ‘the family’ for the long-term care of schizophrenics who present problems which can only be met in a group environment.

In the end ‘the family’ usually comes down to one elderly widow, herself increasingly incapable. The other children grow away and cannot or will not cope. Their once affectionate concern gets calloused with the years. They marry and their husbands or wives will not accept indefinitely roles as nurses, guardians or almoners, or allow them to accept them. What else can one expect?

Unrealistic policy

Perhaps because the study of schizophrenia has been case-oriented, hospital-oriented from the start, the other members of a schizophrenic’s family are seldom fully perceived, still less accepted, as persons in their own right, with their own need for fulfilment, their own lives to lead. But there it is, and a social policy is just not realistic which relies on a continuous supply of saints or of elderly widows who live for ever. In many of the terrible accounts by elderly mothers in my possession there is no evidence of rejection, of a casting out of the schizophrenic member, only of immense weariness, a sense of a loved one deteriorating, and a great fear of the future.

The failure to provide even the bare minimum of shelter and security for permanently handicapped schizophrenics is, I suggest, the biggest current scandal in our social provision.

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