acceptable society. As such, *messianic* friends are always necessarily pushing against the boundaries of oppressive political and economic systems, ideologies, social conditions, and false epistemologies that might cause the suppression of the *imago Dei* in portions of the community. When Christian friends come together in solidarity and loving commitment, they encounter the world at a different level and see it from a different perspective. It is this radical edge to the friendship relationship that images the friendships of Jesus and enables friends to "see the world differently," and in seeing differently, move toward the initiation of liberation.

As the following chapters will show, people living with severe mental health problems are often defined as essentially "other," and marginalized, discriminated against, and excluded accordingly. Due to the nature of their condition and its psychological and social consequences, they are among the poorest and most marginalized within society. This being so, and in the light of the argument of this chapter, it becomes clear that *caring for the needs of people living with mental health problems is not an option for the church. Rather it is a primary mark of its identity and faithfulness.* The church community cannot simply choose whether it should or should not minister to people with severe mental health problems. Quite the opposite. In order to *be* the church in any kind of meaningful sense, it *has* to seek to minister to people living with mental health problems in all of their diversity. To minister within this area is a confirmation of the church's faithfulness to its calling. If God does have a "bias toward the poor," and if the church truly wishes to image Christ in his ministry of liberation and re-humanization, then the church must take the needs of this group of people most seriously. It is out of a desire to enable the church truly to be the church by developing a new and transformative form of ecclesial praxis that images the relationships and attitudes of Jesus, that this book finds its rationale and its goal.

Chapter 2

Setting the Context

Deinstitutionalization and Care in the "Community"

Recently the care of people with mental health problems has begun to move away from large institutions toward a model of care that focuses on the community. In most Western countries, the last few decades have shown a dramatic fall in the number of hospital beds, combined with modest increases in community resources.[1] In the United Kingdom and in the United States, there has been a major reduction in the amount of available institutional care that has led to a very large and rapid emptying of mental hospitals. It is estimated that "90 percent of the people who would have been in the hospital 40 years ago are not in the hospital today."[2] Within this context there have been fundamental changes in the way in which care for persons with mental health problems should be provided. It is now considered that people with mental health problems should be admitted to the hospital only where this is absolutely necessary for specific treatments. In the field of acute psychiatry this has led to more frequent admissions for shorter periods. Patients already in the hospital who could benefit from community based care have been discharged. Admission to the hospitals has thus been reduced, as have the number of long-stay patients.[3]

It is not possible or necessary here to offer an in-depth critique of the various policies, controversies, and political agendas that lie behind the current emphasis on deinstitutionalization. However, it will be helpful to reflect on some of the implications of this movement as they relate to the model of care that is being developed within this book. The movement from hospital to community has both positive and negative aspects. Positively, there are many long-term patients with various types of psychiatric difficulties who simply should never have been in the hospital in the first place. As one reads through the case notes of people who have been in the

hospital for many years, one is struck by the frequency with which one finds loose and often nonexistent diagnostic criteria for admission. Several long-stay patients whose case histories I examined in researching this book were incarcerated for such things as "moral insanity" (having an illegitimate child), or the vague "diagnosis" of "causing a public affray." Many of these people would certainly not be admitted to the hospital today. In fact, Fuller Torrey speculates that the vast majority of all individuals discharged from institutions could live successfully outside the hospital if medication and aftercare services were provided. "In that sense deinstitutionalization was and is a humane and reasonable idea."[4] Despite a good deal of handicapping caused, among other things, by long-term institutionalization, the side effects of pre-atypical neuroleptic medications, and inadequate material or relational support, many live good quality lives and are reasonably well integrated within society.

On the other hand, the reality is that deinstitutionalization has been a disaster for many people with mental health problems. As Stewart Govig observes, for the most part the project of deinstitutionalization as it has worked itself out within the United States has been a notable failure. It has become "a psychiatric Titanic, the largest failed social experiment of twentieth-century America." The ideal may have been to liberate individuals from the bondage of psychiatric institutions, but the reality reveals countless sad, lonely, isolated individuals for whom deinstitutionalization has been a movement away from varying degrees of security and friendship to nothing. A similar tale of lonely, discarded people could be told regarding the consequences of closing the large psychiatric hospitals in Great Britain.[5]

The Problem with Institutions

There can be little doubt that the old psychiatric institutions, many built before the turn of the century, have failed as caring institutions. "Most of them were built for custodial rather than therapeutic care and a lack of resources has prevented many of them from being substantially up-graded."[6] The reality is that, while offering a degree of safety and security, they often created

dangerous subcultures that were frequently abusive, sometimes violent, personally destructive, and often fundamentally oppressive. The potentially abusive nature of psychiatric institutions is shown very clearly in Erving Goffman's book *Asylums*. Fictitiously, but no less powerfully, it is described in popular novels such as *One Flew Over the Cuckoo's Nest*,[7] and Paul Sayer's novel, *The Comforts of Madness*, which offers a harrowing account of a man with schizophrenia who is subjected to the regimented and routinized confines of a psychiatric hospital. As McKie comments:

> Until recently care has been predominantly institutional. . . . Too frequently [these institutions] were staffed by nurses (or attendants) who had little training, if any at all, in therapeutic or interpersonal skills. There was little concept of rehabilitation or contact with the outside world. . . . With the use of legal detention . . . psychiatric hospitals were rife during the sixties and seventies with reports of mistreatment of patients, poor staff morale, and crumbling buildings.[8]

Most large psychiatric institutions were physically situated on the outskirts of towns and cities, which compounded the real and perceived sense of difference and otherness which existence in such institutions brought about.[9]

As Browning observes, "When the large psychiatric hospitals were built they were frequently erected in remote areas behind high walls. Those who were admitted for treatment and care were therefore out of sight and when out of sight there was the danger that they were out of mind and forgotten."[10]

More positively, the past few years have seen major changes in the way such institutions are managed and the types of regimes under that they function. Psychiatric hospitals certainly *can* show a more tolerant environment where "basic human needs such as adequate accommodation and nutrition, companionship, social interaction, employment and leisure activity are at least to some extent ensured. Because of their centralization of resources, the hospitals can provide many different types of therapeutic facilities and patients are not confined to treatment by medication or other physical methods alone."[11]

Hospital care encompasses both positive and negative aspects. On the one hand, psychiatric hospitals *can* provide a safe place for troubled individuals, an asylum in the positive sense of the word. Well-organized multidisciplinary teams can bring effective holistic care to individuals and genuinely enhance their life opportunities. However, hospitals can also be highly oppressive places, particularly for those suffering from severe and chronic mental health problems. The nature of such impairments means that people are very vulnerable and open to various forms of abuse and exploitation, both by members of staff and by their fellow patients.

Oppressive Institutions

The vulnerability of people within psychiatric institutions is an important point to reflect upon. Due to the nature of their conditions and the types of depersonalizing social forces that they encounter on a daily basis, people with long-term mental health problems are among the most vulnerable within our societies. However, within the confines of the institution, their vulnerability is increased manyfold.

Total Institutions

In his book *Asylums*, Erving Goffman develops the concept of "total institutions," such as prisons or psychiatric hospitals.[12] A total institution is a place of residence that contains a large number of persons who, for whatever reason, have been isolated from wider society for lengthy periods of time. Such an institution is closed, insular, and runs according to an enclosed and formalized administrative regime. All aspects of life within the institution are conducted within the same location and all activities are determined by the regime of the institution, taking place according to a strict timetable that is dictated by the power of the regime. In situations such as these, inmates have little or no moment-to-moment powers of decision making. On admission they abandon, or have forcibly taken from them, their right to agree or disagree to specific actions. There is a strict demarcation between staff and inmates, and staff attitudes toward inmates tend to be narrow and marked by hostile stereotypes. The institution is total in the sense that it

forms an insulated subculture that differs greatly from the culture at large. Within such a situation, the potential for explicit and implicit degradation and abuse is high. Patients have no power, and no control over what happens in their lives. Any signs of autonomy or "rebellion" are pathologized and dealt with through medication or physical restraint.

I remember as a trainee nurse being ordered to tell thirty patients to strip and line up in the bathroom in rows of ten, in order that they could be shaved and bathed by nursing assistants. On reflection, this was not an act of care but a method of control. Simple acts of personal hygiene became tests of willpower and evidence of the total control that nurses had over patients. Any dissenters would be isolated, and if they became "violent," held down and injected with powerful sedatives. The medication was not for the benefit of the patient; rather it was a means of control used by nursing staff to ensure that the regime carried on without challenge or interruption. Routine almost always took precedence over people. Total institutions not only strip all power from patients, they frequently effectively disempower and dehumanize staff as well. It is true that within this situation, I did have a choice: either I rebelled against the system and threw away my career, or I conformed and threw away something of my humanity. Sadly, and to my shame, when you are nineteen, altruistic needs often take second place to career needs.

We may not want to take on board all of the critiques of psychiatry presented by the antipsychiatry movement; nevertheless, there are within institutions serious issues of power and control that we ignore at our peril. While technically holding onto their basic rights such as the right to shelter, protection from the law, decent food, appropriate healthcare, and so on, in terms of *meaningful* citizenship, patients within institutions can be deeply oppressed. What use is the right to free speech when everything you say is assumed to be the product of your "madness"? What is the point of thinking of yourself as a citizen when those around you often may not even see you as a person? What use is it to have a right to buy property when the stigma that surrounds your illness means that you have very little chance of getting employment when you are released?

Such difficulties concerning citizenship and mental health problems are not unique to the asylum system. Many people with mental health problems living within the community suffer similar forms of abuse and deprivation of human rights.[13] However, within the confines of the subculture of the institution, such abuse can be concentrated and exacerbated in a highly destructive manner.

The Problem of Community

Caring for people with mental health problems within the community also has much to be said both for and against it. Potentially it offers a much wider range of possibilities for the individual to build relationships, become a member of a faith community, develop interests and find useful forms of employment, all of which are obviously beneficial in terms of self-esteem, acceptance, general life enhancement, and mental health development. In the philosophy of policies of deinstitutionalization, "the ideal is that people should live a normal life in normal circumstances, and not be unnecessarily distinguished as mentally ill."[14]

In a very real sense this philosophical ideal is in line with one of the primary objectives of this book, which is to enable those whose personhood is threatened by negative societal attitudes and values to live their lives as fully valued human beings. However, there is a huge gulf between the *ideal* of a caring community and the *reality* of the situation on the ground. Apart from the financial difficulties that policies of deinstitutionalization have created, there is another more significant dilemma faced by community care policies: within an individualistic culture such as is found within Western societies, there is really no such thing as community in the sense of a cohesive moral community that strives to offer care and attention to others. When official policies speak of "community" they are really only talking about life outside the institution. The term "community" is seen as designating a geographically or administratively defined area as opposed to a close network of positive, sustaining, human social relationships. In other words, the concept of community is understood in terms of *location* rather than of actual social or moral content. The word "community" used in this context is a morally neutral term that

says nothing about the potential quality of life that an individual might expect to experience upon entering it, or the types of difficulties he or she will encounter. As Peter Barham astutely observes, "Community conceived as a mere site, without reference to the forms of social relationship that are embodied there and to the constraints of those relationships, certainly offers no guarantee whatsoever of any improvement in the form and quality of our moral relationships with psychiatric patients."[15] It doesn't take much reflection to realize that there is a general uncertainty over what the concept of community actually means, and by implication what "caring-in-community" might consist of in practice.

> To the politician, "community care" is a useful piece of rhetoric; to the sociologist, it is a stick to beat institutional care with; to the civil servant it is a cheap alternative to institutional care which can be passed to the local authorities for action (or inaction); to the visionary, it is a dream of the new society in which people really do care; to the social services departments it is a nightmare of heightened public expectations and inadequate resources to meet them. We are only just beginning to find out what it means to the old, the chronically sick and the handicapped.[16]

This being so, there is no guarantee that deinstitutionalized care carried out within the "community" will be any more life enhancing or less abusive than institutional care, though it holds the potential for being so.

One major difficulty with all policies of deinstitutionalization is that it is notoriously difficult to assess their success. Little exists in the way of hard facts and figures on which to base a proper assessment. This is a highly unsatisfactory situation. The danger is that while community care policies have indeed enhanced the lives of many people and, given proper funding and planning, do have much to offer in terms of mental health care, the only thing that the public hears about is the high profile and mainly negative cases when community care has gone wrong. This simply confirms and propagates negative stereotyping and makes the possibility of creating *real* community for persons with mental health problems even more problematic. Although all of the implications of these

observations cannot be drawn out here, it is necessary to point toward the need for a thorough assessment of deinstitutionalization policies and an accessible way of communicating that knowledge to the general public. In this way public perceptions of how people with mental health problems *actually* function within the community (as opposed to how they are perceived to be functioning) can be given the opportunity to be shaped in an authentic and more positive manner.

Caring for "Strangers"

Community and institutional care both have much to be said for and against them. Yet the continuing emphasis on policies of deinstitutionalization and community care means that people with mental health problems inevitably form a significant part of our social landscape. The need for genuine community is perhaps the most pressing need in the process of caring for those individuals. If there really is no meaningful community, then it is the task of the church as a community of friends to create communities within which people can genuinely be cared for and find a place of solace, acceptance, and hope in the midst of loneliness and frequent experiences of hopelessness. A church that takes seriously its ministry to the poor *must* be prepared to offer a positive and constructive response to the presence of people with mental health problems within society. *Community care is considerably more than governmental policy. Community care is a fundamental responsibility of the community-of-friends.*

Chapter 3

What Is Schizophrenia?

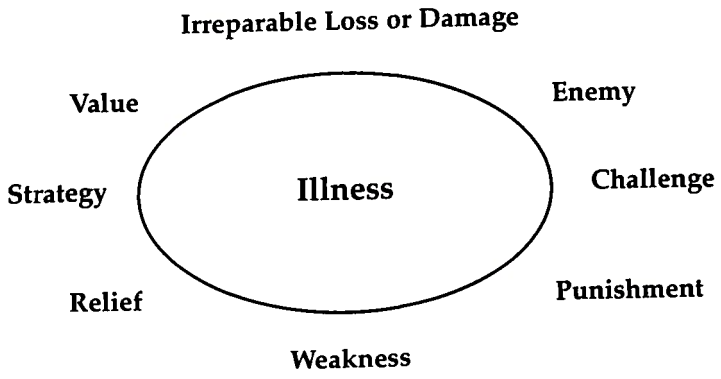
Having set the context for the investigation, we now begin to explore the nature and experience of mental health problems by developing a holistic model of schizophrenia. By holistic model, I mean one that not only seeks to *explain* the technicalities of schizophrenia, but also to give full consideration to what it *means* for a person within the context of his or her whole life. In working through some of the complexities of this phenomenon, it will be possible to uncover some of the hidden injustices and forms of oppression that infiltrate the lives of people diagnosed with enduring mental health problems. As we explore schizophrenia, the subtle ways in which individuals are moved from the status of persons to nonpersons by the social and relational structures of Western societies will become clear. Along the way, we will point beyond the boundaries of schizophrenia in order to illustrate how the experiences of people with this particular disorder might apply to other mental health problems.

Interpreting Illness

It is worthwhile to begin by reflecting on some of the complex dynamics involved in understanding mental health problems. Current research strongly suggests that many forms of mental health problems have some kind of biological cause. However, it is crucial to recognize that mental health problems, while quite possibly biological in origin, are also human experiences that happen to real people within specific social contexts. As such, they are open to a multitude of different understandings and interpretations, all of which have implications for the ways in which they are perceived and the forms of treatment approaches deemed legitimate for dealing with them.

Medical anthropologist Z. J. Lipowski points out that there are a number of different ways in which people can conceptualize particular illnesses. Lipowski argues that illness can be conceptualized as *irreparable loss or damage*, a *value*, an *enemy*, a *challenge*, a *strategy*, a *relief*, a *weakness*, or a *punishment*.[1] His theory is outlined below by the author in diagrammatic form.

The Meanings of Illness



This model shows some of the ways in which people can define situations and attribute meaning to illness experience. For example, from the perspective of the family of people with severe mental health problems, the narrative is often one of irreparable damage or loss. From their viewpoint, the person they knew and loved, along with the dreams, hopes, and expectations that they may have had for that individual, are shattered and destroyed by the illness. In their eyes, very often the person—that is, the person they knew—is lost to the illness. Alternatively, some might see the illness as a relief, a strategy, or even a mystical experience. Some Christian writers such as Jay Adams see mental health problems such as schizophrenia as strategies that people embark upon to avoid the admission of personal sinfulness.[2] In the midst of all of these competing interpretations of the illness, the person with the

problem may well have a radically different perception of what it means and the types of priorities and responses that should be deemed appropriate.

The question of which interpretation of illness experiences is correct was raised in chapter 1. Within a social context where the medical model reigns supreme and the power of the mental health professions exceeds the power of the individual, the possibility of the medicalization of illness experiences (that is, an interpretation of an illness that places primary emphasis on issues of pathology and control as opposed to personhood and growth) is very real. It is difficult to talk about conditions such as schizophrenia, depression, bipolar disorder, and so forth, without beginning with issues of pathology rather than people. The ways in which militaristic metaphors are frequently used in defining treatment approaches in medical and psychiatric textbooks are interesting and highly suggestive. From this perspective, illness and disease are seen as *challenges* to be *overcome*, or *enemies* to be *battled against*. However, the approach of the medical model, while highly influential, is only one, and not necessarily the most appropriate, interpretation of what mental health problems actually are as human experiences. Nevertheless, its powerful diagnostic and treatment approach along with its concomitant emphasis on *cure* rather than *care* retains a powerful hold on public and professional expectations. As we progress, it will prove useful to bear in mind the significance of the interpretative context of the subject being explored, and the possibility that our own Enlightenment worldview might blind us to some fundamental truths.[3] As we proceed to reflect on the nature of schizophrenia, we would be wise to bear in mind these underlying power dynamics. As the various issues are addressed, we should be aware that our own thinking may well have been conditioned by cultural expectations and assumptions that stem from an interpretation of mental health problems that is bounded by the assumptions of the medical model.

Clinical Perspectives on Schizophrenia

Schizophrenia affects about one percent of the world's population. It is a condition that appears to affect the most basic mental functions that give people their sense of personhood, individuali-

ty, uniqueness, and direction. It is primarily a thought disorder that presents itself in the form of disordered thinking and feelings, that in turn leads to disordered activity. Schizophrenia is classified as a psychotic disorder. As such it is characterized by a distortion in the person's perception of reality, giving rise to misinterpretations of the environment in such a way that logical responses appear to fail.

Contrary to common assumptions, *schizophrenia is not a split or dual personality.* There is a condition called multiple personality disorder in which a person's personality is split and the person takes on different personas, but this is *not* schizophrenia. Rosenhan and Seligman note that a common misconception about schizophrenia is

> that it involves a split personality of the Dr. Jekyll and Mr. Hyde sort, with its attendant unpredictability and violence. This error arises from the origins of the word schizophrenia: schizo = split, phreno = mind. When the Swiss psychiatrist Eugene Bleuler (1857–1939) coined the term in 1911, he intended to suggest that certain psychological functions, ordinarily joined in normal people, are somehow divided in schizophrenics. When non-schizophrenics perceive, say, a horrifying incident, they immediately have an emotional reaction that corresponds to their perception. But, according to Bleuler, this does not happen to schizophrenics, for whom thought and emotion are split. Bleuler never meant to imply that there were two or more alternating personalities residing in the schizophrenic.[4]

The split that the term schizophrenia implies is between the way a person *perceives* reality and the way that reality actually is. Because of this, people going through acute periods of schizophrenia, in some senses "do not inhabit the same world" as others. Consequently, and understandably, the primary outcomes of schizophrenia are *alienation, dislocation,* and *incomprehensibility,* both on the part of people with this mental health problem and on the part of those around them.

The Experience of Schizophrenia

Put briefly, the main ways in which persons diagnosed as having schizophrenia experience their condition are as follows:

Hallucinations Hallucinations are false sensory perceptions that have a compelling sense of reality.[5] Persons with schizophrenia may hear, see, or smell something that in reality does not exist, such as voices telling them what they should or should not do. Barbara Turner offers a powerful and personal example of the impact hallucinations can have on both the sufferers and their relatives and friends. She wrote about the continuing voices:

> "Hurt yourself!" "You're so stupid!" "You'll never be any good!" I was crouched sitting up in the corner of the living room. I had to make them stop! Leaning forward I rocked back and slammed my head against the wall. The voices got a little quieter, so I did it again. And again and again. Through the hubbub of voices berating me, I heard a small voice. "Mommy?" I opened my eyes and saw my four-year-old son, Travis, standing there in his rumpled pyjamas. He clutched his Big Bird doll to his chest. "Mommy, are you OK?"[6]

Delusions Delusions are false beliefs that are not subject to reason or contradictory evidence and are not part of a person's culture. Delusions can involve themes such as persecution, religious mysticism, and grandeur. In the fascinating autobiographical monograph *Wild Haemorrhages of the Imagination,* this experience is described in the following terms.

> Paranoia is one of the most difficult frames of mind to live with. For one thing I find that I have absolutely no means of privacy as I am under the illusion of people—friends, relatives and worst of all, strangers—who can see into my mind and determine what my innermost thoughts are. With their eyes they can bore into the top of my head (and at times I often feel as though the top of my skull has been opened up) and somehow my thoughts are reflected into their brains and that their very worst ideas are being transmitted into my brain ending in total turmoil and confusion.[7]

Disordered Thinking Often the person's thinking is affected by the disorder. Consequently, the person may speak in a way that others cannot easily follow.

> There is difficulty keeping to the point and separating the relevant from the irrelevant. The person's thinking may be slow, or skip from one subject to another often going off at a tangent. . . . Thoughts may be jumbled and disjointed. It is difficult for the person to organize his thinking in any way at all.[8] . . . My thoughts race and don't seem to connect in a rational way. They are disjointed and because I cannot remember what they were seconds previously, I therefore cannot construct a sensible conversation, action or deed.[9]

Because of this disruption of thought and perception, the sense of self that normally gives people a feeling of individuality, cohesion, uniqueness, and self-direction is frequently disturbed in schizophrenia. This is sometimes referred to as a loss of ego boundaries,[10] and frequently is evidenced by extreme perplexity about a person's identity and the meaning of his or her existence, or by some of the specific delusions described above, particularly those involving control by an outside force.[11] In the words of pastoral theologian Charles Gerkin, the person diagnosed as having schizophrenia has lost a "sense of story line," and therefore lost the sense of self.[12] Their personal story no longer holds together, and the ravages of a broken narrative shatter their sense of personal identity.

Withdrawal and Loss of Initiative, Energy, and Motivation

It is important to understand that there are *two* sets of symptoms that persons diagnosed as having schizophrenia may experience at some points in their lives: positive and negative.

Positive Symptoms Positive symptoms are those described above—hallucinations, delusions, thought disorders—all of which might normally be associated with profound mental disturbance. These symptoms are primarily associated with the acute phases of the illness. Some people experience these symptoms all or most of the time, whereas others experience them intermittently. However, with schizophrenia there is a second, and often unacknowledged or misunderstood, set of negative symptoms.

Negative Symptoms The term "negative symptom" is descriptive of the sufferer's general attitude toward self, others, and life.

People diagnosed as having schizophrenia are often emotionally withdrawn with respect to self and others, and generally suffer from some degree of impaired functioning interpersonally, vocationally, and academically. Enjoyment of normally pleasurable leisure activities is destroyed. Failure to acknowledge the importance of negative symptoms leads to misunderstandings, interpersonal friction, and accusations of laziness and unsociability. These negative symptoms can have a profound impact on a person's life and, although not as obvious to the outsider, can be equally as devastating.

> The worst thing about this illness is that it tears out your soul. You know? If I could just find the strength I could beat it, but I am always so tired, so lethargic I just can't move against it. I was . . . still am I suppose, a student . . . studying Geography. But I think I am going to have to pack it in. I can't concentrate on a book for two minutes. If I do manage to read anything I can't remember . . . its gone before I finish the page! I just want to sleep. If it wasn't for my mother constantly hassling me I would just sleep all day! I once slept for 22 hours! Even then I was knackered when I woke up. I hate it when the voices start, but at least then I feel like I am alive. Just now I think I'm dead, but I just don't know it yet!

Abnormal Emotions Abnormal emotions occur when a person reacts emotionally in a way that is deemed to be inappropriate to present circumstances. For example, a person may laugh at a funeral, or cry when receiving good news.[13] However, the most common manifestation of this symptom is simply the blunting of emotions, whereby a person cannot feel any kind of emotional response, no matter how happy or sad a particular event might be.

Lack of Insight Despite the apparently bizarre and inappropriate nature of their behavior, these people with schizophrenia do not recognize that anything is wrong with their feelings or their behavior. Lack of insight is considered to be one of the primary identifying features of psychotic illness.

It is important to bear in mind that schizophrenia varies greatly in type and intensity from person to person. People will vary in the

symptoms they experience, with a minority experiencing most or all of them for most of the time and others experiencing some symptoms intermittently while managing to function reasonably normally for large portions of their lives.

The Course of Schizophrenia

The average age of onset of schizophrenia in men is between 20 and 25, whereas the average onset for women is between 25 and 30. "Before the illness is recognized there is often a prodromal phase in late teenage with social isolation, interest in fringe cults, social withdrawal (e.g., living alone in their bedroom with minimal contact with family and no friends)."[14] Therefore, symptoms and signs may predate sometimes by many years the next phase that is the "active" phase of the illness, characterized by positive symptoms such as hallucinations, delusions, and so on. Through the use of antipsychotic medication, this active phase can be aborted, but this is not always the case. Although something like a fifth of people suffering from their first episode of schizophrenia may make a reasonable recovery, the majority have multiple episodes, and about half have long-term impairment of function affecting their ability to form relationships and to work.[15]

The actual course and severity of the illness and its accompanying symptoms are extremely variable, with some people living their lives constantly in, or moving in and out of, acute psychiatric hospital wards and others functioning reasonably well (sometimes very well) within a community context. Due to this variability of outcome and the diverse possible life trajectories that accompany this illness, it is important to bear in mind that there is "no such thing as schizophrenia," understood as a universal phenomenon which has a fixed course and an inevitable outcome. Schizophrenia is something that happens to unique individuals in particular personal, social, and cultural circumstances, which can have a profound impact on a person's coping skills, the course of the illness, and the possibility and definition of recovery.

The Treatment of Schizophrenia: Pharmacological Interventions

Antipsychotic medications, or neuroleptics, have been available since the mid-1950s and have greatly improved the outlook for many people diagnosed as having schizophrenia. These medications reduce the psychotic symptoms of schizophrenia and allow people living with it to function more effectively and appropriately.[16] Such drugs do not *cure* schizophrenia or guarantee nonrecurrence of psychotic episodes. Rather, they seek to control the symptoms and allow the person to have a better quality of life.

The Problem with Neuroleptic Medications

One of the main difficulties with neuroleptic medications is that they have extremely unpleasant side effects such as *akathisia*—restlessness; *Parkinsonianism*— muscle weakness, tremor, stiffness, and a shuffling gait; *dystonia or dyskinesia*—involuntary muscle spasms, especially of the eyes and neck. *Tardive dyskinesia* may also appear after a long period on continuous medication. This disorder is characterized by involuntary movements most often affecting the mouth, lips, and tongue. Although these side effects are extremely unpleasant, they can be controlled to some extent with other medications. Nevertheless, one of the major causes of psychotic relapse for people diagnosed as having schizophrenia living in the community is not taking medications, and one of the reasons people stop taking them is because of these unpleasant side effects.[17]

Atypical Antipsychotic Medication

During the 1990s there were important advances in the pharmacological treatment of schizophrenia with the introduction of the so-called atypical antipsychotic medications. These drugs are called "atypical" antipsychotics because they are not thought to work primarily on the dopamine receptors in the brain in the way that typical antipsychotic medication does. These new medicines offer the benefits of the older (typical) antipsychotics, but have a reduced propensity to cause extrapyramidal motor symptoms. A number of recent studies have suggested that these newer forms of

medication may offer important clinical advantages compared to the forms of antipsychotic medication that have been used in the past.[18] Generally, the evidence seems to suggest that they are more effective over a broader range of symptoms with fewer side effects.

One of the reasons that people stop taking forms of medications that have the potential to improve their quality of life is that extremely unpleasant side effects accompany them. One major advantage of atypical antipsychotic medications is that people are more likely to stay on a medication if it is not worse than the illness itself! In reducing the number of side effects, while at the same time maintaining their therapeutic efficacy, atypical antipsychotics have made a significant contribution to enabling people to retain the motivation to continue with their drug regime.

The rare but significant incidences of violence carried out by people with schizophrenia are often tied in with the person's refusal to take any form of medication. In terms of violence to self, family, or others, if atypical medications mean that the person is more likely to continue willingly with a drug regime, and consequently more likely to avoid the circumstances that lead to violent outbursts, then this can only be beneficial. The jury is still out concerning the consequence of the long-term use of atypical medications. Nevertheless, atypical antipsychotic medications currently provide a significant source of hope for people diagnosed with schizophrenia.

However, I make these points with extreme caution. In juxtaposing schizophrenia and violence in this way, I am *not* suggesting that there is an inevitable connection between the two. As I will argue more fully later, people diagnosed with schizophrenia are no more prone to violence than other members of the general public. While atypical medication may help reduce violence in certain people, this is *not* to imply that *all* people diagnosed as having schizophrenia are inevitably violent (despite the fact that schizophrenia's media profile frequently suggests otherwise). This is an important point that I will highlight here and develop more fully as we progress. Likewise, I would not wish to suggest that atypical medication is the magic bullet of psychiatric care. It is not. Medication can be useful, but, as we shall see, schizophrenia is not something that can be dealt with through medication alone.

The Meaning of Medication

While pharmacological interventions may well have an important role to play in improving the quality of life experienced by people diagnosed as having schizophrenia, it is important to be aware of the full implications of having to take medication. If we simply focus on issues of biology and correct chemical intervention—that is, the perspective of the medical model—we risk missing what is of fundamental importance to the *person* taking the medication. For the persons taking the medication, it is considerably more than a technical maneuver designed to control the worst manifestations of their condition. Taking medication is a deeply meaningful experience that has a profound psychological and social impact on the lives of those who have to take it. In order to understand what I mean by this, it is necessary for us to focus specifically on what we might describe as the *social hermeneutics* of pharmacological intervention. By the term "social hermeneutics," I refer to the ways in which taking medications is understood and interpreted within the social experience of individuals, and the specific *meanings* that are ascribed to it.

The question of the meaning of medication is one that needs to be taken very seriously. While there has been a proliferation of research exploring what medication *does* for and to individuals, there is a paucity of research that seeks to explore what medication *means* to individuals. Medications and the act of giving and receiving medications are filled with meaning. These meanings differ according to context and circumstance, and frequently according to lay and professional perspectives. Put baldly, and at the risk of caricaturization, schizophrenia, understood in terms of the medical model, is a biological, chemical, and/or genetic condition that responds favorably to certain kinds of pharmacological intervention. The mental health professional is the healer, and schizophrenia is the target that needs to be dealt with without any necessary reference to the specific context or life-experiences of the patient. Medication primarily means the provision and administration of an effective, safe, clinically tested pharmacological product, aimed at controlling the particular set of signs and symptoms that makes

up the diagnostic category of schizophrenia. The act of medicating is part of the role of the professional and can be interpreted in varying terms as a therapeutic act of care and compassion. It is viewed as an action carried out for the benefit of the individual and the wider society.

However, from the perspective of the *person* with schizophrenia, or any other long-term mental health problem, the meaning of medication is often very different. While one might assume that a person would be glad to take medication if it relieved the worst manifestations of the condition, this is not necessarily so, even with those newer drugs that have fewer disturbing side effects. The mental health professions frequently pathologize the non-taking of medication, labeling patients who behave in such a manner "awkward" and "noncompliant," yet the reality of the situation is often much more complex.

Peter Barham and Robert Hayward in their fascinating study of people diagnosed with mental health problems who have returned to the community after many years in psychiatric institutions, note that there are numerous pressures on individuals to take on the primary social identity of "community mental patients." By this they mean that people tend to become highly stigmatized by their experience of mental health problems and their previous residence within an institution. When they re-enter society, there are a variety of ways in which their identity as persons is eroded by the strength of their unwanted social identity as "mental patients." Within such a context, the taking of medication assumes a very specific meaning. Barham and Hayward suggest that "the pressure to accept a definition of oneself as a community mental patient emerges most forcibly in relation to medication. It is here that awkward questions about the capacities of people with a history of mental illness to exert control over their own lives, and to make rational judgements about matters that concern their own well-being, are brought into sharp relief."[19]

Thus we have here an important power struggle revolving around the interpretation of medication. On the one hand we have the "mental patient," who has now been "released from the asylum," and is struggling to find a new identity and a sense of meaningful citizenship. Within this context medication can become a powerful symbol that can be perceived as a sort of rite of passage between the social state of "mental patient," and that of "citizen/person." Patients do not have the choice of taking or not taking their medication. Citizens do. On the other hand, we have the mental health professions who have multiple responsibilities: to the patient, the psychiatric institution, society, and governments, who view medication as a way of ensuring that the patient does not relapse and can remain within society. Preventing destructive symptoms is, of course, not in itself a bad goal. However, unless the dimension of meaning is addressed, there is a real danger that what may be a genuinely therapeutic gesture becomes a context for misunderstanding, contradictory interpretations, and social control.

The Meaning of Medication in Depression

In order to clarify and develop this point, it will be helpful to draw on the work of sociologist David Karp on the social dynamics of depression. Karp argues that the problem with taking medication for depression (and by implication other forms of mental health problems) is that the act of taking it, and the acknowledgment that one needs it, is a profound statement about what one is and how one's social identity is to be understood. The process of taking medications involves "a complex and emotionally charged interpretative process in which nothing less than one's view of self is at stake."[20] The act of taking medication for mental health problems is a clear affirmation that the person has a stigmatized emotional disorder, and as such, requires a dramatic redefinition of his or her concept of "self." "In this respect, a willingness to begin a regimen of psychiatric medications is far more than a simple medical decision. It is a decisive juncture in one's self-definition as an emotionally ill rather than merely troubled person."[21] One of Karp's interviewees puts it thus: "I didn't want to be told that I had something that was going to affect the rest of my life, and that could only be solved by taking pills. It was sort of definitive. I had a label and it was a label that I thought was pejorative."

Thus, even if medication does reduce symptoms and allow a person to achieve a better quality of life, this does not necessarily

mean that the person will perceive the medication in a favorable way. In my experience this deeper meaning to the process of taking medication, highlighted by Karp, is highly significant with regard to the care of people with mental health problems. I have encountered a number of people who have seen the act of stopping their medication as a highly symbolic gesture that, from their perspective, redefines their self-concept from "mental patient" to "normal citizen." In a sense, ceasing taking medication is seen as a rite of passage or an act of self-liberation, a movement from "mental patient" to "citizen." When, after a period on medication, they have felt better, the next step for them is to free themselves from the symbolic as well as the real bond of medication. By stopping their medication they are enabled to move away from their identity as "mental patients," who will be on medication for the rest of their lives, toward a new identity as "normal persons," whose quality of life is not dependent on drugs. Of course, the consequence of such actions can be disastrous, with relapse and violence—normally self-violence, but occasionally directed toward others—being a not infrequent result.

It is critical that we acknowledge this "hidden" dynamic that is embedded within the process of drug taking and the refusal of medication and think through the consequences of the hopelessness of having a social and personal identity as a "mental patient." There may well be a strong link between issues of personhood and self-esteem and issues of consuming medication that is overlooked or smothered by clinical and slightly polemic terminology such as "noncompliance," "difficult patient," and so forth. It may well be that the problem of the person not taking medication has not simply to do with awkwardness, lack of insight, or delusional activity. Within a community context, it may be that a vital component of their behavior concerns the way in which their mental health problem is defined by themselves and by society, and the consequences of this definition for their experience of self and self-value.[22]

Medication? Yes, but it's not the only thing.

I am not saying that medication is a bad thing and that people should stop taking it. What I am saying is that taking medication is much more complicated than it often appears to be, and that mental

health professionals, families, and all who are involved must seriously address the issues of meaning that I have highlighted here. Barham and Hayward found that the majority of people did not object to taking medication. What they *did* object to was the suggestion that medication was *all* there was to treating their mental health problems, that is, understandings that confined their situation within the boundaries of the medical model of understanding. They note that

> most [of the interviewees] did not object—in the short term at least—to taking medication, and indeed many of them found it beneficial, but they were intent upon ensuring that medication did not interfere with what they held to be the main priorities in their lives. And it was here that conflicts with the medical profession arose. What participants looked for from psychiatrists was an approach in which—to put the matter in more formal terms—the prescription of antipsychotic drugs was an adjunct to a psycho-social understanding of their predicaments rather than a substitute for such understanding.[23]

This is an important observation. There is considerably more to the care of persons living with mental health problems than simply prescribing drugs. As we shall see in chapter 4, there is a strong movement within psychiatry and also within some organizations that offer care and support for people with mental health problems and their families, toward understanding schizophrenia in biological terms. Within such a context, psychosocial intervention is often seen as secondary or even epiphenomenal to dealing with and developing an understanding of the biological and genetic aspects of schizophrenia. Thus the treatment and understanding of schizophrenia is encapsulated within the structure of the medical model, with psychosocial intervention being understood as secondary to biological intervention. Barham's subjects reverse the dynamic of this assumption by suggesting that schizophrenia should be reframed and understood primarily from its social and interpersonal aspects, with medication being understood as the secondary, supportive process within that context. Thus medication is seen to be necessary but certainly not sufficient as a response to schizo-

phrenia. Even if schizophrenia were found conclusively to have organic origins, from the perspective of people's lived experience, the focus of care has a critical interpersonal and social aspect that is at least equal to, and—in Barham's interviewees' opinion—surpasses pharmacological intervention. In order to understand why such a reframe should take place, and what the therapeutic implications of such a shift in emphasis might be, it is necessary to explore something of the social experience of people diagnosed as having schizophrenia. It is to such a critical exploration of the experience of schizophrenia that the following chapter turns.

Chapter 4

Beyond the Medical Model

Schizophrenia as a Neurobiological Disorder

There is increasing evidence to suggest that schizophrenia has some kind of genetic and/or neurobiological component. While there is a growing body of literature surrounding this area, the precise nature of the biological malfunction that causes schizophrenia remains open to debate. Various theories have been put forward suggesting that it is caused by such things as chemical imbalances, obstetric complications, neurological damage, or influenza.[1] Others suggest that schizophrenia is genetic in origin, with social factors acting as exacerbants of a genetic predisposition. Cardno and McGuffin make a strong case for the primacy of genetics in the etiology of schizophrenia:

> The best established aetiological component in schizophrenia continues to be the substantial genetic liability. In most individuals, this is likely to be caused by the collective action of multiple genes. In addition, one or more major genes may be inherited in a proportion of families. Environmental aetiological theories are less well established. If an environmental factor is clearly delineated it is likely to be of relatively small effect and to interact with the genetic liability.[2]

While none of these theories is conclusive, taken together, they do present persuasive evidence for attributing the etiology of schizophrenia to some sort of neurobiological defect. It may be that it is a combination of some or all of these factors that come together under certain circumstances to form the syndrome of schizophrenia. "It is possible that the people who have schizophrenia are a heterogeneous group with different areas of their brains affected to varying degrees by neurochemical imbalances, neurodevelopmental problems, genetic defects, viral infections, or perinatal damage among other causes."[3]

It is beyond the scope of this book to assess critically the complex scientific arguments put forward in support of each of the above biological explanations. For current purposes it will be sufficient to say that there is a growing body of evidence that appears to point toward neurobiology as being a significant contributing factor in the genesis of schizophrenia, even if the precise mechanisms remain unclear. If this is so, then it is important that research continue within this area. Cardno and McGuffin correctly point out that "A treatable cause for a percentage of patients is worth hunting for. Prior to this century, between 10 and 30 percent of schizophrenia-like patients probably had neurosyphilis. Without the knowledge of neurosyphilis that we now have, this group of treatable patients would merely be a sub group of an even larger population of undifferentiated schizophrenia."[4]

If it is possible for people to be spared the very real pain and distress that this condition can bring about, then it is important that time and resources be allocated to research into the etiology of schizophrenia.

A good deal of the information coming from the major agencies dealing directly with schizophrenia in Britain and the United States reflects this emphasis on the neurobiological roots of schizophrenia.[5] These groups are firm in their conviction that schizophrenia should be understood as a neurobiological disorder. Analogies are frequently drawn between forms of chronic physical illness and schizophrenia, the quite correct implication being that one would not blame or stigmatize someone for having diabetes, so why blame or stigmatize a person for having schizophrenia. The following extract is typical of this literature:

> Schizophrenia is a brain disease, now definitely known to be such. It is a real scientific and biological entity as clearly as diabetes, multiple sclerosis, and cancer are scientific and biological entities. It exhibits symptoms of a brain disease, symptoms which include impairment in thinking, delusions, hallucinations, changes in emotions, and changes in behaviour. And, like cancer, probably has more than one cause.[6]

The reasons for this major emphasis on biology are partly an attempt to normalize and destigmatize mental health problems

and partly a response to the work of people like R. D. Laing and Gregory Bateson, who developed theories of schizophrenia that essentially sought to blame the parents of people with schizophrenia for their condition. According to these theories, schizophrenia is seen primarily as an *interpersonal* disorder within which the family is viewed as the primary cause in its development. Bateson and his colleagues at the Mental Research Institute in California studied the communication patterns of adult patients suffering from schizophrenia. The result of their explorations was the *double-bind* hypothesis that they outlined in their 1951 paper entitled "Toward a Theory of Schizophrenia."[7] Waldron-Skinner helpfully summarizes this position.

> They suggested that schizophrenia resulted from a person being placed in an untenable position in relation to someone who was of primary emotional significance to him. Two contradictory messages are received at once, so that there is no way in which the loved person can be pleased or obeyed. For example, a parent holds out his arms to his small child in welcome but his facial expression indicates anger or hostility. The child perceives both love and hostility in the parent's non-verbal messages and is left confused.[8]

Building on this notion of the double bind, the Scottish psychoanalyst R. D. Laing developed the idea that certain types of family were *pathogenic institutions* in that the child is surrounded by overwhelming psychological and social stress. Miles summarizes Laing's thinking thus:

> The experience and behaviour that is called schizophrenic is a special strategy by which a person can live in an unliveable situation. The parents destroy the individual by mystifying him and he responds by counter-mystifying them. Thus Laing's position is that the only difference between the persons called schizophrenic and everybody else is that impossible demands were laid on the former who in turn responded with appropriate, though irrational seeming behaviour. Thus one person in a schizophrenic family becomes the scapegoat on whom all stresses are concentrated. Psychiatry for Laing is coercive and repressive; diagnosis

and treatment are used as means of controlling people who make nuisances of themselves. By calling a person a schizophrenic the psychiatrist is colluding with the family in blaming the patient for the faults of the parents and that much damage is done by consigning a person to a mental hospital. Laing does not accept schizophrenia as a pathological state—such a diagnosis he describes as ascribing stigma in order to suppress.[9]

As one thinks through the implications of this theory, it is obvious why families of people diagnosed as having schizophrenia would be unhappy with it. This model of schizophrenia blames the parents for their child's condition, with psychiatrists taking the role of co-conspiritors against the patient. This interpretation of schizophrenia is firmly rejected on both sides of the Atlantic by many of the major agencies dealing with people with schizophrenia and their families.[10] They highlight the fact that there is no empirical evidence to imply that such a suggestion is anything more than mere speculation.[11] It is certainly true that there is a relationship between stress in families and *relapse* in schizophrenia.[11] However, this does not necessarily lead to the conclusion that family stress *causes* schizophrenia. While Laing's theories may be alluring, imaginative, and undoubtedly evocative, there is no real evidence to suggest that his propositions concerning the etiology of schizophrenia are anything more than speculation.

Nevertheless, such thinking has had a detrimental effect on the lives of people living with schizophrenia and their families. The type of neurobiological explanation that is currently popular is, in many respects, very useful. Though difficult to substantiate, theories that implicate families in the etiology of schizophrenia have been no less influential, and as such require to be taken seriously and addressed thoughtfully. By providing strong, empirically based evidence that points toward a cause that lies primarily within the individual rather than the family, one is provided with an effective counter to such family blaming.

Destigmatizing Mental Health Problems

Another gain that the neurobiological model of schizophrenia offers is with regard to the destigmatization of mental health problems. Drawing analogies from biological medicine "normalizes" the person's condition and thus brings it within the boundaries of the medical model. When this happens it becomes a socially acceptable illness, thus freeing the person from unnecessary stigmatization. This not only offers an effective challenge to the types of family blaming theories we have looked at, it also acts therapeutically in locating the illness firmly within the medical model, thus presenting a person's mental health problem within a framework that is deemed to be acceptable and legitimate within Western societies. By pointing toward concrete, empirical evidence that mental health problems are not the fault of the individual or their families, schizophrenia can be reinterpreted in a way that is acceptable to the individual, the family, and the wider society. Such an approach is thus of great importance in terms of rehumanizing people who are frequently dehumanized by particular negative interpretations of their illness.

More Than Biology

Important and potentially therapeutic as this movement has been, as mentioned previously, it brings with it its own set of problems. The medical model provides a powerful interpretative framework within which diseases can be understood and modes of treatment can be worked out. However, while it might appear to offer a comprehensive picture of disease and illness, the picture, though useful, is incomplete. The danger is that the interpretative power of the medical model comes to dominate all other understandings in such a way as to blind us to some of the highly significant realities that surround the lived experience of schizophrenia. These realities fall beyond the gaze of the medical model, but are nonetheless fundamental for a therapeutic understanding of what schizophrenia is. An overemphasis on the biological aspects of mental health problems tends to locate the persons' difficulties primarily within the boundaries of their own bodies. The persons' problems are *theirs*, and the treatment is focused on specific, neurobiological defects within individual people. However, bodies do not operate in a vacuum, and mental health problems are considerably more than tech-

nological problems that need simply to be solved through the development of greater neurological knowledge and improved pharmacological intervention.

One of the difficulties in attempting to conceptualize schizophrenia primarily in terms of neurobiology or genetics is that it abrogates the wider society from its responsibility in *causing* people with this and many other forms of mental health problems to become seriously disabled. The disability rights movement has taught us to distinguish between *impairments* and *disabilities.* Impairments are "the discrete functional limitations that are present within individuals that cause some manifestation of physical, mental or sensory impedance. Disability relates to the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and/or social barriers."[12]

It is true that persons' biological impairments may profoundly affect their lives in certain respects. However, I would argue that much of the disablement experienced by people with mental health problems has to do with the social context within which they experience their difficulties, and the destructive web of attitudes, false assumptions, and negative interpretations that people bring to their situation. Critical reflection on the lived experience of people diagnosed with schizophrenia reveals society to be as "ill," "disoriented," and "deluded" as the individual with the mental health problem.

If we assume that schizophrenia is *nothing but* a neurobiological disorder, and that once we have identified the particular biological defect within the individual we will know what schizophrenia is, we risk missing the vital social dynamics of this condition that are at least as important as any neurological or genetic dysfunction. I am *not* suggesting that a person's social experiences *cause* him or her to develop schizophrenia (although they may contribute to the exacerbation of symptoms and relapse). What I *am* saying is that a person's experiences within society are as much a part of the illness as the hallucinations, delusions, and other symptoms that make up the clinical diagnosis. As such they should be taken as seriously as biological factors when we are considering what effective care

might mean. Likewise, simply normalizing schizophrenia by bringing it within the medical model, on its own, will not change public opinion. Simply treating an individual's symptoms is not enough. If we are truly to care for people with schizophrenia, then there is a need to "treat" the wider social dimensions of the condition with the same critical rigor we assume to be normal in the treatment of the individual neurobiological dimensions. Useful as the clinical and biological explanations of schizophrenia are in telling us *some* things about schizophrenia, there is much more to this condition than can be captured within standardized psychiatric definitions and treatments. The identification of biological factors is only a beginning in our understanding of what mental health problems *really* are, and neurological interventions are only *one* aspect of caring for people experiencing them.

Professional Care

Another significant difficulty with drawing schizophrenia within the boundaries of the medical model is that, if it is seen to be a purely medical condition, then obviously the care of people diagnosed with it will be assumed to lie primarily with mental health care professionals. The danger is that even if the individual is sent back into the community, the perception remains that she is the responsibility of the specialist. Such a way of framing schizophrenia often means that the primary form of relationship that is open to a person diagnosed with this form of mental health problem is with the "specialist," the professional who is *paid to relate to them.*[13] While it is true that many professionals do all that they can to ensure that their relationships with their clients are personal and meaningful, they are there because they are paid to be there. One young man who had been institutionalized since he was eight years old with a schizophreniform illness told me that he had just been allocated a befriender. To his absolute delight, he had found that he had been able to strike up a good relationship with both her and her boyfriend. "I've never had a friend before who wasn't either a patient or a mental health professional," he told me. Bearing in mind that this man was twenty-four years old, this is a tragic situation. What must it feel like if your only friends are

people who are paid to be your friends! As one social services manager astutely observed, "If your only friends in the world are a psychiatrist, a general practitioner, a community psychiatric nurse, and a social worker, how would your mental health be?"[14] Such limiting of relational possibilities can only be detrimental to an individual's mental health.

Thus, while a neurobiological approach to understanding schizophrenia may be a necessary part of the overall care of persons with this form of mental health problem, it is certainly not sufficient. In order to understand and effectively deal with people diagnosed with schizophrenia, we must take seriously what it means as a social phenomenon, and begin to explore the role of the wider community in creating and sustaining many of the difficulties that people experience.

A Natural History of Schizophrenia

While there may be certain signs and symptoms which together form the criteria for the clinical definition of "schizophrenia," there is no such thing as schizophrenia, understood as a universal phenomenon that manifests itself in the same way irrespective of person, context, or circumstance. Schizophrenia is *always* a human experience that is lived out and interpreted by unique individuals within specific social contexts, contexts that can profoundly influence the course of the condition. However, this diversity is not always acknowledged either within the perceptions of the general public or by the mental health professions. For many, schizophrenia is assumed to have a natural history, that is, a fixed and certain course along which the condition will progress *irrespective* of person, culture, or context. John Strauss notes that historically

> . . . one of the basic hypotheses about schizophrenia was that it embodied and was validated by a uniformly bad outcome. The notion that diagnosis is related to outcome or that "diagnosis is prognosis," is one of those apparently simple ideas that is extremely powerful and goes back at least to the time of Hippocrates. A diagnosis should reflect a pathological process, and a pathological process should have some reasonably predictable evolution over time, some kind of natural history.[15]

There is a danger in using analogies of cancer and multiple sclerosis to illustrate the nature of schizophrenia. While such examples function effectively to normalize the perception of the illness, they can serve to confirm the common public misperception that schizophrenia is necessarily progressively degenerative and that somehow the person is totally enslaved by their neurobiology and consequently "lost" in the midst of their illness. As we shall see, this is not the case. Nevertheless, as W. I. Thomas astutely observed: "If men define a situation as real, they are real in their consequences. . . . In other words, the subjective 'definition of the situation' is just as important as the objective situation in its social effects."[16]

The potentially devastating consequences of such a misperception are well illustrated in the case of Genine, a young woman I recently met, who had just been diagnosed as having schizophrenia. Her psychiatrist presented her with an explanation of her illness in biological terms similar to those highlighted previously. She told me how she immediately went home and took an overdose of sleeping tablets. She simply did not want to live with the hopelessness this particular form of illness definition instilled in her. Certainly her problems had been normalized, but they were normalized in such a way that she perceived no hope for a normal life. As she saw it, in the same way a cancer sufferer is faced with a series of grinding encounters with radiation or chemotherapy and the ever-present possibility of slow and painful death, she was faced with the prospect of a lifetime of medication and the permanent identity of a "schizophrenic," a social and self-identity that, for her, spelled social death. She saw no point in carrying on.

The Loss of the Person

The thinking of many people, including many people with schizophrenia, is still influenced, consciously and unconsciously, by the impact of Emil Kraeplin's 1896 description of the syndrome of behaviors and experiences which later became known as schizophrenia, as *dementia praecox*—literally, early or premature deterioration.[17] For Kraeplin dementia praecox typically occurred in young people and induced a general tendency toward emotional and intellectual deterioration.[18] More positive conceptions were

developed by Kraeplin's successors, Bleuler and Schneider, both of whom acknowledged the possibility of recovery by some people. Yet vestiges of the deteriorative definition still remain within the perception of mental health service users, the general public, and mental health professionals (for example in such commonly used terms as "burnt out schizophrenic," to describe persons who no longer show the acute symptoms of schizophrenia). Undoubtedly there is often a profound and distressing change in the individual who develops this mental health problem. He or she may appear profoundly different during times of acute disturbance, as the descriptions of schizophrenia presented previously have suggested.

Yet it is certainly *not* the case that the person is wholly lost to the illness, at least not in the way that is commonly assumed. There is a good deal of convincing evidence, some of which will be examined as we proceed, pointing toward the fact that, contrary to such historical and contemporary assumptions, schizophrenia does not have a fixed, irreversible course that will *only* respond to specialized clinical interventions.[19] Even if schizophrenia is finally proved to be a genetic or neurobiological disorder, it remains a very personal experience that is open to and affected by the wider social context within which the individual experiences it. As Barham and Hayward observe, the "evidence from a number of studies shows that outcomes in schizophrenia quite heavily depend not so much on factors intrinsic to the disorder itself as on how former patients come to evaluate themselves and their situations."[20] Schizophrenia can be influenced, positively and negatively, by such things as economics,[21] culture,[22] self-motivation,[23] hope and personal relationships,[24] spirituality,[25] and other social factors that are not immediately apparent within the medical model of understanding. While there may be a neurobiological entity that clinically can be described as "schizophrenia," when that entity enters the social arena it is open to numerous social forces and varied interpretations, all of which deeply affect the course of a person's illness experience.[26] This being so, even though there may be shared biological deficits and malfunctions it is inaccurate to talk about schizophrenia as having a *natural* history in the sense of a

fixed and inevitable course that will replicate itself in the experience of all people.

The Social History of Schizophrenia

However, although there may not be such a thing as a *natural* history of schizophrenia, there is what we might describe as a *social* history, that is, a particular set of social experiences and a specific life trajectory on which people diagnosed as having schizophrenia are launched. This social history constitutes the *lived experience* of schizophrenia and society's reaction to it, including the reaction of people with mental health problems themselves. It is here, within the social history, that the person experiences disablement, oppression, and a variety of forms of injustice.

In order to clarify what I mean by the idea of the social history of schizophrenia, it will be helpful to draw upon the thinking of medical anthropologist and psychiatrist Arthur Kleinman. Kleinman highlights the importance of the ways in which one conceptualizes disease processes. In his research he points to the distinction between the concepts of *disease* and *illness*. A person's *disease* refers to the organic, viral, or other physical basis of the condition. Cancer, influenza, and measles would constitute diseases and disease processes. Likewise, the types of biological defects and malfunctions that it has been suggested are instrumental in the development of schizophrenia would come under this banner of disease. The concept of *illness*, however, when applied to a diseased state, refers to the *social consequences* of the disease. "Illness refers to the ways in which the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms of disability."[27] While *disease* may be a biological state existing independently of (but not apart from) human knowledge and interpretation, *illness* is a *social status* directly created and formed by human perception and interpretation. The idea of the social history, as it is used in this book, comes close to Kleinman's concept of illness. Irrespective of the biological basis of schizophrenia, there is a particular illness experience (social history) which is common to many if not most people diagnosed as having schizophrenia. As we will see, this social history includes a history of oppression that mani-

fests itself in material and relational poverty, depersonalization, limited possibilities, rejection, exclusion, marginalization, and stigmatization. I argue that it is the individual's experience within society, his or her "social history," which primarily dictates the person's quality of life, and his or her ability (or inability) to attain and maintain a positive sense of personhood, and ultimately some degree of mental health.

While there is strong evidence to suggest that there are neurological and genetic factors involved in the etiology of schizophrenia, these should not be understood as acting deterministically, but rather should be viewed as significant contributing factors within a complex biopsychosocial and, as we shall see, spiritual phenomenon. Schizophrenia may have certain biological aspects to it, what we might call a *neurobiological narrative* (disease processes) running parallel to this and with equal importance for our understanding. But it is a *personal or relational narrative* (social history) that has an equal, if not more profound, impact on the overall life trajectory of individuals. It is within this second narrative—the social history of schizophrenia—that people experience various forms of poverty, oppression, and marginalization.

Chapter 5

Creating Nonpersons

The Poverty of Schizophrenia

By simply excluding someone from the human group—by which I mean a group that is held together by the needs of survival—we can destroy their possibilities of self-realization, i.e. prevent them becoming a full person.[1]
—Rex Ambler

Creating Nonpersons

Terms such as "oppression" and "poverty" may not immediately be seen to relate to the situation of people with mental health problems, yet on a more critical examination, their appropriateness becomes clear. The social history of people with schizophrenia is marked by poverty, exclusion, oppression, and lack of opportunity that bestows upon them the status of nonpersons within society. However, the oppression is subtle. As Tom Kitwood observes in his discussion of the psychodynamics of exclusion: "Many cultures have shown a tendency to depersonalize those who have some form of serious disability, whether of a physical or a psychological kind. A consensus is created, established in tradition and embedded in social practices, that those affected are not real persons."[2]

When individuals and communities create a relational, communicational, aesthetic and linguistic atmosphere that causes the exclusion and stigmatization of those who are perceived to be different, their oppression is deeply damaging and thoroughly destructive of the humanity of a significant section of the population. It is through the myriad of unnoticed social gestures and negative assumptions that people with mental health problems find their sense of self-worth and personhood constantly being eroded. It is through that same process that they come to be perceived, consciously or subconsciously, as "nonpersons" (by society and, sadly,

often by themselves), and consequently excluded from meaningful participation within society.

Poverty of Personhood

Roy Porter notes that the voice of people suffering from mental health problems "is one deeply conscious of having been made to feel different. Generally they complain that 'alienness' is a false identity thrust upon them, or indeed a non-identity, a sense of being rendered a nonperson."[3]

In the light of the current movement toward deinstitutionalization, Porter's observation is highly significant. Barham and Hayward note that:

> As historians of madness have shown, we have inherited from the last century a "deep disposition to see madness as essentially Other."[4] The transformation of Victorian asylums into gigantic custodial warehouses hastened the "decline of dialogue between society and psychiatrist on the one hand and the disturbed on the other (increasingly 'shut up' in both senses)" and irretrievably established their differences.[5] In crucial respects this custodial history is recapitulated in the traditional account of schizophrenia as a narrative of loss in that the pre-illness person goes missing, seemingly abandoned by the force of the disorder. On this view schizophrenia "is more than an illness that one *has*; it is something a person *is* or may *become*."[6] (Italics added)

Barham and Hayward's comments emphasize two points that are important for present purposes. First, historically (and in a slightly different way, contemporarily) society's response to people with mental health problems has been to isolate them, to shut them away from the rest of the population. Consequently, the majority of society has had little or no contact with them, apart from what is very often a distorted and caricatured picture presented through the media. As a result the "public identity" of persons living with schizophrenia has been defined as essentially "other," that is, not belonging to society proper.

Second, those who have emerged from asylums have emerged with a very uncertain personhood and identity. If schizophrenia

truly does destroy the person, as "natural history theory" would suggest, then one is left with the perplexing question as to what these "schizophrenics," these "nonpersons" are who are emerging from the mental hospitals into our communities, and accordingly, how they should be treated.

In highlighting this confusion over the nature of the humanity of people with schizophrenia, Sue E. Estraff emphasizes that schizophrenia is what one might describe as a *totalizing* condition. Schizophrenia "is an I am illness—one that may overtake and redefine the identity of the person."[7] Unlike measles, the flu, or any other common ailment, a person does not simply *have* schizophrenia, they actually *become* schizophrenia. The tendency in public and professional perception is to regard persons ontologically in terms of their illness, that is, as "schizophrenics." Schizophrenia becomes central to the way in which others identify persons, (their social identity) and how such persons themselves build and understand their own identity (their personal identity). Schizophrenia becomes their primary identifying role, and the mental health services their primary reference group. In this way, these persons *are* indeed "lost" to the illness, but not because of any inevitable natural process of deterioration. These persons are lost to the illness because a particular form of social identity is formed around them, an identity that is created by negative societal negotiation and that subsequently becomes a public persona that people with schizophrenia then internalize and build into their own self-conception.

Once again, it is *not* being suggested that social pressures in some way cause or are responsible for the development of schizophrenia. What *is* being asserted is that these persons' life history and the development of their social self, the personal identity, is adversely affected by the cultural ascription of a negative social identity that confuses the person with the illness. It is in *this* way that schizophrenia becomes a social construction, and it is in *this* way that the "schizophrenic" is created, stereotyped, and marginalized. In a very real sense, people diagnosed as having schizophrenia become *nonpersons*.

People living with schizophrenia are deprived of some of the fundamental social experiences necessary for the development of

healthy human personhood. Basic social opportunities that are foundational for the positive development of personhood are simply not available to people who are perceived in the ways outlined above. The following are rarely available to people with schizophrenia: the opportunity to find one's "true self"—who one is as a unique individual; the chance to discover a valued social identity; the opportunity to feel that one has an accepted and acceptable place within society; the possibility of developing a positive personal and social identity; and the opportunity to develop meaningful relationships with self and others. This deprivation is not simply a result of their clinical condition (which does contribute to their social isolation); rather it is the result of fundamental flaws and false assumptions within society's perception of them and the nature of their condition, which leads to their social definition as fundamentally "other." What greater poverty can there be than to be deprived of the circumstances and forms of relationship that enable persons to live humanly and to be themselves? This enforced poverty of personhood oppresses and alienates people with schizophrenia and confirms them in their status as "non-persons" who are forced to stand on the margins of acceptable society.

Poverty of Opportunity

Carpenter notes the social ambiguity of schizophrenia when he observes that schizophrenia

> strikes at the very heart of what we consider the essence of the person. Yet, because its manifestations are so personal and social, it elicits fear, misunderstanding, and condemnation in society instead of sympathy and concern. Schizophrenia remains unparalleled as a stigmatizing [disorder] with all the societal consequences of personal shame, family burden, and inadequate support of clinical care, research, and rehabilitation. It is ironic that in a society with pride in individual freedom and achievement, the response to a person whose personal capacity is being eroded. . . . is the withdrawal of opportunity.[8]

One of the results of the process of depersonalization is the withdrawal of opportunities to participate meaningfully in society and to gain access to many of the sources of self-respect and self-esteem that are available to others. Poor self-esteem and hopelessness in people with schizophrenia is not simply the product of the disease process; it is also connected to the exclusion from many of the normal relational and material sources from which the majority of the population gain their sense of value, self-confidence, and worth.

For example, within present day capitalist societies, where work is viewed as fundamental to popular understandings of worthwhile human existence, a person's employment is a major source of value, self-worth, and economic sustenance.[9] People with the diagnosis of schizophrenia are often excluded from this primary source of value and income. The positive and negative manifestations of the illness, coupled with destructive public perceptions, attitudes, and stigma, mean that it is very difficult for people with this diagnosis to gain any form of meaningful employment.[10] The condition itself places major barriers to employment, but there are many people who are capable of holding down employment who simply do not get the opportunity because of particular assumptions about their condition. This exclusion from primary sources of value leaves many people with schizophrenia feeling there is no future for them. Consequently, life appears profoundly hopeless and meaningless. For many, the social experience of schizophrenia is one of material deprivation, meaninglessness, hopelessness, and constant devaluation, with no possibility of a hopeful future and no power to alter the trajectory of their lives. This factor may contribute to the 10 percent of people with schizophrenia who commit suicide.[11] It would appear that people diagnosed as having schizophrenia are destined to be dependent persons in a world that values individualism, competitiveness, independence, productivity, and financial prosperity. For those who are in any way dependent, who cannot compete or are not productive, there are few alternative sources of value within a society that no longer understands the meaning of mutual responsibility and "community." As Genine's story suggested, within such a social context it is difficult for an individual to accept his or her illness without acknowledging that it entails a necessary

element of hopelessness and disempowerment accompanied by a withdrawal of opportunity to participate in that which is valued within society.

Poverty of Relationships

The most painful thing for people with schizophrenia is the level of relational poverty they encounter. Certainly some of this is the product of the disease process itself, but schizophrenia seems to provoke society into displaying a particularly negative, impersonal, and at times openly hostile reaction toward those who live with it. These reactions, assumptions, and stereotypes make it extremely difficult for people to find and maintain positive interpersonal relationships—*the* most important source of value and self-esteem available to human beings.

The processes involved in bestowing someone or something with value bear consideration. Things do not have a value in themselves, but only become valuable according to the meanings that are ascribed to them. Thus, for example, "a family portrait may be invaluable to the family concerned, but have tantamount to no value outside of that family. A friendship ring may be of inestimable value to a friend and of absolutely no value to a jeweler. The value of the picture or the ring stems from and depends upon the attitude/relationship of others toward it."[12] David Pailin suggests that a similar principle is appropriate for an understanding of how human beings should be valued: "The fundamental worth of a person is to be seen to lie in the love of others for that person. Worth is not something that belongs to a person as a solitary individual. It is given to each person by the way that others, including—and ultimately—God, regard him or her."[13] This is not to suggest that if a person has no friends or relatives, he or she is not of value. *All* human beings are of ultimate value, and that status is sustained by God's gracious gift of relationship toward them.[14] Nevertheless, on a temporal level, if we gain our sense of value from our human relationships, then we are forced to ask what is the "worth of persons who justifiably consider that no one cares about them? A person who finds herself or himself in such a position is justified in feeling worthless. Furthermore, because no one

at all cares about them, they may regard any affirmation of their own dignity as persons as practically impossible as well as pointless. Self-esteem is the product of being of worth to others."[15] The primary way in which we gain and experience self-worth is not through social achievement, material wealth, or an ability to compete in the market place, but through others' love for us. If such relationships are unavailable, or if we perceive ourselves not to be worthy of them, this can lead to a catastrophic loss of self-esteem and deep feelings of being devalued. People diagnosed as having schizophrenia frequently are justified in assuming a lack of love from others.

The Social Isolation of Schizophrenia

In order to understand fully the social processes that are at work in creating the forms of poverty that have been highlighted, it is necessary to develop a deeper understanding of the complex social and interpersonal processes that underlie such forms of social behavior and negative reactions to mental health problems. It is clear that there are particular difficulties inherent within schizophrenia as a clinical condition that make communication and relationship building very difficult. Poor ego boundaries, bizarre speech and behavior, and an inability to maintain eye contact are just some of the features that interfere with the normal process of relational interaction. Because individuals with schizophrenia do not remain within the unwritten codes of social intercourse, other people often do not understand what is going on when they encounter such an individual. The normal characteristics that are necessary for the development of successful interpersonal relationships—mutual symbolic exchange and interaction, common situational definitions, and adequate communication of shared meanings—at times appear not to be present within such encounters. Because of this, one of the major barriers that separate the person with schizophrenia from the rest of society is the fundamental *incomprehensibility* of their condition. Schizophrenia is confusing and disorienting for those experiencing it *and* for those whom they encounter. As such, it is open to being ascribed a number of different meanings and interpretations. As Van Den Bosch points out, "schizophrenia is a severe psychiatric

disorder of the inner world which proves difficult to understand by the outside world. . . . Schizophrenia is probably the most incomprehensible disorder of the mind."[16]

The incomprehensibility of schizophrenia makes it difficult for people with it to relate to others, and for others to relate to them. It also leaves open the possibility of misrepresentation, misunderstanding, and stereotyping. Consequently, schizophrenia poses a major challenge to the normal framework of shared meanings and reciprocal interaction upon which the communication process is built and on which the cultural norm of friendship, based as it ordinarily is on the "principle of likeness," inevitably depends.

Horwitz, commenting on this distortion of communication, which he notes is present in a number of mental health problems, points to the fact that

> any piece of behaviour is made intelligible either by attributing a socially recognisable motivation to the behaviour, e.g. "he murdered his wife out of jealousy," or by locating the action as an instance of a typical social category, e.g., that man is chopping wood. When observers assume that actors know what they are doing and are guided by rules in their behaviour, social behaviour appears to be meaningful. It is when observers cannot find meaning or comprehensibility in behaviour that they are likely to apply labels of mental illness.[17]

According to Horwitz, when individuals step outside the socially accepted norms of communicative behavior, their action becomes incomprehensible to the majority of the population. It is this incomprehensibility which is then used as a defining line between what is normal and what is abnormal behavior.

The attribution of meaning to any social action is a fundamental requirement of all social interactions. No meaningful communicative interaction can occur unless each participant can understand, at least to a mutually acceptable extent, what the other is doing. Horwitz goes on to argue that *intelligibility* is what marks out mental health problems from other forms of behavior within society.

> All societies need some category to designate behaviours that fall outside the boundaries of comprehensibility. The notion of mental illness is rooted in the basic requisites of social interaction: that persons be able to find each others' behaviour mutually comprehensible. Labels of mental illness are applied to behaviour when the categories observers use to comprehend behaviour do not yield any socially understandable reasons for the behaviour.[18]

The failure of observers to find any meaningful purpose in behavior Horwitz calls *incomprehensibility*, and he considers this to be the essential quality at the core of behaviors that are labeled "mental illness." This is not to suggest that mental health problems do not exist, or that they are simply a construction of society. Rather, what we are considering here are the *consequences* of the specific behaviors (illness experience) that tend to accompany particular forms of mental health problems. These consequences are the social products of particular conditions, rather than things that are inherent within the condition itself.

Horwitz' proposition is interesting: According to his analysis it would appear that, contrary to the conflict theories of mental health problems proposed by antipsychiatrists such as R. D. Laing, the identification of mental illness is *not* a power-oriented conspiracy whereby the psychiatrist abuses his power by labeling "innocent persons" mentally ill with concomitant negative social and emotional consequences. In fact the identification of mental health problems is fundamentally a *lay* enterprize.[19] Individuals are primarily marked out by the general population as having mental health problems when they find themselves unable to participate in social interaction according to the tacit rules of comprehensibility that guide all human social interaction. Once marked out, they are brought to the attention of the mental health professionals, who in turn provide an official diagnosis.

Barriers to Love

The incomprehensibility of mental health problems makes it difficult for the "normal" person to relate with the "other." The tendency *then* is to engage in an "I-It" relationship toward the incomprehensible individual and assume him or her to be incapable of entering into authentic relationship, to withdraw one's own relationship, and to pass responsibility for the individual on to the professional.

These observations are important with regard to schizophrenia. The behavior, experiences, and ways of communicating associated with schizophrenia often strike at the basic properties of normal social interaction and comprehensibility. People find it difficult to *empathize* with the experience of schizophrenia. Empathy is a communication skill that lies at the heart of all interpersonal relationships. Most counseling theories would suggest that the counselor's ability to empathize accurately with the client is foundational for the development of a successful and health-bringing counseling relationship. For example, Truax and Carkhuff suggest that

> accurate empathy involves more than just the ability of the therapist to sense the client or patient's "private world" as if it were his own. It also involves more than just his ability to know what the patient means. Accurate empathy involves both the therapist's sensitivity to current feelings and his verbal facility to communicate this understanding in a language attuned to the client's current feelings.[20]

If Horwitz is correct in asserting that incomprehensibility is a fundamental constituent of any understanding of mental health problems, and if Truax and Carkhuff are correct in asserting that empathy is basic to the development of health-bringing relationships, then it becomes clear that schizophrenia itself may well cause many people with schizophrenia to become isolated and friendless. It is not simply that their illness, in itself, makes them less desirous of relationships.[21] The problem seems to be that the particular symptoms and experiences that the person encounters make normal communication and relational interaction extremely difficult, thus engendering a negative relational response from those with whom they come into contact. Consequently the person is experienced as somehow "other,"[22] and lines of communication and relationship collapse.

Not only is the individual experienced as essentially "other," he also experiences himself as alien and different. The individual internalizes this social definition of "otherhood," which then becomes a part of his social identity, that is, part of the way in which he perceives himself and is perceived in the world. If one

perceives oneself as fundamentally different from the rest of society, it will be very difficult to form any kind of stable and meaningful relationships. If one is perceived by others as fundamentally different, the task can become quite impossible. In this way the "schizophrenic" is created, and defined by self and others as fundamentally different. Under such circumstances, any friendship that is grounded only in the "principle of likeness" is destined to fail both from the perspective of the sufferer *and* the potential friend.

Images of Madness

However, important as these inherent communication difficulties may be, there is a wider social dimension that is inextricably connected with the interpersonal one. It is not only the incomprehensibility of *actual* behavior that causes relational difficulties. There is also a major problem in the way in which an individual is *perceived* in the eyes of the general public, irrespective of her *actual* behavior, speech, or mental state. The tag of "mentally ill" in itself brings about alienation and relational disconnection. Human beings act toward things as they are perceived, interpreted, and defined, and not necessarily as they are. As David Karp puts it, "All objects, events, and situations derive their meanings through human interpretation. We are ultimately free to define anything we choose, including illness."[23] This suggestion is important for developing an accurate understanding of the social history of schizophrenia. The inherent incomprehensibility of schizophrenia is compounded by a socially constructed incomprehensibility that manifests itself in inaccurate, stereotypical, and distorted public images of what schizophrenia is and what a person suffering from it is *actually* like. These images in turn profoundly affect the ways in which schizophrenia is interpreted and understood, and the type of treatment that persons diagnosed as having it will receive.

While such images may not be accurate or truthful, they are no less real in their consequences. Sociologist Agnes Miles, in her research into the public perceptions of mental health problems, found that

> . . . studies have consistently shown that people evaluate mental illness negatively, reject and discriminate against mental patients, and base their views on traditional stereotypes.[24] . . . Overall the public image of a person suffering from mental illness is considerably more gloomy than that of a person suffering from physical illness, and in certain respects it appears to be closer to the public image of a criminal.[25]

Miles concludes that there exists a stereotype of mental health problems and of persons who suffer from them that is negative and widely held by the lay public. A good example of this type of distorted caricature is to be found in media and public juxtapositions of schizophrenia with violence. According to MIND:[26]

> The public's perception of mental disorder is of the raving lunatic or homicidal maniac. . . . In fact the vast majority of murderers have no history of mental disorder—they are as "sane" as you or me—and the vast majority of mentally disordered people pose no threat whatever to anyone except themselves. Violence is a rare occurrence even in acute schizophrenia and is by no means as common as people perceive it to be. . . . The vast majority of patients are in practice more likely to be victims than offenders.[27]

Thus, although there may be a propensity toward violence among some people with schizophrenia (as there is within certain members of society at large), in reality it tends to be directed toward the persons *themselves* rather than toward others. This of course differs from the general perception of schizophrenia that tends to paint a picture of extreme violence as inherent within the condition. Greg Philo highlights this distorted public perception in his research into media images of mental illness.

> Beliefs about schizophrenia were related by group members to images from both factual and non-factual sources. This description from a woman in Motherwell combines both of these: "A lot of things you read in the papers and they've been diagnosed as being *schizophrenic*. These *murderers*—say Donald Neilson, was he no schizophrenic? the *Yorkshire Ripper* . . . on Brookside that man who is the *child-abuser* and the *wife beater*—he looks like a schizophrenic—he's like a *split personality*, like *two different people*. First he gets like self-pity and he brings flowers and works his way back into the house and you could feel sorry for him, then he's a child abuser and a wife-beater."[28] (Motherwell Group, Interview, emphasis added)

This statement contains truths, half-truths, and misinformation, and vividly illustrates the general confusion there is over what schizophrenia is and how people diagnosed with it are assumed to behave. Thus people with mental health problems find themselves criminalized and considered socially unacceptable, not because of what their condition actually *is*, but because of the way it is *perceived* within common folklore. Such false perceptions necessarily lead to disempowerment and the closing down of possibilities for acceptance and a valid and valued place within society.

Disabling Images

Otto Wahl, in his extensive investigation into public perceptions of mental health problems, highlights a study that was done to compare the attitudes of people to cancer and schizophrenia. In this study, undergraduates were read vignettes that portrayed a person as having either cancer or schizophrenia. They were then asked to rate the persons according to a series of traits. Wahl records that "the person identified as having schizophrenia was perceived as less desirable as a friend, less acceptable as a club member or neighbor, and less able to function in the community than the cancer patient."[29]

In the light of Miles' observations concerning the negative attributions that are ascribed to mental health problems, this in itself may not seem too surprising. However, when one takes into account that the vignette descriptions were *exactly the same*, apart from the name of the disorder, one begins to realize that there is indeed a major problem in the public's perception of mental health problems in general and schizophrenia in particular. Wahl's point is of critical importance. It is not so much bizarre behavior or speech to which people react as the particular images of mental illness which they hold.

> It is the public's negative image of mental illness and not the person or specific disordered behaviour to which they respond with discomfort and rejection. They are responding not to what they observe directly about the person with a mental illness, not to the actions or emotions of the psychiatric patients they encounter, but to stereotypes, their expectations, their acquired images of people with mental illness.[30]

People do not respond to the *person as person*, but to the *person as illness*. The fundamental form of relationship that a high proportion of the lay public offer toward people with schizophrenia is grossly ill informed and profoundly *impersonal*. The person living with schizophrenia is thus seen to be highly *stigmatized* in the perception of the public, and almost completely subsumed to their illness.

Understanding Stigma

The observations presented by Miles, Philo, and Wahl make it clear that stereotyping and stigma lie at the heart of the experience of all mental health problems and are intricately tied in with the social isolation that many sufferers experience. Because of the debilitating nature of schizophrenia and its enigmatic public image, people living with this illness are particularly prone to becoming stigmatized. Kirkpatrick and his colleagues in their research into the rehabilitation and social integration of persons with schizophrenia, discovered that "the primary external obstacle [to rehabilitation] identified was stigma, from both society and professionals."[31] Although one might at first consider stigma to be epiphenomenal to the central syndrome of schizophrenia, in fact it is a central part of the experience of people with schizophrenia and is a fundamental blockage to authentic understanding and the possibility of meaningful relationships.

Erving Goffman describes stigma as "the situation of the individual who is disqualified from full social acceptance."[32] The term "stigma" is used to refer to "an attribute that is deeply discrediting."[33] Goffman suggests that when a person is stigmatized because of some defect of character, behavior, or appearance, he or

she is "thus reduced in our minds from a whole and usual person to a tainted, discounted one."[34] Goffman suggests that

> by definition, . . . we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as cripple, bastard, moron typically without giving thought to the original meaning. We tend to impute a wide range of imperfections on the basis of the original one.[35]

Miles makes a similar point concerning the subtle ways in which a person is stigmatized through jokes and everyday conversation:

> Such phrases as "Are you crazy?" or "It would be a madhouse" or "It's driving me out of my mind" or "We were chatting like crazy" or "He was running like mad" and literally hundreds of others occur frequently in informal conversations, and the discussants do not mean to refer to the topic of insanity and are usually unaware that they are doing so.[36]

Through the process of stigmatization a particular form of social identity is created and bestowed upon the stigmatized individual, a social identity that is fundamentally spoiled.

More than that, stigmatization acts to devalue and dehumanize those who become stigmatized. To stigmatize someone is to take one part of a person and make that the definitional point for the whole person. Thus people suffering from depression become "depressives," anxious people become "neurotics," and people with schizophrenia become "schizophrenics." Once persons are stigmatized and set apart by the attribution of a negative social identity, it is much easier for others to think of them as somehow less than human and to treat them as objects rather than persons. When persons become stigmatized, once again, in a very real sense they become nonpersons, a designation that, as we have seen, has profound social consequences.

Significantly, this stigmatization comes not only from others; the stigmatized individuals are also part of the society that stigmatizes them and as such shares in the social expectations and norms that, when broken, cause an individual to become stigmatized. Thus, "shame becomes a central possibility, arising from the individual's perception of one of his own attributes as being a defiling thing to possess, and one he can readily see himself as not possessing."[37]

From Mental Patient to Former-Mental Patient

Central to the situation of the stigmatized individual is his or her inability to feel or to experience *acceptance*, either by oneself or by others. "Those who have dealings with him fail to accord him the respect and regard which the uncontaminated aspects of his social identity have led them to anticipate extending, and have led him to anticipate receiving; he echoes this denial by finding that some of his own attributes warrant it."[38] Even if individuals are able to correct the "blemish" that has caused them to become stigmatized, they are seen as simply having undergone "a transformation of self from someone with a particular blemish into someone with a record of having corrected a particular blemish"[39]—a shifting of the negative emphasis of their social identity from "mental patient" to "former-mental patient," from "schizophrenic" to "schizophrenic in remission."

Conclusion

It has become clear why people with schizophrenia can quite justifiably be considered nonpersons and why effective ministry within this area is fundamental for a faithful, liberating church. The types of relational and social poverty highlighted in this chapter have important implications for a church that seeks to take seriously its ministry of liberation and justice for the poor and the oppressed. Given the nature of the situation and the life experiences of many people with severe mental health problems such as schizophrenia, it is absolutely unthinkable that the church could simply sit back and assume that other agencies should be responsible for the care and welfare of people living under such circumstances. Now that our consciousness has been raised to the lived

experience of schizophrenia, we have no choice but to take prophetic action that will tangibly reveal our critical solidarity with a group of oppressed human beings. It is for such persons that Jesus came, and for them that he has entrusted responsibility for their care to the church that is his body on earth.

Now we need to move on from our social analysis and begin to draw out the implications of the previous discussions for a revised form of praxis for the church community. However, before doing that, it will be helpful to reflect on whether it is possible to generalize the findings of our case study on schizophrenia to other forms of mental health problems.

Chapter 7

Memory, Resurrection, and Hope

Within Western societies, people with mental health problems might justifiably be described as poor, marginalized, and oppressed. The lives of people with mental health problems have been problematicized, caricatured, and stigmatized to such an extent that the fact that they are real persons who are fully human in every respect is frequently forgotten. Toward the end of this chapter, I will draw out three themes that emerge from theological reflection on the concepts that have been presented thus far: *memory, resurrection,* and *hope.* In exploring these three themes, I will develop the central theological theme that runs throughout this book: *the church must maintain critical solidarity with the poor and the oppressed.* A firm practical theological foundation for the revised forms of ecclesial praxis will be developed in the final chapters.

Remembering as Caring

The previous exploration of dementia highlighted the pastoral and personal significance of remembering and being remembered. For people whose memory is being destroyed by the ravages of neurological disease, the knowledge that they remain remembered and loved by others is of ultimate importance. However, the significance of memory for pastoral theology is not confined to the area of dementia care. John Patton proposes that memory and the act of remembering is a central theme in our understanding of what pastoral care is and how it should be done.

> Human care and community are possible only because we are held in God's memory; therefore, as members of caring communities, we express our caring analogically with the caring of God by hearing and remembering one another. God created human beings for relationship and continues in relationship with

> creation by hearing us, remembering us, and meeting us in our relationships with one another . . . [pastoral care is] a ministry of the Christian community that takes place through remembering God's action for us, remembering who we are as God's own people, and hearing and remembering those to whom we minister.[1]

The church is a community of remembrance, called into existence by the memory of the acts of God in history. It exists only because it remembers the story of what God has done and, in remembering, seeks to live out the meaning of that story in its life, worship, and structures of care. Throughout Scripture, memory and being remembered are of great significance. The Psalms, for example, are filled with cries asking God to remember human beings in the midst of their joys and tribulations. In Psalm 119:49-50, the writer recalls the promises of God in his time of distress: "Remember your word to your servant, in which you have made me hope. This is my comfort in my distress, that your promise gives me life." Again, in Psalm 105:5-9 the psalmist recalls the things that God has done in the past, and uses them as assurances of what God will do in the future:

> Remember the wonderful works he has done, his miracles, and the judgments he has uttered, O offspring of his servant Abraham, children of Jacob, his chosen ones. He is the LORD our God; his judgments are in all the earth. He is mindful of his covenant forever, of the word that he commanded, for a thousand generations, the covenant that he made with Abraham, his sworn promise to Isaac.[2]

For the psalmist, the knowledge that God has not forgotten God's people, and that the covenant promises remain secure offers comfort and hope in the midst of suffering, confusion, and chaos.

God's remembering is not an act of sentimental retrospective reflection, but rather a powerful act of affirmation and commitment to his continuing involvement with human beings in history. Memory and action are inextricably intertwined within the process of divine remembering. Patton argues that there can be no dichotomy between God's thought and God's action. God's remembering always implies God's movement toward the object of God's

memory. As Brevard Childs puts it, "The essence of God's remembering lies in his acting toward someone because of a previous commitment."[3] Thus acknowledging that God remembers presupposes that God will act on that memory in the same ways as God has acted in the past. Walter Brueggemann, as quoted in Patton, makes a similar point when he suggests that "the gospel of this God that he remembers. . . . His remembering is an act of gracious engagement with his covenant partner, an act of committed compassion. It asserts that God is not preoccupied with himself but with his covenant partner, creation. It is the remembering of God, and only that, which gives hope and makes new life possible (see also 1 Samuel 1:11, 19; Judges 16:28; Psalms 8:4; 10:12; 24:1-3; Jeremiah 15:15). Above all, Job 14:13 articulates the conviction that God's memory is the last ground of hope in the realm of death."[4]

Thus, remembrance, hope, and faithful action are inextricably intertwined. In recognizing that God remembers us, we are inspired to believe that God is with us and for us in the same way God has revealed Godself as being with and for humanity throughout history, and ultimately within the incarnation and death of Christ.

Remembering Jesus

The incarnation, death, and resurrection of Jesus provide continuing evidence that God has not forgotten human beings, and that God continues to desire relationship and justice. Jesus' presence with the poor and the marginalized reminds the world of the nature and focus of God's actions in the world. God is a God of love, who hates oppression and unfairness and demands justice for those who are the victims of history. However, and of equal importance, the presence of Jesus among the poor reminds those who sit on the margins of acceptable society that God has not forgotten them; that God is with and for them, in sacrificial love that knows no limits, and transcends even the barrier of death. It is this challenging memory of Jesus ministering to the poor that dictates the shape and texture of the caring practices of the church. The task of a liberating church is to reveal signs and pointers to remind the world that the way it *is*, is not the way that it *should be*, and that

loving "the outsider" is not an act of charity, or a function of "specialist ministries," but is, in fact, a "new" way of being human. In remembering God's actions in history and in the life, death, and resurrection of Christ, the Christian community is drawn into a new way of living and of seeing the world. This way refuses to forget the pain of the oppressed, or the degradation of those who are excluded and fragmented by the types of social forces that seek to provide a picture of "normality" that bears little resemblance to the coming kingdom. Such a community embodies the fact that God has not forgotten the world. The church as a community of friends is charged with the task of reminding people with mental health problems that God has not forgotten them, and reminding those who would oppress them, wittingly or unwittingly, that God is with and for those whom they reject and marginalize.

Dangerous Memories

Johan Baptist Metz talks about the Christian church as a community of remembering and storytelling that passes on and nurtures dangerous memories.[5] Dangerous memories are stories of the "other"—the victims of history who have been forgotten by society, but who remain at the forefront of the memory of God. In raising our consciousness to the reality of the lives of the oppressed, such stories become dangerous because they radically intrude upon and call into question, our complacent and comfortable present.[6] When taken seriously, the stories surrounding the lives of people with mental health problems constitute dangerous memories. They reveal forms of deep oppression, and processes of dehumanization that call the church to adopt a countercultural stance of critical solidarity with them, regardless of the cost. In listening to such stories and in sojourning with people with mental health problems, the church is forced to adopt a marginalized position. No longer can it accept "the ways of the world," or stand by silently as people's lives are undermined by social and interpersonal forces that deny the humanity of people with mental health problems and force them to become their illnesses. These stories call the church to a radically new stance of critical solidarity that is difficult and deeply challenging. Such a stance makes little sense in the eyes of

the world, but forms the essence of the coming kingdom. As the Christian community listens to the types of stories that have been recited in this book, and as its consciousness is raised and its memory stimulated, it can do nothing other than give itself fully in commitment to those who are rejected and marginalized. Thus, in remembering and listening to the dangerous memories of people with mental health problems, the church is called out of its apathy, naïveté, and amnesia, and drawn into dangerous new ground.

Remembering the Person

Memory is of fundamental importance in fostering the type of pastoral care that this book hopes to inspire. The lives of many are marked by the experience of being forgotten and discounted by society. We find a process within which the person-as-person is gradually dislocated from society and separated from his or her personhood. This separation happens to such an extent that one's illness takes precedence over one's status as a human being with profoundly negative social and relational effect. Persons with mental health problems may exist as "objects" in the minds of media and public; the fact that they are human beings—made in the image of God, and loved by God beyond all measure—has somehow been forgotten. This being so, the first task of effective liberating care is to *remember* them.

It is clear, from the perspectives of Scripture and common experience, that human beings need to be remembered. This is particularly so for those people with mental health problems who struggle to make sense of life in a "community" that finds it easy to forget about them. To be remembered by God is to realize that we are of eternal worth and value in God's sight. In remembering someone, we acknowledge the person as worthy of memory, and acceptable as a full person. It is easy to forget that the word "remember" means re-member, that is, to put back together that which has been broken. The opposite of remember is not to forget, but to dismember; to take something apart.[7] We have already seen the ways in which people with mental health problems are forgotten and dismembered by assumptions, images, and attitudes that reduce them from persons to illnesses, seeking to identify their whole

being by only one aspect of their experience. Rather than being seen as whole persons with holistic needs and expectations, they are seen as nonpersons whose needs are rarely taken seriously. Thus, their identities are fragmented, as are their relational structures and life opportunities. This being so, the first pastoral action of the Christian community, as it seeks to image Jesus' mission of liberation and hope, will be to participate in God's continuing action of remembering those who have been cast aside and forgotten by society. In remembering people with mental health problems, the Christian community participates in the process of remembering those who have been broken. By drawing them together in our understanding, thinking, and caring, "the person behind the illness," will be re-membered and the Christian community enabled to take a crucial initial step in the process of resurrecting and liberating those whom society considers to be "dead."

Resurrection and Hope

Theological reflection on the pastoral significance of memory leads us into our second motif, that of *resurrection*. If it is true that people with severe mental health problems are forgotten, and often assumed to be "missing" or even "dead," then remembering will necessarily lead to a second pastoral task for the Christian community: to "resurrect" the people who have been lost to their illness. But precisely what do we mean by "resurrection"? Obviously, the primary meaning of resurrection refers to the bodily resurrection of Christ that provides the ground for all hope and new possibilities for the future. But the motif of resurrection also permeates our way of being in the world, as it extends to address all forms of death. Gustavo Gutiérrez notes that the "resurrection of Jesus is never called, in the Bible, a miracle; it's so much more. The Resurrection of Jesus, if I may be permitted to express it this way, is the death of death."[8] Gutiérrez' point is an important one. In the Resurrection of Christ, we do not simply find a miracle or a parable designed to point us to a higher truth. In the Resurrection of Christ, we discover that creation has entered a new era that is radically different from the way things were previously, an era within which God has overcome death in all of its variant forms, and that

there is hope, even in the midst of apparent hopelessness. The question of hope, and its relationship to the Resurrection, is an important one to which we now turn.

A Community of Hope and Revelation

Jürgen Moltmann points toward the critical tension between what is and what will be, a tension that marks the life of the Christian community. The Christian community exists within the dialectical tension between the pain and suffering of the cross and the hope and new possibilities of the Resurrection life. In the cross, we find God adopting a stance of critical solidarity with the world, as God enters into the suffering of humanity in all of its fullness. On the cross, God does not simply acknowledge or inactively remember the pain of the poor, the marginalized, the oppressed, and the rejected. Rather, the cross reveals God proactively entering into the pain of human existence, opening up Godself to the experience of suffering, and sitting in critical solidarity with those who suffer in the face of apparent hopelessness. Thus, the cross reveals God's continuing affirmation that God is with us even in the midst of the most horrendous forms of pain and injustice.

The Resurrection is God's powerful statement that the way things are is not the way they should be, or always will be. The Resurrection informs us that evil has not triumphed, and that God's reign will prevail in the eschatological scheme of things. The Resurrection is "God's great protest against death," and against all the manifold forms of evil and suffering that death takes already in the midst of life.[9] It is the turning point for creation, and the beginning of a process of redemption that is present now in part, but is still to come in all of its fullness.

Such a revelation of the nature and purposes of God has important implications for the church. The Christian community exists in the tension between the pain and chaos of what is, and the fresh and radically different possibilities of what will be, when the Resurrection life becomes the natural life of creation. The task of the church is to reveal pinpoints of resurrection light in the present and, in so doing, inspire hope and meaning in a world that struggles to find both. Thus, to return to Gutiérrez' point, in the

Resurrection we truly discover the death of death, but not only physical death. The light of the Resurrection signals the end of death in all of its forms, including the types of social and spiritual death that are central to the experiences of many people with mental health problems. The Resurrection contains God's cry of assurance to people with mental health problems that they are not forgotten, and that God desires to "resurrect" them in the here and now, to call them to experience the fullness of life within the kingdom of God, where there is neither Jew nor Greek, slave nor free, male nor female (see Galatians 3:28) black nor white, nor schizophrenic, nor depressive—only whole people loved and cared for by God beyond all measure. The Christian community is called to reveal the firstfruits of this resurrection life and to participate in the process of resurrection that begins now, and finds its fulfillment in the eschaton.

A Community of the Resurrection

But, what do we mean when we speak about "resurrecting persons" in the here and now? Marcella Althaus-Reid asks the question: "How do people resurrect? In a future moment outside history and with trumpets and angels coming from heaven? Or in the tension of the present, but 'not yet among us,' reign of God?"[10] The answer is probably both. At one level, it is obvious that the Resurrection is a once-only historical event that cannot be repeated. It is the historical truth of the Resurrection that inspires hope and new possibilities for the present in the light of the future. However, at another level, the Resurrection, understood as the "death of death" reveals it to be a continuing, eschatological process within which the Christian community is called to adopt a critical stance against all forms of oppression that lead to death, whether physical, spiritual, relational, or social death. Therefore, resurrection has a threefold meaning. At one level it is a historical event within which God acted decisively to raise Christ from the dead, and in so doing, set in motion a redemptive process that is the ground of all human hope and realistic expectation. At a second level, the Resurrection contains the promise of an eschatological event within which human beings will be raised to life in the new kingdom. At a third level, the

Resurrection is a continuing process, a way of being, wherein the Christian community is called to live in such a way that death, in its wider sense, is recognized and the reality that it has been overcome lived out in its continuing praxis in the world.

Resurrection and Community

The historical resurrection of Christ was a multivocal and communal event. While hope was inspirited into the human condition by the revelation of the resurrected Christ, the inspiration was both a personal and a communal event that led to the Resurrection of a community to a new life of hope and fresh possibilities. Thus, the Resurrection can be understood as *both* a personal event within which Christ was raised by God in the power of the Spirit, *and* a corporate experience within which a community was brought back to life by the radical revelation of the risen Christ.

> The fact is that Jesus' resurrection was also a community event: women and men witnessed how he came back from death, walked among them and continued the dialogue that existed before his crucifixion. . . . So it is legitimate to think that, starting with Jesus' resurrection, a whole community of people who suffered his loss when he was crucified came back to life again. Their eyes were opened in the sense that death took on another meaning; the Resurrection became the paradigm showing us the durability and indestructibility of life and justice.[11]

If that was so at the time of the Resurrection, so it is also true for the church today. Resurrection, in the wider sense that is being explored here, is a personal and a communal event that occurs when the bonds of death are broken, and the blindness that has kept the community from recognizing the signs of death is healed through the process of remembering. When the Christian community remembers the poor and acknowledges and seeks constructively to address those elements of death that scar their existence, it finds itself resurrected from a form of spiritual, social, and relational death within which it remains ignorant to issues of suffering and injustice. It is resurrected into a new life within which the purposes of God and the coming kingdom provide a radical new

horizon and a transformed set of goals. Such a resurrected community is called to a ministry of memory, resurrection, and hope, as it seeks to develop forms of relating and ways of being with the poor and the "nonpersons," who have been forgotten and "buried" within the corporate psyche of present day Western societies. It is called to remember those whom the world has forgotten; to participate in the Resurrection of people whose personhood and relational possibilities have been destroyed by the social forces that have been outlined in the previous chapters; and to inspire hope in those whose lives at times appear to be profoundly hopeless. The church is called to initiate such a community of resurrection.

Resurrecting the Person

Friendship, Hope, and Personhood

We have laid down a reasonably full and critical analysis of what mental health problems are, both as clinical diagnoses and as social experiences. We have also reflected theologically on how the situations of people experiencing them might be understood, and how that theological knowledge might function in shaping the identity of the Christian community and the focus of its caring actions. Schizophrenia provided us with a central focus for analyzing the experience of mental health problems. In this chapter, we will begin to explore ways in which we can develop effective pastoral strategies that will deal with the experience of people with mental health problems. The question is: *How might the major barriers to relational development be overcome, and ways found to enable individuals living with mental health problems to fulfill their personhood, and to live lives worthy of creatures made in the image of a God who is love?*

In the light of the totalizing tendencies of mental health problems, perhaps the most appropriate place to begin is by examining the relationship between the person and his or her particular mental health problem. We have seen that people with mental health problems tend to become totally identified with their disorders. This leads to their developing a social identity as "schizophrenic," "dementia victim," "manic depressive" and so forth—forms of identity that can be highly destructive of opportunities to develop healing relationships with God, self, and others. This leads to a form of social death that demands the full attention of a community that is seeking to live out the Resurrection life. A first step is to explore whether it is possible to separate a person from his or her illness, conceptually and psychologically, in such a way that, in line with Kitwood's emphasis in dementia care, "the person comes first." If this can be done, then it may be possible to develop ways

of ensuring the healthy development of persons-as-persons, while taking their mental health problems seriously and offering appropriate care. One possible way of achieving such a goal is to reconceptualize mental health problems in order to acknowledge the seriousness of a person's problems while remaining focused on the person-as-person, rather than the person-as-illness.

Many people living with mental health problems are relatively symptom free at times, and at other times are deeply troubled and disturbed.[1] This being so, in many important respects a person may be deemed "insane" at one moment in time, but at other times be regarded as completely sane.[2] If this is the case, it may be more appropriate to think in terms of pathological thoughts and actions, rather than pathological people. In other words, a more appropriate way of conceptualizing and understanding the actual experience of people with mental health problems is to *separate the person from the illness.*[3]

Separating Mental Health from Mental Illness

The important thing about such a change in conceptualization is that it allows us to develop an understanding of mental health quite apart from mental *ill* health. In other words, it allows us to focus on the person, quite apart from the illness. In terms of "resurrecting persons," such a conceptual shift is of great significance. Keith Tudor notes that "it is commonplace to view the relationship between health and illness—and, therefore, mental health and mental illness—as two ends of the same continuum."[4] Within such a model, health is defined in opposition to illness with individuals being more or less healthy, depending on their position between the polarities. According to this model, people with long-term mental health problems will always be understood as mentally ill. Any conception of mental health care will primarily have to do with symptom control and the administration of appropriate medication. However, this is only one way of conceptualizing mental health and ill health. Tudor suggests that a more appropriate way of defining the relationship between mental health and illness is by "viewing each one as a separate continuum: the one, a mental disorder continuum; the other a mental health continuum."[5] This conceptualization enables one clearly to separate health from ill health and in so doing, focuses attention on issues of mental *health*, rather than simply mental *ill health*. It also enables one to conceptualize and experience being in different places on the two continua at the same time.[6] In this way, it is possible to consider mental health, apart from ill health and disorder, and to consider what it might mean in practical terms, to talk about developing the mental health of the people with long-term mental health problems. This understanding resonates with the "two narrative" theory of mental health problems highlighted earlier in this book. We might suggest that the maximal to minimal health continuum, with its primary emphasis on *illness*, represents the primary focus of the traditional psychiatric biomedical narrative. The specific training, research techniques, and forms of practice typical of mental health professionals result in a tendency to understand and define mental health according to the absence or presence of pathology. However, to persons living with a mental health problem, their primary concern frequently revolves around the maximal to minimal *health* continuum. This level focuses on meaningful personal relationships, spiritual direction, the quest for meaning, a valued place within society, and so forth. Within this continuum, mental health can now be understood in terms of growth and personhood, rather than by the person's illness experience, which affects, but does not define, the person. It is then possible to define mental health in terms of the whole person, rather than simply one aspect of the person, or his or her experience. Mental health can thus be understood as a complex process of psychosocial and spiritual development, that may or may not involve the eradication of specific mental health problems. Mental health involves a complex and reciprocal relationship between the physical, psychological, social, and spiritual domains within an individual, so that the health and illness status of each domain affects and is affected by the status of the other domains. Understood in this way, mental health is viewed in terms of a person being provided with adequate resources to enable him or her to grow as an unique individual and to live humanly as persons-in-relationship. As such, mental health inevitably incorporates such aspects as the capacity for growth,[7] adequate sources of mean-

ing,[8] and hope for the future.[9] Additionally, mental health includes a sense of empowerment;[10] an ability to accept challenges and to grow in the midst of them;[11] adequate resources to ensure the possibility of sustaining healthy interpersonal relations with self, God, and others;[12] and an experience of feeling there are possibilities for the future, regardless of one's circumstances.[13] All of this contributes to enhancing the personhood of the individual and allows development of the strength to live humanly, even in the midst of profound mental health problems.[14] Seen from this perspective, mental health is a considerably more open and positive construct than might otherwise be thought.

According to this understanding, a person with a mental health problem may be relatively free from the major symptoms of the illness, and yet still be mentally unhealthy, in that relational opportunities are poor or nonexistent, and opportunities for constructing a hopeful future are minimal. Similarly, a person with chronic, unremitting mental health problems may still be able to develop some degree of mental health. If they are given the opportunity to experience appropriate supportive relationships, situations, and experiences, these may enable them to develop confidence, self-esteem, and a sense of possibility for their lives. There is, of course, an inevitable overlap between the two continua. Nevertheless, this structure offers a constructive approach to mental health and ill health by opening up new vistas of hope and possibility for those whose mental health problems are interminable. While the primary focus of the mental health professions is often on illness, this model opens up the possibility of effective interventions from other sources, such as the Christian community, who can find a strong focus on the development of *mental health.* In this way, a clear *collaborative* role for the Christian community can be delineated, and possible avenues opened up for supplementing and enhancing the current caring strategies carried out by the mental health professions.

Most important, this understanding allows one to focus on the *person* rather than the manifestations of the mental health problem. Instead of working according to specific pathology or cultural stereotypes, this reconceptualization of mental health problems

allows us to consider questions of personhood and the possibility of mental health, even in the midst of interminable difficulties. If there is a separation of illness from person, then there can no longer be such a thing as a "schizophrenic," or a "manic depressive"—only whole persons who, at various times and to differing degrees, live with the symptoms of particular forms of mental health problems.[15] As a first step toward resurrection, such reconceptualization is invaluable.

Defining the Person Apart from the Illness

This focus on the person, rather than on the illness, in the care of people living with mental health problems, is an important one. This view has strong precedent within present day psychiatric research literature. John Strauss, a professor of psychiatry at Yale University, in his research into the subjective experience of schizophrenia hypothesizes that

> . . . the role of the person in mental disorder is not peripheral, merely as a passive victim of a disease to be fixed by medicines. . . . My hypothesis [does not] agree with the view that the person and the disorder are the same, as is implied by much psychoanalytic theory. Rather, I propose that clinicians consider the person and the disorder as separable for the purposes of understanding both more adequately.[16]

Strauss suggests that when one conceives of an individual who suffers from a mental health problem, one must think in terms of the individual as a *person* who also has a disorder, rather than a person who *is* a disorder.[17] He goes on to make a number of observations that are significant for the purposes of this book: "In a series of interviews with persons who had improved after ten years or more of severe mental disorder, several suggested that a key turning point for them was a change in attitude. . . . Somehow, after an extended period, they found themselves wanting not just to live with their illness but to have a life along with it or in spite of it."[18] Thus, in stark opposition to the view that mental health problems have a natural and determinative history, and that "diagnosis necessarily equals prognosis," Strauss's research suggests that, given

the correct circumstances and support, persons with mental health problems can gain a particular attitude that can enable them to view their situation and themselves from a more positive and constructive perspective. From there these individuals begin to develop some degree of mental health, and hope for a possible future.[19] Strauss continues:

> Some stated that they came to accept their disorders. But this was not the kind of giving-up acceptance or resignation that often seems generated by the attempts some professionals make at helpful teaching (e.g., "You have an illness like diabetes and will have it all your life. You'll need to stay on medication and there are certain things you'll never be able to do."). The acceptance described by these subjects was one that involved hope for a better life and the resolve to work for it. In several instances subjects noted that symptoms—even delusions or hallucinations—then started to become less dominating and often faded considerably.[20]

To suggest this is not to imply that medication is necessarily inappropriate or unhelpful, only that—on its own—it is not enough. There is considerably more to the process of recovery and rehabilitation than simply controlling symptoms. Strauss suggests that particular circumstances and events within a person's life can help him or her reframe the situation, and define it in a way that may be totally different from the way it is seen by others, such as family, friends, mental health professionals, and society at large. By reframing his or her situation, the person can be enabled to accept the illness in a proactive, constructive, and potentially health-bringing way.

Recovering Friendship as a Mode of Liberation

How then might such an attitude be initiated? How can one suffering from profoundly demoralizing difficulties be enabled to reframe one's situation in a way that will allow for the possibility of hope and healing? The final chapters of this book will argue that a key to such reframing of illness experience and the instillation of hope lies in friendship. The model of friendship presented in the life and work of Christ offers real possibilities for therapeutic

change. Committed friendship that reaches beyond culturally constructed barriers and false understandings and seeks to "resurrect the person"—who has become engulfed by their mental health problems—is a powerful form of relationship. It offers hope and new possibilities to people with the types of mental health problems that are the focus of this book.

Foundational to a person's experience of mental health problems are feelings of hopelessness, worthlessness, and poor self-esteem. While biological and biochemical factors may contribute to this, one of the main factors underlying poor self-esteem and hopelessness is the exclusion of people with mental health problems from many normal relational and material sources from which the majority of the population gain their sense of value, self-confidence, and worth. For many, the type of acceptance Strauss describes, which is marked by "hope for a better life and the resolve to work for it,"[21] seems unrealistically idealistic. Nevertheless, it is by no means an impossible ideal.

Finding Hope in the Midst of Hopelessness

One of the primary ways in which hope is inspired within human beings is through personal relationships. Helen Kirkpatrick and her colleagues echo the line of thinking we have been pursuing, in observing that many long-term studies are challenging the traditional view that severe mental health problems necessarily have a chronic deteriorative course.[22] Studies suggest that from one-half to two-thirds of people with schizophrenia show significant levels of recovery.[23] In line with Kitwood's observations of dementia, such research suggests that "the possible causes of chronicity may be viewed as having less to do with any inherent natural outcome of the disorder and more to do with a myriad of environmental and other psychosocial factors interacting with the person and the illness."[24] These researchers argue that the literature, and their own research, strongly suggest that the ability of the sufferer to develop some degree of *hope* is fundamental to the recovery process. The primary way in which hope is engendered within an individual is in and through *personal relationships*. Drawing on the definition offered by Judith Miller, they describe hope as:

> . . . anticipation of a continued good state, an improved state, or a release from a perceived entrapment. The anticipation may or may not be founded on concrete, real world evidence. Hope is an anticipation of a future which is good and is based upon mutuality (relationships with others); a sense of personal competence; coping ability; psychological well-being; purpose; and meaning in life as well as a sense of the "possible."[25]

In line with what has been suggested thus far, they argue that mental health problems are marked by "a cycle of disempowerment and despair that leads to symptoms of learned helplessness, including apathy, resignation, anger, submissiveness, depression, anxiety, withdrawal and compliance."[26] However, they present convincing evidence to support the thesis that hope, as it is manifested through interpersonal relationships, can break through this cycle and enable the individual to get "a foot on the rung" of the ladder back into society.

Byrne and colleagues in their paper entitled "The Importance of Relationships in Fostering Hope,"[27] also acknowledge the centrality of personal relationships in the development of such a hope that heals. They argue that personal relationships seem "to be the catalyst that allows hope to develop exponentially. The 'sense of the possible' expands when two individuals in a trusting relationship can work together."[28] This being so, as Kirkpatrick and Collins point out, mental health problems "may not affect psychological well-being to the extent that psychic energy cannot be mobilised to maintain hope."[29]

An important point that can be drawn from such research findings is the suggestion that the sufferer's ability to hope and to cope with their illness seems to inspire hope in the carer, *and* be inspired by the hope that is present within the carer. Several of the respondents within a research project conducted by Byrne and her colleagues referred to what they describe as a "contagion effect," wherein the carer's hopefulness could positively influence the hopefulness of the cared for. Put simply, *hope inspires hope.*[30]

In terms of pastoral care at a congregational level, this is a very important point. Hope lies at the heart of the message of the gospel—hope for the broken-hearted; hope for the afflicted; the

poor; the marginalized; those whom society casts aside. Likewise, hope and the inspiration and maintenance of hope lie at the heart of the *church's* ministry of mental health care. The Christian community, as a community of memory, resurrection, and hope, has the potential to make a valuable contribution to the type of caring strategies proposed by Strauss. If congregations can be enabled to offer this type of hope-bringing relationship, it will not only benefit people with mental health problems, but it will also empower church communities to become hopeful communities that are able to care effectively for "the outcast and the stranger." If we can find some way to initiate such a cycle of hope, we will have moved toward the type of resurrection that is fundamental to effective mental health care.

Friendship and Hope

Byrne and colleagues highlight the central features of healing relationships that inspire hope as *empathy, unconditional positive regard, respect, warmth, commitment and caring.*[31] Kirkpatrick and colleagues emphasize that, from the perspective of the sufferer, vital to the relational process is the ability to listen, to value the individual as a whole person, to understand the sufferer's perspective and to accept the person for who they are. One of the most significant interventions in the treatment of mental health problems is *understanding.* While pharmacology and therapy may well be useful in the treatment of mental health problems, *understanding is a vital form of intervention that is fundamental to the process of rehabilitation.* Thus we find that "support becomes more than an adjunct to the task of treatment; support becomes the task itself."[32] Supportive relationships such as friendship are not secondary to the therapeutic process—they are *fundamental.*[33]

Reclaiming Friendship

It now becomes clear that friendship has great potential for the mental health care of people living with long-term mental health problems. Strauss, Kirkpatrick, and Byrne present evidence of the kind of change of attitude that is needed, and indicate that this changed attitude can be initiated when people are enabled to enter

into a particular type of relationship that embodies the qualities of the proposed model of friendship. This type of committed caring that focuses on the person behind the diagnosis is very much in line with the kind of relationally based, committed caring that is revealed in the life of Jesus and in his friendships. Friendships that image the friendships of Jesus "fit the mold" presented by the research reviewed within this chapter. These friendships have the potential to be powerful counters to the dehumanizing forces that have been discussed.

If we reflect for a moment on the friendships of Jesus, one of their primary aims was to enable hope and relational wholeness to those who had been broken, isolated, and marginalized. For example, in his encounter with the Samaritan woman (John 4:7), someone who was heavily stigmatized and outcast by the Jewish people, he begins not with her race, gender, or dubious morality, but with her as a person worthy of relationship and respect. In speaking with her and sharing her drinking vessel, Jesus makes himself marginalized and unclean. However, in doing this he takes her into the community of God, resurrects her personhood, and heals her brokenness.

Likewise, his meeting a Gerasene man who was said to be possessed by demons and whose bizarre behavior had become his social identity shows a profound respect for the man as a person worthy of a valued place within the community (Luke 8:26). He takes time to commune with him and to listen to his story. In doing so he brings a depth of healing that surpasses the simple exorcism of demons. The effect of their encounter is so powerful that this man who has lived alone for many years, suddenly craves the company of Jesus. It is more than a coincidence that Jesus' final act toward this man was to send him back to his community to move him toward a place of integration and acceptance (Luke 8:26-39).

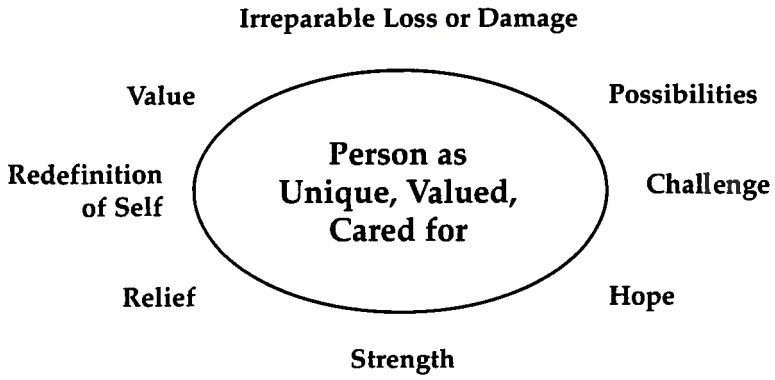
Jesus' friendships were always personal, as opposed to instrumental, primarily aimed at regaining the dignity and personhood of those whom society had rejected and depersonalized. Jesus' friendships reached beyond the socially constructed identity of individuals and, in entering into deep and personal relationships of friendship with them, he was able to reveal something of the nature of God and enable the development of a positive sense of

personhood based on intrinsic value rather than on personal achievement or outward behavior. Whether he was calling to Zacchaeus, the much hated tax collector, to come down from the tree and eat with him (Luke 19:2) or preparing for his death while communing with his friends (Matthew 26:26) the friendships of Jesus reached beyond social expectations to reclaim the personhood of the other.

This type of friendship is catalytic.[34] Unlike other more instrumental relationships such as those found in counseling and psychotherapy, which set out specifically to do something, it is a form of relationship that acts as a catalyst that enables health and rehumanization simply by being there. Unlike many agents with whom people with mental health problems may come into contact, the task of the Christlike friend is not to *do* anything for them, but rather to *be* someone for them—someone who understands and accepts them as persons; someone who is *with* and *for* them in the way that God is also *with* and *for* them; someone who reveals the nature of God and the transforming power of the Spirit of Christ in a form that is tangible, accessible, and deeply powerful.

In concluding this chapter, we might conceptualize the function of such friendships within a modification of the model of meaning and illness that was presented earlier.

Friendship and the Redefinition of Personhood



In this revised model, it is the *person* who sits at the center of our understanding, and it is from that starting point that we begin to learn about his or her mental health problems. Certainly the person's problem may well remain a challenge and an irreparable loss. However, the damage or loss is not the last word. Now there are new possibilities. In and through the development of hopeful relationships, new possibilities are opened up that focus on growth, hope, and a redefinition of the self that can bring value, meaning, and healing.

The role of the Christian community truly must be to become a community of friends who take seriously their ministry of resurrection; a community that acknowledges that relational isolation, social marginalization, and exclusion are not compulsory parts of the experience of mental health problems. The Christian community must strive to overcome death as it manifests itself in the marginalization and oppression of a very vulnerable section of the population. Such a community will be prepared to struggle alongside those who are oppressed and marginalized, in order that they may find a place of value and acceptance within which hopeful relationships can bring healing, hope, and resurrection.

Enabling Friendship-in-Community

A Ministry of Introduction, Education, and Enablement

Understanding Friendship Formation

In reflecting on the difficulties encountered by people living with mental health problems, one clearly sees that the development of meaningful friendship will not happen of its own accord. Even within the Christian community, there is no readily available pool of friendship that people can tap. The type of friendship this book is calling for will have to be *enabled, nurtured,* and *sustained,* if it is to become a realistic possibility.

Friendship is a learned skill. Friendship is the product of an ongoing process of socialization that continues throughout the life cycle, within which individuals learn the rules of communicating and relating and work out the boundaries that encompass their encounters. One learns how to develop friendships in the process of encountering others in community. As one experiences friendship, one is enabled to share that experience with others. However, there are many groups within our society—men and women who suffer from AIDS, homeless people, people with mental health problems, and people who are cognitively disabled—with whom the Christian community has little or no contact. Consequently, the types of countercultural friendships which are the focus of this book frequently are not developed. The vast majority of friendships within most Christian communities are based on the principle that like attracts like. If an ethic of solicitude does exist, it tends to be property rather than agape-based. Yet, as Elliot Liebow quite correctly observes, "Whatever one's view of mental illness, it is probably true that the more one gets to know about a person, the easier it is to put oneself in that person's place or to understand his or her viewpoint, and the less reason one has for thinking of that person or treating that person as mentally ill."[1]