# 1. EDITOR'S INTRODUCTION

David Ingleby[1]

The phenomenon of forced migration dates back to the beginning of human history. In our time, however, it has become one of the world's major problems. Since 1945 a virtual epidemic of armed conflict, both within and between nations, has created vast numbers of asylum seekers, refugees and displaced persons. This has led in turn to increasing involvement on the part of professional care workers and agencies, both governmental and non-governmental. In the last two decades, the provision of appropriate mental health care for the victims of organized violence has become a major focus of concern.

That care should be provided is - fortunately - increasingly accepted: however, considerable controversy has arisen about the *kind* of care that is necessary. The assumptions and models which initially informed mental health care provision for displaced persons, refugees and asylum seekers have come under scrutiny. As professionals become better acquainted with the problems, alternative approaches are starting to come to the fore.

This book aims to present a critical review of mental health care provisions for these groups of people and to review the controversies currently surrounding this topic. Part I discusses issues arising in humanitarian aid and reconstruction programs; Part II focuses on service provision in host countries. In both areas, we set out to highlight the controversies and new developments.

## 1. BACKGROUND

In the decades following the end of the Second World War in 1945, the number of armed conflicts in the world increased dramatically. According to the criteria used by Gleditsch et al. (2002), it reached a peak of 56 in 1992, but has been declining since then. This decrease is usually attributed to the ending of the Cold War. Nevertheless, the level of conflict remains alarmingly high and current developments in the Middle East – including the situation in and around Israel and the 'pre-emptive' strike launched against Iraq by a US/UK led coalition in March 2003 – do not bode well for the future.

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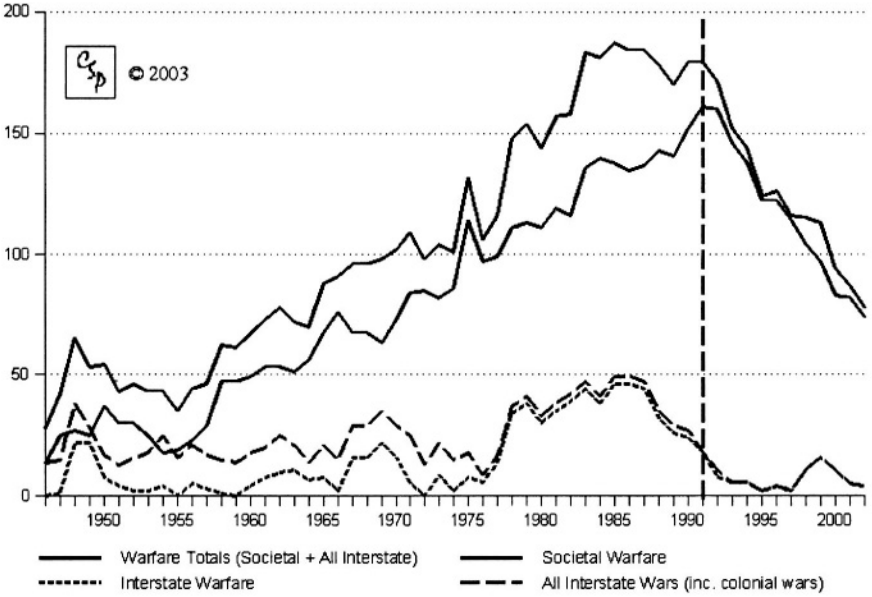
[1] David Ingleby, Faculty of Social Sciences, Utrecht University, The Netherlands

In their survey of global conflict, Marshall and Gurr (2003) have attempted to quantify the total magnitude of armed conflict, taking account not only of the number of conflicts but also their intensity. Figure 1 shows the results of their survey. As can be seen, *internal* conflicts, which typically inflict high levels of suffering on ordinary men, women and children, are by far the most prevalent type of organized violence in the modern world.

**Figure 1.** The total magnitude of conflict worldwide, as calculated by Marshall (2002)[2]. The uppermost line represents warfare totals; the vertical dashed line indicates the ending of the Cold War in 1991.



According to the United States Committee for Refugees (USCR)[3], at the end of 2003 some 35.5 million of the world's population had been forced to leave their homes in search of shelter from organized violence. Most of these (23.6 million) remained within the borders of their own country, becoming 'internally displaced persons' (IDP's), while 11.9 million went abroad to become refugees. Figure 2 illustrates the global trends since 1964 in the totals of IDP's and refugees.

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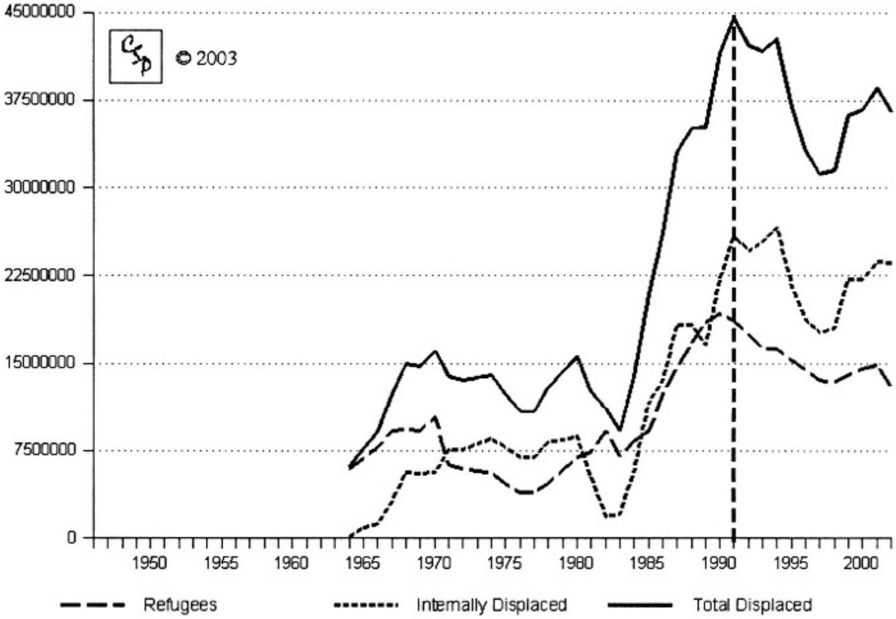
[2] Source: CSP (2003). Reproduced by kind permission of the author.

[3] The statistics quoted here are taken from the *World Refugee Survey 2004* (USCR, 2004). This survey relates to "refugees in need of protection", defined as "asylum seekers awaiting a refugee status determination" plus "refugees who are unwilling or unable to return to their home countries because they fear persecution or armed conflict there and who lack a durable solution" .

**Figure 2.** Totals of displaced persons, 1964-2002[4].



Of course, the amount of forced migration is not simply determined by the level of organized violence. Many other factors play a role. One such factor is transportation – the ease which with migrants can reach another country. Another is government policy, which determines how easy or difficult it is to enter that country and stay in it. Though the 1951 Geneva Convention on Refugees set out to regulate the right to asylum worldwide, differences in the extent to which its provisions have been adopted and in the way they have been implemented have led to wide variations in the accessibility of different countries for those seeking asylum.

At present, the major refugee burden is shouldered by non-Western countries (Middle East 37%, Africa 27% and Southern & Central Asia 16%). Relatively few of those seeking shelter are to be found in European countries (7%), while the combined total for the USA, Canada, Australia and New Zealand is even lower (3%). The 10% who flee to the West are almost by definition a select and atypical group, able to plan, pay for and undertake a hazardous and uncertain enterprise.

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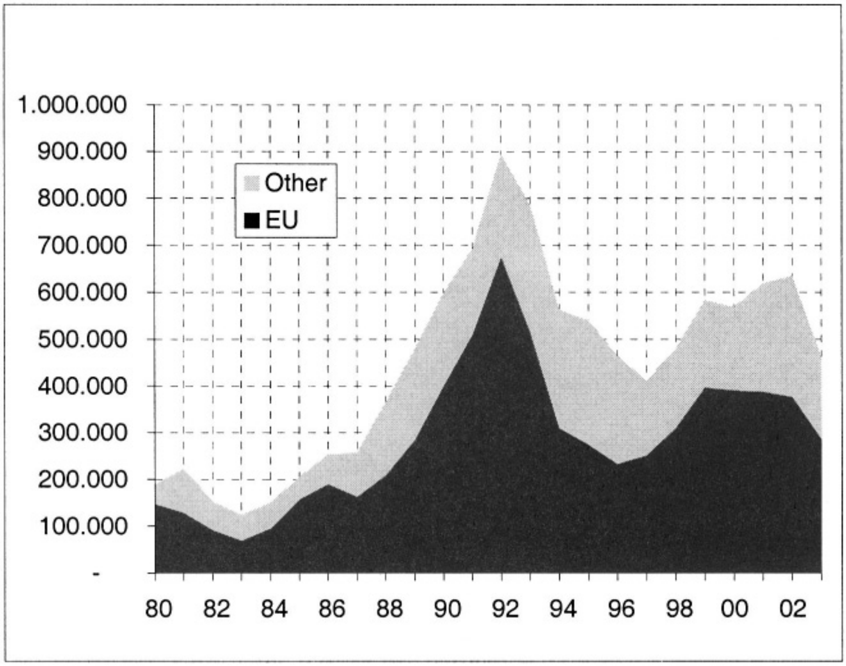
[4] Source: CSP (2003). Reproduced by kind permission of the author. Data derived from the USCR's *World Refugee Surveys.*

Since the 1970s the proportion of refugees reaching Western countries has increased considerably, mainly because of better transport facilities. However, the surge which industrialized countries experienced during the 1990s had a political backlash: it led to a tightening-up of the laws and procedures governing asylum which is still going on. Together with the decline in the amount of conflict world-wide, this has led in the last three years to a fall in the annual numbers of those seeking asylum in Western countries (see Figure 3), as well as the proportion who are allowed to stay.

**Figure 3.** Annual asylum applications in 36 industrialized countries, 1980–2003[5].



As can be seen, asylum applications in industrialized countries increased nearly ten-fold between 1983 and the peak year 1992. Subsequently, the number of asylum seekers declined – partly due to the ending of certain conflicts, but also to the adoption of the increasingly stringent policies referred to above. Towards the end of the 1990s, the figures rose again, but in the last three years they have shown a steady decrease: 614,650 in 2001, 579,040 in 2002 and 463,130 in 2003.

In a relative sense, then, the pressure is off Western governments concerned about a 'tidal wave' of asylum seekers 'swamping' their countries – at least for the time being. However, these statistics can be misleading. They say nothing about the numbers of forced migrants entering countries illegally, or the number of asylum seekers who disappear into illegality after their application is rejected. As policies in Western

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[5] Source: UNHCR (2004), p. 4. Reproduced by kind permission of the Population Data Unit, UNHCR Geneva.

countries have become stricter, the numbers of these 'undocumented' migrants have increased – though since these are people who officially do not exist, it is of course hard to obtain reliable estimates. Anders Hjern and Olle Jeppsson draw attention to this increasing human rights problem in Chapter 7.

Moreover, the recent decline in the number of asylum applications in industrialized countries does not make the problem of providing adequate care any less urgent. This problem does not concern only the newcomers, but also those who may already have spent several years in the host country.

## 2. PHASES IN THE DEVELOPMENT OF SERVICE PROVISION

The provision of effective health and social care for asylum seekers and refugees is partly motivated by principles of human rights and partly by pragmatic considerations. The right to care is laid down in the 1951 Geneva Convention on Refugees; more recently, the European Commission adopted on 27th January 2003 a directive laying down minimum standards on the reception of asylum applicants in Member States, including standards of health care. But apart from the question of human rights, governments also have an interest in ensuring that this group is not neglected. Ignoring the problems people have usually leads to more serious problems at a later stage. For example, a refugee handicapped by psychosocial problems is likely to have difficulty getting a job and integrating into the host society, thereby becoming even more dependent on the state.

### 2.1. Prior to 1980

In the period preceding the dramatic rise in the number of refugees during the 1980s, the concept of humanitarian aid was restricted to the provision of the most basic necessities: food, water, shelter and basic medical care. These were the priorities of the relief programs organized by NGO's working with IDP's and with refugees in the countries surrounding a conflict zone. In a sense, these remain the priorities for relief programs in any setting, because it is universally recognized that basic material needs have to be met before psychological and social problems can be properly dealt with.

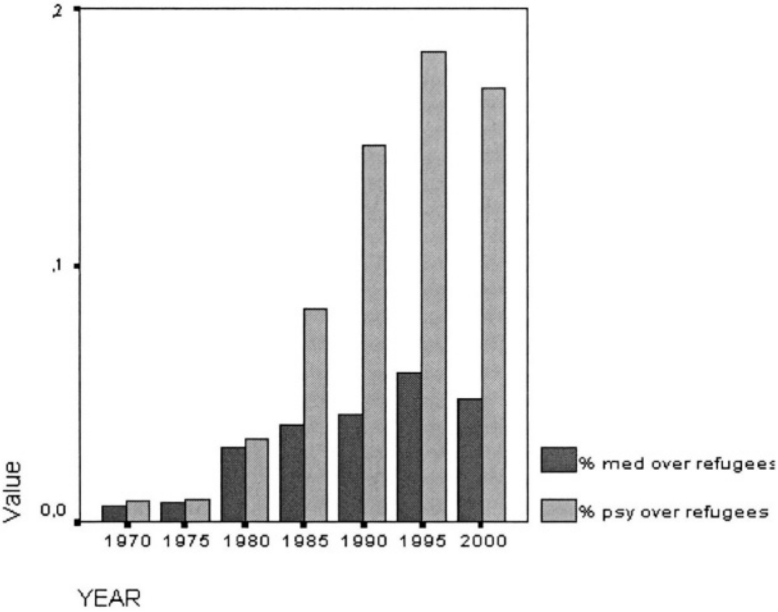
However, for refugees who had sought refuge in Western countries, psychological help was also available. Once admitted to a country, refugees could make use of its mental health services. The numbers concerned were small and there are few data on the demand for services and their adequacy. Nevertheless, it is clear that one category of problems received special attention: physical and psychological disorders resulting from torture or exposure to other forms of violence. Treatment for these problems was often provided by professionals with prior experience in helping victims of the Second World War and other armed conflicts. This is the background of centers such as the Medical Foundation for the Care of Victims of Torture (Britain) or Icodo and Centrum '45 (The Netherlands). Insofar as there was special provision for refugees in this period, we can say that the mental health services viewed refugees primarily as *victims of organized violence.*

## 2.2. The 1980s

From about 1980 onwards we see a dramatic increase in the attention paid to the psychological problems of refugees, accompanying a steep rise in their numbers. One rough-and-ready way of quantifying this attention is by examining the number of articles published in the scientific literature which make reference to refugees. If we do this for the medical literature, using the MEDLINE database, we can see a small but steady interest in refugees from 1968 to 1977, which then increases dramatically until 1995, falling back slightly after that date. The psychological literature can be surveyed in the same way using the PsycINFO database: this shows the same general pattern, but the expansion between 1977 and 1995 is much more marked. In the last two decades, therefore, we see that psychological attention for refugee problems has increased faster than medical attention.

In absolute terms, there are many more medical publications than psychological ones, but even in these terms the trend is clear. Between 1968 and 1982 there were seven medical articles mentioning refugees for every psychological article. After 1982, however, this ratio was only about 2:1. Figure 4 shows the rise in the percentage of publications mentioning refugees in both areas.

**Figure 4.** Percentage of all publications in the medical and psychological literature in which the words 'refugee' or 'refugees' appear in the bibliographical data (title, summary, keywords)[6]. The year 1970 stands for the period 1968–1972, 1975 for 1973–1978, etc.



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[6] Source of data for figures 4-6: Ovid Technologies ERL® WebSPIRS® 5.

When we examine the *content* of the psychological articles concerned with refugees, we see that they continue to be primarily focused on the effects of past sufferings: there is little attention to the effects of forced migration itself or the problems of readjustment in a new country. In the field, psychosocial teams began to be sent to conflict regions by NGO's during the 1980s to work alongside those providing material relief and basic medical care. This increased activity owed a great deal to the sudden upswing in the acceptance of the concept of 'trauma'.

Most commentators agree that the origin of the new concern for traumatization lay in the Vietnam War. Many U.S. conscripts returned home with psychological problems and difficulties of adjustment, but the military authorities at first denied any link between these problems and their war experiences. Acceptance of the concept of 'post-traumatic stress disorder' as a psychiatric category was signaled in 1980 by its adoption in the Diagnostic and Statistical Manual of the American Psychiatric Association. This was a victory for groups lobbying for the interests of Vietnam veterans. It entitled veterans to the treatment, the public sympathy and the financial assistance which up until then they had mostly been denied. The diagnosis of PTSD, in the words of Summerfield (2001), "was meant to shift the focus of attention from the details of a soldier's background and psyche to the fundamentally traumatogenic nature of war". The current diagnostic criteria for PTSD include a specification of the traumatizing event (actual or threatened death or serious injury, etc.) and the patient's response to it (intense fear, helpless, horror etc.), together with the three characteristic symptoms:

1. Persistent *re-experiencing* of the traumatic event (distressing images, nightmares, flashbacks etc.), causing distress and signs of panic;
2. Persistent *avoidance* of stimuli associated with the trauma, numbing of general responsiveness.
3. Persistent symptoms of increased *arousal* (e.g. insomnia, irritability, concentration problems, hypervigilance and increased startle responses).

All these symptoms must be present and severe enough to cause substantial impairment in social, occupational or interpersonal domains. Moreover, the symptoms must be present for at least one month.

### 2.3. The explosive growth of the trauma approach

Originally developed in the light of the experiences of Vietnam veterans, the PTSD concept also became widely used in relation to victims of sexual and domestic violence, accidents and natural disasters, as well as organized violence. The notion of 'having a trauma' became part of everyday language. Trauma therapy became a flourishing specialty, most treatments being based on some version of the notion of 'working through' or re-experiencing of the traumatizing events. Quite apart from the relief these treatments brought, the diagnosis of PTSD offered victims of violence the possibility of social recognition and financial compensation.

Some idea of the spectacular increase in the amount of attention paid to trauma can be obtained from Figure 5, which shows the percentage of publications during successive 5-year periods in which the concepts 'trauma', 'psychotrauma' or 'PTSD' figure in the PsycINF database. It is worth noting that publications over refugees make up only a tiny fraction of the trauma literature: during the past 15 years this proportion has remained steady at around 3%.

**Figure 5.** Percentage of publications in the psychological literature with the words 'trauma', 'psychotrauma' or 'PTSD' in the bibliographical data.

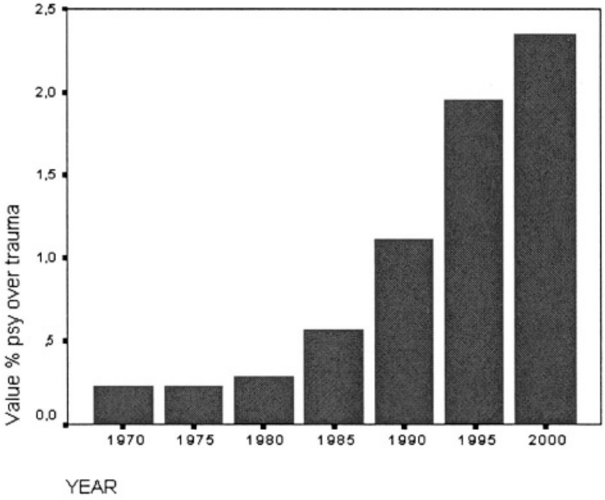
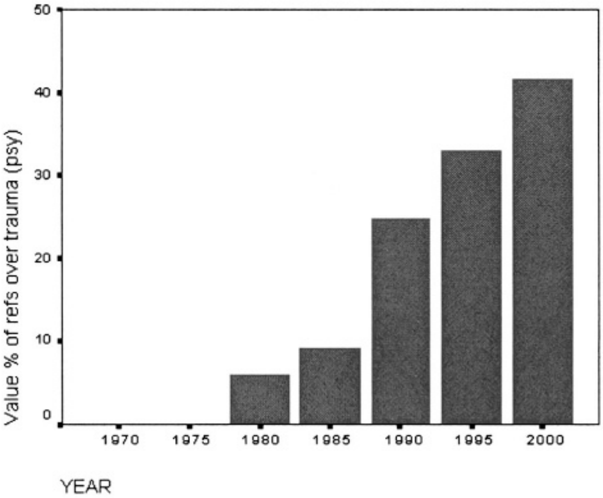


**Figure 6.** Percentage of articles in PsycINF with the words 'refugee' or 'refugees', in combination with the words 'trauma', 'psychotrauma' or 'PTSD', in the bibliographical data.



The way in which the trauma concept suddenly rose to prominence has attracted much attention as a social phenomenon in its own right. Notions of 'medicalization', 'social construction' and 'professional imperialism' were applied to this phenomenon by authors whom we will discuss in later sections. The extent to which the trauma concept came to dominate the psychological study of refugees can be seen very clearly in Figure 6, which shows the percentage of articles on refugees in which the concept figures. Whereas there are *no* mentions of 'trauma' in connection with refugees during the decade 1968-1977, almost half of all psychological articles on refugees during the last five years make reference to the concept.

A simple statistical analysis enables us to answer the following question: is the number of publications about "refugees and trauma" primarily related to the level of interest in refugees, or to the level of interest in trauma? Multiple regression analysis reveals the existence of a highly significant relationship with the latter variable, yet none at all with the former. This is an extremely interesting finding: it suggests that it was trauma researchers who became interested in refugees, rather than refugee researchers becoming interested in trauma. More detailed analysis of the literature would be necessary to confirm this interpretation, but it suggests that the research in this field has been more 'theory-driven' than 'problem-driven'.

From about 1980 onwards, then, the concept of 'trauma' increasingly formed the basis of studies and interventions concerning the mental health needs of refugees, whether they were living in the industrialized West or in conflict zones. Very soon, the trauma approach became a self-perpetuating, almost closed system. Criticism of the one-sidedness of this approach was routinely waved aside as callous indifference to the plight of those suffering. The word 'trauma' itself was used to describe *both* the situation causing the disturbance, *and* the disturbance itself: this elision reinforced the notion that if a situation was 'traumatic', those experiencing it would automatically be 'traumatized'. Yet many studies show large, unexplained variations in the extent to which experiences of violence lead to symptoms of PTSD.

In many studies, only data related to PTSD were collected: other ways of looking at refugees' problems were not considered. Data were routinely collected using diagnostic instruments which had never been validated for the population studied. A recent example of this was a study in Sierra Leone (De Jong et al., 2000) which reported that 99% of respondents had scores on the Impact of Events Scale (IES) "that indicated very high levels of disturbances, indicative of severe PTSD in western Europe". Although the first author later modified this claim (De Jong, 2001), it is entirely typical of the tendency to 'talk up the numbers' which characterized, for example, reports by NGO's during the Balkans Wars (see Paul Stubbs in Chapter 3).

Some authors ascribe traumas to whole populations, giving the concept an extremely broad interpretation which bears little relation to the official definition of PTSD. An example of this can be seen in a report on the children of Iraq, undertaken in the run-up to the invasion in 2003 (International Study Team, 2003, p. 6): "Iraqi children are already badly traumatized by 12 years of economic sanctions". Some people evidently feel that the end justifies the means, as long as such statements generate more concern for victims of violence: but perhaps refugees and asylum seekers would be better served by more respect for the precise nature of their problems.

### 2.4. Growing doubts about PTSD

During the 1990's, as we can see from Figures 5 and 6, the popularity of the 'trauma' approach continued to increase. Nevertheless – almost inevitably, when we consider how uncritically the trauma approach was embraced to begin with – doubts soon began to be voiced about the universality and relevance of the PTSD diagnosis. Kleber et al. (1995) and Marsella et al. (1996) marshal some of these criticisms.

- Authors such as Kleber et al. (1992) argued for toning down the pathological connotations of PTSD by introducing a distinction between 'normal' and 'abnormal' ways of reacting to extreme stress: the former was designated as 'Post Traumatic Stress *Reaction'*. (This view receives support from a recent article by Yehuda (2003), which argues that 're-experiencing', 'avoidance' and 'arousal' are virtually universal reactions to extremely shocking experiences, and that PTSD should be seen as the *abnormal persistence* of these symptoms.)

- The DSM definition of 'trauma' presupposes one or more catastrophic events, capable of being localized in space and time. This, however, does not do justice to the fact that refugees have often experienced a long series of stressful events. The concept of 'sequential traumatization', developed by the Dutch psychiatrist Keilson in the course of his work with child survivors of the holocaust (Keilson & Sarphati, 1979) struck many critics as more appropriate.

- Researchers such as Silove (1999) pointed out that the prevalence of PTSD among refugees was highly variable and that it is hard to predict, purely on the basis of what someone has experienced, whether they will develop the condition. Kessler et al. (1995) had already noted that only 9% of men and 20% of women who were exposed to a potentially traumatizing experience in terms of the DSM criteria, actually developed symptoms of the disorder.

- Others (e.g. Summerfield, 1999) regarded the emphasis on PTSD as misplaced. People with PTSD symptoms may not regard them as their most serious problem, and such symptoms may not always cause much impairment of functioning. Chapter 4 by Olle Jeppsson and Anders Hjern, a study of the 'lost boys of Sudan', provides a graphic example of this. In an epidemiological study of 824 asylum seekers from Kosovo in Great Britain (Summerfield, 2002), almost all respondents mentioned *work, schooling* and *family reunification* as their major concerns; very few respondents seemed to be bothered by their psychological symptoms. This finding contrasts sharply with the conclusions of Turner et al. (2003), who studied the same group of 824 asylum seekers and estimated that half of them had PTSD.

- A number of authors (e.g. Summerfield, 1999, Angel et al., 2001) have expressed doubts about the advisability of therapies involving 'working through' for people whose cultures place a high value on stoicism and 'active forgetting'.

Alongside these specific points of criticism, the limitations of the PTSD concept led to many frustrations among refugee mental health workers and their clients. Like a narrow funnel, the concept seemed to reduce both *causes* and *effects* to a drastically simplified form, which on its own was seldom encountered in practice – at any rate among refugees. This led to a sort of 'tunnel vision' among mental health workers, researchers, policy makers and financial donors, in which awareness of other problems was seriously attenuated.

- The *causes* of the psychological problems of refugees cannot be reduced to a single catastrophic, life-threatening event, or even to a sequence of such events. Not knowing what the fate of one's family is, for example, or whether one will obtain asylum, is not an *event* but a *situation.* There is a further difference between a refugee and the accidental victim of a plane crash or an armed robbery. The traumatic events which refugees have experienced do not come out of the blue, but are intimately connected with the rest of their lives. They are embedded in a context of threat, uncertainty, deprivation, oppression and suffering. As Shakespeare put it *(Hamlet, Act iv. sc. 5):* "when sorrows come, they come not single spies, but in battalions". The concept of PTSD thus focuses on only a part of the stressful experiences which most refugees have undergone.

- Likewise, the PTSD concept focuses on a small selection of the *effects* of these experiences. Out of the whole panoply of forms of psychological (and other) problems which this group can suffer from, three symptoms are singled out: re-experiencing, avoidance and arousal. Anything which does not fall under these headings is relegated to the category of 'co-morbidity'. This hardly does justice to the wide range of complaints which those working with refugees encounter daily. Considered from the perspective of system theory (see Chapter 10 by Julia Bala), the PTSD diagnosis is even more inadequate, because the concept refers only to the individual patient and does not consider possible disturbances of the social system in which they operate. Some problems may go beyond the boundaries of what is usually designated 'mental health': consider, for example the *moral* crisis which Ian Clifton-Everest describes (Chapter 5) in former child soldiers. In sum, PTSD focuses attention on a highly limited cluster of symptoms, which may cause great hardship to some refugees, but may be totally absent among others, or overshadowed by more complex problems.

Even though the 1990s saw the emergence of critical views on PTSD, the concept continued to dominate the field of mental health care for refugees. However, other approaches began to receive attention. Other disciplines started paying more attention to the problems of refugees – in particular, anthropology, where publications on this topic showed a marked upturn in the 1990s. As a result, other issues apart from 'trauma' were introduced, problematizing the situation of refugees in different ways. In this way, the field of refugee mental health care has recently become an unusually lively and controversial scientific arena, with a wealth of different viewpoints competing for attention. In the following section we will identify some of the different perspectives which have influenced thinking about service provision.

## 3. SCHOOLS OF THOUGHT INFLUENCING SERVICE PROVISION

Watters (2001) has presented a review of 'emerging paradigms' in the care for refugees; the following discussion overlaps to some extent with that article. It should be borne in mind that the 'schools' we discuss are 'ideal types'. It is often unclear where the boundaries between schools lie and who the main protagonists are: on some issues, different schools may overlap with each other. As a starting-point, however, we propose the following rough taxonomy.

1. Mainstream health care approaches
2. Multicultural mental health care
3. Sociological approaches
4. 'Managed care'
5. The role of users' movements.

### 3.1. Mainstream health care approaches

It is a mistake to assume that 'mainstream' health care represents a uniform way of thinking. Quite apart from 'alternative' medicine, there is a broad spectrum of established approaches. One way of ordering these is on a continuum from 'hard' (positivistic) approaches to 'soft' (humanistic or interpretative) ones.

At the 'hard' end of the spectrum is the biomedical model, embraced by psychiatrists, neurologists and clinical psychologists who attempt to model their work on the natural sciences. Within the field of mental health, this approach came under heavy fire from the critics of the 1960s and 1970s, but since then it has made a remarkable comeback. This approach pays scant attention to the social context and meaning of people's complaints; symptoms are described as 'objectively' as possible and successful treatment is equated with their removal. The symptoms, one might say, are the target of attention – not the person who is bothered by them. (In clinical medicine, indeed, it is still commonplace to talk about 'the brain tumor in bed three').

What we refer to as 'soft' approaches to health care are those in which a more important role is accorded to the social context and meaning of behavior and experience. The most important are perhaps *psychotherapeutic* approaches, the classical exponents of which are such figures as Sigmund Freud and Carl Rogers, and *social medicine* and *public health* approaches.

#### *3.1.1. Positivist, biomedical approaches*

In these approaches, refugees' problems are most often described in terms of PTSD, seen as a specific psychiatric disorder and formulated in terms conforming to the biomedical paradigm and the 'descriptive' nosological tradition of Emil Kraepelin. For Kraepelin, mental disorders were illnesses like any others: the advancement of medical science required a precise, objective description of the symptoms of the illness, in which the meaning, context and suspected cause of the symptoms played as small a role as possible. Workers in the psychodynamic tradition, in particular, have looked on in dismay as present-day Kraepelinians have gained more and more influence within the mental health field – particularly during recent revisions of the DSM (the Diagnostic and

Statistical Manual of the American Psychiatric Association). Since the DSM forms the basis of mental health practice in many Western countries, this represents a substantial shift of power.

In one conspicuous respect, however, as Young (2002) has pointed out, PTSD does *not* fit into a purely descriptive approach to nosology: the supposed cause is part of the definition, constituting one of the *criteria* for the disorder. In all other respects, however, the concept fits perfectly into the biomedical tradition. Nevertheless, this tradition is only one of many which are represented in the whole field of mental health. Mental health care is not a homogenous entity, but a complex arena in which different disciplines, professions and approaches continually struggle for supremacy. The debates which have arisen about PTSD, therefore, are anything but unexpected: they reflect fundamental and persistent tensions within health care itself.

### *3.1.2. Psychotherapeutic approaches*

Here – in contrast – the experience of the client occupies a central place and 'idiographic' (one-off) characterizations are preferred to standardized diagnostic instruments. Compared to the Kraepelinian approach, much more attention is paid to the relational context of the individual. Moreover, the client's general well-being and level of functioning is regarded as more important than merely the presence or absence of symptoms. The task of the therapist is seen in terms of communicating, conferring and negotiating with the client, rather than as applying a 'treatment' in the medical sense. The psychotherapeutic approach can also be characterized as a 'humanistic' one, because the client is seen as an *agent* and a *subject* rather than a passive 'patient', wholly at the mercy of external forces. Another important difference is that while the biomedical approach focuses on 'disease', psychotherapeutic approaches attend to 'illness' (see section 3.2 for a discussion of this contrast).

### *3.1.3. The social medicine or public health tradition*

This approach differs from the biomedical one in two respects. Firstly, more attention is paid to peoples' social and physical environment: social medicine focuses both on a person's place in society, and on the place of illness in their life. Secondly, social medicine is not simply concerned with symptom reduction, but also with the promotion of health. Moreover, health – according to the famous definition written into the constitution of the World Health Organization in 1948 – is seen as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". According to this view, health care is not only concerned with pathology, but with the whole range of conditions (including the social context) which influence health in this broad sense.

Exponents of the social medicine or public health tradition have played an important role in shaping the identity of the WHO and – at both national and international levels – in setting up policies concerned with the care of refugees. In the Netherlands, for example, the centre which the Government set up to coordinate health care for refugees (Pharos) worked from this perspective and the publications of its first director, Loes van Willigen, provide a good illustration of its scientific principles (see, e.g., Van Willigen & Hondius, 1992; Van Willigen (ed.), 2000; Van Willigen, 2003). In mental health care, this approach is closely related to the 'mental hygiene movement' which played a vital role during the twentieth century in developing alternatives to the biomedical model. It is an approach which regards *prevention* as no less important than *cure,* paying detailed attention to the sources of stress and disability which may be located in the present environment of refugees and asylum seekers. Such an emphasis is more often found in the field of *primary care* than among providers of specialized, clinical services. In the present volume, Chapter 7 by Anders Hjern and Olle Jeppsson provides a good example of work in the tradition of social medicine and public health.

Closely related to this tradition are the so-called 'psychosocial' approaches to the care of refugees, which are often underlie reconstruction work in post-conflict societies. Chapter 2 by Derrick Silove and Chapter 3 by Paul Stubbs devote specific attention to these approaches. Silove also gives prominence to a third approach, which he calls the 'severe mental illness' model. This approach focuses on a group which is relatively small in size (1% or more), but urgently in need of help because of severe emotional or behavioral disorders. Some of these individuals may have been disturbed before the conflict situation arose; whatever the cause of their problems, Silove argues that the excessive focus of debate on the trauma model has diverted attention from their needs.

### *3.1.4. Observations on theoretical approaches to refugee mental health care*

When we examine the competing paradigms within the field of mental health, we see that the criticisms of PTSD listed above are not simply directed at the concept itself, but at the positivistic model of clinical practice which gave rise to the concept of PTSD in the first place.

I have referred above to the criticism of PTSD as a 'funnel' that narrows down both causes and effects to a stripped-down version (a criticism that has often been voiced by workers in the psychotherapeutic and public health traditions). The great riddle of PTSD is this: how did a concept that is so incapable of doing justice to the experience of mental health workers and their clients come to occupy a position of exclusive dominance in the field of mental health care for refugees? Are the proponents of PTSD really so powerful and cunning, and the professionals and their clients so naïve, that almost everyone failed to notice the glaring inadequacy of the concept?

In section 3.3 I will suggest that the emphasis on PTSD can only be understood if we consider the *social consequences* of such a diagnosis. Similar paradoxes can be found in other areas of health care. Certain concepts drawn from the biomedical tradition, for example 'anorexia nervosa' or 'attention deficit hyperactivity disorder' (ADHD), are applied far more often than is strictly warranted in terms of the clinical criteria. Yet the popularity of these labels is easier to understand when we take account of the sociological dimensions of sickness, in particular the question of power: sometimes a biomedical category has to be used *in order to get things done.* Before developing this point further, however, I will first examine other approaches which have been applied in research and care programs for refugees.

### *3.1.5. Eclecticism*

What is immediately striking when surveying this area is the enormous diversity of both the theories and methods adopted, and the problems to which they are applied. Despite the dominance of the PTSD concept, alongside the purely 'clinical' approach there is ample attention for the context of the refugees' lives and the myriad factors which can influence their well-being. This diversity of approaches is not surprising when we consider the diverse sorts of professionals in collaboration with whom this theoretical knowledge has been generated: not only clinicians but also general practitioners, youth workers, teachers, voluntary workers and policy makers.

Theory development in this area has thus a predominately *eclectic* character. Even clinicians concerned explicitly with the treatment of 'trauma' seldom limit themselves to a symptom-oriented, Kraepelinian approach: most of them also try to pay attention to 'the person in context'. True, some therapies (for example, 're-exposure therapies' such as 'implosion' or 'flooding') are narrowly focused on the symptoms of PTSD. But most therapies used for trauma patients have a much broader focus: indeed, there is hardly any form of therapy which has *not* been applied to this group! This fact is not as strange as it sounds, when we take account of the fact that PTSD can be accompanied by depression, anxiety, addiction, relation problems, aggressive disorders and even schizophrenia. Nevertheless, when the client is a refugee, it is usually the PTSD symptoms which are highlighted: the rest tends to be seen as merely 'co-morbidity'.

### *3.1.6. Prevention*

Another important theme in research and theory development in this area is *prevention.* Especially in the so-called 'psycho-social' approach, models of normal functioning such as Garmezy's (1985) model of 'risk factors' and 'protective factors' are applied to the question of fostering the well-being of refugees. Also popular in this field is the 'stress and coping' model of Lazarus and Folkman (1984).

Occasionally, a concern with prevention leads mental health workers to become involved in advocacy or political campaigns for the dignity and human rights of refugees and asylum seekers. 'Professional detachment' has nothing to do with turning a blind eye to social wrongs, and health care workers are sometimes the only witnesses to these wrongs. In such cases, their duty is not only to help their patients, but to ensure that the injustices that they have witnessed are dealt with. Those concerned with the care of refugees and asylum seekers are constantly confronted with examples of disregard for the human rights of this vulnerable group. Many refugees who have fled to neighboring countries are victims of what the U.S. Committee for Refugees (op. cit.) has dubbed 'warehousing': more than 7 million of the world's 12 million refugees have been confined for ten years or more in camps or separate settlements. This disregard is also manifested in the way in which asylum seekers are treated in prosperous Western countries by lawmakers, bureaucrats, state organizations, media and the general public. Lately, human rights organizations have expressed particular concern about the detention policies operated by (among others) the UK, Australia and the USA, and the deportation policy for those refused asylum – sometimes after years spent living in the host country – by the Netherlands. 'Group advocacy' and public protest against these forms of injustice is an integral part of the care worker's responsibility (see Silove et al., 2000; Ingleby, 2001).

The problem with effective care delivery for refugees and asylum seekers, as will become clear in the following chapters, has nothing to do with a shortage of theoretical perspectives and research findings on this topic. On the contrary, a wealth of ideas and research is available, and the problems of refugees have been approached from many angles. The problem of providing care for this group, as Ingleby and Watters argue in Chapter 12, is to *integrate* all these different perspectives – to provide 'holistic' care in which all the different problems refugees can have are tackled in a coherent way, rather than being divided up between services that are more inclined to compete with each other than to cooperate.

## 3.2. Multicultural mental health care

As Suman Fernando points out in Chapter 11, the care of refugees is almost always *multicultural* care. In the last two decades there has been an upsurge of interest in the relevance of the cultural context to all types of service provision.

In the 1950s the discipline of 'transcultural psychiatry' came into being. This branch of psychiatry is concerned both with service provision in different countries and with problems within culturally or ethnically diverse societies. The effects of migration and the problems of migrants are a central topic in this branch of health care. During the 1990s we see steadily more focus on *the refugee as migrant,* supplementing and sometimes replacing the emphasis on *the refugee as victim of organized violence.* Within this approach, the problems of service provision for refugees are viewed in relation to multicultural service provision in general. This has encouraged concern for the other kinds of problems refugees may have apart from traumatic experiences in the past.

### *3.2.1. Refugees as migrants*

An important article marking the shift towards viewing the refugee as a migrant was published by Van Dijk (1996). This shift occurred during a decade in which refugees were beginning to make up a significant proportion of the migrant population. Up to the mid-1980s, the numbers of refugees were very small and care for them was mostly provided outside the mainstream. There was little common ground between professionals and services dealing with refugees and those helping other immigrants. Refugee clients were often well educated and were regarded as having a rather esoteric clinical problem (trauma), calling for specialized individual psychotherapy. At least until the late 1980s, the public image of the refugee was also generally positive: refugees enjoyed a sort of moral credit, in the eyes of the public, which labor migrants totally lacked. This gave them an almost self-evident right to respect, compassion and help.

Professionals helping labor migrants, on the other hand, mostly had clients with low educational qualifications and low incomes, who displayed a range of diffuse and overlapping problems often related to a socially marginal or disadvantaged position. Psychotherapy was seldom felt to be suitable for these clients, who were often shunted directly into intramural care or social psychiatry. For a variety of reasons, then, there was little overlap and exchange of views between those working with refugees and those concerned with multicultural health care in general.

Within health and social care, however, the contrast between 'political' and 'labor' migrants is beginning to blur. Firstly, the dominant public image of asylum seekers has changed. Far from being moral heroes, they are often viewed nowadays as moral blackmailers, exploiting the goodwill of the host nation to gain access in a fraudulent way to welfare benefits. This may be a question of political attitudes, but in certain ways the reality has also changed. In recent years, an increasing proportion of asylum seekers with low educational qualifications have migrated to the West from non-industrialized countries. Moreover, it has become obvious that the problems of refugees and asylum seekers are not confined to PTSD, but also concern less esoteric problems such as aggression, school maladjustment, family conflicts and drug or alcohol addiction - the roots of which are just as likely to be found in the present situation as in the past. So we see that it is not only the *profile* of asylum seekers that has moved closer to that of other immigrants; so too have their *problems.*

Added to this, there has been a recent shift towards integrating services for refugees within regular health and social care provisions. In the UK, this has been a consequence of the new policy of 'dispersing' refugees in remote areas of the country. Regions such as Northumberland – parts of which have seen few foreigners since the Roman soldiers who built Hadrian's Wall – suddenly found themselves having to provide health and social care to new arrivals from all over the globe. In the Netherlands, a dispersal policy had been in place since the 1980s, though up until 2000 most care was provided within accommodation centers. After that date, these separate services were scaled down and asylum seekers had to make use of 'mainstream' facilities. In both countries, the integration of refugee services into regular health care has given a new impetus to the development of multicultural care provisions.

The sheer numerical increase in the proportion of refugees in the population is another factor working against separate service provision. In Western countries, particularly those with a highly restrictive policy on labor immigration, refugees make up a considerable proportion of the immigrant population. The result of all these developments has been to bring those concerned with the care of refugees in closer contact with those developing care services for a culturally diverse population.

### *3.2.2. The evolution of multicultural mental health care*

The cross-cultural study of psychiatric conditions begins in the colonial era with studies by psychiatrists and anthropologists of the disorders found among 'natives' or 'aboriginals'. The description of these disorders was strongly biased by assumptions about white supremacy; writers tended to produce descriptions which emphasized the 'otherness' of the colonized peoples and the 'exotic' or 'bizarre' nature of their disturbances. The study of 'culture-bound' disorders has its roots in this period.

One nineteenth-century psychiatrist who broke with this tradition was Emil Kraepelin, regarded by many as 'the father of modern psychiatry'. His classic work on transcultural psychiatry (Kraepelin, 1904) was the result of an expedition to Java to validate the concepts of dementia praecox and manic depression. Instead of stressing the 'otherness' of the native, Kraepelin was concerned with the opposite: to demonstrate the universal applicability of his biologically based classification system. However, his pioneering work was not continued until half a century later.

The development of modern ‘transcultural psychiatry’ received a boost from the founding of the WHO, which initiated the first systematic attempts to study health on a worldwide basis and to coordinate global health policy. This work had a firmly universalistic starting-point. Western disease categories and Western treatment methods were assumed to be relevant in all countries; at most, a little ‘fine tuning’ would be required to adapt them to different cultural settings. The provision of ‘culturally sensitive care’ was seen, at most, as a question of accurately translating universal core concepts of illness and treatment into different cultural idioms.

In service provision within multicultural societies during and after the 1950s, the same assumption can be discerned: the basis of service provision was the model developed within the (white) majority culture. Immigrants were expected to adapt whatever notions about sickness and health they might have on arrival to conform to this model. In this respect, health policy was in line with the ‘assimilationist’ approach to migration in this period.

However, from the 1970s onwards a shift away from universalistic, Western-centered approaches to a more relativistic version of transcultural psychiatry can be discerned. On the global level, Kleinman (1988) criticized the epidemiological studies of the WHO and promoted the discipline of ‘anthropological psychiatry’. In the major Western nations, the shift from ‘monocultural’ to ‘multicultural’ social policies was reflected in increasing concern for ‘culturally appropriate’ service provision. This was a logical consequence of the notion of equal rights and citizenship for members of all ethnic groups. It was not enough to ensure that all groups were offered the same care, because *identical* care for minorities actually meant *inadequate* care. Thus, from around 1980 we see major efforts to improve the accessibility and quality of care provisions for minority groups. Similar efforts were undertaken in the field of education.

### *3.2.3. Principles of multicultural care*

Central to modern multicultural health care is the distinction between ‘disease’ and ‘illness’. According to Kleinman (1981, p. 72), “disease refers to a malfunctioning of biological and/or psychological processes, while the term illness refers to the psychosocial experience and meaning of perceived disease”. Whereas it is possible that certain disease processes have universal characteristics, *illness* in the sense described above is inextricably linked with its social and cultural context. Cultural factors do not simply affect the superficial appearance (‘presentation’) of psychological disorders: they influence their genesis, recognition, course and remedy.

According to this view, multicultural health care is not simply a matter of formulating Western categories and treatments in the appropriate local idioms. Problems are inevitably shaped by the framework of social meanings which structures thought and feeling. Moreover, the *social* consequences of having a particular illness can influence its course drastically. Thus, culture plays a role at all stages of an illness: in its causation, the way it is construed and experienced, the accessibility of treatment, the response of the professional, the form of treatment given and its effectiveness, and the prognosis for later life.

Such an approach is hard to reconcile with the standard procedures of Western mental health care, which pay little attention to the social context of illness and its treatment. In the biomedical model, the individual is regarded in isolation from his or her cultural, political, economic and historical context. Trauma, loss, grief, mourning, breakdown, coping, healing and recovery are all regarded in current clinical models as *intrapsychic* processes, whereas the reality is that they are embedded in a cultural and social context. They are things that people go through *together* - not simply in 'collectivist' non-Western cultures, but the world over. A steadily increasingly number of anthropological studies (see, for example, Summerfield, 1995; Robben & Suárez-Oroczo, 2000) has shown how indispensable an anthropological approach is in understanding the supposedly intrapsychic processes that clinicians refer to.

Important for the quality of service delivery, and thus to the definition of 'good practice', is the 'goodness of fit' or 'matching' between the help offered and the people receiving it. Help must *make sense* to the recipients and take account of their life-style and current situation. Kleinman et al. (1978) used the term 'explanatory models' to describe people's ideas concerning their illness (its cause, timing, effects, mechanism, severity, duration, prognosis), the kind of treatment they thought appropriate, and their hopes and fears. This concept has played a seminal role in work aimed at 'matching' service provision to users.

For multicultural health care, the life world and meaning systems of users must become important objects of study. Moreover, such study must consist of more than filling in predetermined response categories in standardized questionnaires: it must use *qualitative* methods which give a voice to the persons studied and allow them to answer within their own perspective (cf. Chapter 8). To carry this approach to its logical conclusion, users themselves must play a role in designing services. Both in research and policy-making, the 'new transcultural psychiatry' (Littlewood, 1990) implies a radical shift in the balance of power away from researchers and professionals and towards users: a 'bottom-up' instead of 'top-down' approach. This gives a much more radical meaning to the notion of 'cultural sensitivity'. Instead of being seen purely as a matter of bridging a communication gap, this notion actually implies *changing the culture of service providers themselves.*

### *3.2.4. Rethinking the concept of 'culture'*

From about 1995 onwards, new developments have occurred in the field of multicultural care which challenge the notion of 'culture' previously assumed by transcultural psychiatrists. These developments are related to emerging views within anthropology. Firstly, Geertz (1973) argued replacement of the static, monolithic concept of 'culture' with an approach that does justice to the heterogeneous and dynamic nature of real cultures. Instead of treating culture as a categorical variable on which each individual can be assigned a single value, we should recognize that many people position themselves simultaneously within two or more cultures: this is especially true for migrants. Secondly, researchers on ethnicity influenced by Barth (1969) have argued that 'culture' itself has no objective existence, but should be viewed as a social construction: cultural properties are actually 'ethnic markers', called into being when strategic considerations make them necessary. The example of Bosnia-Herzegovina is sometimes cited - a society in which cultural differences were allegedly not regarded as important until the outbreak of war between ethnic groups in 1992.

In retrospect, then, early attempts to put culture on the agenda of health care may have led us down a blind alley. ‘Cultural sensitivity’ has often been often interpreted as adapting service delivery to the cultural peculiarities of different racial or ethnic groups (Blacks, Hispanics, Asians, Moroccans, etc.). Yet whether these groups actually exist as culturally homogeneous categories is highly questionable; the effect of using these distinctions may have merely been to reinforce existing myths and stereotypes and actually *increase* the distance between service providers and users.

Treating cultural differences as objective phenomena forming inevitable barriers to communication can, in fact, actually make matters worse. If cultural differences are more aptly viewed as ‘ethnic markers’, treating these differences as objective ‘facts’ getting in the way of good health care may simply furnish professionals with an alibi for inadequacies and shortcomings which have quite different origins (see Van Dijk, 1998).

## 3.3. Sociological approaches

Transcultural mental health care is currently strongly influenced by anthropology, but medical sociology also contains concepts that have contributed to critical thinking about the care of refugees. Two important notions are ‘the social construction of illness’ and the importance of power relations in health care.

### *3.3.1. The social construction of illness*

The notion of illness as a social construction was already implicit in the ‘new transcultural psychiatry’. Kleinman (1988) criticized what he called the ‘pathogenic / pathoplastic’ model, in which biological factors *determine the form* of an illness, while cultural factors merely *influence its content.* This model, which De Jong (1996) wittily dubbed the ‘striptease model’ of illness, is implicit in the WHO’s epidemiological studies and in many notions of ‘cultural sensitivity’. As we saw above, illnesses (according to present-day transcultural psychiatrists) are inextricably rooted in a cultural context, so that it makes no sense to regard cultural factors as ‘secondary’.

Within medical sociology, the notion of ‘illness as a social construct’ (cf. Wright & Treacher, 1982) has its roots not in interpretative anthropology, but in symbolic interactionism. The two approaches share many presuppositions in common, but tend to be academically separate. In positivist medicine and psychology, it is assumed that illnesses have an objective existence regardless of the way we think about them. Psychiatrists *discover* illnesses, just as botanists discover plant species. The notion of social construction, however, implies that illnesses are not so much discovered as *invented.* They come into being within a particular way of framing experience and cannot meaningfully be said to exist outside of that framework.

The concept of ‘trauma’ has been a favorite target of attention for social constructionists. In an oft-quoted passage, Allan Young (1995, p. 5) wrote:

> The disorder is not timeless, nor does it possess an intrinsic unity. Rather, it is glued together by the practices, technologies, and narratives with which it is diagnosed, studied, treated, and presented by the various interests, institutions, and moral arguments that mobilized these efforts and resources.

The sudden rise of the trauma concept in the 1980s in the context of a dispute about the compensation of Vietnam veterans makes it an ideal candidate for such an analysis. Those who believe 'trauma' exists independently of the way people think about it, regard it as simply a new name for a phenomenon that has long been recognized under labels such as 'railway spine' or 'shell shock'. If 'trauma' is a quasi-biological phenomenon whose essence lies outside culture, then it is logical to assume that the concept developed for dealing with U.S. service personnel will be equally useful for categorizing victims of organized violence all over the world – indeed, throughout history.

An example of the objections to this view is given by Jones et al. (2003). These authors argue, on the basis of an extensive analysis of patient records, that 'flashbacks' – a crucial ingredient of PTSD – were virtually unknown in previous wars. If we view 'trauma' as a social construct, there is no *a priori* reason to expect it to be the most relevant or the most fruitful concept to apply to a particular group of refugees. Of course, it *is* routinely applied to such groups and often functions as the basis for service delivery – but that is not to say that other concepts, specifically tailored to the groups in question, would not do the job better.

However, two caveats need to be applied to the social constructionist approach. Firstly, it must not be forgotten that saying an illness is 'invented' does not mean that it is *fictitious* – that those claiming to suffer from it are not 'really' ill. An illness concept is a way of framing experiences, and those experiences may be as harrowing and severely handicapping as any. To regard an illness as a 'social construction' is not to say that all those with the diagnosis are simply malingering.

Secondly, following on from this point, we should bear in mind that a diagnosis has important social and legal consequences as well as medical ones. Regarding 'trauma' (or 'anorexia', or 'hyperactivity') as a social construction may be misinterpreted as implying that it is not 'real' and that all such diagnoses are mistaken. This misunderstanding can have disastrous consequences for the people whose pension rights or asylum status are jeopardized by it (cf. Watters, 2001, p. 1710).

An analogy may be instructive here. In the hey-day of coal mining, a diagnosis of 'miner's nystagmus' was the royal road to compensation for incapacitated miners. By the 1930's, this disorder had become in Britain the most important item of compensation in the mining industry. Carl Figlio's (1982) social-constructionist account of this diagnosis shows much resemblance to the story of PTSD. For example, the link between the central symptom of nystagmus (oscillatory movements of the eyes) and incapacitation was actually quite weak. Nystagmus had above all a *symbolic* function: it was the emblem of a 'deserving case'. For all that, few people today would deny the right of those miners to their money. Likewise, a PTSD diagnosis is the royal road to compensation for victims of many different sorts of violence, including refugees, and until a better system can be devised it would be wrong and until a better system can be devised it would surely be unjust to block off this road[7].

Perhaps these considerations can provide a key to understanding the spectacular rise in popularity of the PTSD concept. In section 3.1, I referred to this popularity as a 'riddle': how could a concept which so inadequately describes the hardships refugees are

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[7] In this connection we may note that the critical study by Jones et al. (2003) was financed by the US Army.

exposed to, and the problems these give rise to, have enjoyed such success? In my view, the answer has mainly to do with the *social consequences* of a diagnosis of PTSD.

Experience has shown that legal agencies, government departments and insurance companies tend to be unimpressed by problems formulated in terms of the approaches which we characterized in section 3.1 as 'soft'. Phenomenological, holistic accounts paying regard to social context, meaning and illness experience, however indispensable they may be for effective care delivery, do not get you very far in a court of law: a clever lawyer can demolish such an account in no time. Far more suited to this arena are the categorical, black-and-white descriptions which characterize the 'biomedical' approach, in which a fundamental distinction is assumed between normality and pathology.

A recent example illustrates this clearly. At the beginning of 2003 a Congolese asylum seeker, Jean-Claude Mputu-Bola, was refused asylum on humanitarian grounds by the British government. His request for political asylum had been turned down because his accounts of mistreatment and torture in Angola failed to convince government investigators, who also regarded the country as a safe place for him to return to. Subsequently, asylum on humanitarian grounds was requested on the grounds that he was severely depressed as a result of his sister's having been tortured to death after being found in possession of a letter from him. However, this request was turned down because, in the words of the Home Office, depression would be *'understandable in one so far away from his family who has seen grim sights'* (source: NCADC, 2003; my italics).

This example shows that the effects of concepts in a judicial setting are quite different from their application in a care setting. Many mental health workers strive to avoid 'pathologizing' or 'medicalizing' their client's problems and try to blur the distinction between normality and pathology. However, this 'normalizing' approach (Ingleby, 1980), which emphasizes that many supposed forms of pathology are 'understandable' in everyday terms, can be disastrous in a court of law. Managers of mental health services are another group with a traditional preference for the cut and dried, no-nonsense character of biomedical concepts. Indeed, the need to agree on a framework for setting treatment costs was one of the main considerations underlying the introduction of the DSM as a universal frame of reference for mental health services.

So we see that it is no accident that PTSD, a limited and by no means representative example of the problems refugees may have, acquired such a special status. Like the example of miner's nystagmus discussed earlier, it functions as an *emblem* for the effects of organized violence, as a key which can open certain doors. At the present time, the same phenomenon can be observed in two other areas:

- Large numbers of young women show various kinds of *eating disorders,* but the concept of 'anorexia nervosa'- which is strictly speaking only applicable to a tiny minority of all cases – has acquired the status of emblem for this group (see Schoemaker, 2002).
- Among boys, many kinds of *conduct disorders* cause considerable problems for themselves and others. However, these problems tend not to get taken very seriously unless the child is regarded as suffering from ADHD (attention deficit hyperactivity disorder). Again, very few children with conduct disorders actually conform to the diagnostic criteria for ADHD.

Characteristic of these four diagnoses – nystagmus, PTSD, anorexia and ADHD – is that they are liberally applied (respectively) to miners, refugees, young women and boys, mostly without a rigorous diagnostic procedure being followed. What I have tried to make clear in this section is that this should not be dismissed as mere exaggeration: such a label is an important way – sometimes, the only way – to get something done about the underlying problems.

### *3.3.2. The sick role: illness and power*

The social consequences of 'having PTSD' are an illustration of the American sociologist Talcott Parsons' theory of the sick role. Ascription of sickness does not simply indicate what is going on inside your body: as we have just seen, it redefines your rights and your place in society. Critics of what they regard as excessive diagnosis accuse professionals of 'medicalizing' human difficulties or deviance, with the effect of stigmatizing people and consigning them to the role of passive victims who have lost control of their lives. According to this view, those concerned may often simply be reacting in a normal way to abnormal experiences or situations. Though the status of 'victim' may help in obtaining political asylum, it can create an extra handicap when it comes to social integration. Opponents of medicalization therefore insist on using the term 'survivor' for those who have experienced violence; they prefer to describe help as 'empowerment' rather than 'treatment' (see Chapter 9 by Choman Hardi).

This discussion is centered on issues of *power,* a concept which does not figure in purely biomedical models. Such models ignore, in particular, the power of the health professionals themselves: these workers are seen as performing a purely technical task, whose necessity is self-evident. Yet professions are not purely idealistic organizations without any interests of their own. They form, in Freidson's (1970) words, a 'labor market shelter', with an inherent interest in delineating, claiming and controlling a market. These activities are sometimes referred to as 'professional imperialism'. An enormous expansion of the demand for trauma therapy, for example, redistributes the *economic* power of the different caring professions and also shifts the balance of power between professionals and the public. The term 'trauma industry', coined in reaction to the spectacular rise of the concept after 1980, is not just a disparaging metaphor but points to important political and economic realities.

## 3.4. Managed care

An increasingly important factor influencing service provision in the last two decades has been changing approaches to care management. In Western countries, the phenomenon of 'managed care' has arisen in response to the enormously increased demand for health services of all kinds. Governments and insurance companies that financed these services urgently needed to find ways of controlling costs and increasing efficiency. To this end, management techniques and personnel were imported from other sectors and organizations, the assumption being that principles of good management were universal.

This increase in the power of managers caused much resentment among health care workers, who saw their professional autonomy being whittled away by functionaries who might have no medical or psychological knowledge whatsoever. Management principles typically dictate an increase in the size of organizations through reorganizations, fusions and closures. The large agglomerations which came into being in this way were criticized as being ‘impersonal’ and ‘monolithic’. A second principle of managed care was the ‘rationalization’ of treatment procedures. Standardized procedures for diagnosis and treatment were introduced which made it easier to quantify and monitor ‘input’ and ‘output’, but diminished still further the autonomy of the individual health worker.

Rationalization also influenced the *type* of information collected on clients. Checklists of symptoms which could be easily coded in digital form acquired priority over complex, contextualised narratives, in which human intuition or professional experience played a part. Unfortunately, standardized protocols for diagnosis and treatment presuppose standard clients, and this approach pays little attention to individual differences. Nor does it recognize the importance of *group differences,* such as cultural variations in the way problems are experienced and expressed. No allowance is made for the additional work of getting to know and understand clients with different cultural backgrounds. In this sense, rationalization has thus hampered the provision of ‘culturally sensitive care’.

Yet there is another side to modern management approaches, which has actually been very useful for those trying to improve service provision for minority groups. The emphasis on *quality* and *quality control* gives these approaches, in theory at least, an inherently critical character. ‘Managed care’ has toppled many idols from their pedestals: treatments which could not produce evidence of their own effectiveness, institutions which refused to look critically at their traditions and cultures, professionals who subjected patients to their own fads or out-of-date knowledge – in principle, all of these could be undermined by the simple means of cutting off the money supply. There are important shortcomings in the way ‘quality control’ is presently operationalized, in particular the equation of ‘evidence-based’ approaches with quantitative methods of evaluation. The applicability of quantitative methods, especially in cross-cultural research, is actually quite limited. However, the notion of ‘quality control’ itself is an important stimulus to change in service provision, and the notion of ‘good practice’ is probably here to stay.

Moreover, some modern philosophies of health care management place an emphasis on the contribution of users which is totally at odds with the traditional ‘top-down’ culture of health care institutions. To ensure quality, service providers must look at their activities from the users’ viewpoint. Do the services make sense to users? Do they inspire confidence and get people involved in their own recovery? How accessible are they? Usually, feedback from users is confined to a “patients’ platform”, but this excludes those for whom the service provision is so poorly designed that they never even come into contact with it.

If services have to be adapted (‘tailor-made’) to suit the needs of users, then it is inevitable that users must be more closely consulted about how this should be done. Effective services must therefore be ‘user-led’ rather than ‘service-led’. In this respect, some strands of management philosophy agree in their conclusion with the multicultural health care movement discussed in the last section and the ‘self-help’ movement discussed in the following one.

### 3.5. The role of users' movements

Advocates of a 'self-help' approach often base their approach on the critique of 'professional imperialism' described above and focus particularly on the issues of power involved in handing over problems to professionals. They are, in other words, deeply ambivalent about the professionalization of human problems and promote as much as possible the solution of problems by the group itself.

Most self-help groups are intended for sufferers from a particular condition and/or their relatives. This focus on a particular diagnostic category ties them in, whether they like it or not, with the health care system. Other groups, however, arise within minority communities or special groups whose needs are not felt to be met by existing services. Their activities are typically directed towards 'empowerment' and 'advocacy' (lobbying and campaigning for the interests of their members).

In recent years, these groups have found an unexpected ally in policy makers who argue that users should have a hand in designing their own services. Sometimes the innovations they develop are indeed taken up and incorporated into 'the system'. Among the most successful examples have been women's groups or immigrant groups providing alternative services for specific needs. However, many refugees (especially asylum seekers) are handicapped by their insecure and transitory existence when it comes to forming their own organizations. Partly because of this, we see that most NGO's working for refugees are not themselves staffed by refugees (though some make an effort to rectify this situation). In spite of these disadvantages, a number of self-help organizations for refugees do exist.

Although there are hardly any countries in which asylum seekers and refugees have much influence in the design of their own service provisions, a comparative study carried out for the European Commission (see Chapter 12) revealed some interesting international differences. Compared with the British care system, the Dutch system emerged as a highly regulated, tightly-knit and somewhat closed system, allowing little room for initiatives or influences from outside groups. This may account for the fact that user involvement is much more in evidence in the UK than in The Netherlands.

One way in which users can influence the design of services, apart from through users' groups, is through their contribution to research. However, most research studies, because of their methodology, give a very limited opportunity for refugees and asylum seekers to describe their needs and problems in their own terms. This is because they make use of standardized questionnaires or diagnostic procedures, instead of methods which have more the character of a dialogue and allow the person interviewed to express themselves in their own way. Only field work using qualitative methods is capable of bringing the users' own perspective into focus. Ahearn (2000) describes the methodological dilemmas of research in this area. Such methods are seldom used within the health care system, though Sander Kramer describes in Chapter 8 a series of studies which have specifically set out to explore users' perspectives.

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