

# **‘Trauma’ and the Lives of Women Refugees in Resettlement**



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*To Pat and Kathleen for teaching me everything I really needed to know, supporting me in everything that I do, and encouraging me to learn all that I could.*

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## ABSTRACT

‘Trauma’ has emerged as a central defining construct within professional and popular discussions on refugee health. Refugees are considered to be at risk for psychological distress due to traumatic events experienced in the context of conflict and natural disasters in their countries of origin as well as in the context of exile. Following migration, life in resettlement is often an unstable process marked by poverty, social exclusion, as well as poor health status.

The importance of ‘trauma’ in the discussions on refugee health has left health professionals struggling to make sense of and react to groups of people now defined as ‘traumatised’. However, we have little understanding of how trauma is understood, experienced and addressed by individuals, their advocates and the service provider’s impacts upon the experiences of refugees in resettlement. Juxtaposing information from three distinct sources, I examine the discourse(s) surrounding refugees and health in resettlement, focusing upon the definitions and meanings attached to the issue of ‘trauma’. The analysis draws on 16 qualitative interviews with health and social care professionals, qualitative ‘resettlement history’ interviews with 25 women refugees, as well as an examination of a selected body of authoritative knowledge (academic articles and conference reports) in the UK.

At the heart of this analysis are contrasting perspectives in relation to the dominant paradigms of psychiatry, the metes and bounds of localised frameworks of distress, and the margins of socio-political action and interpretation. Definitions of trauma as a psychiatric disorder have implications for the clinical and social care responses of health professionals. In turn, women refugees are encouraged to engage with psychiatric systems of care and to

learn a new language of distress that is psychologically informed, and may be distant from the socio-cultural context of their lives in resettlement.

At the same time, the construct of 'trauma' has significance in the context of political asylum, where a diagnosis of 'traumatised' may be perceived as evidence supporting asylum claims. The highly politicised context of resettlement raises issues of social justice, which are interspersed with notions of trauma, as professionals seek to reconcile ideas of testimony and therapeutic interventions. These ways of seeing trauma rely upon the use of conventional Western notions of mental health and well-being that are grounded in a psychiatric paradigm and make use of related clinical strategies. Particular emphasis is placed upon the value of 'talk' as a means of achieving recovery. The women interact with popular and professional discourses on trauma in their daily lives. How they perceive and respond to these discourses (whether accepting it in whole, in part or rejecting it) offers insights into the meaning of trauma in resettlement and the coping strategies they employ in response to a psychological framing of their experiences.

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## I. INTRODUCTION

Life in resettlement<sup>1</sup> following forced migration is often an unstable process marked by poverty, social exclusion, as well as poor health status. Refugees are considered to be at additional risk for psychological distress due to the events experienced in the context of conflict and forced migration. Extreme events may transpire across the phases of conflict and into the process of exile with varying degrees of intensity. These can range from economic deprivation to profound social disruption (persecution, fragmentation of social and family networks, as well as the more extreme situations of violence) (Ager 1999).

The concept of 'trauma' has come to encapsulate the core elements related to such experiences; referring to the nature and intensity of the event(s) itself through to the psychological after-math for individuals and communities. The struggle to comprehend the nature of 'trauma' and suffering has coincided with the rise of particular forms of traumatic response. Post-Traumatic Stress Disorder (PTSD), a formally defined psychiatric disorder, has emerged as a particular framework for understanding the psychological impact of extreme events upon individuals.

For many refugees, PTSD has become the particular lens with which their experiences are viewed (Clinton-Davis and Fassil 1992, Friedman and Jaranson 1994, WHO 1996). The war in Yugoslavia, for example, came to be viewed through a popularised prism of 'trauma', one heavily ingrained with the markings of PTSD.

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<sup>1</sup> The term 'resettlement' is used in the broad sense of the word, and does not refer to specific programmes of support for refugees, unless otherwise specified.

For NGOs and refugees, the war in Yugoslavia was a watershed. By this time the diagnostic criteria; “PTSD” had become part of the agency jargon. Millions of dollars became available for humanitarian agency-sponsored “psychosocial” interventions and a myriad of foreign organizations migrated there to establish programs on behalf of the victims of war. These interventions were underpinned by the assumption that *all* former Yugoslavians, including their mental health professionals were too traumatized to help themselves or their fellows (Harrell-Bond 2000:xiii).

Despite its frequent use there is seldom an explicit elaboration of the working understandings (and misunderstandings) of trauma beyond the use of diagnostic labels such as Post-Traumatic Stress Disorder (PTSD). Current thinking on trauma may – in practice -- be broader than the framework of PTSD, influenced by academic and clinical frameworks, as well as localised understandings at the service professional and lay-public levels.

Yet we have little insight into how trauma is defined, experienced and addressed in a practical sense by the individuals, their advocates and the service providers who actually help to shape refugee resettlement. How (and whether) understandings of trauma translate into clinical practice has implications for the socio-medical experiences of women refugees in resettlement. This thesis examines how trauma is defined, conceptualised, and operationalised for women refugees from Kosova<sup>2</sup> who have sought political asylum in the United Kingdom (UK).

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<sup>2</sup> Throughout this dissertation the term ‘refugee’ will be used to refer to people who are both recognised refugees and asylum seekers. In addition, outside of quoted text or bibliographic references, the terms Kosova and Kosovar will be used when referring to the place or origin and cultural identity of my respondents. This choice of terms (as opposed to Kosovo and Kosovan) reflects the women’s preferred terms for speaking about their homeland and cultural identity (Nuzi, L. 2003).

## Conceptualising Trauma

Critical to this work is the need to recognise the dynamic quality that exists around definitions and perceptions on trauma. Part of the difficulty in conceptualising trauma is its broad use as a formalised construct in medicine (psychiatry) and its more generalised, informal use in popular culture. Throughout the history of conceptualising trauma definitions emerge and recede, with core elements re-appearing over time. Current working understandings of trauma place it in the realm of psychological health issues (with any physical expressions reflective of emotional experiences).

As a concept encapsulating intense psychological distress (popularly and psychiatrically) the term is used in multiple ways, adding an ambiguous quality. 'Trauma' describes both an event as well as a response to an event, one deemed to be overwhelming or devastating in magnitude. In the lives of refugees, critical events that are conflict related are most often highlighted as 'traumatic', including rape, torture, loss of family and friends, witnessing horrific events. However, the notion of what constitutes a traumatic event remains open to interpretation.

The multiple meanings attached to the concept of trauma have meant that the term has achieved 'embeddedness' in popular culture, where popular and professional concepts intersect and overlap with each other. The result is a concept that is often conceptualised as neither wholly one nor the other, marked instead with aspects of both. The terminology of trauma (traumatic, traumatised) suggests something that is diffuse and intuitive in nature (Alexander 2004). This contributes to a sense of 'rooted-ness' in everyday life, allowing the concept to go largely unquestioned. The challenge is to pull 'trauma' out of the ambiguities

of daily use and away from a one-dimensional psychopathological paradigm of trauma to uncover some of the alternative meanings and working definitions that operate for refugees in resettlement.

In public health a great deal of attention has been directed towards the operationalisation of trauma as a diagnostic construct, and the charting of its epidemiological patterns and trends. The psychiatric diagnosis of PTSD has provided a particular framework for outlining the meaning of trauma in emotional or behavioural terms. This framing however reflects a biomedical psychiatric paradigm. Trauma as a reaction then comes to reflect a pathological response, severe enough to warrant some form of intervention or clinical strategy.

Beyond a clinical reading, trauma has also come to signify less formalised definitions of psychological suffering. Popularised understandings of distress -- which may mimic or shadow formal psychiatric definitions but suggest less intrusive and intense psychopathology -- have come to be incorporated into working understandings of trauma.

A rich body of literature in public health and medical anthropology serves as a foundation for thinking about the intersections of medical paradigms and cultural readings of trauma and suffering (Kleinman, Das, and Lock 1997, Zwi and Ugalde 1989). More specifically core works on defining and understanding socio-medical issues and the uses of a psychiatric paradigm for disadvantaged populations stand out as central influences to this dissertation. In particular, how distress and mental health issues are interpreted and understood by individuals and professionals, across institutional and community-based settings (Estroff 1985; Rhodes 1995). My introduction to this literature came about through direct clinical and research experiences related to homelessness and mental illness in urban populations.

These works offer critical insights into popular and professional perceptions and interpretations of health experience, as definitions of mental illness shift over time and circumstance, and strategies of care and resolution (socially and medically) are negotiated throughout.

Conceptually this body of work shares important themes with emerging studies of refugee populations around trauma and other forms of distress. A strong and persuasive link has been made in public health between individual distress and social conditions or circumstances, making these critical areas for study and intervention (Hopper 1988, Meyer and Schwartz 2000, Morrissey and Gounis 1988). Ethnographic work with homeless mentally ill men and women in the United States, for example, points to the social and political functions of diagnosis and the language of psychiatry in the lives of individuals who are increasingly viewed in light of mental health rather than social or structural issues (Desjarlais 1997).

The strength and influence of a psychologising discourse lies in its ability to explain behaviours and actions (or non-actions). The marginalised state of homelessness in urban shelters quickly becomes obscured by the identification of individuals as clinical (psychiatric) cases (Lyon-Callo 2000). Through the practices of clinical work in homeless services (i.e. an intake assessment to evaluate socio-medical areas of need) a critical link is established between housing need and clinical need. Homelessness then is no longer exclusively defined as a structural issue, but becomes evidence of psychological need, one that is highly individual in nature (Mathieu 1993). This premise is often accepted without challenges and may be quickly adopted over time. Individuals are urged to accept 'their' diagnosis and begin to work upon a clinical transformation in order to 'recover'. Regardless

of the fluctuating presence or absence of symptoms, the label around mental illness retains a sense of permanence, designated as a chronic condition, at best 'in remission' (Estroff 1993).

Understandings about the nature of mental illness and the experience of being designated as a patient owes a great deal to the work of Estroff (1985), whose ethnographic study of a community of psychiatric outpatients provided fundamental insights into the way in which patients work with and against a clinical diagnosis. More recently the work by Rhodes (1995) has provided insights into the decision making processes around diagnosis and clinical planning made by health and social care professionals. This work has helped to highlight the coexisting philosophies of medicine, psychology and psychoanalytic theory, which operate within mental health practice. In shaping 'discourse' professionals often rely upon this assortment of theoretical influences, towards shaping what feels like a naturalistic and pragmatic model/perspective. This knowledge is presented by professionals along with specialised understandings that they believe are particularly 'rooted in local and specific circumstances'. Local knowledge is understood as highly contextual, strategic and personal, and contrasts greatly with the formal knowledge of diagnosis, treatment, and management. Ultimately while diagnostic frameworks provide scaffolding, much of the clinical work is actually guided by professional reflection and intuition. This is knowledge that is complicated; acquired over time and honed by experience. The nature of this type of work involves an ongoing negotiation between specialist training and experiential knowledge.

These critical works intersect in their understandings of language and practices as they shape and define emotional or psychological experiences and suitable professional and non-professional interventions. Through the everyday familiarisation of terms from medicine

and psychiatry, there is often a shared appreciation for diagnostic categorizations that emerges -- even if the labels are not always a good fit (Lynn-Callo 2000). There comes a certain comfort with the use of some label. Over time the sense of discomfort diminishes and the familiarity allows terms to be used in new and less confined ways (Desjarlais 1997: 108). The language of 'traumatic stress' has similarly given shape to a standardised list of physical and behavioural symptoms that providers and patients learn to use as part of a particular local language and incorporate into conceptualisations of stress and distress (Donnelly and Long 2003).

## Charting Discourse

Discourse within medical anthropology has included an examination of the construction and sustainability of medical knowledge to uncover structural, cultural and social dynamics that are inherent to these processes (Kleinman, Das, and Lock 1997). Work in medical anthropology has moved further into the dynamics of medical knowledge and practice as discourse recognising that language operates as a socially mediated tool, bringing to light the ways in which particular ideas or constructs are shaped and granted authority and legitimacy over time (Kleinman 1995, Kuipers 1989). There is a strong body of work that has looked at discourse within medical situations, for example considering the interactional practices that take place between patient and provider as they draw upon, implement and negotiate the use of specific knowledges (Kleinman 1981).

Looking at discourse(s) in settings like clinics, hospitals, and medical consultations shed light upon the uses of particular knowledge as they are enacted in clinical practices.

Psychiatric discourse has received considerable attention (Georgaca 2000, Rhodes 1993,

Skultans 2003). Specific to trauma, Allan Young (Young 1993, Young 1995) has traced the genealogy of traumatic memory to its current conceptual manifestation in Post-Traumatic Stress Disorder (PTSD). Young's work stands out as a definitive examination of this disorder from aetiological origins and diagnostic features through to treatment practices and expectations, providing critical insights into a particular (and prominent) interpretation of trauma. Outside of formal diagnostic categories and clinical settings, anthropologists have moved towards exploring social conceptualisations of suffering as a particular way of understanding trauma (Green 1998, Hastrup 2003, Kleinman, Das, and Lock 1997). These works often critique trauma as it is defined in medical frameworks and clinical or treatment encounters, and seek to place notions of suffering and trauma into the social worlds of those who have lived through these experiences.

Between medical discourse(s) and local understandings and interpretations of trauma, there is a value to exploring the points at which they intersect and diverge in practice.

This thesis strives to delve into discourse on trauma as it functions outside of formal texts and guidelines, and operates on the ground. Moving outside of solitary formal positions this work seeks to recognise that people may grapple with a range of influences in order to make sense of trauma for refugees: drawing upon elements of authoritative frameworks, responding to academic and clinical perspectives that are both localised and open to debate.

The authoritative texts with respect to trauma are primarily the Diagnostic and Statistical Manual of Mental Disorders (DSM) and now as well the International Classification of Diseases (ICD) (APA 1994, WHO 2003), and secondarily through practice and professional guidelines shaped in response to these diagnostic systems, such as the recently developed National Institute for Clinical Excellence guidelines (NICE) (NICE 2005). Less formal

influences comes through academic (and clinical work) which are often more localised and open to greater dispute and debate. These texts provide an operationalised account of concepts like trauma, which can then be applied to evaluations of refugee health in resettlement. While documents like the DSM and other clinical texts are important in setting the parameters of the psychiatric paradigm, they provide little insight into the ways in which these concepts are utilised in daily life – for providers and for refugees.

Discourse in this dissertation refers to the nature of perceptions and experiences with the concept of ‘trauma’ as it is employed beyond authoritative texts in clinical and academic work to the everyday uses in clinical practices and day to day life (Potter 1997, Potter and Wetherell 1987). In this sense the aim is to uncover some of the current ‘taken for granted’ assumptions that are operating for both individual refugees and for the health and social providers working with them. The habits or routines related to resettlement for women refugees and the ‘tasks’ of adaptation bring them into close contact with various discourses on refugees and trauma. Providers who work at the frontlines of refugee health may respond to particular works that they come into contact with professionally, but may also resist disciplinary boundaries and operate with great independence in shaping their working understanding of trauma for refugees. Refugees themselves may defy standardised expectations of how people respond to significant life events (particularly expectations that are particular to marginalised populations). Finally providers and refugees process and live out their perceptions and experiences related to trauma within a particularised climate. The arguments and assumptions that are articulated across these competing (and sometimes contradictory) perspectives on trauma are considered here in light of refugee health and resettlement in the UK. Discourse as defined in this work reflects systemized patterns of speech –often epitomized by the use of ‘jargon’ or ‘buzz words’ which help to define the

nature of work being conducted across various settings. This framework is helpful for example, for unravelling some of the discourse within non-institutional settings such as at professional conferences, which operate largely on this pattern of shared assumptions.

## Primary Research Objective

This research seeks to explore and describe the perspectives on trauma for refugees, and how these definitions and understandings inform practices ‘on the ground’ that configure the landscape of refugee resettlement. The study examines interviews with service providers<sup>3</sup>; individual interviews with women who are refugees from Kosova; field-notes detailing observations and interactions with the women outside of interviews<sup>4</sup>; as well as fieldnotes of observations at professional conferences and refugee community events. Contemporary academic discourse was examined across relevant disciplines (anthropology, psychology, medicine and psychiatry, and public health) to acquire some sense of the competing and contrasting perspectives that are operating. To illustrate the ways in which academic discourse specific to the UK may influence and shape discourse ‘on the ground’ a discrete selection of academic papers (across professions and disciplines) was selected and reviewed.

This work contributes to the growing body of public health work related to refugee health. Little attention has been directed towards refugee health within the context of resettlement.

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<sup>3</sup> All of the provider interviews bar one were individual interviews. The exception was the Refugee Counselling Centre. While originally scheduled as an individual interview, the nature of the setting (a staff kitchen) allowed for the transformation of a one-to-one meeting into a ‘group’ interview of two therapists from the centre, with a third individual joining briefly towards the end. The impromptu nature of this was valuable and allowed the staff to react to each other’s comments as much as they responded to my points of inquiry.

<sup>4</sup> I was fortunate to have the opportunity to interact informally with the women through events sponsored by the Besim project, through observation and participating in activities.

The widespread acceptance of a conceptual framework of ‘trauma’ as synonymous with PTSD has a direct impact on the psychosocial interventions that are designed and implemented for refugee populations. Specifically this study will examine the discourse(s) that exist related to trauma as a part of refugee health in resettlement, how this is expressed within professional practices and its meaning in daily life for women refugees. The findings from this research will be able to contribute to the debate on the appropriateness of trauma discourse and interventions in the lives of refugee women.

## Thesis Structure

This thesis aims to explore definitions and understandings of trauma as they operate within the context of refugee resettlement; what shape this takes within clinical practice, and how women refugees experience and respond to trauma. In order to achieve this, there is a need to trace the histories of conflict, forced migration and resettlement relevant to the lives of Kosovar women. The decision to focus upon Kosovar women from the Former Republic of Yugoslavia (FYR) reflects two key observations. First, the time frame of residency in resettlement was a critical parameter from a methodological perspective. Research on refugee health issues has indicated that a time frame of 3 to 5 years was considered an optimal period for examining issues related to resettlement (Bloch 1999a). Moving beyond this time frame could result in a distorted reading of resettlement experiences, where the early experiences of resettlement become too distant, or where (within the first year or so) there may be limited interaction with systems of care. Second, in trauma studies, the collapse of Yugoslavia in particular has stood out as a critical moment, a turning point where an awareness of ‘trauma’ as an issue for refugees gains strength and prominence. As

a result there has been a massive rise of psychosocial programmes internationally; some imported to post-conflict zones such as Yugoslavia, and more recently to settings of refugee resettlement in host countries (Ager 1999).

This background, described in Chapter II, provides an overview of the key concepts that are relevant for discussion, including the core elements of discourse on forced migration and political asylum. Relevant socio-cultural and historical elements specific to Kosovar society are then touched upon in order to offer some insights into the particular experiences of Kosovar women refugees. This helps to establish some of the socio-historical and political features that have shaped their experiences of conflict and exile. Examining the hallmarks of this conflict and of Kosovar culture has relevance for exploring women's narratives, the way that they are viewed as a population in exile, and how this relates to definitions of trauma.

Contextual and structural issues that are critical to the processes of political asylum and resettlement are examined in Chapter III. Asylum has emerged as a highly charged political issue within the UK. The public discourse on asylum has raised fundamental questions about the credibility and legitimacy of refugees and their claims. Whether an individual seeking asylum is deemed 'legitimate' or not is regularly questioned in tenacious media coverage, which frequently casts refugees as 'bogus' or 'illegal'. Against this backdrop social care and health professionals struggle to identify and respond to the needs of refugee populations who are seeking to live in the UK.

Current health and social research point to a strong relationship between poor physical and mental well-being amongst refugees across contexts and situations. In resettlement,

psychological and physical health issues may arise, complicating the adaptation of individuals to a new setting. Moreover structural barriers may emerge that are specific to the socio-medical needs of refugees (for example, access to care, appropriate cultural and language services). This chapter begins to explore some of the broad physical and psychological health issues that have been identified as critical amongst refugee populations in resettlement.

Current conceptualisations of psychological trauma and suffering reflect a theoretical evolution over time. In recent history, the concept of trauma has developed and transformed dramatically from the late 18<sup>th</sup> century through to present day. Chapter IV maps out a historical timeline charting the core paradigms and working definitions of trauma throughout this time period, shedding light upon how current paradigms have come to exist.

Chapter V outlines the core elements of the research design including the both conceptual and investigational issues. The specific features of the research study are outlined, including aims and objectives, research methodology, data collection, analytical framework and a description of the research sites and primary participants. In addition insights are offered into the challenges of the research process through a brief discussion of the more reflexive aspects of this work.

Chapters VI and VII provide a discussion of academic and clinical discourse(s) on refugees and trauma. First, the literature on refugees and trauma is explored through two primary perspectives: epidemiology and public health; and anthropology (Chapter VI). These two broad academic fields have contributed to understandings of trauma, health and suffering in the lives of refugees. Second, a limited number of academic and clinical texts, specific to

the discourse currently surrounding trauma for refugees in the UK were selected for in-depth analysis (Chapter VII). The debates, issues and theories raised in these influential texts bear a relationship to the practical understandings of trauma within clinical work targeting refugees in the UK. These texts reflect health-related fields in the UK, covering a mix of perspectives and philosophies ranging from biomedical and psychodynamic readings of trauma, to more socio-cultural or anthropological interpretations.

Chapters VIII and IX explore the perspectives and practices of a sample of front line service providers working with refugees in London. Qualitative interviews were conducted with service providers (n=16) working in health and social care with refugees and covering a range of issues related to refugee resettlement. In particular attention is focused upon the ways in which providers maneuver through the complexities of trauma discourse for refugees, working within the demands of an over-burdened system, and how they come to reconcile these issues within clinical practice.

Chapters X and XI explore the experiences and discourses related to resettlement, health and trauma within the lives of a group of women refugees from Kosova now resettled in the UK. Interviews were conducted with Kosovar (Albanian-speaking) women (n=25) refugees or asylum seekers in a community in East London. Through ‘resettlement history’ interviews women were asked about their experiences in coming to the UK, their use of health and social services, as well as their physical and mental health and that of their immediate families since coming to the UK. The women interact with popular and professional discourses on trauma in their daily lives. How they perceive and respond to these discourses (whether accepting it in whole, in part or rejecting it) offer insights into

localised understandings and interpretations of trauma that they now hold themselves, and the strategies they use to exercise personal agency and choice.

Chapter XII explores the forms that ‘talk’ takes across provider and refugee perspectives and experiences, from clinical practices of disclosure and therapy to the nature of disclosure practices amongst members of a Kosovar refugee community, and the perceived ‘value’ of talk as a currency in accessing social care and assistance with asylum claims in resettlement.

In Chapter XIII the core findings from each perspective are contrasted with one another and considered in light of existing research in public health and anthropology specific to understandings of trauma and suffering and the clinical strategies for intervention. The strengths and limitations of this research are outlined, with an indication of directions for future research in this area. Finally, Chapter XIV provides a brief summary conclusion of the central research findings.

## II. BACKGROUND

### Conflict and Forced Migration

The terms ‘refugee’ or ‘asylum-seeker’ have quickly become commonplace in the socio-political environment of post World War II Europe<sup>5</sup>. Conceptualisations of a broader populace of ‘refugees’ emerged in the aftermath of the second World War, largely in response to the widespread displacement of peoples across Europe. Early international efforts at addressing this displacement focused upon the repatriation of individuals to their homeland. As the political landscape shifted -- marked by greater polarization during the Cold War era and shifting economic markets within western countries – resettlement surfaced as a second possible trajectory for those displaced or seeking political asylum (Collinson 1999). The 1951 Convention Pertaining to the Status of Refugees provided an international framework to guide humanitarian responses, including an operationalisation of the term ‘refugee’ (UNHCR 1996). Critical to this document is the principle of ‘*non-refoulement*’, which formalises an obligation around the protection of a refugee, ensuring that an individual is not returned to a state where he or she would face persecution<sup>6</sup>. Originally developed to address the needs of displaced persons following WWII, the convention (and UNHCR) has instead provided an international framework for the protection of refugees, and has served as the backbone to asylum policies. For the more detailed definition of ‘refugee’ as outlined in the 1951 Convention, see Appendix 1.

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<sup>5</sup> Up until recently a different vocabulary and conceptualisation was used for people seeking asylum in Western countries ‘exile’, conjuring a very individualized image of political activism and its adverse repercussions.

<sup>6</sup> The principle of *non-refoulement* outlined in Article 33 of the 1951 convention states: ‘No Contracting State shall expel or return (“refouler”) a refugee in any manner whatsoever to the frontiers of territories where his life or freedom would be threatened on account of his race, religion, nationality, membership of a particular social group or political opinion’ (UNHCR 1996).

The interpretation of the 1951 convention has not been without controversy, and has been, at times, applied in inconsistent ways<sup>7</sup>. Nevertheless the convention has helped to shape legal responses to conflict and forced migration and remains the primary framework under which refugees seek asylum and resettlement within western countries.

The geopolitical transformations of the 1980's and 1990's led to a significant escalation of the number of refugees seeking political asylum worldwide (Black 2001, Robinson 1995). Migration patterns have swelled and shifted in response to armed political conflict as well as economic fluctuations (IOM 2000, UNHCR 2000). The conflicts which surfaced during this period have been felt strongly across Western Europe, which found itself grappling with a sudden increase of refugees and 'economic' migrants from Central and Eastern Europe (Robinson 1995).

This significant increase in numbers of refugees has prompted strong reactions, including a fervent rise in xenophobia (Kundnani 2001). The conflation of 'asylum seeker' with 'economic migrant' has been a particularly negative association, reflecting the disdain felt in direct response to the increased numbers of people seeking asylum. The highly politicised nature of asylum places greater focus upon immigration as a system of control rather than access. 'Fortress Europe' has become a shorthand expression referring to the increasingly harsh immigration policies within many Western European countries. The strong presence of xenophobic discourse in the UK and elsewhere in Western Europe is important in the

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<sup>7</sup> The obligation under the principle of non-refoulement has met with legal challenges, for example, in situations involving international waters. In a controversial case in 1993, U.S. immigration officials seized boatloads of Haitians in waters outside of U.S. territory and the Haitians were 'involuntarily repatriated'. The U.S. Supreme Court later ruled that this decision did not – in a strict sense – violate the 1951 Convention. More recently there have been statements by the Conservative party in the UK that should they come into power they would advocate a withdrawal from the 1951 Convention, thereby challenging the principle of non-refoulement (US-Supreme-Court. 1993).

way that it has shaped a sequence of new policies of immigration control, as well as forging public debates about the deservedness of applicants. An often inflammatory media has fuelled a reductive discourse that assigns refugees to a position within a dichotomy of victim or threat, with the greatest consistency falling upon a language of ‘threat’ (Buchanan and Grillo 2003, Lynn and Lea 2003). It is important to be mindful of this representation of refugees in the UK. Efforts to counteract the negative tone may promote a discourse that emphasises the vulnerabilities of refugees, particularly as victims of extreme circumstances.

### Kosova and the Collapse of Yugoslavia

The collapse of the Federal Republic of Yugoslavia (FRY) ‘resulted in the largest refugee crisis in Europe since the WW II (UNHCR 2000). The Federal Republic of Yugoslavia comprised six provinces (Slovenia, Croatia, Bosnia-Herzegovina, Montenegro, Macedonia and Serbia) including two ‘autonomous’ regions that were under the control of Serbia (Vojvodina and Kosova)<sup>8</sup>. Central to the successive Balkan wars was the rise of extreme nationalist movements linked to territory and historically based territorial disputes (Malcolm 1998). Campaigns to secure geographical control within the region used the imagery of ethnically based nationalism to promote unrest and calls for political action (such as that exhibited by the Serbian majority under Milošević or in the case of Croatia and Slovenia to assert the need for independence and secession from the federal republic). Within each region, the population became polarised into discrete ethnic identities that functioned largely in opposition to the controlling Serb power: Albanians in Kosova, Slovenes, Croats and

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<sup>8</sup> Autonomous regions do not have the same degree of political autonomy as provinces, and ultimately have been under the control of Serbia.

Muslims in the regions of Slovenia, Croatia and Bosnia-Herzegovina respectively (Hayden 1996, Wilmer 1998). The conflict in Kosova was the culmination of more than a decade of political unrest. Geographically the region is situated in the southern part of Yugoslavia, sharing borders with Albania and Macedonia to the South, Montenegro to the West and Serbia to the North and East. Politically, Kosova was defined in the post WW II era as an 'autonomous region' under the control of the province of Serbia (Malcolm 1998). Status as an 'autonomous region' allowed Kosovars to self-govern to a degree, however, the decision-making process ultimately rested with Serbia, and absolute power rested within the Serbian parliament.

The late 1980's saw a dramatic shift in the relationship between Serbia and Kosova. Growing discontent surfaced between the minority Serb population in Kosova, and the majority ethnic Albanian population, with claims of persecution by the Serbs and growing calls for an independent Kosova by the Albanians. Critical to the progression of conflict in the former Yugoslavia was the re-conceptualisation of identity into ethnic extremes. The architects of conflict in the Balkans skilfully utilised ideas of difference predicated on ethnic origin. Ethnicity became a simplistic, and highly effective, marker of 'identity' (Hughes and Foster 1996). People who had previously identified as Yugoslav were now categorised as a member of a specific ethnic group. In Kosova, this meant being identified as either Albanian or Serb<sup>9</sup> despite a more complex history of inter-marriage between groups across the region<sup>10</sup>. These essential tensions over autonomy and territory set the groundwork for

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<sup>9</sup> There has been little attention paid to the 'other' minority populations, for example the Roma, who comprise(d) a small proportion of the population and, as elsewhere, have been severely marginalised within society (IREX 2000). Montenegrins and other smaller minority populations likewise received little attention.

<sup>10</sup> Ethnic inter-marriage was more prevalent in other parts of Yugoslavia, such as in Bosnia for example. Nonetheless this was not uncommon in Kosova. Within the sample of 25 women for this study 4 women spontaneously revealed this about their personal histories. This information was, however, not uniformly asked of respondents.

the emerging 'ethnic' conflict. The transformation of identity within each of the provinces or regions of Yugoslavia was achieved through the introduction of exclusionary practices limiting legal and political rights for certain groups, the aggressive revival of historical traditions and myths, and the marketing of these through the media (Hayden 1996).

The political weight of Slobodan Milošević as a national figure has in part been attributed to his ability to articulate the disquiet of the minority population of Kosovar Serbs<sup>11</sup>. In addition, ethnic-Serb nationalist campaigns drew upon the perceived threats associated with an escalating Albanian population, and a diminishing Serb birth rate throughout the region<sup>12</sup>. With growing unrest, the formal autonomy of the region was revoked and policies and practices introduced that severely constrained the personal and political freedoms of ethnic Albanians in Kosova.

Already under new Serbian laws passed in 1989, Albanians in Kosovo were forbidden to buy or sell property without obtaining special permission from the authorities. And on June 26 1990 a new wave of decrees, officially described as 'temporary measures' was made possible... These temporary measures, which have remained permanent, would include the suppression of the Albanian language newspaper *Rilindja*, the closing of the Kosovo Academy of Arts and Sciences, and the dismissal of many thousands of state employees (Malcolm 1998:346).

The early 1990's in Kosova were marked by a series of bureaucratic measures which sought to limit the political power of ethnic Albanians, and over time to actively exclude participation in the wider social structure – including schools and the health care system (OSCE 1999). During this time political unrest surfaced elsewhere in Yugoslavia, resulting in ethnic conflict in the provinces of Slovenia, Croatia, and Bosnia-Herzegovina. Attention

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<sup>11</sup> Milošević is credited with winning the support of Serbs when he commented after a skirmish between Serbs and police where a Serbian civilian was beaten up. Milošević seized the moment, publicly denouncing the act and stating "No one should dare beat you!" to the Serb minority, apparently sealed his popularity (ICK 2000:40).

both within Yugoslavia and internationally was fixated upon these events. It was not until 1998, after the situations in Slovenia, Croatia and Bosnia had been resolved in one way or another that political unrest in Kosova shifted in tone and intensity, marking the full transition into armed conflict<sup>13</sup>. The situation quickly escalated resulting in the forced migration of an estimated 200,000-300,000 persons between April and September 1998 alone (OSCE 1999).

The rapid escalation from unrest to conflict as well as the strong media presence that accompanied this conflict ensured that international attention could not ignore the wars in the Balkans. Images not seen since the second world war were resurrected – most notably that of concentration camps – which provoked strong and immediate public reaction (Engelberg 1992, Sudetic 1992). The phraseology of ‘ethnic cleansing’ – introduced in the Bosnian conflict -- captured international attention and came to be understood as the hallmark of ethnic conflict in the region.

The success of nationalistic campaigns by any of the groups relied upon a number of elements: the use of historical mythology; the separation and labelling of identity by ethnic group; the resurrection of traditional images of family and culture; and the implementation of policies and practices that altered the political and economic structure of the region (Hayden 1996) Together, these strategies paved the way for armed conflict and forced

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<sup>12</sup> The term ‘Albanianization’ was used to describe this phenomenon. The term was officially circulated in a memo prepared for the Serb-controlled parliament by the Academy of Science, which warned of the threat of Albanian fertility rates in the region (Sofos 1996).

<sup>13</sup> Slovenia successfully declared independence in 1991 following a 10 day war. Croatia eventually succeeded after 4 years of war beginning in 1991, with the last Serb-controlled enclave returned in 1998 from the Yugoslav republic. The conflict in Bosnia and Herzegovina resolved following the Dayton agreement in 1995, with the creation of a new multi-ethnic democratic government (C.I.A. 2004).

migration to occur across the Balkans. Kosova stands out uniquely as the place where the unravelling of Yugoslavia both began and ended (Malcolm 1998).

## Historical and Cultural Features of Relevance in Kosova

Kosovar society prior to the war was predominantly agricultural, with a majority population of ethnic Albanians (estimates hover at around 90%) with the remainder comprised of minority populations of Serbs, Montenegrins, and Roma (Malcolm 1998). While there is an extensive body of literature exploring the political history that gave rise to the war in Kosova and the collapse of Yugoslavia in general, there is limited information about the social and cultural elements of Kosovar society in the pre-war era. There are some ethnographic accounts of the region from the early part of the 20<sup>th</sup> century. In particular, the travel writings of Edith Durham (1909) and Rebecca West (1994) offer intriguing and unique insights into Kosovar, Serb and Albanian societies of the time. However they also carry with them strong temporal impressions, largely reflecting the biases and judgements that are associated with colonialism. Ethnographic study of the region (in English) during the latter half of the 20<sup>th</sup> century has been somewhat limited, and largely restricted accounts of traditional kinship systems within pastoral communities (Denich 1974). Two key aspects of Kosovar society have been, however, strongly emphasised, with considerable convergence between the two: the role of customary law in conflict resolution and the gendered norms articulated within the cultural codes of honour and shame.

Kosovar society is traditionally built upon a network of families and clans. The clan structure is patriarchal in design, with lineage determined through the male bloodline (Sluzki and Agani 2003). Traditionally, cultural norms and practices are governed through

the customary laws of the clans. The most highly publicised example of codified practices is laid out in *Kanuni I Leke Dukagjinit* (The Code of Leke Dukagjini) (Fox 1989)<sup>14</sup>. The Kanun is one of the only examples of written customary law, and has in recent years achieved prominence as one of the key cultural influences in northern Albania and Kosova (Shingjergji 2000). The Kanun is largely credited with providing a cultural template for roles, responsibilities and conflict resolution amongst members of a community. The principle of *besa* or ‘word of honour’ is the decisive element that guides action and reaction, most famously in outlining the circumstances under which a blood feud occurs as means of restoring one’s honour. The power of the Kanun in scripting roles and responsibilities in the community had waned in power and intensity over the past fifty years, only to be resurrected within the decade prior to war (Schwander-Sievers 2001).

The re-emergence of the Kanun confirmed a sense of ethnic identity and culture within the setting of ethnic unrest. The revival of traditions may serve to further delineate distinction as an ethnic group, and therefore reaffirm a sense of community (Littlewood 2002, Schwander-Sievers 2001). A great deal of the Kanun addresses the issues of honour and shame which are considered paramount within Kosovar and Albanian societies. The blood-feud which has re-emerged after falling out of use has been brought back to life with particularly harsh effects, evidenced by a dramatic rise in the numbers of blood feud deaths. While women have historically been exempt from the blood feud (based upon the belief that women’s blood is not of equal value to a man’s), the principles of ‘honour’ and ‘shame’ under the Kanun do detail circumstances when violence against women is both accepted and

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<sup>14</sup> Leke Dukagjini (1410-81) is attributed with the creation of the Kanun, a code of customary law in northern Albania and Kosova which has been in use from the 15<sup>th</sup> century to present day. The code outlines community rules and responsibilities covering an array of areas, including family, marriage, livestock and property, the spoken word, honour, legal issues and resolutions (Fox 1989).

endorsed. In a somewhat brutal fashion the subordinate position of women in Kosovar society is made clear:

A woman is a sack, made to endure as long as she lives in her husband's house. (...) For two acts a woman may be shot in the back: adultery and a betrayal of hospitality (Fox 1989:38).

The codes of honour and shame are called upon as cultural guides and in a sense work to cement the strength of the clan network and reinforce a sense of ethnic unity (Olujic 1998, Schneider 1971). The control of women's sexuality within such as belief system becomes a paramount concern. The critical element in the honour/shame dichotomy is "the highly guarded aspects of women's virginity, chastity, marital value, and especially fertility" (Olujic 1998:34). A woman who fails to 'control' her sexuality in appropriate ways, for example, failure to remain a virgin until marriage, places the honour of male kin and the broader community at risk (Denich 1993, Mostov 1995).

Whether this principle was in fact shaping 'normative' behaviour in pre-war Kosova remains unclear. In the decade leading up to conflict however, the revitalization of traditional cultural beliefs and practices was common (Luci 2002, Schwander-Sievers 2001). The construct of honour/shame is however critical to understanding sexual violence within Kosovar society, particularly in terms of the recent political conflict. The renewed discourse on women and honour presents a specific cultural perspective on sexual violence. The power of these traditions lies in their ability to shape a social template for reading and reacting to sexual violence within Kosovar communities at home and in resettlement, and in shaping how it is understood and confronted (if at all) by professionals that Kosovar refugees come into contact with.

## Sexual Violence & Ethnic Cleansing

Occupying a woman's uterus is synonymous with occupying territory. Rape is used to pollute and dilute the bloodline. In the Balkans, *soil* and *blood* are metaphors for male honour. If a man can not control them, he has no honour (Olujić 1995a: 198) (*Italics in original*).

There is considerable historical and cross-cultural evidence of sexual violence being used as a weapon in political conflict (Bennett, Manderson, and Astbury 2000, Brownmiller 1976, Kelly 2000). The perception of sexual violence during wartime has historically tended to alternate between defining it as 'a random event' to 'a regrettable but unavoidable' part of war (Skjelsbaek 2001). With the war in Yugoslavia new understandings emerged about sexual violence in wartime, where the pervasiveness of sexual violence and its strategic use in conflict became a visible and public issue, no longer relegated to the background.

The conflict in Kosova shared key defining features with those that had occurred in other areas of the former Yugoslavia. Ethnic cleansing, the use of force or intimidation to drive certain populations from a region, was a hallmark of these conflicts, with sexual violence figuring prominently (ICRC 2000). The same would be true of Kosova (HRW 2000). In Kosova, as in other conflicts within the former Yugoslavia, the cultural frameworks of honour and shame (re)surfaced in powerful ways in response to conflict. In practical terms this meant, at a minimum, a curtailing of women's reproductive and sexual freedoms (Hughes, Mladjenovic, and Mrsevic 1995, Mertus 1999). At its worst this has played out in extreme and targeted sexual violence, with the aim of damaging the honour of her kinship network and her community (HRW 2000). These are powerful concepts not only in dictating behaviours for women, but also functioning to delineate markers of the network of kinship at a community wide level (Schneider 1971, Simic 1983). Sexual violence in this

context managed to serve a critical objective of undermining social cohesiveness, ultimately unhinging a community at large (Charles and Hintjens 1998).

What marked the situation in the former Yugoslavia as unique was not that rape was so prevalent but that it had emerged as a very 'public' event. The high visibility of the media in the Balkan wars ensured an immediate visibility to the civilian experiences of war. Rape quickly emerged as a pivotal issue, capturing the attention of the international media, it came to be symbolic of ethnic cleansing (Stiglmayer 1994b). The association between sexual violence and 'ethnic cleansing' marked a critical divergence from past explanations of sexual violence during wartime (Card 1996, Hayden 2000).

The previous Balkan war, in Bosnia, initially drew attention to the issue of sexual violence in conflict zones (Meznaric 1994, Stiglmayer 1994a, Swiss and Giller 1993). The international media clamoured to the cause – at once shedding light upon the horror of events -- whilst simultaneously exploiting the situation. An unlikely mix of socio-political groups had an interest in making the widespread violence against women public on an international scale. Ethnically defined political groups used the imagery of women from their group as the victims of rape for propaganda purposes. At the same time, international medical and human rights advocates sought to ensure that women's experiences were not ignored or brushed aside and that action was taken on their behalf.

Rape, like genocide, will not be deterred unless and until the stories are heard. People must hear the horrifying, think the unthinkable and speak the unspeakable (Tompkins 1995:847).

The emergence of sexual violence as a core narrative for women's experiences in war has also raised questions about rape as a particular form of torture and as a war crime

(Skjelsbaek 2001). This has led to calls for the recognition of the gendered experiences of war, with sexual violence representing a specific form of persecution. These debates have repercussions for the decisions that are made regarding political asylum in Western countries where certain types of victimhood may carry political weight (or is perceived to). The public nature of coverage of rape in FYR, however, was often motivated less by altruistic or procedural-justice incentives, and the international media have acquired a reputation for a predatory and highly exploitative approach towards women<sup>15</sup>.

When armed conflict erupted in Kosova there was a consciousness of the use of rape as a mechanism for ethnic cleansing, based upon the previous conflicts in Yugoslavia.

Rapes were not rare and isolated acts committed by individual Serbian or Yugoslav forces, but rather were used deliberately as an instrument to terrorise the civilian population, extort money from families, and push people to flee their homes. Rape furthered the goal of forcing ethnic Albanians from Kosovo (HRW 2000:1).

In their investigation of human rights violations in Kosova, the Organization for Security and Co-operation in Europe (OSCE) (OSCE 1999) documented systematic patterns of sexual violence including the use of ‘rape camps’<sup>16</sup> and intentionally public acts of sexual assault. ‘Ethnic cleansing’ through sexual violence operated on two key ideas: the fragmenting of communities through humiliation and shame; and forced pregnancies due to rape (HRW 2000, Niarchos 1995, Salzman 1998).

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<sup>15</sup> A tale – verging on urban myth -- that circulated during the Bosnian war is that of unnamed journalists approaching women at refugee camps asking, “*Is there any woman who has been raped, speaks English and is willing to be interviewed?*” A similar story surfaces in relation to the war in Kosova, only the key actors are now representatives of an NGO collecting data: “*Last week a male humanitarian staff member of an international organization, in a camp set up in a sports center in Tirana, used a loud speaker to invite any women who were victims of violence to come up to him and obtain a questionnaire which was to be filled out*” (Fitamant 1999:6).

Symbolic of their ethnic group, a woman raped was interpreted as a failure on the part of men to 'protect' their honour and their community (OSCE 1999). Forced impregnation on the other hand could effectively alter the integrity of ethnic lineage. Ethnic identity has historically been transferred through the father's 'identity': if the father is Serb, then the child is Serb. The woman's ethnic identity in this framework is regarded as irrelevant (Denich 1974, IHF 2000).

The number of women raped in any of the respective Balkan Wars remains at best vague. A recent evaluation by the International Helsinki Federation for Human Rights (IHF) places the number of women raped during the war in Kosova, for example, at approximately 13,500 (IHF 2000). Such figures are, at best, estimates based upon population demographics (speculations on the number of women of reproductive age, with conservative projections of sexual violence on a population-wide basis). There remain no conclusive means of establishing the numbers<sup>17</sup>.

The dominant cultural norms and beliefs around sexuality and women are frequently cited as impeding efforts to determine the extent of rape during (and leading up to) the war, again invoking the powerful dichotomy of honour and shame. Stigma for women who have been raped is understood to be intense and pervasive (Dybdahl and Pasagic 2000, Meznaric 1994, Stiglmayer 1994b). While the stigma associated with sexual assault is common cross-culturally and cross-nationally<sup>18</sup>, the reification of traditional belief systems of

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<sup>16</sup> The question of 'rape camps' is one that has not been resolved: some authors assert their presence throughout the Balkans, whilst others have found no evidence of their existence (Fitamant 1999).

<sup>17</sup> There is considerable variation in the figures cited on victims of sexual violence in the in the Balkans. These need to be critically evaluated against the political agendas of each interest group.

<sup>18</sup> One argument as to why this is so is that societal rehabilitation relies upon a silencing of victims, specific to rape. This in effect allows for the re-construction of community identity (and an idealised past) that has been proposed as critical to post-war reconstruction.

honour/shame and women in Kosovar society creates an impression of a society particularly harsh in its labelling of women.

Rape is typically not openly discussed in Kosovar society for fear of immense social repercussions – at a minimum bringing ‘shame’ upon her family, in the more extreme jeopardising the stability and security of the family unit (leaving her open to the threat of divorce or the loss of custody of children). Less attention has been paid to the health impact of sexual violence and rape-related injuries or pregnancies (except to say that there was a ‘systematized’ effort towards impregnation).

The pervasiveness of social stigma coupled with renewed ‘traditional’ beliefs regarding gender and sexuality has become like a self-fulfilling prophecy with numerous reports of Kosovar women committing suicide or being encouraged to do so after testifying about being raped or having their status as a survivor of sexual violence made public (Niarchos 1995, Walsh 2000). Yet, despite the strong presence of social stigma, international war crimes researchers have met with considerable success in documenting the widespread rape (IHF 2000). Nonetheless, as with such statistics elsewhere, conventional wisdom suggests that there is a substantial under-reporting of incidents. In some areas of Kosova, for example, there is a widespread belief that as much as 50% of the female population were victims of sexual assault (OSCE 1999).

The prominence of sexual violence in the war and the publicity that has surrounded the women of Kosova regarding this is critical to their experiences and their interactions in resettlement. The pervasiveness of this discourse on women and sexual violence has translated into a particular identity for women refugees from Kosova. The observations of

one Kosovar woman astutely captures the legacy of sexual violence following the war: “*Now when people speak about Kosovar women they will only remember rape*” (Fitamant 1999:7). This bears highlighting in considering the perceptions that surround women refugees in resettlement: the assumptions that are made about the pervasiveness of sexual violence amongst refugee populations; the centrality that is accorded to rape as a definitive traumatic event for women; and the implications of these elements in shaping their experiences of health and social care in the UK.

### III. ASYLUM IN THE UK

I gaze fixedly at the map, I trace the contours of mountains and rivers with my finger, I count the places where I have been, I sink into it inwardly to the point of exhaustion, the map, like good blotting-paper, absorbs a strong sense of loss. *'I'm shipwrecked'* (Ugresic 1996:105).

The conflicts in the Balkans have resulted in successive waves of refugees seeking asylum in Western European countries. The collapse of Yugoslavia created the largest body of refugees within Europe since the Second World War. This along with significant conflicts elsewhere challenged the existing systems in place in terms of their ability to deal with an escalating number of individuals seeking political asylum. Political conflict in Central Europe allowed for unprecedented mobility amongst individuals fleeing a war zone, as well as those seeking to move from the chaotic and crowded refugee camps in bordering countries (Ingleby 2004).

In total, an estimated 850,000 ethnic Albanians were forcibly displaced from Kosova (HRW 2001). As with other conflict zones, the majority of refugees found themselves in camps hastily put up along the borders of the region (Ingleby 2004). In the case of Kosova, refugees fled primarily to Albania and Macedonia. Considerable political pressure came to bear in the case of Kosovar refugees for the UNHCR to institute a 'humanitarian evacuation' from this region to Western Europe and North America. As part of this planned evacuation, 4345 Kosovars were admitted to the UK in April of 1999 (IPPR 2003). This operation – known in the UK as the 'Kosovo Humanitarian Evacuation Programme' involved the selection and airlifting of people from refugee camps on the border of Macedonia (Bloch 1999b). In addition, from about 1997 onwards, there were a growing number of 'spontaneous' applicants arriving through independent means, with a peak of

11,495 in 1999 (Watson and McGregor 1999). During 1999, one-sixth of all asylum applicants to the UK came from the former Yugoslavia,<sup>19</sup> the majority of whom were Kosovars (Smart 2004).

Immigration policies in the UK have undergone frequent and substantial changes in recent years reflecting shifting political efforts to address (and control) the rise in numbers of people seeking asylum. These changes have been complicated. Whilst the UK has drawn upon the principles of the 1951 Refugee Convention to guide its domestic policies and practices towards asylum, it was not until 1993 that the Convention was formally incorporated into domestic law. Prior to this period there was no legislation specific to the process of 'asylum', with such matters falling under the broader remit of immigration. Numbers of asylum applications fluctuated greatly throughout the 1990s, with sporadic declines followed by periods of consistent escalation.

More dramatically, since the formative act of 1993, there have been four separate revisions of asylum law in the UK (HMSO 1993, HMSO 1996, HMSO 1999, HMSO 2002, HMSO 2004). Each of the successive immigration acts (1996, 1999, 2002 and 2004) has been fashioned to meet two primary goals. One, to introduce corrective measures to the bureaucratic process (thereby stream-lining the systems in place and reducing existing backlogs); and two, to implement a system that in practice acts as a deterrent, thus minimising the number of false or 'bogus' asylum claims. With each successive immigration act there have been changes in the policies and practices related to the decision making process on asylum and the nature of support offered to individual refugees as they

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<sup>19</sup> The only designation made in the official statistics of asylum applicants in the UK refers to country of origin, not region within a country (IPPR 2003).

move through the asylum process. For a more detailed summary of the successive immigration acts from 1993 through to 2004 and their differing policies and practices, see Appendix 3.

The early 1990s saw a dramatic rise in the number of asylum applications in the UK (Zetter et al. 2003). In 1990 there were roughly 40,000 applicants. By the following year, the number of applicants had nearly doubled, reaching a high of 73,400. Asylum figures continued to fluctuate throughout the decade reflecting the shifting topography of political conflicts worldwide<sup>20</sup>. By the late 1990's, figures had risen again to over 90,000 applicants in 1999 (Watson and McGregor 1999, Woodbridge, Burgum, and Heath 2000).

In terms of resettlement experiences there has been considerable variation in how the Kosovars were treated (Bloch 1999b). Evacuees were typically granted a new hybrid status of 'Temporary Protection' with the aim to repatriate within a designated period of time. Individuals who entered on their own accord were considered for the more established legal categories of refugee, exceptional leave to remain and indefinite leave to remain each with varying degrees of rights and entitlements. For the majority of individuals the process has not been straight-forward and is instead marked by a process of lengthy delays and appeals following Home Office refusals, with many Kosovar refugees still awaiting a final decision<sup>21</sup>. For a more detailed outline of asylum procedure and status categories, see Appendix 2.

Throughout this period, political and popular discourses in the UK fuelled a dichotomy

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<sup>20</sup> The resolution of conflicts in Croatia, Bosnia, as well as Rwanda saw numbers drop significantly.

‘deserving’ versus ‘un-deserving’ asylum applicants (Sales 2002) . Situated within this politico-legal discourse about the legitimacy asylum seekers and the right to residence are the everyday life of refugees. The experiences of those seeking asylum within the UK are marked by a continued state of legal uncertainty and marginalisation as identified ‘refugees’.

The rapid emergence of new refugee communities has inspired a considerable body of research into the issues and experiences of refugees in adapting to life in the UK.

Methodological issues have, however, plagued research on refugee communities (Bloch 1999a). On a national level, inconsistencies in the way in which data has been collected – such as demographic data, for example, has hampered the ability to document the resettlement patterns of refugees in comprehensive ways (Robinson 1998). Despite these issues, there is a strong body of work that has begun to map the social, economic and cultural changes that refugees encounter.

First, there are practical issues related to the physical circumstances of resettlement. These include socio-economic issues, such as housing, income, access to services for health and social welfare issues. Second, there are a range of complex shifts that accompany the process of cultural adaptation around the issues of beliefs, roles, and identity. Finally, interacting with these are issues specific to health and well-being. These three components: practical issues; cultural adaptations; and socio-medical issues are influenced by life experiences in the UK as well as the enduring influences of past experiences within their homeland.

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<sup>21</sup> The majority of Kosovars have only recently been granted permission to remain in the UK under the conditions of an ‘amnesty’ for families who entered the Britain before 2000.

## Practical Issues

For many refugees practical issues related to socio-economic matters are of central importance. Policies around the economic support of refugees have been highly contested in the UK. The financial support offered (whether in cash payments or in vouchers) is, despite popular belief, quite low. Allowances for direct support are set at a maximum of 70% of basic income support rates for adults and at 100% support rates for children under the age of 16. Rates are justified on the basis that they are in addition to ‘in-kind support’ which includes housing costs, utilities, and general home furnishings<sup>22</sup>. For the current rates of financial support offered to asylum seekers, see Appendix 4.

Housing placement, which currently falls under the auspices of the National Asylum Support Service (NASS), is provided in a complicated array of sites including hotels, bed-sits and other temporary accommodation settings. ‘Temporary accommodation’ placements have however been of questionable suitability, particularly for families or women with children. More permanent accommodation has also been problematic due to insufficient regulation and monitoring. Shelter (a national homelessness charity) in an investigation of health and safety standards of private accommodation placements for refugees found serious health risks present, with 17% of sites rated as “unfit for human habitation” by local environmental health officers and overcrowding a significant issue in 86% of the dwellings (Garvie 2001). Few of the housing placements had undergone previous formal health or safety reviews. Individuals who are housed in such settings may be especially vulnerable;

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<sup>22</sup> The coverage of costs associated with housing placement do not include the following: new furniture, telephones, television licenses or cleaning for example. Housing conditions should be habitable accommodation as defined in the Housing Act 1985, furniture should be to a reasonable standard, and the costs associated with gas, electricity and water covered (NASS 2004).

unfamiliar with their rights regarding housing and housing law, and reticent to complain for fear of this affecting their asylum claim.

One of the most extreme forms of social exclusion, homelessness, has emerged as a visible issue only relatively recently for refugees in the UK. Section 55 of the Nationality, Immigration and Asylum Act of 2002 (formally introduced in January of 2003) is explicit in its denial of all NASS support to individuals who fail to claim asylum ‘as soon as reasonably practicable’ (HMSO 2002). The scope of this legislation is broad, potentially impacting upon all individuals seeking asylum in-country. The condition of ‘reasonably practicable’ has – at a minimum -- been approached with inconsistency and the imposition of questionable time limits. As a result of legal challenge, the Home Office has moved toward a ‘less restrictive’ interpretation of Section 55, which, while not eliminating the non-support clause, aspires to be less punitive for the majority of applicants (Ward 2004).

Section 55 has however been an issue only for individuals who arrived in the UK after 2003. Historically there have been considerable inconsistencies in the nature of support given to refugees from the early 1990’s onwards. This has meant that some individuals, particularly those who have chosen not to be dispersed outside of urban centres have been at considerable risk of homelessness. Many of these individuals would lack a familiarity with the ‘homelessness sector’, typically relying upon less formal services, for example, living in over-crowded ‘hidden’ homeless situations with friends and family (Crisis 2004).

Economic resources are a key issue for refugees in resettlement whether they receive formal support or not. Legal barriers exist to employment, with a minimum six month restriction (NASS 2004) Access to employment is often cited as an issue for refugees, even when they

have been granted formal permission to work. Language fluency and the recognition of skills and training acquired elsewhere emerge as key barriers to successful employment for refugees in the UK. These practical issues are likely to contribute to greater social exclusion and marginalisation (Samers 1998, Wong 1991, Zetter and Pearl 2000). The abrupt placement in an unfamiliar landscape already marks refugees out as the visible 'other' (Parr 2000). Social exclusion may operate in subtle and complicated ways, socially and culturally through isolation, stigma and discrimination; and spatially through homelessness or substandard housing (ODPM 2004).

## Cultural Issues

The transformation(s) that accompany the processes of forced migration, exile and resettlement are, without a doubt, substantial. Dealing with the impact of significant losses (of home, of family, of livelihood) are fundamental themes that shape life in a new country. Social isolation within the host country may be amplified by the absence of an existing migrant community, as well as a lack of language fluency in English.

Research on the experiences of new immigrant populations has noted that challenges emerge when traditional beliefs clash with those of the new host country (Oxman-Martinez et al. 2002). This is especially pronounced for women in terms of gender roles and may lead to new situations of risk, particularly related to domestic violence (Smith 2004). At the same time, for women arriving from extremely patriarchal societies, Britain offers exceptional freedoms and opportunities. Typically women adapt quickly to the new environment, in part due to the necessities associated with caring for their children and other family members. The tasks of enrolling children in school, or registering with a physician

force women to engage with the systems of social care in ways that men may not. This process calls for women to act more independently and to acquire a greater familiarity with the English language and cultural habits within a shorter time period (Mrvic-Petrovic and Stevanovic 2000). These transformations are just two examples of how newly arrived women immigrants may adapt to the new environment. Still, it is commonly accepted that these transformations may contribute to considerable strain within families where decision-making has been traditionally a male dominated area. Preliminary research within refugee communities point to an escalation in domestic violence, often attributed to the dramatic changes in gender roles (Smith 2004). The adaptation to new cultural behaviours and expectations may be amplified as refugees struggle to familiarise themselves with professional networks, while seeking to create new social ones for support. Furthermore refugees may find themselves identified in negative ways within the mainstream society as xenophobia surfaces more and more in Western countries.

Socio-political commentaries on asylum in the UK have over the course of the past decade, turned from a cautious antipathy to a more visible, and at times extreme, xenophobia. The European Commission Against Racism and Intolerance (ECRI) noted that compared to other European countries, the UK has been particularly intolerant towards refugees and asylum seekers (ECRI 2001). Media portrayals of refugees have been characterised by the use of inflammatory imagery and a provocative use of language (Buchanan and Grillo 2003, Kundnani 2001). Immigration policies since the mid-1990s have veered away from a 'human rights' perspective and towards legislation that decidedly accentuates deterrence and exclusion.

This scenario is not unique to the UK, but instead is part of a growing trend in Western countries (Marx 1990, Mrvic-Petrovic and Stevanovic 2000). Increasingly individuals are categorised as legitimate and “deserving” versus illegitimate and “undeserving” claimants (Khan 2000). Individuals escaping conflict or war may be regarded as bona fide claimants whereas those seeking economic opportunity are inevitably designated as ‘unworthy’ applicants<sup>23</sup>. However even these categorisations are inconsistently applied, with ‘worthiness’ sometimes dictated by national identities (read stereotypes) rather than a reflection of the circumstance that brought the individuals to the UK (Mollard 2001)<sup>24</sup>.

The language quickly becomes the reality, the way we talk about people ultimately influences the way we act towards them (Smith 1975:57).

Language plays a critical role in shaping the perceptions of refugees. The words and phrases used characterise refugees as a threat to the ‘traditional way of life’ (effecting a cultural revolution of sorts). Accompanying these images are vivid suggestions that Britain is being ‘overrun’ by ‘swarming’ groups of refugees, arriving in large numbers. Labelled as “bogus” or “illegal” the connotations are of criminality and exploitation; an influx of people who are *taking advantage of a system* meant for legitimate British citizens (Kundnani 2001). The impact of language here in shaping perception, and then action or reaction should not be under-estimated. The words we use to describe people are quickly normalised in the context of everyday speech, making them less likely to be detected and less likely to be challenged (Cohen 1999, Smith 1975). Khan (2000) notes how language is used to

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<sup>23</sup> These characterisations are malleable to shifting political climates, exemplified by the onset of ‘compassion fatigue’ where the tone in host country shifts to one of suspiciousness and scepticism (Robinson and Coleman. 2000).

<sup>24</sup> Mollard (2001) notes how the media have contrasted the merits of asylum claims based upon national identity and stereotypes, in particular comparing the Roma and Kosovar refugees, with Roma considered to be ‘bogus’ and the Kosovars to be legitimate. In this instance, timing is everything for the Kosovars who were depicted as the unwitting victims of Serb aggression. At a later point in time the image of the Kosovar refugee becomes more closely aligned with stereotyped imagery of ‘Albanian criminality’ (Thompson 2003).

depoliticise the experiences of asylum seekers; separating the individual from the political context that led to forced migration. Attention is instead focused upon the perceived economic and social burdens placed upon the host country (again as a threat to an idealised ‘way of life’), as well as a distortion of the ethnic identity. The process of ethnic profiling trades in the use of caricatures, where certain features are exaggerated, distorted, but also accepted as irrefutable evidence of inalienable traits or of part of an unsavoury cultural backdrop that “they are used to”<sup>25</sup>. For certain groups – ones experiencing a highly publicised war or conflict the markers of identity may be at first used to emphasise victimhood.

For Kosovar refugees in the UK, the public characterisation has oscillated over time, from threat to victim to threat once more. Kosovars in the UK prior to the escalation of war in 1998 were regarded largely with suspicion, if not contempt as ‘economic migrants’. Later, with the onset of war this perception shifted, drawing upon cultural (and gendered) stereotypes. Initial images of refugees from Kosova strategically confirmed the ‘victimhood’ of those fleeing, and the benevolence of countries taking in refugees. This is clearly illustrated in the representation of women fleeing the former Yugoslavia (del Zotto 2002). The characterisation of women, in particular, has relied upon strong imagery. Typically the images used depict women in traditional roles and representations, best encapsulated as “woman in headscarf” frequently clutching a child (Seu 2003, Stetz 2000). These portraits trade on caricatures of difference, and perhaps more worrying, may lead to perceptions of refugees in stereotyped ways.

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<sup>25</sup> This has been clearly illustrated with the concept of “tribal hatreds” which flooded the Western media’s political analysis of the conflicts: “*Balkanization* was reintroduced into the vernacular implying incessant feuding and fragmentation (Udovicki and Ridgeway 1997).”

The 'pro-refugee' media coverage of the evacuation and resettlement of Kosovars, quickly gave way to 'compassion fatigue'<sup>26</sup>. As with other groups entering the UK before them, Kosovars were quickly subsumed under the generic label of 'asylum seeker' or worse 'Albanian criminal'. The demonisation that comes with the label 'asylum seeker' has rendered marginalisation and social exclusion more complete (Sivanandan 2001). As compassion fatigue sets in, the initial stereotype as 'victim' is likely to fade in intensity and the image of group shifts, increasingly perceived as a threat to the host country (Moeller 1999).

In the aftermath of conflicts such as those witnessed in the former Yugoslavia, there has been widespread acceptance of the reformulated ethnic identities that played such a key role in shaping the circumstances of conflict. More pointedly, the designation of a specific identity can be critical to the process of asylum, granting political credibility to an individual's legal claim (Crawley 1999). In the process of accepting such identities however, accompanying frameworks may also be uncritically accepted, such as ideas about traditional gender roles and behaviours (Indra 1996). Extreme patriarchal traditions linking women's identities to reproduction may emerge with greater prominence, effectively casting women as one-dimensional (Allen 1998, Stetz 2000).

The label of 'refugee' in itself, however, involves only a limited discussion of sexuality or gender roles. At best, there is an effort to relocate women's identity in the traditional cultural frameworks of the homeland, often contrasting this complex and modern images associated with the new host country (Walsh 2000). To some degree the desexualisation of

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<sup>26</sup> In part this stems from the perception that the situation in Kosova had been resolved and repatriation a realistic option.

refugees mimics the experiences of other marginalised populations where service providers may make use of cultural stereotypes (Binder 1985) or conclude that in the face of competing issues, there *“just isn't time or energy to think about them as women or men”* (Test and Berlin 1981). From a health perspective the desexualisation of refugees combined with a re-gendered stereotype of women has repercussions in terms of health care and services being offered. Women who are identified as ‘traditional’ or ‘desexualised’ may also be viewed as reluctant to discuss issues of a sensitive nature including sexual violence – or may be cast as ‘not at risk’ for a range of health issues, including sexually transmitted diseases. Alternately the considerable publicity given to rape in Kosova may lead providers to assume that most or all Kosovar women have been victims of sexual violence. The cultural images that providers hold about refugees may have significant implications in health assessment practices and in turn impact upon the use of health services by refugees.

## Health Issues and Refugees

An array of physical, psychological and social issues have been identified specific to the health experiences of refugees; from the emergence of conflict through the ‘exile journey’ and into resettlement (BMA 2002, Burnett and Peel 2001a, Woodhead 2000). The physical and mental health issues that are related to conflict and forced migration – vary from the difficulties ‘routinely’ associated with poverty and deprivation to the extreme(s) of war-related injuries, torture, and sexual violence (Clinton-Davis and Fassil 1992, Friedman and Jaranson 1994, LHO 2000). Recent materials presented by the British Medical Association outline an array of potential health and health-related issues that refugees may face (see Table 1). Epidemiological data on health issues amongst refugees in resettlement

however remains limited and highly speculative. Broad figures suggesting considerable impairment are often-cited, for example, 1 in 6 refugees in the UK suffer from sufficient physical health problems to affect their lives (Carey-Wood et al. 1995). Such data are routinely used however to advocate on behalf of the health needs of refugees. Yet they offer little insight into the nature of health problems, the circumstances surrounding them, or the characteristics of those affected beyond the label of 'refugee'.

However limited and problematic, existing research does suggest that refugee populations are at an elevated risk for poor physical and mental health in resettlement (Connelly and Schweiger 2000, Hargreaves, Holmes, and Friedland 1999). Issues that are specific to their country of origin (conditions endemic in their home country, or cultural practices such as female genital mutilation), the experiences of refugee camps (sudden rise of infectious diseases, for example) and the intra-war experiences of conflict (such as torture, physical and sexual assaults) may continue to pose problems or emerge as difficulties once in resettlement (Clinton-Davis and Fassil 1992). Many of the physical issues affecting refugee communities in resettlement bear a greater relationship to poverty and social exclusion than the experiences of conflict and forced migration (Woodhead 2000). In particular some health issues have received more attention than others, most notably conditions that have been associated with stigmatised identities. Infectious diseases (such as Tuberculosis and HIV/AIDS) (Coker 2003, IOM 2000) and psychological issues related to trauma have emerged as issues at the forefront of refugee health, eclipsing the less dramatic issues of chronic diseases or immunisations (Friedman and Jaranson 1994, Hollifield et al. 2002).

Table 1: Health problems and contributory factors experienced by some asylum seekers and refugees

<p>Communicable diseases</p> <ul style="list-style-type: none"> <li>• Tuberculosis</li> <li>• Hepatitis A, B, C</li> <li>• HIV/AIDS</li> <li>• Parasitic infections</li> </ul> <p>Effects of war and torture</p> <ul style="list-style-type: none"> <li>• Landmine injuries</li> <li>• Amputated limbs</li> <li>• Lameness</li> <li>• Partial loss of vision</li> <li>• Hearing difficulties</li> <li>• Mental health problems (see Column two)</li> <li>• Injuries arising from beatings and torture (including dental torture)</li> <li>• Rape / sexual assault</li> <li>• Malnutrition (could affect development in children)</li> <li>• Lack of personal protection</li> <li>• Conscription into army (adults and children)</li> <li>• Prolonged squalor in camps</li> <li>• Detention</li> <li>• Witnessing death and torture of others</li> <li>• Held under siege</li> <li>• Forcible destruction of home/property</li> <li>• Disappearance of family/friends</li> <li>• Held hostage /human shield</li> </ul>	<p>Psychological and social health problems</p> <ul style="list-style-type: none"> <li>• Depression</li> <li>• Anxiety</li> <li>• Stress</li> <li>• Stress-related physical ill health: <ul style="list-style-type: none"> <li>Heart disease</li> <li>Cancer</li> </ul> </li> <li>Increased susceptibility to infection</li> <li>Gastrointestinal disturbances</li> </ul> <ul style="list-style-type: none"> <li>• ‘Fear syndrome’ or fear of people in authority</li> <li>• Deprivation of human rights</li> <li>• Political repression</li> <li>• Harassment /racial harassment</li> <li>• Loss of status</li> <li>• Homesickness</li> <li>• Separation from family</li> <li>• Change in climate</li> <li>• Uncertainty around the process of claiming asylum in the UK</li> <li>• Lack of awareness about services available</li> <li>• Coping with new culture/limited or no access to community network</li> </ul>
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Source: British Medical Association (2002: 7).

Health care services have rarely been proactive with refugee communities, instead tending to react to issues and difficulties once they have emerged. For refugees there are structural issues related to service delivery that can limit access to care, therefore impacting upon health and health-related needs. Despite an entitlement to NHS services, access to services is often impaired due to language barriers, cultural barriers in the articulation and defining of health concerns, miscommunication about the rights and obligations of patient and professional, and finally, a lack of awareness amongst providers about the nature of health issues facing refugees (Hargreaves, Holmes, and Friedland 1999, Woodhead 2000). These difficulties are further complicated by a system that is already over-burdened and under-resourced, particularly in poor communities. Access to critical health services may be severely undermined by these logistical limitations and lead to the inappropriate use of services. There is for example, widespread recognition that amongst marginalised groups the inability to enrol with a GP may lead to disproportionate use of Accident and Emergencies (A&Es) in lieu of a primary care physician, at a greater cost to the system and likely at a more advanced stage of health crisis (Jones and Gill 1998).

The complications of accessing appropriate care may mean that some health issues receive less attention than others. Under-examined are issues related to chronic (often critical) conditions. Recently there has been some exploration of the health care needs of refugees around addressing disabilities, although this still remains limited (Roberts and Harris 2002). However attention to chronic conditions such as epilepsy, diabetes or cardiovascular conditions has been absent from discussions on refugee health. Furthermore in the pre-exile period, health care systems in the country of origin have often collapsed, meaning that

‘routine’ health matters, including immunisations or reproductive health care for women have likely been absent for some time.

In resettlement the more visible socio-medical issues for refugees are often related to violence. Sexual violence against women in many recent conflicts has brought to the forefront some issues related to reproductive health. Public health work examining reproductive health amongst refugees in resettlement is, however, sparse. Instead much of this work has focused upon reproductive health issues for refugees in camp situations (Davidson and Lush 1995, Krause, Jones, and Purdin 2000, McGinn 2000) with little attention directed towards women in resettlement (McLeish 2002).

One study that did look at sexual and reproductive health amongst refugees in resettlement considered the prevalence of STDs and cervical abnormalities, as well as the use of contraceptives comparing refugees from the former Yugoslavia with non-Yugoslavian women attending a medical clinic in London (Newell et al. 1998). Substantial numbers of Yugoslavian women reported no contraceptive use (48% as compared with 30.4% of the controls); the majority had never had a cervical smear (30.5% compared with 17.5% of the control group), and STDs were more prevalent amongst these women (26% vs. 16%). These findings suggest that these women had limited exposure to accepted sexual and reproductive health education and screenings in the period leading up to their migration to the UK. For women from Kosova, similar trends are likely to be the case given that health care services for the ethnic-Albanian population had virtually collapsed a decade prior to the war.

Recent studies conducted with refugee women in terms of maternity experiences in the UK have shed some light upon some reproductive health-care issues in resettlement. The findings point to a context of poor health and social care service provision, which was linked with creating situations of risk for pregnant women, and women with children (McLeish 2002). In the community many women find themselves housed in inappropriate settings for both themselves and their children: overcrowded housing, of poor quality, and dominated by single men --- which may pose a considerable threat for harassment or assault (Goodchild and Ober 2003). In addition there are little or no provisions for the health needs associated with pregnancy (ante-natal care) or the care of newly born children. Coupled with the extreme social isolation common to the experience of resettlement, this may amplify the vulnerability of these women.

In addition, Kennedy and Murphy-Lawless (2003) note that a dichotomy exists in how refugees who are pregnant are perceived. On the one hand there are apparent links made between reproductive health and rape. The pervasiveness of rape in conflict and as a form of persecution may mean that pregnancies are potentially viewed as linked with sexual violence (at least in the period shortly following arrival). Subsequently women may be categorised as victims in need of specialised care and support. However Kennedy and Murphy-Lawless also note that there has also been a strong negative reaction to the visibility of a pregnant refugee within services, where women face questions about their legitimacy in accessing care, inspired by a pervasive xenophobic discourse on refugees.

The reluctance to explore sexual and reproductive health amongst women refugees may reflect apprehensions about how to deal with the cultural complexities or sensitivities inherent to such discussions. Research exploring the barriers to dealing with sexual health

issues in primary care, suggests that providers categorised sexual health as particularly problematic, expressing a wariness about approaching the topic in a proactive way (Gott et al. 2004).

Discussions on health issues facing refugees (and other marginalized groups in general) quickly move from the physical to the psychological. Despite a considerable body of work both in the UK and elsewhere on the experiences of violence, forced migration and the nature of human suffering there is a lack of uniformity in understanding what this means in terms of psychological outcomes.

... among the indigent, the traumas are so terrible and so frequent... that searching for the depressed among them is like checking for emphysema among coal miners (Solomon 2001:113).

The portrait of 'mental health problems' amongst refugees remains nebulous and broad. Psychiatric morbidity is generally accepted as common amongst refugee populations, with depression, anxiety, and stress reactions, such as PTSD frequently highlighted (Silove et al. 1998). The epidemiology while mixed, does point to elevated rates of psychiatric distress amongst refugee populations (Friedman and Jaranson 1994). The emergence of PTSD as a particular framework for defining trauma and suffering for refugees has meant that other forms of psychological distress remain relegated to the background, often examined only as a co-morbid condition associated with PTSD. PTSD however reflects a specific understanding of the responses to critical events, one informed by a psychiatric paradigm on distress and trauma. PTSD itself remains controversial as a summary diagnosis for trauma and suffering. Its use raises pertinent questions about the appropriateness of a psychiatric paradigm as a way of understanding refugee experiences.

The evolution of 'trauma' into PTSD is something that can be traced throughout much of the 20<sup>th</sup> century, with each conceptualisation marking a shift in knowledge, understandings, and socio-political contexts. This has direct relevance to the current conceptualisations of trauma that operate within the field of refugee health. The epidemiology of PTSD in general will be discussed in greater detail as part of the evolution of Trauma Discourse in Chapter V. In addition, a more directed examination of the epidemiology and construction of PTSD specific to refugees is discussed in Chapter VI.

#### **IV. 'A HISTORY OF TRAUMA' DISCOURSE**

Tracing the historical timeline of 'trauma' as a psychological construct helps to give shape and coherence to features of the diagnosis of Post-Traumatic Stress Disorder, and the application of the language of 'trauma' to refugee populations. Present-day professional and lay discourses on trauma draw heavily upon popularised aspects of PTSD, as well as metaphors about suffering and dealing with difficult life events. Trauma emerges as a 'diagnosable reality' as PTSD in the Post-Vietnam War era in the United States. Its historical roots are, however, more extensive, with complex understandings of trauma and suffering emerging throughout the 19<sup>th</sup> and 20<sup>th</sup> century ranging from the chaotic and gendered representations of 'hysteria' (Logan 1997) to 'traumatic neuroses' and militarised forms such as 'shell shock' (Mosse 2000). Each respective configuration offers valuable insights into the shifts in knowledge and perception over time of how extreme events impact upon people, the way this is manifested and the pathological forms this may take. These conceptual frameworks outline the recent ancestral past of 'trauma' informing current professional and popular understandings.

This chapter will briefly trace the history of 'trauma' discourse throughout the past century to illustrate the ways in which our understanding(s) have shifted and transformed research and clinical practice. In presenting a more complex history to current understanding(s) of trauma, I am not putting forth the argument that PTSD has a 'timeless' quality to it. Rather that there are important ancestral threads that should be examined which I think help to explain current conceptualisations of trauma and its application to refugees.

Beginning with an overview of hysteria and nervous conditions, 'trauma' is explored through to definitions of psychological stress that emerge in psychobiological theory, and on to Post-Traumatic Stress Disorder. Particular attention is paid to the evolving understanding of trauma through an aetiology of external pathology and at times internal vulnerabilities as definitions adapt to particular contexts.

'Hysteria' has a long and complex history, documented as earlier as the 4<sup>th</sup> century BC up until the 20<sup>th</sup> century AD (Huopainen 2002). The term evokes an exotic past: a disorder punctuated by a constellation of physical contortions and signs, and heavily linked with female sexuality (Evans 1991). Throughout its history there is a link between social distresses and bodily discomfort. With hysteria explicit links are made between the expression of social issues including social transformations related to gender roles, social class, and by the end of the 19<sup>th</sup> century, trauma (Beizer 1994, Evans 1991). At this point in its history there is an effort to come to terms with – in definition and treatment – the nature of individual pathology associated with trauma, beginning with the exploration of trauma related to childhood sexual abuse (Huopainen 2002). In hysteria the emerging field of psychoanalytic thought found a syndrome that embodied the psychosomatic, where physical expressions function as representations of the psychological that have long been repressed. This understanding of trauma posited through psychoanalytic thought has had a profound impact upon modern psychiatry and the conventional understandings of mental ill health at both the professional and lay level. It has helped to give shape to the ways in which people talk about psychological health and distress and understandings about how an individual processes traumatic events at conscious and unconscious levels.

Historically, hysteria has been linked with a range of experiences and disorders, most notably with melancholy and a generalised state of ‘nervousness’ marked by an eclectic array of symptoms including ‘tics’ (involuntary spasms), ‘fits’(convulsions), paralysis and the sudden appearance of ‘stigmata’ (Beizer 1994). The term ‘hysteria’ is derived from the Greek word for uterus and as such was largely understood as a ‘gendered’ disorder believed to be caused by a ‘wandering womb’. By the mid-19<sup>th</sup> century a conceptual shift occurred, whereby the aetiology was no longer presumed to be of physical origin. Informed by the theoretical works of Charcot, Freud, and Janet, hysteria came to be understood as a ‘disease of the mind’. Collectively their work contributed to this profound shift in re-defining the nature of hysteria.

In this new framing, hysteria comes to be understood as a nervous reaction to a traumatic event. For women this remains heavily linked with aspects of sexuality, at points considered the result of an excessive sexual drive (Evans 1991). The phenomenon is characterised by the conversion of psychological reactions into physical symptoms, and the transformation of memories, perceptions and feelings from a conscious to an unconscious or ‘dissociative’ state. The emergence of ‘traumatic neurosis’ as a label comes at this time, largely supplanting the term ‘hysteria’. The previous associations with sexuality, and in particular repressed female sexuality reduced the usefulness of ‘hysteria’, and may have contributed to the term falling largely out of favour. Nonetheless the disorder, or at least shades of it, have managed to carve out and maintain a place within international diagnostic classification systems (WHO 2003). While both formal disease classification systems, the International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual for the Classification of Mental Disorders (DSM) have removed the term ‘hysteria’ as a formal diagnosis, its impact can be felt in the continued recognition of ‘conversion’ and

‘dissociative’ states, as well as its use as an adjective, describing ‘personality types’. The separation of ‘hysterical’ features from traumatic neurosis has allowed for a broader application of these concepts across situations (e.g. Dissociative Disorders).

A specifically male version of ‘hysteria’ does not emerge, however, until late in the 19<sup>th</sup> century when events accompanying rapid industrialisation and combat-related military service emerge as critical events. Industrialisation brings with it a new and unlikely source of traumatic stress across a broader spectrum of the population in the late 19<sup>th</sup> century.

While relatively obscure in relation to hysteria and combat stress, ‘Railway spine’ is an intriguing example of the expansion of notions of traumatic stress to events of daily life. In the medico-legal discourse of the mid and late 19<sup>th</sup> century, ‘Railway spine’ refers to the injuries sustained in the course of rail travel and as a result of railway accidents (Harrington 2003).

*... the symptoms of "railway spine" begin imperceptibly after jolting of the spinal cord - a jolt that tends to be especially severe in railway accidents - and leads to a serious pathologic picture of inflammation in the spinal marrow. After days or weeks the patient feels himself undergoing changes; he becomes pale, he wastes away, his concentration powers are reduced, and his memory is deranged; he sleeps badly and has horrible dreams (Weisaeth and Eitinger 1991:2).*

While the onset was consistently linked with an abrupt and violent ‘jolt’ to the spinal cord<sup>27</sup>, the manifestation of symptoms went well beyond a localised injury, including difficulties in psychosocial functioning, memory, and sleep disturbances. Symptoms did not emerge immediately following the index event. This delayed onset contributed to a sense of ambiguity about the disorder. However, more importantly, this idea of a latency period

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<sup>27</sup> Despite efforts within medicine towards establishing a physical basis for the disorder actual spinal injury could not be proven (Weisaeth and Eitinger 1991).

between exposure and the emergence of symptoms helps to shape a new perception about the ways in which trauma related to critical events may be processed by an individual.

The emergence of 'railway spine' coincides with emerging models of traumatic neurosis – adapting concepts from and moving beyond the framework of hysteria. This expansion of an understanding of traumatic events, accompanied by physical and psychosocial manifestations (including paralysis, muscle spasms, loss of memory and 'intellectual derangement') occurred at a time of dramatic social and economic change, manifested in industrial and technological advancement and an emerging professionalisation of medicine (Harrington 2003). The exploration of injuries and reactions to railway spine, it could be argued, furthered an understanding of reactions to sudden events and the concept of 'nervous shock' which was soon to become an issue for soldiers in combat, and therefore, for the military. With this transformation the gender neutrality of traumatic reactions becomes obscured, reflecting the predominantly male makeup of western military at that time.

With the onset of World War I in 1914, there was a growing call to acknowledge the profound effects of experiences such as war. Despite early signs of combat-related stress in other situations of armed conflict<sup>28</sup>, the First World War marks a turning point where there is an active exploration of combat stress as a definable entity (Mosse 2000). Though at points an uneasy alliance, collaboration between the military and the newly emerging field of psychiatry emerges as significant to this exploration.

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<sup>28</sup> For example, during the American Civil War there was a loosely defined condition known as 'soldier's heart'. This is often identified as a predecessor to 'shell-shock'.

Stress related to combat emerged as one of the most common injuries associated with battle in the First World War (WWI). The expression ‘shell shock’ was employed to summarise the experience of profound (and physical) shock associated with being in close proximity to an exploding shell (Mosse 2000). However it would not take long to discover that few of the soldiers suffering from shell shock had actually been in such circumstances:

By the winter of 1915, however, both British and French physicians (...) had noted that the vast majority of soldiers diagnosed as suffering from shell shock had not been close enough to artillery bursts or other explosions to have suffered physical commotional damage. Thus, there was no external event that could physically produce the symptoms and altered behaviours. Indeed when some of these casualties died, autopsy produced no evidence of brain haemorrhages, even at the microscopic level, or of other central nervous system insults or lesions that might be held accountable. The logical alternative was then to conclude that the greatest contributors to such illnesses were emotional and psychological stresses, brought on by the strains of the battlefield and the war zone. The sources that were drawn upon for diagnosis were the standard categories of hysteria, neurasthenia, and traumatic neuroses (Marlowe 2000:33).

Lacking a physiological rationale for these reactions led researchers to consider the more sociological aspects of war at that time. One theory, for example, is that the shifting nature of military strategies and battlefield formation patterns facilitated new situations of psychological risk. Prior to WWI soldiers were not directly responsible for independent manoeuvres on the battlefield. Instead the pattern of engagement operated on the integrity of a ‘line of battle’.

World War I saw the return, from the time of the Roman Legions, of the segmental organization of the force on the battlefield, with battalions, companies, platoons, and even squads achieving a new tactical and social criticality in battle—a process that was to accelerate rapidly throughout this century (Marlowe 2000:35).

The re-configuration into smaller, more tightly organised groups placed a greater burden of responsibility upon individual soldiers: intensifying the interdependencies between a soldier and the other men of his unit. Further amplifying this was the strong socio-cultural

associations with 'honour' and 'glory', which served to heighten expectations of soldiers both within and outside of the military (Marlowe 2000). The emergence of combat-related stress at this time coincides with a growing interest in the ability (or inability) of individuals to react to major life events in presumed normative ways.

Despite speculation about contextual factors underlying traumatic responses, there was still very much an emphasis on determining a biological origin which could help to explain individual predisposition to combat stress or differences in the nature of symptoms. The rapidly evolving field of medical science at this time directed attention towards the study of the biology of traumatic responses with less focus upon the social psychology underlying such reactions. Fuelled by the now collaborative interests of psychiatry and the military, a new phase of trauma and stress research was promoted through psychobiology.

In the period leading up to the World War II (WWII) -- roughly 1919-1941-- the focus was directed more towards uncovering the physiology of nervous reactions. The interest in psychobiology reflected largely military goals of identifying soldiers with 'weak nervous systems' and therefore a potential risk in combat settings (Bourke 1998). Two key theories help to shape this new understanding of 'stress': the 'fight or flight' response developed by Walter Cannon; and the General Adaptation Syndrome (GAS) by Hans Selye (Marlowe 2000).

The 'fight or flight' response refers to the physiological reaction that is experienced in the face of a perceived threat. When faced with a potential threat the instinctual physiological response is to react in a self-protective way. This is achieved through either evading the

threat, or engaging with it in a combative way. This can be clearly understood in terms of physical threats and reactions. Understanding and conceptualising trauma however also leads to an examination of psychological reactions and responses to threats (real or perceived). Protective mechanisms that can subsequently emerge include ‘dissociation’ where the individual unconsciously establishes psychological distance from the event in the form of repressed memory. Cannon couched the ‘fight or flight’ response within a broader process of ‘homeostasis’. This refers to a state in which the body has actively resolved any conflicts (internal or externally induced) and through a complex self-monitoring process achieved a sense of regulation and internal balance.

Building upon this work, and drawing upon the language and imagery of engineering, Hans Selye developed a framework for understanding the tension and strain experienced by a body in the face of pressures, calling this ‘stress’. In his model, the General Adaptation Syndrome (GAS) he posited that in essence fear, injury, and strain could all trigger a protective reaction within the body. It was however the repeated demands on the body to adapt to additional strain which could prove counter-productive. This conceptualisation of ‘stress’ is the heart of current conventional Western understandings of the power and impact of stressors on individuals and the ability to adequately process the body’s regulation of the autonomic nervous system (Kemeny 2003).

World War II (1939-1945) in many ways marks a ‘watershed’ in the evolution of understandings of trauma in the 20<sup>th</sup> century. There is a merging of psychobiology and the understanding of psychological consequences of combat and critical events within a war zone. The war begins with an effort to use this knowledge of psychobiology to screen out

individuals who are considered 'inherently weak' and subsequently a risk for combat stress. By the end of the war a new consciousness is emerging, where the physiology of stress becomes fused with the psychological. The guiding principle is no longer that some men are inherently weak but rather that every man has a 'breaking point' (Marlowe 2000). This concept of stress as a combination of psychological and physiological reactions is reinforced over time and, becomes somewhat accepted within military psychiatry.

The atrocities of the Second World War also brought non-combatants into the fray in significant numbers through the internment of civilians in concentration camps and the extermination of millions in the process. The response of civilians to the horrors of the war adds an important dimension. These are the reactions of average people in exceptional circumstances, not military personnel trained to endure extreme circumstances. This in particular bears a direct relationship to the experiences of refugees in present-day situations.

The Second World War challenged perceptions and experiences of conventional warfare. The psychobiology of 'breaking points' for soldiers was now recognised within military circles (Marlowe 2000). The Holocaust marks a turning point for civilians in contemporary conflict zones. 'Concentration Camps', similar in design to forced labour camps, were constructed by the Nazi regime. However these differed greatly from labour camps, functioning instead as formalised sites of imprisonment, torture and extermination. The extreme and horrific conditions within the concentration camps have been well documented by international agencies pursuing criminal charges for perpetrators of war crimes, as well as in the vivid post-war testimonies of survivors (Amery 1998, Borowski 1992).

The construct of ‘concentration camp syndrome’ refers to the long-term impact of the war upon survivors. The stresses and strains associated with life in the camps -- what was witnessed and experienced -- were believed to throw the individual into a marked state of psychological disturbance. As Ryn (1990) notes in his research with former concentration camp prisoners in Poland, the clinical nature of this syndrome is revealed more through existential questioning than physiological stress reactions. The phenomenon is epitomized by ‘psychic pain’ in which the individual continually challenges their own “moral self-portrait”; striving to reconcile what they have seen, what they have done (or not done) leading to, in essence, a disfigured personality. The extreme nature of these experiences has contributed to a conventional belief that having survived an experience of such intensity and atrocity leaves the individual permanently scarred.

The stamp left by experiencing camp stresses seems to be something permanent or even progressive, in the physical and in psychic spheres. The stigma *sui generis* of the concentration camp has been transferred to the second or even third generation of the progeny of former prisoners. It has become fixated in the population that suffered in the concentration camps and the war. It is then a process lasting in time and extending beyond the individual life of prison inmates. It displays a dynamic of its own kind and is subject to evolution (Ryn 1990:23).

The framework of the ‘concentration camp survivor’ incorporates three interconnected elements: events that occurred challenge the core of our sense of humanity and morality; witnessing or being part of those acts (victim or aggressor) renders the person indelibly marked by this contact; and finally, that life afterwards is characterised by a dichotomy between the need to publicly acknowledge what has happened, and the need to remain silent. The permanent marking that accompanies the process becomes, as some argue “*a cognitive trap (...) [where] everything that happens subsequently tends to be interpreted in light of that experience*” (Gambetta 1999:7). This notion of permanence has been key to the framing of the post-Holocaust lives of survivors: the experience leads to permanent

disability in a way that other conceptualisations of trauma and traumatic reactions fail to articulate<sup>29</sup>. Living with the events of the Holocaust becomes understood through this lens.

Unlike previous conceptualisations of traumatic stress, the psychopathological effects of the Holocaust have come to be widely perceived as transmissible in some form -- where stigma and shame can be passed on at a multi-generational level (Danieli 1998, Hoffman 2004).

This theory suggests that profound and disturbing events can have an effect beyond the individual survivor, leading to the spread of pathology to the children of survivors.

[W]hat we children received, with great directness, were the emotional *sequelae* of our elders' experiences, the acid-etched traces of what they had endured. This, perhaps, is always the way in which one generation's legacy is actually passed on to the next – through the imprint of personal and historical experiences as these are traced on individual psyches and sensibilities. But in the aftermath of the Shoah, the traces left on survivors' psyches were not so much thoughts or images as scars and wounds. The legacy they passed on was not a processed, mastered past, but the splintered signs of acute suffering, of grief and loss (Hoffman 2004:34).

This concept of an *incompletely processed past*, described by writer Eva Hoffman above, is critical to the way in which the Holocaust and the experiences of individuals throughout the war are perceived. In part this relates to more abstract discussions about the 'silencing' effect of extreme pain and suffering (Scarry 1985). What people have undergone becomes cast as 'unspeakable'. Merging with this is the post-war uneasiness with the recognition of atrocities: there is on the one hand a need to 'never forget', and on the other a desire to selectively promote a discourse of sanitised liberation (Wood 1999). The periods immediately following the war were marked by a profound 'silencing' of individual

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<sup>29</sup> The writer Jean Amery struggled with this notion, noting: "*Do you always have to be there just because you were there once?*" (Stark 2001:93).

experiences<sup>30</sup> and the privileging of a narrative of military achievement by allied forces.

The silencing that accompanies this has been acutely noted (Laub 1992b, Laub and Auerhahn 1993, Lentin 2000)

The paradigm of an ‘unprocessed’ or ‘insufficiently processed memory’ is a defining feature in the evolution of trauma theory. Within the framework of Post-Traumatic Stress Disorder this feature takes shape and begins to inform a new understanding of how traumatic events may impact upon the individual. Chronologically many of the concepts around the legacy of being a survivor of the Holocaust have surfaced decades later, either immediately preceding or emerging concurrent to PTSD.

Running parallel to these developments in trauma discourse is the evolution of psychiatry as an established field within medicine (Scull 1999). First issued in 1952, the Diagnostic and Statistical Manual of Mental Disorders (DSM) (APA 1952) sought to codify psychiatric diagnoses, providing a template for practitioners<sup>31</sup>. Heavily influenced by psychodynamic theory, the aetiology of mental illness was understood as reflecting a continuum of factors including exposure to environmental events. This perspective remained in place until the third edition of the manual in 1980 (APA 1980).

DSM-III marked a significant departure from previous editions (Mayes and Horwitz 2005).

Conceptually a shift had occurred away from psychodynamic theory and towards a system

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<sup>30</sup> This silencing has been especially poignant for women, for whom the question ‘*What did you do to survive?*’ became linked with the idea of trading sex for survival. The question has resulted in the silencing of women about their experiences in the Holocaust for fear that they would be stigmatised in this way (Lentin 2000).

<sup>31</sup> Throughout this dissertation, reference will be made to the DSM as the primary classification text. While many diagnoses exist in both the ICD and the DSM, the DSM is specifically a psychiatric classification system. Moreover the relevant diagnosis of PTSD first emerged within the DSM system.

of standardised diagnoses. The intent was to establish an understanding of psychiatry that was in a sense ‘atheoretical’ informed by empirical evidence (medical and epidemiological) and ideally less speculative in nature than previous diagnostic frameworks: this was to reflect a science of psychiatry, determinedly less philosophical in tone than psychodynamic theory had been. The DSM-III strived to reconfigure the underlying premise of the entire classification system in psychiatry, placing it firmly within the framework of a medical model. The medicalisation of psychiatry was promoted through the use of epidemiological data that made the psychobiological aetiology and symptomatology of disorders explicit (Gaines 1992). Notably there was the introduction of a ‘multi-axial’ system to allow for the assessment of functioning across five axes.

Table II: The DSM-III Multi-Axial System

<b>Diagnostic and Statistical Manual Multiaxial System</b>	
<b>Axis I</b>	<b>Clinical Disorders</b>
<b>Axis II</b>	<b>Personality Disorders and Mental Retardation</b>
<b>Axis III</b>	<b>General Medical Condition</b>
<b>Axis IV</b>	<b>Psychosocial and Environmental Factors</b>
<b>Axis V</b>	<b>Global Assessment of Functioning</b>

Source: (APA 1994)

Ideally the multi-axial system could allow diagnosticians to consider and weight the impact of a range of factors when rendering a diagnosis. Significant life events or circumstances, social and cultural influences and physical health complaints could, therefore, be evaluated in light of their bearing on mental health and psychosocial functioning.

The subsequent revised editions – DSM-III-R and the DSM-IV extended the principles of this work, further refining diagnostic categories and criteria. With a newly structured classification system came a revisiting of diagnoses (APA 1968, APA 1980, APA 1987, APA 1994). Famously some diagnoses were unceremoniously dropped (homosexuality, for example, was removed in 1973) while others began to appear (anxiety and panic disorders, along with PTSD for example).

Traumatic stress reactions throughout the history of the DSM have ranged from ‘Gross Stress Reaction’ to account for ‘conditions of great or unusual stress’ (APA 1952), to ‘Adjustment Reaction of Adult Life’ (APA 1968) to describe reactions to ‘overwhelming environmental stress’ to ‘Post Traumatic Stress Disorder’ where stressors ‘evoke significant symptoms of distress in almost everyone’ (APA 1980). Common to each permutation is the concept of extraordinary events that overwhelm the normal capacity for processing stress, that the effects are typically transient, and that they can be effectively treated. However each diagnosis assumes a new complexity in the manifestation of traumatic stress, influenced in part by the shifting socio-cultural understandings of this construct.

The emergence of Post-Traumatic Stress Disorder (PTSD)<sup>32</sup> reflects the convergence of socio-cultural trends, political will, and the emerging influence of American psychiatry through the DSM. The post-war psychological experiences of American soldiers served as the core features of a new ‘syndrome’ of traumatic stress. This new syndrome, it was argued, carried with it distinctive symptomatic features -- anger, guilt, a sense of alienation

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<sup>32</sup> The history of Post-Traumatic Stress Disorder (PTSD) has been well documented elsewhere (Young 1995) subsequently I will only briefly summarise relevant aspects of this.

and stigma -- and was inspired by the combination of combat experiences and returning to a hostile home country.

The experiences of soldiers in the post-Vietnam war era is a departure from the previous conceptualisations of 'combat related stress' associated with earlier conflicts, most notably in the time frame of onset. Unlike the experiences of soldiers in previous conflicts, for Vietnam veterans symptoms begin in the post-conflict phase rather than in the context of the combat zone (Marlowe 2000).

The post-war context in the United States was underscored by profound social transformations. The emergence of the civil rights movement and the women's liberation movement coincided with a growing sense of discontentment amongst Americans with the political decisions of their government, most dramatically with the US involvement in Vietnam. Returning Vietnam Veterans have been popularly portrayed as the targets of active abuse by anti-war activists in the media. Questions have been raised about the validity of this portrayal. Lembcke (1998) disputes the 'mythology' of the isolated and abused Vietnam veteran, citing no conclusive evidence for the widespread abuse of veterans as compared to other young men.

Nonetheless the high visibility of these claims has granted them a sense of legitimacy. The discourse of psychiatric casualty assumes a prominence in explaining the veterans experiences of the war and the difficulties they encountered upon returning home. While a new trauma diagnosis in this era may have taken the experiences of Vietnam veterans as a starting point, the full working diagnostic framework that emerged was broader in its recognition of aetiologies. This allowed for the recognition of experiences such as sexual

violence and childhood abuse, both of which had emerged as critical social issues in the United States (Herman 1992).

The diagnosis of PTSD has undergone slight revision from its original conceptualisation in 1980 (DSM-III) to the current form in the DSM-IV. Currently the disorder is characterised by three distinct symptom clusters: re-experiencing (i.e. flashbacks, persistent and intrusive recollections); avoidance (for example, dissociative features); and arousal (for example, exaggerated startle response, or irritability). The experience of an extreme life event remains the core aetiological element. For a complete outline of the diagnostic classification of PTSD (from DSM-III through to DSM-IV, and as presented in the ICD-10) see Appendix 5.

With the reworked classification systems of the DSM, epidemiology garnered a position of importance. Psychiatric epidemiology has played a significant role in the shaping of disorders, outlining who is at risk and under what circumstances. The DSM classification system has sought to make use of that evidence, summarising and translating it into a manageable format for clinicians. This enables clinicians to feel empirically supported in their diagnoses, drawing upon incidence and prevalence data as well as observable symptomatology and features of clinical presentation. For trauma studies, PTSD emerges as the diagnosis which folds together these ideas, providing a template for clinicians to work with.

The epidemiological evidence that surrounds PTSD is extensive and complex. As outlined in this brief history of trauma, paradigms of trauma have undergone conceptual shifts, reflecting new insights and understandings. The conceptualisations of disorders held within

the DSM are no different in this respect, shifting slightly to reflect new ways of thinking about the existing (and emerging) evidence. Despite slight changes in the clinical understandings of symptom clusters from DSM-III to DSM-IV, the integrity of the construct remains intact.

Epidemiological evidence, used to support these earlier DSM classifications of PTSD, remain useful still as indicators of the epidemiology of the disorder. Many of the large scale studies come from the United States (U.S.). In particular, the Epidemiological Catchment Areas (ECA) studies and the National Co-morbidity Survey (NCS) have both sought to document current and lifetime prevalence of disorders at community levels across several sites in the U.S. (Helzer, Robins, and McEvoy 1987, Kessler et al. 1995). Kessler and colleagues (1995) documented a lifetime prevalence of PTSD across a general population sample (7.8%). This study helped to confirm distinctions in the nature of PTSD: noting variation by gender, and event (with key events demonstrating a greater link to onset of the disorder) as well as documenting the presence of co-morbid disorders (such as depression, anxiety, substance abuse). Further research on the prevalence of PTSD within community samples have demonstrated fluctuations in the epidemiology of the disorder (Breslau 2002, Breslau et al. 1998, Davidson et al. 1991, Narrow et al. 2002). Despite the variations that occur across studies, some notable trends have emerged.

Violent assaults, including rape or sexual molestation are highly associated with the onset of PTSD, lending credence to the idea that some events may be more traumatic than others (Yehuda and McFarlane 1995). Co-morbidity is frequently an issue with dramatic rates of individuals meeting the criteria for at least one other condition coeval with PTSD (Brunello et al. 2001, O'Donnell, Creamer, and Pattison 2004). Substance use, one of the more

frequent co-existing conditions is often conceptualised as part of the avoidance and numbing strategies employed (Najavitis 1997). Finally there is some distinction according to gender, with women considered to be at a higher risk than men (Breslau et al. 1998, Davis and Breslau 1998). The link between gender and PTSD is not straightforward, however, with differences noted in the exposure to traumatic events, the nature of events exposed to, and the emergence of symptomatology (Gavranidou and Rosner 2003). Across studies it is however accepted that women have higher rates of PTSD as compared to men, and that this may be related to the stronger presence of sexual violence in the lives of women (as children and as adults) (Breslau 2002, Kessler et al. 1995).

There are, however, a number of areas that remain less clear. The application of standard epidemiological concepts to PTSD (e.g. ‘dose-response’) fails to yield clear results. Whilst there is substantial evidence that would suggest that increasing the severity of the trauma would lead to a worsening of symptoms, there is also contrasting data which suggests that having multiple stressors may not necessarily translate into a greater severity of traumatic stress: “.. *a person who has been tortured a dozen times may be no more symptomatic than one who was only tortured twice*” (McNally 2003:230). While there may be a ‘threshold’, a point at which symptoms emerge, this remains unclear. Efforts to establish consistent prevalence rates of PTSD have been mired by methodological issues across research studies, questions of definition and measurement ‘on the ground’, and the transformations of clinical features and criteria over time (Breslau 2002, Narrow et al. 2002).

The application of PTSD across situations and sub-groups of the population (beyond war veterans) quickly followed its formal codification: rape victims; child abuse survivors; victims of torture; Holocaust survivors; and survivors of political conflicts (Halligan and

Yehuda 2000, Herman 1992). Changes in the diagnostic framing of PTSD have also seen the conceptualisation of what constitutes a traumatic ‘stressor’ undergo a fundamental shift away from the idea of an event outside of the realm of *normal* experiences towards a definition that allows for a greater inclusiveness of experiences – such as those which may be normative but sufficiently ‘sudden and unexpected’ to evoke ‘intense fear, helplessness, or horror’ (APA 1994). The emphasis now is less upon the nature of the event itself, and more upon the way in which the individual perceives the event and responds to it (Breslau 2002). The range of experiences blanketed under the framework of PTSD does raise important questions about the soundness of the construct. As the understanding of what stressors exist has grown, the concept of who is deemed at risk has subsequently expanded as well.

No longer must one be the direct (or even vicarious recipient of trauma; merely being horrified by what has happened to others now counts as a PTSD-qualifying event. Such second-hand exposure seems qualitatively distinct from being subjected to artillery bombardment for days on end while huddled in a muddy trench. Yet prevailing nosologic practice brackets both kinds of event under the same stressor rubric (McNally 2003:232).

Despite some attempts to establish a more graded set of diagnoses (according to the nature and complexity of experiences) (Herman 1992, Vandervoort and Rokach 2003) the criterion have instead been reconfigured over time *within* the one diagnosis to reflect new understandings of the way traumatic reactions may manifest – both in children and in adults (Yehuda 2003).

New clinical categories of stress, have however, also failed to adequately address these concerns. The latest version of the DSM (IV) includes an additional diagnostic category – Acute Stress Disorder (ASD) – for example, which allows for the clinical recognition of

severe reactions to a traumatic event within the initial period following exposure (APA 1994). The controversial inclusion of this diagnostic category raises important questions about when an experience becomes a symptom (Brant and Harvey 2000). The temporal limitations of the category mean that the move from experience to diagnosis is swift. Critics argue that such a rapid translation may be pathologising normal reactions to critical events (Marshall, Spitzer, and Liebowitz 1999). Whilst advocates argue that the predictive value of ASD warrants its inclusion in the DSM, they have also voiced concerns about the clinical parameters laid out by the category. In particular, there is a heavy reliance upon dissociative features which may not fully reflect the ways in which people experience severe stress reactions (Marshall, Spitzer, and Liebowitz 1999, Schnurr, Friedman, and Bernardy 2002).

The widespread acceptance of PTSD as an established psychiatric diagnosis has led to growing interest in efforts to further delineate variations within the diagnostic category (Yehuda 2003). The identification of risk factors that may suggest a particular vulnerability to the disorder is extensive including aspects of individual personality, coping strategies, family history and support networks. Problematic in this search for individualised risk factors is the question of what this means from a conceptual point of view of the diagnosis: whether predisposition is inherent to the individual or in the nature of the event (Yehuda and McFarlane 1995). Research on PTSD shows some signs of divergence on this point, with the divide being between socio-structural determinants of trauma and an increasing body of work that seeks to establish a neurobiological aetiology for the disorder (Hull 2002).

As the framework of PTSD has been exported for use across settings, cultures and populations, a core debate surfaces about the appropriateness of privileging of a particular discourse on trauma where understandings of and reactions to traumatic events are entrenched in psychiatric terms and treated using western clinical modalities (Eagle 2002). The language of psychiatry has, to some degree, been subsumed into popular western culture, as part of everyday language. Terms such as ‘depression’, ‘anxiety’ and ‘traumatised’ have now entered into generalised use, meant to convey something akin to, but not as extreme as a clinical disorder (Lee 2003). Psychological distress as a concept, therefore, becomes broadened and accepted as a natural part of everyday life (Killen 2000). In recent years there have been some efforts to recognise these popularised notions around mental health and illness, through the idea of ‘shadow disorders’. Shadow disorders are ‘conditions’ that fail to meet the explicit clinical thresholds of established psychiatric disorders, yet are deemed sufficient to warrant some form of clinical intervention (Ratey and Johnson 1997).

At the same time there is a heightened and rapid exploration of the psychobiology of traumatic stress reactions (Hull 2002, van der Kolk 1994a, van der Kolk 1994b). This locates the pathology associated with trauma within the individual – and back to the possibility of identifying predisposing factors (van der Kolk 1994b, Yehuda 1999). Conceptually the linking of PTSD with neurological changes contributes to a framing of the diagnosis not unlike other medical disorders (and increasingly a biologically evidenced field of psychiatry) (Kendler 1999). The suggestion that changes occur on a neurobiological level, however, raises new issues about the identification, and treatment of individuals deemed to be both susceptible to PTSD, or suffering from this disorder (Hull 2002).

Challenging conventional ideas about trauma and its impact is not restricted to neurobiological discourse. There is a growing questioning of the widespread application of PTSD both within and outside of academia. In part this reflects the struggle to recognise socio-political elements of trauma which have been diminished and muted in relation to a framework that emphasises individual manifestations of stress and distress.

Across the timeline of trauma history there are features that emerge, fade and re-appear. Early conceptualisations of trauma are distinctly gendered, first with hysteria and then with the militarised definition of 'shell shock'. Over the historical timeline we can see the development of a framework for understanding the impact of critical events in physical and emotional ways (nightmares, psychosomatic). The emergence of a psychobiologically informed model has lent certain credence to the idea of a physical 'breaking point', a limit to people's ability to cope. Moreover pivotal events in conflict, particularly for civilians increasingly drawn into situations of war, new understandings of the long term impact of traumatic events have emerged. Current conceptualisations of trauma are informed by these influences, increasingly operationalised through the clinical documentation of behavioural signs and symptoms. For refugees, trauma has emerged as a pivotal issue, reflected in the broad designation of refugees as a particularly 'traumatised' population.

## **V. RESEARCH DESIGN AND METHODS**

This research aims to shed light upon the competing perspectives operating about ‘trauma’ and refugee health for women refugees in resettlement. How trauma is defined and understood by key players in refugee resettlement impacts upon its operationalisation within health and social care practices, and the everyday experiences of refugees as they interact with systems of care and establish new communities.

Traditionally public health research has emphasised the use of epidemiology as a core methodological strategy for understanding the nature of health and illness. The documentation of disease prevalence and incidence has helped to define populations at risk and establish common manifestations and outcomes (Bhopal 1999, Pearce 1996). In modern psychiatry, particularly in DSM-III era, epidemiology has played a critical role in the delineation of syndromes and disorders (Mirowsky and Ross 1989). This biomedical framework underscores much of the work conducted in psychiatric epidemiology, striving to confirm the presence or absence of specific symptoms (thereby proving or disproving the existence of disease) (APA 1980). However, these methods may fail to convey the lived experiences of trauma outside of a psychiatric framework.

Understanding the complex nature of experiences of trauma and displacement requires that we look at a range of dimensions and contextual features which may influence perceptions and ultimately actions. Medical anthropology has urged a conceptual shift, beyond a biomedical framework for understanding health and illness experiences, calling for a greater attentiveness to the conceptual and technical tools that can do justice to the complexities of

differing realities. This is particularly true in relation to the experiences of mental health and illness where there may be greater variation in the working definitions of symptoms and disorders depending upon social or cultural context. What is understood to be a mental health issue and what constitutes an appropriate strategy for resolving (or minimising the impact of) pathologies may be open to both interpretation and negotiation (Hopper 1991). Anthropologically informed work on health begins from a starting point of dismantling the assumptions that exist behind the relations between the individual and their social and cultural systems. Increasingly qualitative methodologies informed by a joint framing in public health and medical anthropology allow for the exploration of complex (and sometimes ambiguous) perspectives and experiences around health and illness through an exploration of definitions, practices and relationships.

## Aims and Objectives

This research seeks to explore and describe the competing paradigms of 'trauma' which operate within the context of refugee resettlement. This study will examine the meaning of trauma from three unique perspectives: academic literature; professional knowledge as it is put into practice by service providers who are key actors in shaping resettlement for women refugees in the UK; and from the perspective of the women who have undergone forced migration. In order to achieve this, there are specific questions that are central to the meaning of trauma from each discourse, which need to be addressed.

*For academic and clinical discourse:*

1. What are the primary disciplines that have contributed to a discourse about refugee health in the UK?
2. How does each discipline currently conceptualise and define and measure trauma?
3. What are the specific socio-medical issues identified as relevant to trauma and refugees, in particular?

*For service providers:*

1. Who are the central actors (agencies) that shape the UK resettlement experiences for women refugees?
2. How do service providers define and understand trauma? What do they see as specific features to be addressed?
3. What do they see as the health needs (physical and psychological) of women refugees in terms of trauma?
4. How do they see their own roles with respect to resolving issues of trauma?

*For the women:*

1. What is the narrative of their exile and resettlement?
2. How do they describe and define their physical and mental health issues?
3. What are the women's experiences with services in the period of resettlement?
4. How does the language of 'trauma' feature in narratives of resettlement and encounters with services?

## Research Methodologies

In public health, there is a strong tradition in the use of quantitative research methods to establish 'standardised' epidemiological features of disease (risk factors, criterion for diagnosis, and the range of symptomatic expressions). Numerous quantitative research instruments have been specifically designed and tested for use with refugee populations around the issue of trauma (Hollifield et al. 2002, Mollica et al. 1992). These instruments operationalise trauma from a psychiatric framework, drawing on explicit diagnostic categories such as PTSD, and classification systems such as the DSM and the ICD. Symptoms related to trauma are assessed in refugee populations through the use of standardised diagnostic interviews that are either designed for use with a refugee population or modified and adapted from research with general population studies. These clinical instruments aim to mark the presence or absence of specific symptoms, towards the diagnosis of conditions.

Important questions emerge about the validity and reliability of these instruments (Hollifield et al 2002). Problematically, these instruments approach trauma exclusively from a psychiatric paradigm, one that defines trauma as a form of pathology. Shaped in accordance with diagnostic criterion, the core dimensions that are being evaluated reflect Western concepts of psychiatric distress that are itemised into checklists and administered across populations (Lee and Young 2001, Mollica et al. 2001). Fundamentally, these instruments offer little opportunity to explore the nature of experiences that may be relevant to refugee health and refugee trauma from a local perspective, or within an alternate framework. Where there has been attention directed towards this, cultural expressions are critically dislocated from contextual factors, and condensed to mimic formal western

conceptualisations of distress. As such their appropriateness for use with certain populations, such as refugees comes into question (Hollifield et al. 2002).

Methods used in anthropology (ethnography and participant observation) challenge us to re-evaluate some of the categories and assumptions that are made in public health research. These elements warrant closer examination not just as a backdrop to competing discourses, but as to how frameworks of meaning intersect and interact with one another (French 2004). These methods can offer insights into the ‘insider perspective’ as well as shedding light upon the contextual elements that shape individual perceptions and experiences, allowing opportunities to reveal and produce new knowledge as people explore the assumptions and patterns within their experiences, and specific to their socio-political circumstances. Work of this nature has been successfully conducted across a range of populations including refugees and immigrants (Dossa 2002) across similar health-related concepts such as ‘stress’ (Pollock 1988) and ‘nerves’ (Davis 1988, Foss 2002), as well as more general experiences of coping with psychological distress and a clinical diagnosis (Estroff 1985).

For particularly elusive topics – such as the exploring the intangible experiences of distress and trauma – qualitative research methods can offer new insights into alternative understandings of experience (i.e. from outside of a psychiatric paradigm) and challenge perceptions or assumptions that may be influenced by or integrated with concepts from popular culture. By its nature however ethnographic research requires lengthy periods of time spent within an identified community (Agar 1980, Rabinow 1977). Ideally it is through extensive participant observation that insights into the nature of beliefs and perspectives can be explored within communities over time. The limitations of time and the

nature of new emerging communities may make this approach either impractical or difficult to achieve.

Qualitative methods that are jointly informed by public health and anthropology are more ideally suited to the exploration of contrasting perspectives and experiences around health and illness and may be helpful in refining understanding of health-related issues at local levels – how this transpires within peoples lives, identification of alternative manifestations of trauma at a social level and the strategies for resolution (Eastmond 2000). Open-ended research (whether in interviews or through the practices of observation and informal discussion) can help to improve our understanding of the lived experiences of trauma and psychological distress– which may or may not be interpreted as symptoms or defined locally by the use of medical categories or labels. Ensuring that there are broad and open categories operating allows for a greater representation of a range of definitions and experiences, allowing for greater differentiation of when those experiences may emulate symptoms, as well as when or where impairment begins.

Ideally, the insights and perceptions of competing discourses would best be explored through detailed observations in situ or analysis of interactions and practices as they have been documented via textual accounts. The exploration and analysis of discourse often relies upon an exposition of textual accounts (Potter 2004). For example in situations where naturally occurring discussions or dialogues may provide insights into specific perspectives but also allow for some illumination of the configurations and parameters that are sculpted through personal interactions. Documentation of clinical encounters between providers and refugees would be one way to illuminate the nature of trauma discourse as it plays out in their interactions and discussions. However, there are important ethical concerns inherent to

such an evaluation, such as issues of confidentiality and the maintenance of clinical integrity critical to such relationships.

Beyond ethical concerns, evaluating the nature of discourse within such encounters can be problematic however in that they reflect a particular framing of the interactions between provider and refugee, one that locates trauma and its meaning in a clinical context. Analysis of discourse within clinical settings may provide limited insights into ideas about trauma outside of a psychiatric perspective.

Document review and analysis formed a critical backbone to this research and the core data source of academic discourse within the thesis. Contemporary academic literature was examined across relevant disciplines (anthropology, psychology, medicine and psychiatry, and public health) to acquire some sense of the competing and contrasting perspectives that are operating here. Furthermore, to illustrate the ways in which academic discourse specific to the UK influences and helps to shape discourse ‘on the ground’ a discrete selection of academic papers (across professions and disciplines) was selected and analysed separately. In addition, semi-structured qualitative interviews were conducted with a diverse selection of service providers representing social and health-related services for refugees in London<sup>33</sup>; individual interviews with women refugees from an Albanian-speaking community in East London; field-notes of participant observation experiences with the women outside of the context of interviews<sup>34</sup>; as well as fieldnotes of observations at

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<sup>33</sup> All of the provider interviews bar one were individual interviews. The exception was the Refugee Counselling Centre. While originally scheduled as an individual interview, the nature of the setting (a staff kitchen) allowed for the transformation of a one-to-one meeting into a ‘group’ interview of two therapists from the centre, with a third individual joining briefly towards the end. The impromptu nature of this was valuable and allowed the staff to react to each other’s comments as much as they responded to my points of inquiry.

<sup>34</sup> I was fortunate to have the opportunity to interact informally with the women through events sponsored by the Besim project, through observation and participating in activities.

professional conferences and refugee community events. Ethnographic and participant observation completes the source data for this project, providing insights into the day-to-day context of resettlement for refugees, and the daily practices and professional exchanges experienced by providers in the field of refugee health in the UK.

This work seeks to gather a broader sense of the meaning of trauma beyond a clinical interpretation. Conducting directed interviews with providers and refugees offered an opportunity to actively explore respective ideas about trauma outside of this framing, considering how these concepts are (or are not) translated into practice. For providers this means examining the ways in which training and institutional philosophies inform the use of trauma as a particular concept in refugee health. For women, there is a greater attentiveness to how particular cultural concepts are embedded into perceptions of trauma. This work seeks to read the interaction between these particular perspectives and shed light upon the use of trauma in practice.

Given that the women targeted in this research represent a community-based, non-clinical sample (not recruited through medical or clinical services) individual interviews offers a valid context for the active exploration of women's experiences both in and outside of services. Through individual interviews, women refugees and health and social care providers working with refugees were able to offer reflections based upon the totality of their experiences, not limited in time and location.

Accepted qualitative interview strategies for uncovering competing ideas about health and illness include the use of 'illness narratives' to unpack individual insights into definitions of illness, and beliefs about diagnosis and treatment (Bury 2001, Kleinman 1988). In the

context of interviewing women refugees for this research, however, this particular approach seemed premature, imposing an interpretation of women's experiences of trauma and resettlement as an 'illness' experiences (which may or may not reflect women's impressions of their experiences). Resettlement interviews allowed for a modified personal history to be gathered, with questions directed towards specific life experiences (the processes of exile and resettlement, and interactions with health and social care). The sensitive nature of events associated with war and forced migration rendered more extensive life histories somewhat taxing for individuals already uncomfortable with the act of divulging personal details. Semi-structured resettlement interviews were less invasive in nature and enabled the women to exercise some control over the information that was revealed.

## Research Design

The research study design was divided into three phases. Each of these phases was marked by targeted data collection – so that a greater emphasis was on providers at one time-point (August 2002 to April 2003) followed by a period which was more focused on the experiences of the women (February 2003 to September 2003). The literature-based data was collected throughout the study (February 2002 to September 2003).

Ethical approval for conducting research with human subjects was obtained through the London School of Hygiene and Tropical Medicine Research Ethics Committee. See Appendix 6 for a copy of the ethical approval application form submitted to LSHTM and the certificate of ethical approval awarded for this research.

## Phase One

The first phase of the research involved a literature-driven inquiry into the conceptual and practical discussions that have emerged on 'trauma' and refugees within and across the sociomedical disciplines (psychiatry, psychology, medical anthropology, and public health). In addition, the shifting political discourse in the UK was considered through an examination of policies and perspectives related to immigration and the popular media. These form a prism through which understandings are filtered and refracted, shaping action and reaction of professionals working with refugees.

## Phase Two

Phase Two allowed for the preliminary identification of agencies working with women refugees and the Kosovar community specifically. Beginning with highly visible broad-based refugee community organisations, I identified the primary agencies working with refugees in general, with women specifically, and on the issues of trauma and refugee health. Through some of these core providers and through professional networks (established through conferences and other professional meetings) I identified geographical areas with high concentrations of refugee populations. Targeting local community services (not necessarily specific to refugees) allowed me to focus more directly upon the opinions and experiences of 'front-line' agencies and the professionals who are central to the trajectories of resettlement for refugees in the UK. Specifically, governmental and non-governmental agencies (NGO's) providing health and social care services for women refugees were identified and a sample of providers (n=16) recruited for semi-structured interviews. These interviews sought to elicit from providers their insights and working definitions of trauma, their experiences with refugee communities and the sociomedical

issues that they face. These interviews examine the philosophies and working practices that are operating on the ground level of social and medical services related to refugee health and trauma.

### Phase Three

The final and critical phase of the study was fieldwork with Kosovar Albanian-speaking women refugees or asylum seekers living in the UK. In resettlement interviews, women were asked about their experiences in coming to the UK, their use of health and social services, as well as their physical and mental health and that of their immediate families since coming to the UK. In addition, women were invited to discuss issues that they felt were of immediate concern, most notably their experiences with the asylum system in the UK. Participant observation was also conducted throughout the course of fieldwork within the community.

### Community Mapping and Participant Recruitment

The mapping of health and social care agencies and refugee communities began with the identification of a cross section of prominent agencies based in London serving refugees either on a regional or national level, and addressing issues of health or trauma for refugees. These resources functioned as a critical source of information about the nature of services specifically addressing refugee health and trauma. In addition to the identification of broad-based organisations, I began to identify services serving more discrete communities (neighbourhood specific health teams and advice agencies). Through these interviews I identified a loosely formed community of Kosovar refugees in East London. Women were recruited through community contacts (primarily through a London-based charity serving

the Albanian-speaking refugee and migrant community: The Besim Programme) and qualitative interviews were conducted about their experiences in resettlement.

Interview topic guides helped to shape the nature of the interviews, allowing for consistency across interviews<sup>35</sup>. Within both the providers and the women's interviews there was an attentiveness to the personal experiences of the individual and how they situated themselves in relation to the issues of refugee health and trauma (Dossa 2002). This data collection was by nature inductive, allowing the interviews to be dynamic in nature and to respond to topics and themes as they emerged. Finally, a critical backdrop to this work has been the inclusion of ethnographic observations across relevant settings (informal meetings with key informants, professional conferences targeting providers on refugee issues, 'hanging out' with women refugees in local groups, for example) over the course of field work (Agar 1980, Rabinow 1977). Documented in field notes, these observations serve to enhance the interview data, 'fleshing out' insights into the experiences and perspectives of providers and women refugees.

Service providers were targeted across *types* of agencies to gain some insight into the nature of services at both the primary and secondary health services levels, voluntary agencies (charities), as well as through locally-based community organisations (governmental and non-governmental). Sixteen semi-structured interviews were held with service providers. Providers selected to participate in a semi-structured interview were initially approached by letter explaining the nature of the research and the extent of their commitment, should they agree to participate. There were few formal refusals. However, there were a number of

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<sup>35</sup> Copies of the topic guides are presented in Appendices 7 and 8, for providers and women refugees respectively.

individuals whose failure to respond to any correspondence was considered indicative of a refusal, as were those who agreed and then failed to follow through.

More informally a sense of the wider discussions and debates engaged in by service providers was documented in ethnographic field notes of informal meetings with key people in services, documenting the local discourse(s) within London-based conferences on refugee issues (and specifically those addressing issues of refugee health), as well as pertinent research and policy briefs circulating from 'key' agencies serving the broader refugee communities, as well as localised borough or neighbourhood specific agencies.

Professionals from a range of agencies and services providing assistance to refugees and migrant communities in London were asked to participate in an informal interview.

The agencies involved covered a wide remit: from advice on benefits and immigration to the provision of direct health care and psychological therapy. This range was deliberate to ensure a breadth of perspectives and experiences. Providers in whatever their capacity had some direct contact with women refugees<sup>36</sup>. The interviews covered a range of topics including: their role and working philosophy, health and health care issues, psychological trauma; and social issues related to refugee resettlement in the UK.

Providers often strived to differentiate when they spoke on behalf of their employers and when they were putting forth individual perspectives or opinions. However, as is often the case with conversational interviewing, these lines may at points become blurred.

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<sup>36</sup> Many of the services worked with both men and women refugees. They were asked to give their impressions and talk about their experiences with the broader refugee population, and then more specifically with women.

Owing to this possibility, the names of all participating agencies and individual providers have been concealed to ensure complete confidentiality for disclosures or opinions expressed in the spirit of the moment.

The women were targeted through less formal means. Through interviews with service providers in East London I learned of a community of Kosovar refugees. One of the providers at the Besim Programme facilitated access and recruitment to Kosovar and Albanian women in an East London community through her professional and personal contacts. This provider was unique in that her role within the community was as an informal community leader<sup>37</sup> and a fellow refugee. Her endorsement of the research was critical to its success. As the initiator and organiser of a community-based programme for the Albanian refugee and migrant community, she was well poised to act as a key informant and was keen to support new projects that recognised issues facing her community. The recruitment of participants was in the context of formal and informal events sponsored by the Besim programme, as well as through the social networks of the women. Over the course of eight months I attended regular events run by the charity including women's groups, cultural events, and summer activities organised for children. The families that have taken part in these groups reflect the broader Albanian-speaking communities; including refugees and migrants from Albania and Macedonia as well as Kosovars. For the purposes of this thesis I will limit the discussion to the women who identify as Kosovar. To ensure complete anonymity all of the women will be identified as Kosovar only and not by any of the more specialised ethno-cultural identities that exist (such as Albanian, Serbian or

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<sup>37</sup> Deni would be unlikely to call herself a 'community leader', tending to minimise the position she has carved out for herself and the degree of influence she now holds within the Albanian-speaking community. Traditionally women would not hold positions of such influence within Kosovar society. The women are very consciously making use of new gender norms and rules and the possibilities this has for them here in the UK.

Roma). All of the women in this sample were last living in Kosova before exile<sup>38</sup>. While it is difficult to fully convey the range of personalities, perspectives and experiences of this group of women without revealing personal details, it is critical that their privacy is protected as completely as possible. As such individual identifiers have been kept to a minimum and all names have been replaced with pseudonyms.

### Characteristics of a Community in East London

'Downsview' (a pseudonym) is a borough within the city of London. A dramatic mix of cultures, the area is traditionally known for its successive waves of immigration. The region is known as a highly deprived local authority, marked by socioeconomic characteristics associated with poverty (Barer, Fitzpatrick, and Traore 2004). For example, the borough is noted for the highest proportion of 'economically inactive' population within London despite its relatively young population. While known for relatively reasonable housing costs, there is considerable overcrowding and substandard housing still in active use. These tend to be some of the features of regions that support newly arrived immigrants and refugees (GLA 2001). In terms of health indicators, recent data suggests that people in Downsview tend to be less healthy and use services more as compared to the general population in the British Household Panel Survey (BHPS). Rates of TB are one of the

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<sup>38</sup> The majority of the women would identify as being of Albanian origin, with some women identifying themselves as being of Serbian origin. Adding this more specialised ethno-cultural identifier would make it impossible to disguise the accounts of those few women of Serbian origin. Given the close-knit nature of this newly formed community, the use of these identifiers could expose the women and their families in ways that may be uncomfortable or upsetting.

highest in London, suggestive of both a highly mobile population, as well as substandard and overcrowded housing (Coker 2003).

My access to the Kosovar community came through a meeting with Deni, the woman starting the Besim programme. I had been given her name by the director of a local advice service for refugees in east London. Deni and I met to discuss my work and the self-help women's groups that she was running in Downsvie. The groups were informal chat groups that enabled the women and their children to meet on a regular basis, to share information and experiences, and to begin to develop a support network. The groups initially took place in two different settings, serving two specific neighbourhoods within Downsvie: Roxton Park and Edwin Avenue.

In both settings the women's groups were housed within existing community organisations. The group at Roxton Park was temporarily<sup>39</sup> housed in the Transfiguration Community Centre – a community centre attached to a local church. A permanent site for the Besim programme was established in the Edwin Avenue area, near a local library and a Sure Start<sup>40</sup> programme. The site allowed for close proximity between the programme administration and the weekly women's group.

Weekly events have continued to be run through the community centre at the Transfiguration church, most notably Mother Tongue (Albanian language) classes, Albanian

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<sup>39</sup> This was only during the start-up period of the Besim programme (lasting several months) while the site at Edwin Avenue became established as the primary location for the Besim women's group.

<sup>40</sup> Sure Start is a UK-wide government initiative to provide comprehensive child care services on a local level, with particular focus upon reaching marginalised populations and providing ongoing parent support. The Sure Start programme provided on-site crèche services for participants in the women's groups, as well as offering parenting courses to the women.

folk dancing and assorted summer activities for children in the Albanian and Kosovar communities. The close geographical proximity between the two sites (less than 5 km apart) has meant that the women were often involved in events at both locations. All of the events organised and sponsored through Besim work towards the following mission: *“to enable Albanian-speaking refugees, asylum seekers and migrants to: settle fully and participate in society; gain confidence and make progress in their life.”*

## The Women

Semi-structured ‘resettlement history’ interviews were conducted with 29 women refugees within an identified immigrant community in East London. For this analysis interviews with 25 women were examined. Four women have been excluded from this analysis as they were refugees fleeing Albania, and not the former Yugoslavia. The reasons for women fleeing Albania are different in nature than those women who have fled a situation of armed conflict, and may reflect differences in experiences of trauma. Interviews with the women from Albania were however important to conduct within the context of this community. Excluding these women from participation at the point of disclosure that they were Albanian fleeing Albania would have been more disruptive than beneficial. The community in which these women interact is a close knit one. Turning these women away could have implied that their experiences were less valid or their needs less critical. Alternately their exclusion in the data collection process could have been publicly perceived as identifying individuals as having gone through particularly stigmatising experiences (such as rape or torture), which in a small community could have adverse effects.

The individual interviews with women refugees focused upon their life in resettlement, and in particular their health, mental health and use of any relevant services. An Albanian interpreter was present for interviews to translate when necessary. The women ranged in age from 18 to 41, with an average age of 34. Almost all of the women were married and had children; one woman was unmarried and one was widowed. For a list of all of the participants, see Appendix 10.

The majority of women entered the UK in 1998 and 1999, corresponding with armed conflict in Kosova. All of the women who participated were ‘spontaneous’ arrivals, meaning that they were not sponsored through the UNHCR humanitarian relief effort. The majority travelled to the UK via lorry, with two arriving by ferry and two by train.

The women were recruited informally through a community based organisation, and ‘snowballing’ through the social contacts of one of the interpreters. As such this group is in a strict sense a ‘non-clinical sample’. However in the course of interviewing these women it became quite clear that the overwhelming majority either have been or currently are receiving some form of community-based mental health treatment. For a summary of the types of treatment received by women and primary family members, see Appendix 11.

All of the women were approached for consent with an interpreter present. Once they had given oral consent, they were asked to sign a written consent form. A sample consent form is provided in Appendix 12. Information sheets were prepared which outlined the specifics of the research. A sample information sheet is provided in full in Appendix 13. It is worth noting that the title indicated on both the consent form and the participant information sheet differs from that of the official title of the project. This was a conscious decision to allow

the topic of trauma to emerge in a natural way within the context of a more general discussion of health experiences and services that the women have received.

As part of the consent process, each woman was advised of the voluntary and anonymous nature of the study, the kind of questions that would be asked, the fact that the interview would be audio-taped, and the precautions that would be taken to protect the data.

Participants were advised that they could decline to answer any question(s) that they felt were too sensitive or intrusive, or to stop the interview at any time and refuse at any point to continue to participate in the research. 'Process consenting' (Sinding and Aronson 2003), a strategy where consent is confirmed throughout the course of the interviews, was employed. This ensured that the continued participation of women was based upon choice, particularly in the context of discussing sensitive topics. This notion of regularly verifying consent serves in a way a means of allowing the women to set the parameters of the discussion. This was particularly important amongst a group of women largely unfamiliar with research interviews – whose experiences of the acts of personal interviews (and being taped) may be reminiscent of therapeutic settings – or worse, interrogatory ones (Parr 1998)

Few women who were approached opted not to participate. Only one woman clearly articulated a refusal, as described in one of my fieldnotes.

D. and I approached another woman about being interviewed. She seemed reluctant and we talked in great detail about my research and what I was asking of her. She was really on the line. Initially she said she would talk a little, but then said that she was tired of being asked to talk about things that had happened – that it made her very sad and was not very helpful. D. explained that I would not do that to her and that she would not have to talk about difficult things. But the woman said it starts from the beginning – *'when you ask how many children do you have? And I have lost 2, they were killed in the war. So how do I explain how many children I have without explaining that?'* (Fieldnote 17/07/2003)

This articulate and poignant refusal manages to convey a great deal about the meaning of trauma in this woman's life. Moreover she highlights in a clear and assertive way the inability of 'talk'—something she had been repeatedly encouraged to do across settings -- to alleviate her profound sense of loss<sup>41</sup>

Other women were less assertive in their refusals, but nonetheless effective. These women refused in 'non-refusing ways'; not showing for scheduled interviews, or elusively agreeing to 'next time'. Because of the strong potential for 'social desirability' to influence their participation, women were formally approached on only two occasions for consent to participate in the research. Two coercive elements could have been at play here, influencing women's participation. Firstly, the lead interpreter was someone well-liked and perceived as influential within the community, as such there could have been a sense of pressure to agree. Secondly, several women noted that they would like to have an 'English' friend and subsequently could have felt that agreeing to participate could be helpful towards establishing a friendship or gaining assistance of some form.

Few of the interviews were conducted fully in English, with the majority conducted with 'consecutive interpretation' by a professionally trained interviewer (Sanders 2000). While this created a more complex interview setting, being active in the process of interviewing was helpful, allowing me to ask follow-up questions and raise new issues as appropriate. Temple (1997) has commented that the inclusion of interpreters or translating staff is more than simply a technical matter: the nature of translation has the ability to change the tone of

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<sup>41</sup> This assumption that participants may benefit from the interview process through the therapeutic value of 'telling their story' is one that often goes unquestioned in both clinical work and social research, often being actively encouraged instead (Agger 1992). This concept will be touched upon later in the discussion of the primary research findings.

the interview, affecting what is discussed and how. Every effort was made to minimise the intrusiveness of this effect through the careful selection and training of interpreting staff.

Two interpreters were used in total, with one woman (DN) interpreting for the majority of interviews. Over time, we achieved a balance whereby her role was more active in the research process as a collaborator and instrumental in identifying previously unexamined areas of inquiry, for example, the procedural twists and turns of women's asylum claims (Edwards 1998). She helped to shed light upon issues that she recognised within her community but were not always spontaneously articulated by the women themselves, such as shifting gender roles. In addition she helped to inform me about the broader cultural features of Kosovar society, which are explored in detail within the field notes.

Following interviews, informal 'de-briefings' took place between the interpreter and myself. This was an opportunity to discuss any difficult moments that may have emerged during the interview -- for example, women often became quite emotional and would cry -- as well as an opportunity for the interpreter to openly give their impressions and for me to raise questions about the discussions that took place within the interviews, as well as broader issues, such as cultural expectations, gender roles, or community experiences.

The nature of conducting research within this community meant that interviews were conducted when and where circumstances permitted: sometimes in the privacy of a respondent's home, at other times in a make-shift interview 'room' in a community centre or church hall. Children were inevitably not far away in either circumstance and this is likely to have impacted on both my willingness as an interviewer to probe about sensitive matters and the ability of the women to express themselves fully and without restraint. Despite the limitations or constraints on interviewing, women allowed themselves to discuss intimate things and, at times, in very frank and emotional ways. The intention of the

interviews was to establish to some degree the nature of women's experiences in the UK – post-exile, therefore their experiences in the context of resettlement remained the primary focus.

## Data Coding and Analysis

All of the interviews with service providers and with women participants were taped and transcribed. These documents were then converted for in Atlas-ti files to enable data coding and analysis (Muhr 1999). All reasonable protections against loss of confidentiality have been taken for all research participants, including key informants. All interview subjects were assigned a number as the only identifying marker for their interview. All field notes, interview notes, and interview transcripts were anonymised, identified only by an assigned number. Respondent names only appear on written consent forms, which are not linked with their numerical alias. Personal identification data has been kept separately from other data and all data has been held in a secure location with the London School of Hygiene and Tropical Medicine.

Individual interviews and fieldnotes were read and re-read to allow complete familiarity with the data set in its entirety, and to confirm narrative consistency within individual interviews. This review process also helped to shape preliminary codes. The process of coding also relied upon the specific themes spelled out in the Interview Guides that had been developed and used (see Appendix 7 for the interview guide for interviews with providers, and Appendix 8 for the interview guide used in interviews with women respondents). These guides allowed for a directed and consistent coverage of the domains that were the focus of the actual interviews. Additional codes were developed to

accommodate unforeseen topics that had spontaneously emerged in the course of interviewing.

Reviewing the transcripts helped to formulate a preliminary sense of the overarching themes. These themes helped to give shape to initial codes which were then applied to the transcripts in preparation for analysis. All of the interviews were coded using an initial set of 'open codes' using the qualitative program Atlas-ti (Muhr 1999). The codes covered core domains such as: working definitions of trauma; concepts of aetiology; manifestations of trauma – behavioural and verbal; the nature of trauma impact (temporary versus permanent; point of onset). Codes were expanded, broken down or merged to capture a greater sense of the patterns emerging in the data (Pope, Ziebland, and Mays 2000). For a summary outline of the initial codes used in the analysis, see Appendices 14 and 15.

Appendix 14 reflects the initial codes applied to the transcripts of the provider interviews, and Appendix 15 contains the initial codes applied to the transcripts of interviews with women.

Theoretical 'memos' – a strategy used in Grounded Theory – were a tool used to elaborate upon the ideas that emerged during coding and the reviewing of transcripts (Corbin 1986). Theoretical memos are essentially detailed examinations of emerging themes, with an eye towards the delineation of patterns and relationships within the data in relation to the primary research questions. This process relies upon the practice of constant checking and confirming against the raw data.

As hypotheses emerged about conceptual frameworks attention was paid to detailing the conditions that shape a given discourse and the ambiguous or contradictory elements that

exist. Comparison between the core data sets lies at the heart of this analysis. The use of theoretical memos helped to map out the relationships between working definitions and understandings of trauma and relevant clinical or socio-cultural responses.

## Study Limitations

The small-scale nature of this research may limit the generalisability of the research findings. Studies of this nature, while offering insights into the complexities of women's lives, offer at best only a snap-shot perspective and are limited by temporality (Dossa 2002). An issue that has been noted as a potential bias or limitation is the uniqueness of this sample of women. Kosovar women who have resettled in the U.K. following forced migration may represent a relatively small number of women refugees from Kosova. It could be argued then that the experiences of these women are unique and offer few contributions to a broader understanding of trauma and resettlement post-conflict.

However, the construct of gender roles such as those found in the Former Yugoslavia share common features across patriarchal societies. Anthropological evidence has long noted the ways in which women's experiences (particularly around sexuality) have been linked with broader constructs of identity, nationhood and the systems of honour and shame (Denich 1974, Ortner and Whitehead 1981). In addition, the nature of life events experienced by the women share common features with those of other situations of conflict, including significant loss and sexual violence (Brownmiller 1976). Recent conflicts elsewhere dramatically illustrate the commonality of sexual violence (Kelly 2000). Moreover, issues of stigma related to these issues are by no means isolated. Rather stigmatisation associated with women who are victims of rape is again found across cultures and contexts. These

shared features would suggest that some of the themes that have merged through this research could have application to the experiences of women elsewhere.

From a methodological standpoint, recruitment for this study has brought with it certain limitations. Recruitment of providers was shaped by a willingness and ability to devote time to being interviewed. There were a number of individuals who expressed an interest in participating only to find that their heavy professional schedules left them unable to meet during the period designated for data collection. Alternately some agencies have found themselves inundated with requests to participate in ongoing research studies (including doctoral work) and have opted to limit their involvement to non-student projects only. The providers who did respond and were interviewed are likely to represent a group that is not only interested in the issues covered within, but perhaps more likely to engage in a reflective process about the nature of their work and working practices. An anonymised list of the providers who participated in this research, specifying their professional position, the type of agency they worked for and the population they served is contained in Appendix 9.

The women participants represent a non-clinical sample of spontaneous refugees arriving in the UK. However as is common to much research within refugee communities, recruitment has relied upon contact with locally based agencies, such as the Besim programme (Bloch 1999a). As such the make-up of women participating in the study may reflect a particular cluster of women, and may not reflect the broader composition of the Kosovar community. There is an under-representation of single women without children in this sample. Whilst this may reflect the culture issues highlighted previously (strong social pressure to marry and have children), it may also mean that this community is comprised of a certain slice of Kosovar society. In the aftermath of conflict there are without doubt women who are made

widows or are travelling without close family members. This research does not fully represent this segment of the population. As well some women refused participation in the research study. This may pose a bias to the research. Women with particularly sensitive narratives of trauma may self-select out of the research.

## Reflexivity

“Are you a girl, or are you a woman?” (*Kosovar expression*)

In my work with women in a Kosovar community in London, there were both cultural advantages and disadvantages. As a foreigner living and studying in the UK I was able to share many informal observations with the women about life in the UK and the peculiarities of life in London. This helped to establish a comfort level based on ‘shared experiences’. However there were obvious differences in lifestyle and beliefs that quickly emerged, casting me as quite different from the women in key ways.

Marriage and having children are pivotal events within Kosovar culture. For women being married and having children (especially sons) confers a sense of status and functions to some degree as a marker of the transition into adulthood, as evidenced by a popular expression noted above (where womanhood is achieved through childbirth). As a single woman without children (and studying for a PhD), my societal role was not always clear to the women. A number of women seemed simply perplexed by my unmarried status, while others comfortably ‘explained’ this as a cultural difference. What was accepted in terms of me and my life would be unlikely to be condoned for a Kosovar or Albanian women in their

community. For example, there was some anxiety for women in their early twenties who were without an appropriate pool of potential spouses (the only single young men being in their teenage years at the most). Nonetheless there were moments when issues about marriage and children surfaced, where I was pointedly asked (over and over) why I was unwed or gently teased about the need to find a husband. In my continued involvement in the Kosovar community, this does still emerge from time to time. For the most part this is a minor issue certainly. The women gave me the benefit of the doubt and accepted me into their lives, despite whatever reservations they may have harboured. Had I been married or had children, however, it may have opened up additional areas of discussion. Fortunately, during the course of my fieldwork with the women I was also engaged in research on the experiences of new mothers in the UK, this at least provided me with some insights into reproductive health concerns and issues related to parenting, and some sense of the nature of relevant services in the UK.

Representing the lives of women refugees in resettlement, as well as the range of viewpoints and experiences of providers who work with refugees can be a challenge. With any research of this nature there is a danger of making perspectives appear rigidly defined on paper as opposed to fluid and dynamic. Through conversations and observations outside of the context of formal interviews I had the opportunity to confirm impressions and explore ideas more fully. Language was a recurring issue in conducting the fieldwork with women. I was fortunate enough to conduct many of the interviews in English, and it was clear in the interviews with interpreters that the women generally understood more English than they were comfortable speaking. However, my inability to speak Albanian meant that there were points both in and out of interviews where I was unable to bridge the cultural divide between myself and the women.

Previous research experience can carry advantages and disadvantages. Having a history of work experience in psychiatric research ensured that I was familiar with many of the standard concepts in Western psychiatry, including the terminology of diagnostic categories and a knowledge of medications and forms of therapy. Having spent a great deal of time eliciting the perspectives of ‘psychiatric consumers’, I felt confident about my ability to elicit the unique perspectives of distress and trauma that women refugees held. Initially however, my knowledge of Western psychiatry may have worked to my disadvantage. Unlike identified users of formal mental health services (‘psychiatric consumers’) the women were not fully engaged with an extensive vocabulary of personal psychology, which at times translated into a poverty of terms to describe their experiences. During the initial phase of data collection an interviewing reflex I experienced was to turn to my knowledge of mental status exams and a checklist of standard symptomatology. This was something that I needed to be conscious of within the interviews and not lead the women into the use of standard psychiatric terminology.

In addition, it became clear over time that in the process of interpreting, both women interpreters were trained to use a vocabulary that included medical and psychiatric terms that the respondents themselves may not have thought to use. Working with one interpreter over time meant that the nature of terminology did change somewhat, with a greater emphasis upon a more literal translation of words and phrases used by the women.

However the women themselves often relied upon many terms that they have learned in resettlement. All materials quoted in this text reflect the vocabulary used by the women themselves. In discussions, the women were asked about specific terms that might be used to describe trauma in Kosova, the women emphasised a lack of native terms. This poverty of expression was often spoken of as a contrasting of their home culture and UK culture.

The women suggested that life in the UK required them to learn a new conceptual language as well as a practical one.

Individual interviews formed the core of this research, providing insights into the perceptions and interpretations of providers and women as they are transformed into practices on the ground level. Whilst most providers were well-versed and comfortable with the processes of interviewing, the women's experiences were often restricted to formal scenarios such as immigration hearings, meetings with attorneys and clinical meetings with health professionals. The manufactured nature of a research interview means that it is something quite unreal within an individual's life: not simply a conversation, but at the same time not clearly something of instrumental value to the person being interviewed. Inevitably in the process of conducting these interviews there is in effect a replication that occurs, which draws upon the more formal experiences of interviewing.

Research interviews with the women about their experiences in effect reproduces the nature of their previous exchanges with health and social care professionals, despite the best intentions. I was very conscious of the need to forge some distance from the structure and form of these exchanges which are a customary part of resettlement for these women. Initially I felt a greater need to ensure that a distance was achieved between my interviews and those conducted related to asylum and immigration claims. Adopting a more conversational format to the actual process of interviewing and a willingness to explore topics that the women defined as pertinent to their resettlement (i.e. the adjustments that their children are going through, their experiences with attorneys and the appeal process) helped to move away from the tone and format of their previous experiences in interviews. While I strived to ensure that women had greater control in determining what they revealed,

there is an inevitable pressure that exists within the interview setting where people may feel that they have less control and a sense of obligation to disclose. Women were nonetheless called upon to reveal aspects about themselves, their families and their lives. In this sense the interviews unintentionally mimic the essence of clinical exchanges in particular, where women are called upon to disclose critical aspects of their lives as part of a therapeutic process. As the study progressed and I came to question the value of 'talk' as a therapeutic strategy, my assumption about the benefits for women in participating in the research interview was, therefore, also something to question.

Little was asked about specific events encountered in the context of the war. All of the women had experienced events in the course of fleeing Kosova that could be defined as 'traumatic' whether restricted to the loss of homes and livelihoods to separation from family and friends or to the most severe experiences (sexual violence, torture, witnessing events). A number of women spontaneously revealed experiences of sexual violence, and almost all commented on experiences of suffering in a broader sense, along with the issues of loss and struggle. In the course of conducting field work in this community I learned that the decision not to question the women *directly* about specific wartime experiences had been a good choice. Many were understandably uncomfortable talking openly about the events that they experienced or witnessed in Kosova with someone that was a stranger. Yet many of the women's experiences in the UK have involved an expectation that the women should reveal very intimate things within a short period of time. First, this emerged in terms of providing detailed accounts of their experiences for asylum claims; and secondly, in the context of health and social care assessment interviews<sup>42</sup>. It was particularly important to distance

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<sup>42</sup> Failure to disclose 'quickly' within immigration proceedings may cast doubt about the validity of experiences, whereas in health care, non-disclosure may acquire a pathological aspect, as evidence of 'denial'.

myself from any association with these roles. By adopting this approach I allowed women the opportunity to discuss particularly difficult experiences as they saw fit, but not to impose the expectation to do so. Many of the women did share details of their lives that are extremely personal, including their experiences of war, their journey into exile and their experiences in terms of mental well-being.

As is the case with ethnographically-directed work, issues emerge about the boundaries between research and personal interactions. Friendships have emerged from the fieldwork, which has meant that I have been privy to a different level of insider experience. As a friend or even close acquaintance, people have allowed themselves to talk freely about issues that they may not have before. 'Providers' who become friends could choose to reveal more about the inconsistencies and professional frustrations they experienced within their roles, and the pressure to respond to refugee health issues in specific ways. Women participants have invited me into their homes and shared very personal aspects of their lives, things that may contribute to an understanding of trauma and certainly to an understanding of issues that come with resettlement. These difficulties were present during the data collection of the field work. For me, one day this comes to the surface when another researcher approaches Deni and the women to participate in a study.

Once the group ended, Deni and I spoke about this [another research study] for a moment. Then she said there was a new and growing interest in Kosovar women! We joked about what it was like to be so heavily studied. But I have to say the whole thing made me uncomfortable especially as my role there increasingly shifts and fluctuates from researcher to friend [Fieldnote June 17, 2003].

The transition of my relationship – with Deni in particular – moved from researcher to collaborator to friend in the course of the study. At different points the issue of keeping field notes of my impressions and observations became an issue for me: what situations

were noted, and what ones were not? I resolved this by continuing to note my observations and impressions, feeling that it was better to err on the side of comprehensiveness. Any materials that I felt were inappropriate for inclusion in the data were excluded from analysis.

For both providers and the women, the sometimes unclear boundaries of relationships may have also contributed to a greater reluctance on my part to challenge inconsistencies as they arose within the interviews, or to push for greater clarity in responses. At the same time there is considerable value in the dynamics that became a part of the interview process, allowing for a greater sense of intimacy in addressing topics that were at times wrought with heavy emotions.

## VI. TRAUMA AND REFUGEES

The circumstances that shape refugee experiences vary by situation, geography and conflict. Yet there are persistent commonalities of loss and injury that accompany the journey out of conflict and into exile. It is more specifically the extreme events of conflict that underscore current conceptualisations of trauma for refugees. Physical torture and sexual violence have, in particular, assumed a prominence in discussions about the aetiology of trauma related to conflict and forced migration. For example, sexual violence is increasingly underlined as a gendered experience of trauma for women refugees (Kelly 2000). This accenting of extreme events makes the use of the term 'traumatic' seem both natural and inevitable when describing the core events that make up the refugee experience.

Accompanying this is the widespread belief that these events lead to profound psychological distress; understood as capable of psychologically 'unmaking' individuals (Scarry 1985).

The prominence of these concepts has contributed to the dominance of a psychiatric paradigm in defining and understanding trauma itself. For refugees this has meant a marked emphasis upon particular notions of distress and its manifestation, largely coinciding with the symptomatology of traumatic stress, embodied in the diagnosis of PTSD.

### Public Health and Epidemiological Perspectives

As outlined in the history of trauma, paradigms of trauma have undergone dramatic conceptual shifts, reflecting new insights and understandings over time. In public health and epidemiology, much emphasis has been placed upon PTSD as an indicator of distress and suffering experienced by refugees (Favaro et al. 1999, Hollifield et al. 2002). Despite the growing recognition of co-morbid psychiatric disorders (i.e. depression) (Silove et al. 1998)

and efforts to re-think the application of fixed categories of traumatic stress (Eisenbruch 1991), PTSD remains the highly visible standard of trauma against which refugee experiences are measured. Public health's exploration of refugee health and trauma has been primarily fixed upon two core areas: epidemiology and health promotion.

Epidemiological research into refugee health issues has sought to establish the extent to which refugee populations are experiencing psychiatric morbidity related to trauma, and health promotion has emphasised the implementation of clinical interventions to alleviate symptomatology and diminish the long-term impact of conflict related trauma.

Using Western definitions of psychopathology (as laid out in the DSM and ICD) there is a considerable body of work in public health which suggests that refugee populations experience substantial rates of psychiatric morbidity overall (Narrow et al. 2002, Neugebauer 1997, Orley 1994). The concept of 'trauma' in particular has come to be understood in terms of psychiatric morbidity, commonly in the form of Post-Traumatic Stress Disorder (Ai, Peterson, and Ubelhor 2002, Kivling-Boden and Sundbom 2001, Weine et al. 1998b). PTSD has been a particularly influential concept, linked with definitions of trauma across populations and situations. For refugees this has come to be reflected in the broad designation of them as a 'traumatised' population, regardless of unique contextual factors or population-specific experiences.

Prevalence rates of PTSD for refugees range from relatively low population rates to virtually endemic depending upon the context, specific population, and tools of assessment. The unevenness of findings has been extreme with some research demonstrating rates as low as 4% (amongst Vietnamese refugees in Australia) to near endemic rates (86% amongst Cambodian refugees in the US) (Hollifield et al. 2002). More recently Mollica and

colleagues (2004) have documented prevalence rates of PTSD ranging from 17.1% amongst Kosovar Albanians in Kosova to 37.2% amongst Cambodian refugees in Thailand. Subsequently, despite the dominance of PTSD as an area of inquiry in refugee health, the epidemiological data remains, at best, inconclusive. In addition to the charting the epidemiology of PTSD, public health researchers have sought to delineate the overlapping relationships that trauma holds with other conditions, including depression and substance use. Amongst refugee populations, excessive rates of depression are also noted. However, depression has been primarily considered a “co-morbid” diagnosis that accompanies PTSD, seldom receiving attention as an independent disorder from trauma for refugees (O'Donnell, Creamer, and Pattison 2004). Where depression is noted the prevalence rates vary considerably: from a ‘low’ of 39% for Bosnian refugees in Croatia to 67.9% of Cambodian refugees in Thailand (Mollica et al. 2004)

Despite fluctuations in the epidemiological data, discussions on the impact of conflict and political instability, often paint a portrait of extreme and profound psychological impact. For example, one study of women and children in post-war Afghanistan suggested a “lasting legacy” of near-permanent psychological damage as a result of experiences of conflict (Bhutta 2002). Other assessments of PTSD in specific conflicts point to exceptionally high rates of the disorder, some virtually universal. A study of civilians in post-conflict Sierra Leone documented endemic rates (99%) of psychiatric disturbance “indicative of severe PTSD in western Europe” (de Jong et al. 2000). These elevated rates may, however, be more indicative of the *presence* of ‘trauma-related symptoms’ at specific phases, rather than full-blown conditions.

These research studies raise key questions about the evaluation of symptoms and diagnoses related to trauma. Many studies are conducted during the acute phase immediately following conflict and so may reflect the uncertainties of that time rather than the presence of clear and persistent psychiatric conditions. The fact that much of the epidemiological data on PTSD amongst refugees has been gathered in the context of refugee camps, or in situations of close proximity to conflict, would seem to support this perspective (Silove 2004). Moreover the high rates of PTSD documented amongst refugees may be less a reflection of consistent patterns of psychiatric morbidity, but rather represent the tactical use of diagnostic categories by clinicians to facilitate access and the allocation of resources through “talking up the numbers” (Stubbs 2004, Watters 2001).

Recent work that examines psychiatric morbidity amongst refugees may challenge previous epidemiological findings and contribute to a more nuanced appreciation of the symptoms that persist over time and across settings. The few longitudinal studies that have been conducted with refugees indicate perplexing trends as psychiatric symptoms intensify for some individuals and abate for others over time in post-conflict settings (Lie 2002, Mollica et al. 2001, Weine et al. 1998b). These studies do however point to critical areas for further exploration and may provide insights into situations and experiences that specifically correspond with a psychiatric model of trauma. Research on the experiences of refugees in Sweden, for example, indicates that the continued experience of PTSD symptomatology over time was strongly associated with poor adaptation to the host environment, rather than specifically linked with events in conflict (which is at the heart of aetiology for PTSD). Those individuals who had had limited participation in the labour market, a lack of fluency in Swedish, and the absence of a meaningful social network were more likely to experience

greater psychiatric symptomatology (Kivling-Boden and Sundbom 2001, Kivling-Boden and Sundbom 2002).

Research on the epidemiology of PTSD amongst refugees raises fundamental issues about the nature of cross-cultural psychiatric research. While issues of validity in epidemiology are not new, methodological errors may be more likely to surface in the course of transcultural epidemiology (Van Ommeren 2003). Questions have emerged about the construction of core concepts and whether Western notions (and descriptive features) of a psychiatric model of trauma can accurately demonstrate validity, reliability and relevance in other settings and amongst non-Western populations (Eagle 2002). The interrogation of these issues has led to some divergence within public health on the cross-cultural application of PTSD as a diagnosis to capture experiences of trauma and traumatic stress.

Methodological questions have surfaced about the validity of measurement and the ability to translate psychological and emotional concepts of distress cross-culturally (Westermeyer 1985). The diagnostic frameworks which guide epidemiological research in this area are fundamentally based upon a Western perspective with little attention to culturally constructed features and understandings (Kirmayer and Minas 2000). As a result the definitions and categories used to indicate the presence of pathology are entrenched in one particular viewpoint, leaving little opportunity for variation in terms and meanings. This may confound and compromise research leading to erroneous assumptions based upon faulty data.

Cross-cultural psychiatric epidemiology has been guided by the drive to establish uniformity in assessment and to enhance the ability to conduct international comparison (de

Jong, Komproe, and Van Ommeren 2003). However assumptions about uniformity may undermine the integrity of research in this area and subsequently fail to reflect alternate understandings of health and illness. The framing of symptoms of distress within a psychiatric paradigm and reliance upon western understandings of health and illness can fail to encompass the impact or influences of a myriad of socio-cultural features. This remains problematic when considering mental health issues for refugees who reflect a continuum of experiences, beliefs and backgrounds (Bibeau 1997, Stubbs 2004). This tension – between the reliance upon a specifically western psychiatric model of trauma and one more inclusive of diverse perspectives on the nature of experiences and manifestations of distress -- creates an uncertainty in public health around the epidemiology of trauma and its importance as a health issue for refugees.

These fundamental debates about definitions of trauma and the extent of psychiatric morbidity have implications beyond epidemiological surveillance, informing the nature of health promotion and intervention, an integral part of public health work. While there is an accepted link between traumatic events and psychological distress, the nature of how to intervene (in view of prevention and treatment) remains less clear. Conventional techniques for alleviating symptoms and conditions include therapeutic talk, psychopharmacology, and cognitive-behavioural techniques to name but a few. Counselling, or talk therapy has in particular assumed a dominant position as a means of intervention for trauma and distress. Original ideas about therapeutic talk emerged out of psychodynamic traditions in the form of psychotherapy (Neill and Ludwig 1980). Less formal ‘talk’ strategies such as psychosocial counselling have emerged out of grassroots efforts to re-locate therapy in non-professional sectors. Emerging out of an early framework of peer led services, this premise of ‘counselling’ (attributed largely to the work of person-centred theories of Carl Rogers),

was to offer non-judgemental and non-specialist support to people encountering an array of mental health or 'life problems' including alcohol and drug use, domestic violence and family conflict as well as other health and social issues (Rogers 1951). In part the construction of this role of the counsellor was to offer support that was more experiential in nature and less theoretical, reflecting shared experiences. Along with psychopharmacology, 'counselling' has become the hallmark of modern psychotherapeutic intervention. These forms of intervention operate in highly individualised ways, quite contrary in nature to the population-wide interventions historically associated with public health.

Psychosocial interventions have however grown commonplace as part of the international (Western) response to conflict and forced migration. Trauma counselling services have become a common component of international programmes directed at refugees. These programmes have, however, come under fire in recent years, as questions arise about their appropriateness for refugee groups worldwide (Summerfield 1996). The value of these programmes has been debated, raising once more core conceptual issues in the framing of trauma and mental health issues cross-culturally.

## Anthropological Perspectives

Anthropological studies of illness and suffering contribute alternative 'ways of seeing' the concept of trauma amongst refugees. Studies of 'social suffering' in medical anthropology offer a new framing of violence and critical events associated with conflict, and the meaning these events take on for individuals, communities and states (Das and Kleinman 2001, Kleinman 1995). The tensions that emerge between individual and social representations of distress is something that has been actively explored through ethnographic research on the

experiences and impact of political conflict and terror, as well as the more muted forms of violence and suffering that exist within the structure of everyday lives (Feldman 1991, Olujić 1998).

Conceptualising illness, disease and healing, is at the core of understanding perspectives on trauma, as well as questioning the explanatory frameworks that accompany the roles (and practices) of provider and patient (Kleinman 1981). Much of the emphasis has been upon challenging existing assumptions and uncovering the interactions between medical and lay discourses, how they operate with or around each other, what are the localised ('emic') understandings of how trauma is defined, interpreted, manifests and is addressed across discourses (Boehnlein 2002). Insights into these aspects of illness and disease are at the core of anthropological and cultural studies of social suffering (Breslau 2004, Kleinman, Das, and Lock 1997).

The literature on 'social suffering' raises new questions about the applicability of a psychiatrically charged paradigm of trauma in the lives of refugees. Specifically this work draws attention to the micro and macro features of the social, cultural and political landscape which contribute to experiences of suffering, challenging the perspective which locates trauma within the individual (Das and Kleinman 2001, Green 1998). Pivotal works include the exploration of the impact of sustained violence upon or within distinct communities (Feldman 1991, Jenkins 1991), challenges to our understandings of specific forms of violence, for example 'wartime rape' as opposed to 'peacetime rape' (Olujić 1995b, Olujić 1998); the uncertainties of life in displaced settings for refugees (Malkki 1995b); and the way in which societies 'make sense' of violence within the structures of everyday life (Ferre 2001).

The exploration of social suffering has sharpened the examination of discourses on the meaning of psychological trauma at individual and societal levels, tracing the ways in which these have interacted, and in some cases fused. Jenkins (1998) summarises the intent of much of this work as investigating: the structures that promote and sustain violence (across a continuum of forms); the ways in which this is embodied on an individual level; and the specific dimensions that follow according to situational or demographic factors. This reflects more than simply an examination of medical versus non-medical perspectives: it is an effort to understand health, illness and distress across and within structures – how traumas are expressed and lived within the everyday, particularly for ‘marginalised’ populations such as victims of political violence and conflict (Feldman 1991, Kleinman 1995).

An alternative explanation (beyond a psychiatric paradigm) of the meaning of trauma offers particular insights into people's lives, and about how people make sense of suffering. Coker (2004) for example in her ethnographic work with Sudanese refugees in Egypt, explores how dislocation and trauma are experienced and expressed via descriptions, narratives, and metaphors of illness. Within a perpetual state of uncertainty, people struggle to define and reclassify themselves and their cultural practices. This operates as a means of re-configuring identity of self and community where the body functions as a location for expressing ‘loss’. She notes that for these individuals there is no pre-existing vocabulary or cultural script for expressing what they are experiencing. However, there are bodily experiences that carry reflections of their culture of origin and can be used to articulate the metaphors of pain and hurt. In the process of this work, she raises pertinent questions about the conceptual paucity of the term ‘somatisation’. Whether or not the symptoms that emerge constitute a measurable disease is somewhat irrelevant. She explores instead the

ways in which “*illness becomes an avenue for discourse about the refugee trajectory*” (Coker 2004:19). The explanatory model she proposes is more complex than a dichotomy between somatised distress and verbalised (psychologised) distress which often emerges in a psychiatric reading of distress. What emerges instead are interrelated existential and social traumas that appear in physical actions and experiences and more importantly are understood to reflect the current anxieties that are experienced by an individual, living ‘anguish through the body’.

Through ethnographic explorations of trauma amongst refugees, links are established between disease, illness and healing systems along with the dynamics of power, agency and social relationships. These themes play out in nuanced ways where social influences and cultural meanings merge to create the expression of physical and psychological ‘idioms of distress’ (Nichter 1981). Emotions and experiences related to situations of powerlessness may come to be expressed through a range of physical and psychological mechanisms, for example ‘nervousness’ or ‘dizziness’ (Nichter 1989).

These may function as metaphors, symbolic of broader social relations and inequalities, or represent culturally sanctioned ways of articulating struggle or unrest, as well as more epistemological debates about ‘being in the world’. Ethnographic work exploring the experiences of homelessness and mental illness in the United States, for example, highlight the complex relationships that exist between states of being for individuals who are faced with an encroaching ‘clinicalisation’ of their daily lives (Desjarlais 1994, Desjarlais 1996). Diagnostic designations come to form a core part of an explanatory discourse for the experience of homelessness in addition to whatever emotional or psychological issues the individual may be facing. Lynn-Callo (2000) echoes some of these sentiments where

homelessness and mental illness become merged in discourse, evidenced by structural practices that promote the individual as a clinical ‘cases’.

Understanding the meaning and means of expressing trauma on local levels helps to also shed light upon the means of community-based resolution. For some populations -- victims of political or state sanctioned violence, refugees, or victims of violence related to identity or sexuality, for example -- there is believed to be a therapeutic value at the individual level as well as a judicial element on a broader societal level to the making public of traumatic events and their after-effects (Chopp 1986). For example, the merging of public and private narratives of suffering through ‘truth and reconciliation’ hearings stands as one example of the chaotic interrelationships between individual and collective traumas (Scheper-Hughes 1998, Wilson 2000).

This merging of individual and community interests also figure prominently in the discourse around refugees and trauma – promoted as evidentiary of the need for asylum, as a mechanism of social justice, and fundamentally, having clinical (psychological) merit (Salis-Gross 2004). In this sense, ‘particularized understandings’ of trauma and resolution help to make sense of what are the implications of beliefs, practices and discourses across social levels, contributing to the debates on trauma and refugees through a complex reading of the micro and macro interpretations of suffering (Feldman 1991). For example, situating refugee experiences within specific socio- political contexts helps to illuminate the individual and social functions of particular discourses on trauma, health and refugees in general. A challenge however, is how to link anthropological insights appropriately with public health perspectives on trauma, and effectively bridge ideas that are localised with

ones that have population-wide implications. This remains an inherent part of the struggle in conducting cross-disciplinary academic and clinical research.

Anthropology has helped to illuminate some of the issues around perceptions of trauma, offering important insights into the ways in which refugee health issues specific to trauma are defined and understood beyond a psychiatric paradigm. Within the field there has been a marked attentiveness to broader understandings of trauma and suffering – beyond individual psychopathology towards interpretations that are more cognizant of socio cultural dynamics and influences. A challenge for anthropologically informed work has been to reflect on larger trends operating cross-culturally, which may contribute to understandings of refugee health and some of the shared elements of distress and trauma that may exist across contexts.

Public health and anthropology offer distinctive readings on trauma, influencing academic discussions and the perspectives of practitioners working in the area of refugee health in noteworthy ways. Common to both perspectives is a somewhat unresolved relationship to the psychiatric paradigm on trauma. Public health has largely focused upon the epidemiology of psychiatric trauma amongst refugee populations, with an emphasis on the presence (or absence) of psychiatric symptomatology, often as defined within the diagnostic category of PTSD (Friedman and Jaranson 1994, Neugebauer 1997). There is however, considerable debate within public health about the usefulness of PTSD as a clinical construct, and a growing sense of disquiet at the popularised use of this concept as interchangeable for ‘trauma’.

Core methodological issues have been raised about the ability to define and evaluate experiences of trauma in universal ways. The implications of these conceptual issues in relation to the development of interventions remain a highly contested area. These ongoing issues in public health and anthropology help to shape disciplinary perspectives for professions working within refugee health, shaping academic and clinical discourse that is currently operating within the UK with respect to trauma and refugees.

## VII. ACADEMIC AND CLINICAL DISCOURSE IN THE UK

Academic and clinical discourses pertaining to health, trauma and refugees include a combination of perspectives and philosophies ranging from biomedicine and psychiatry, via psychodynamic and social psychology, to socio-cultural and medical anthropology. These perspectives vary in defining philosophies, tone and nature. Across these orientations there is considerable debate about the meaning of ‘trauma’ generally and its meaning in reference to the experiences of refugees more specifically. Incorporated within each perspective is a consideration of the scope of clinical intervention techniques and strategies and their applicability (and suitability) across socio-cultural contexts and populations.

In a strict definitional sense, “academic” discourse centres more upon the exposition of theory, whilst “clinical” discourse investigates more of the pragmatic issues that relate to meaningful intervention and treatment. In reality, both academic and clinical discourses strive to link theoretical models with practical insights that emerge through a combination of action and theory driven research (Stubbs 2004).

There is considerable mutability across disciplinary perspectives, which finds many academics and clinicians displaying fluidity in the perceived and actual roles that often accompany professional domains, and in exercising choice related to theoretical frameworks. There is in fact a strong collaborative relationship between fields and disciplines, with many of the stakeholders engaging with discourses on trauma and refugee health across multiple levels as researchers and clinicians simultaneously. In this sense, any division into discrete categories or models of theory and practice is an artificial one. There

is some value, however, in separating out disciplines in broad terms for exploration and comparison, allowing for some discrimination across central themes. Within the UK three broad areas of academic and clinical discourse emerge as most relevant to refugee health and trauma: Primary Care medicine (largely informed by biomedical understandings of health); Psychotherapeutic Care (ranging from bio-medically defined psychiatry to more socially and psychoanalytically informed psychology); and Cultural and Social Theory (informed by social medicine and anthropology)<sup>43</sup>.

Using a selected group of essays and articles, I explore the core understandings and debates that emerge within these bodies of work. A complete listing of the essays and articles used in this analysis are listed in Appendix 17. The literature which comprises the current state of knowledge and theory within each field is vast and has expanded considerably throughout this research study. This discussion does not aspire to provide a review that is exhaustive, but instead to offer some key insights by examining only a select number of texts that are representative of the core disciplinary perspectives in UK academic and clinical work on refugee health and trauma. This will provide some insights into the nature of the academic and clinical discourse with respect to health and trauma for refugees in the UK. Key areas of inquiry include: current conceptualisations of trauma, working definitions and modes of evaluating or measuring trauma, as well as an examination of what the practical and policy driven discourses in academia in the UK identify as socio-medical issues specific to refugees, related to trauma.

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<sup>43</sup> Public health is represented across these categories in a diffuse way, informing (primarily) the perspectives of social medicine and biomedicine (in an epidemiological sense).

## The Nature of Discourse

Within primary care - as within the other broad categories of inquiry here – there is a strong collaborative relationship between clinical and academic discourse. Whilst primary care literature displays a more decidedly “clinical” intent, it nonetheless seeks to include theoretical impressions of trauma that reflect current biomedical reasoning and evidence. Primary care covers a breadth of general and specialist medicine built upon a biomedical paradigm. Generalist literature is directed towards primary health care services and their providers (general practitioners and nurses across a variety of settings). Specialist literature that deals explicitly with refugee health is typically governed by disciplinary boundaries. For example, within public health, the infectious disease literature has focused upon issues of surveillance and the treatment of communicable diseases amongst refugee and immigrant populations (Coker 2003). For refugee health issues related to ‘trauma’ there are two primary specialist categories: psychiatry and psychology. These disciplines are clearly distinctive in terms of background, training and philosophical orientation. Psychiatry emerges from a definitely biomedical perspective, whereas Psychology is more broadly informed by social theories of human development and adaptation including psychodynamic or psychoanalytic thought.

Psychiatric research in the UK is underpinned, fundamentally, by a biomedical framework, which establishes the formal parameters of discussion within the field. Both the International Classification of Diseases (ICD) and Diagnostic and Statistical Manual (DSM) classification systems are present within psychiatry here, each contributing to the ways in which ‘disorder’ is understood. For certain psychiatric disorders, such as PTSD, deference

is to the DSM definition, which has been accepted, adapted and incorporated into the ICD nosology<sup>44</sup>.

Psychology has made a very strong contribution to the understandings of trauma related to the experiences of refugees within the UK. As a specialist field, the focus of attention is upon mental health issues. Physical issues are appreciated, fundamentally, as symbolic of emotional distress. While in primary care and in psychiatry, there is a greater emphasis on the tools of assessment and medical intervention (i.e. alleviation of symptoms), in psychological texts there is a greater emphasis upon clinical engagement and ‘working through’ processes of care. As such, therapeutic models of care assume a greater importance.

In the socio-cultural literature, the accent is less upon the tangible processes of clinical work and more upon theoretical debates about the social construction(s) of health and illness (and the resolution of illness) across cultures and populations. Drawing upon a rich literature in fields like medical anthropology and human geography, socio-cultural theory that examines the constructs related to refugee health and ‘trauma’ in the UK has emerged largely out of health-related research in psychiatry, psychology and social medicine. In terms of the nature of discourse, the influences of medical anthropology are acutely felt, as researchers strive to highlight issues and debates about trauma related to refugee health (Bracken 1998, Watters 2001); call into question issues of identity for individuals labelled as refugee (Malkki 1995a); and consider the strategic uses of psychiatric narratives (Skultans 1999).

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<sup>44</sup> Appendix 5 provides an outline of PTSD through its evolution in the DSM (from DSM-III to DSM-IV) (APA 1980, 1987, 1994) and in its current form in the ICD (WHO 2003).

Socio-cultural studies in the UK reflect a broad fusion of academic disciplinary influences, coupled with professionally acquired insights (through ethnographic work or clinical studies). Less tied to the conventions of one particular approach there is a greater sense of autonomy in merging theoretical constructs. This may, however, deliver a more uncertain framework against which to evaluate the issues of refugee health and trauma, where only one side of the equation is given a complexity of shape: theoretical over practical, providing limited direction for the translation of ideas into practice.

## Locating Trauma in Refugee Health

‘Trauma’ has emerged as a prominent area of inquiry in academic and clinical work. Multiple dimensions have been identified, leading to the use of the construct descriptively across situations and experiences, and fundamentally, as an indicator of adverse mental health functioning. The considerable variation in meanings can pose challenges in defining and establishing the presence or absence of pathology, as well as responding accordingly. Discourse that reflects primary care medical work typically aims towards clarifying a theory of trauma that can work within or adjacent to biomedicine, working to diagnose and treat from within this paradigm.

The work of Burnett and Peel (Burnett and Peel 2001a, Burnett and Peel 2001b, Burnett and Peel 2001c) for example, is strongly directed towards influencing general practices amongst physicians and other health professionals within primary care. In a series of papers in the *British Medical Journal*, they strive to clarify the essence of refugee health issues within a medical care framework that is inclusive of an understanding of trauma. They

identify health issues specific to refugees, provide a guide to interpreting the signs and symbols of physical and psychological distress, and outline practical guidelines for “evidence-based” clinical care, primarily for physicians. The perspective offered is broader than conventional understandings of ‘biomedicine’; chronicling refugee health issues offers an opportunity to revisit and re-establish the core principles and philosophies that underlie biomedicine. They propose a framework shaped by clinical observation and assessment towards the identification of medical issues. Physical and psychological health are equally evaluated and studied within this paradigm. In highlighting common complaints that a primary care physician may come across, they strive to normalise the health needs of refugees and grant equal weight to physical and mental health needs:

Headaches, backache, and non-specific body pains are common; they may be of musculoskeletal origin, as a consequence of trauma, muscular tension, or emotional distress (Burnett and Peel 2001b:545).

They downplay the sometimes speculative (and often highly stigmatising) impressions that may exist about refugees and work towards re-configuring discussions towards the more familiar territory of non-specific complaints, de-emphasising any hints of exotic pathology (psychiatric or otherwise).

In shaping an understanding of trauma, non-specific physical health issues are highlighted as a *‘consequence of trauma’*. In this context Burnett and Peel (2001b) draw upon the duality of trauma as aetiology and as bodily effect (physical or psychological). Ideas of trauma in this context begin with identifiable physical health complaints (largely non-specific in nature) and not (initially) a psychological reaction. Indeed their discussion on ‘psychological reactions’ actively steers clear of the ‘language of trauma’, preferring to detail specific behaviours and symptoms ranging from physical health issues through to

issues of ‘anxiety and depression’ with guidance on ways of “*disentangling the web of history, symptoms and coping mechanisms*’ within primary care consultations (Burnett and Peel 2001b). They move onto deciphering the dynamics of torture as specific health-related ‘trauma’ experienced by refugees (Burnett and Peel 2001c).

Whilst these papers are not explicit in presenting a conceptual paradigm for defining trauma and its relevance to refugee health, there are some core features that emerge. Attention is directed to the physical impact of critical events that are most clearly spelled out in terms of torture. Psychological impact is discussed largely through a range of possible behavioural and emotional reactions, mimicking the strategies of the DSM, which confirms psychopathology through the process of documenting the presence or absence of descriptive symptoms (Gaines 1992). When ‘trauma’ is mentioned in the form of Post-Traumatic Stress Disorder, there is a concerted effort to define this as ‘one diagnosis’ (but not the exclusive one) in relation to the severe psychological effects that may come with conflict and forced migration, most notably for victims of torture.

In specifically highlighting situations of torture – the most extreme encounters of physical and psychological violence -- a matrix of trauma is established. On the one hand trauma exists in a multitude of well-travelled and relatively benign physical manifestations (e.g. headaches, backaches, non-specific pain) that later may be suggestive of psychological distress. On the other hand, it is embodied within the potentially extreme tangible physical injuries and more clinically viable symptoms of distress (e.g. nightmares, dissociation) associated with torture.

Shying away from the diagnostic category of PTSD, Burnett and Peel aim to promote an understanding of refugee health and social care issues that is grounded in observable reality which they suggest avoids the unnecessary medicalisation of experience. This series of articles are clearly directed towards the work and understandings of front line health care providers, most notably physicians<sup>45</sup>.

While these articles offer a limited insight into the paradigm of refugee health in primary care, their importance can not be underestimated. They provide practical clinical guidance in the identification and treatment of health issues that are critical for refugees in the UK. Similar messages are found within professional guidance through the British Medical Association (BMA) (BMA 2002) and more recently in the consultations for clinical practice guidelines issued by the National Institute for Clinical Excellence (NICE) (NICE 2005).

Emphasis within these texts is placed firmly upon the processes for dealing with physical and mental health issues, outlining methods of assessment and evaluation, with a call for a proactive primary care medicine that engages with the patient-body (in this case, refugees) towards early intervention and prevention. This normalising component seeks to reduce apprehension and emphasize the routine qualities of health complaints. Cautious of the overuse or inappropriate use of PTSD to understand trauma, these texts instead offer the warning that PTSD “*turns very common reactions into medical problems and assumes a universally valid and applicable mode*” (Burnett and Peel 2001c:608).

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<sup>45</sup> Similar discourse has been developed and presented within the professional texts of related health professionals, such as nurses and health visitors. However, these tend to offer a definition of trauma that is more closely affiliated with the framework of PTSD (Childs-Clarke 2003; Maddern 2004).

In contrast, literature stemming from British traditions of psychiatry and psychology positions itself on the whole as more supportive of the construct of PTSD. However, authors differ vastly on whether PTSD is understood as one of a range of expressions for distress, or on a continuum of conceptualisations of trauma for refugees. PTSD functions akin to a benchmark against which circumstances are weighed and measured. However, there are decidedly two streams: one, where despite caveats there is an endorsement of PTSD as a starting point at least for the initial assessment and definition of trauma for refugees; alternately, a perspective is offered that proposes a broader vision, one that strives to balance the descriptive symptomatology associated with DSM-criteria with more ambiguous constructs that are associated with distress (such as ‘loss’), but resist a formal clinical classification. In broad terms, psychiatric literature tends to be more supportive of the framework of PTSD, whilst psychology is more engaged in mapping a range of experiential elements on a continuum of “trauma” and health issues for refugees.

Although not specific to refugees, Mezey and Robbins (2001) offer an illustration of the first perspective. The crux of their argument is to endorse the legitimacy of PTSD as a valid diagnostic category, arguing that whilst socio-cultural elements may contribute to the shaping of our understandings of disorder; this does not in any way undermine the credibility of the phenomenon. However, theirs is a tangled position. On the one hand they state empathically:

Post-traumatic stress disorder is associated with clinically important distress that transcends ordinary misery and unhappiness as well as with disruption and impairment of daily functioning (Mezey and Robbins 2001:561).

The phrase “*clinically important distress*” here warrants attention as a particular distinction that is commonly made within academic and clinical discussions on trauma. There is a

concerted effort to distinguish the pathogenic risk of trauma versus what would conventionally be defined as “normal” grief or sorrow associated with significant and negative life events. The line between these distinctions is, however, thin, and a matter of interpretation. Moreover, as Mezey and Robbins go on to emphasize, they interpret the intent behind PTSD as a disorder is to accord recognition of traumatic responses as normal in the face of exceptional events:

The diagnosis of post-traumatic stress disorder was developed partly as an attempt to normalise the psychological, cognitive and behavioural symptoms observed in many traumatised people. It redefined the symptoms of the disorder as a normal response to an abnormal event rather than a pathological condition. (Mezey and Robbins 2001: 561).

This oscillation between *minimising* the pathological nature of symptoms, striving to normalise and not accentuate the concept of disease, or *maximising* the situation, suggesting that the presence of observable symptoms is merely the ‘tip of the iceberg’ and that the problem represents a large and uncharted epidemic, is an ongoing struggle for academics and clinicians alike.

The cautiousness that surfaces and drives these oppositional perspectives suggests an apprehension about the uses of diagnostic frameworks and the vulnerabilities that may accompany the process of “medicalisation” with respect to distress and trauma. Hodes (2002) argues that this fear has led to a misunderstanding of the usefulness of a psychiatric perspective on trauma which pits a conceptual dichotomy between the framework of PTSD and more culturally informed understandings of suffering or trauma: “*as if the two perspectives are mutually exclusive*” (p197). Instead he argues that the epidemiological data demonstrate the validity of a psychiatric framework of PTSD when applied to refugee health, further evidenced by the existence of similar symptomatology cross-culturally.

Hodes returns to the ideological principles that underscore modern psychiatry, revisiting the nature of the diagnostic classification system and using this as the bedrock for his appraisal of the merits of PTSD for use with refugee populations.

A re-assertion of profession-based philosophies and practices comes through this text, similar in nature to that found in articles from primary care. Support for the use and applicability of PTSD in refugee health comes from the basic scaffolding of Anglo-American psychiatry itself: the multi-axial system within the DSM. Ideally, the DSM allows for a broad spectrum of aetiological features and symptom manifestations, as well as the incorporation of localised features to be incorporated into a diagnostic assessment. Citing the inclusion of “social impairment” measures, as an example, Hodes asserts that this method can accurately evaluate the mental health of young refugees. Triangulation of information from a variety of sources, he asserts can shed light upon social and cultural patterns:

It is believed that they have some cross-cultural validity as scores are derived from information from multiples informants including the children and parents. They assess the level of functioning in locally and culturally specified age and gender appropriate roles, rather than in roles defined by outside investigator. (Hodes 2002:201).

The point that Hodes is making is that there is an opportunity within the psychiatric framework to account for culturally or socially determined variations. In essence, he argues that the failure to utilise these elements reflects a fault with the diagnostician rather than the diagnosis itself. This outlook on trauma seeks to locate it within the realm of a conventional psychiatric diagnosis, using the tools of the trade itself – but in a thoughtful way, that is conscious of the social and cultural features as well.

Locating refugee health related to trauma within a medicalised psychological framework is common within psychiatric texts. There is however, a concerted effort to incorporate an understanding of the salient socio-cultural elements to health and trauma, which traditionally may not have been accounted for within psychiatry.

Stuart Turner (1995, 2000, 2004) a prominent academic researcher and clinical psychiatrist, offers a similar approach to the uses of mental health diagnosis and treatment options for understanding and addressing the issue of trauma amongst refugees. Much of his work focuses upon the more extreme health issues in survivors of torture. Careful to not oversell the merits of diagnostic labels like PTSD, Turner offers a perspective that recognises trauma as a mental health issue, but does not overlook the social and cultural complexities:

It is important to find the right balance, acknowledging that these conditions (especially PTSD and depression) are common and that they may be treatable, while at the same time recognising the complex and human nature of the experience and of the response (Turner 2000: 297).

The starting point is the assumption that '*these conditions are common*', regardless of whether they 'fit' PTSD or another conceptualisation of mental illness. Mental health evaluation and treatment then is a logical starting point in refugee health, although with the caveat that individual experiences may inspire health and health needs in distinctive ways.

Similar to the refugee health model offered by Burnett and Peel, Turner offers a framework that is comprehensive in its attention to detail and linked fundamentally with a specific professional ideological discourse. Whilst trauma is understood within a perspective of psychiatric pathology, stipulations are offered about the need for holistic care that recognises unique features including the individual interpretation of experiences and a range

of therapeutic interventions. Because his work is so firmly placed within extremes (torture survivors and psychiatry), there is a sense of naturalness to the depiction of ‘traumatised’ individuals, despite his cautions about the need to avoid making assumptions.

That many psychiatrists in a strict sense locate trauma for refugees within the framework of their discipline (psychiatric pathology) is no more surprising than primary care physicians locating trauma for refugees within a paradigm of general medicine. Both make quite visible the flaws that exist within a medical approach, and so are consciously inclusive of features of a socio-cultural dimension, suggesting willingness to modify the core professional model to meet the needs of their client group. It is within the work of psychologists, however, that a slightly more adventurous leap is willing to be made around defining and understanding trauma for refugees.

Whenever one thinks of refugees, from a psychological perspective, the first association is to trauma rather than to home. Home is after all, not a psychological concept, as such. Yet loss of home is the only condition that all refugees share, not trauma (Papadopoulos 2002: 9).

Understandings of trauma, as Papadopoulos notes (Papadopoulos 2002), have “*become synonymous with painful experience: there is a widespread tendency to call traumatic most of the disrupting, distressing, disturbing, unsettling, tragic and hurting experiences*” (p 26). The imperceptible way in which this understanding of trauma has been subsumed into daily discourse (within Western society) translates into assumptions about the naturalness of trauma as pathology in individuals who have undergone severe adversities. This has led to the pervasive assumption in and outside of academic and clinical circles that refugees are a ‘traumatised’ population. Moreover he argues this perspective is shaped only with a limited idea of what poses an aetiological event (what he terms the ‘devastating event’). Linked

with this notion of a core defining event is the model of PTSD, which Papadopoulos asserts needs to be demystified and regarded for what it is: a medical construct. Though he acknowledges some value to the use of PTSD as a diagnostic tool, he warns of its tendency to separate out the socio-political circumstances which contribute to the overemphasis upon 'devastating events' that creates the refugee in the first place. Moreover PTSD ignores what he terms the 'intrapsychic' dynamics and early development experiences that are traditionally central to the work of psychoanalytic psychology (Papadopoulos 2002). There is a call to recognise socio-political features within the assessment of and clinical intervention with refugees who have experienced trauma. In a practical sense this may lack the air of tangibility that is integral to the diagnostic framing of PTSD. However there is an effort to promote a framing of trauma that is more closely aligned with the social and political realities of refugees, including the introduction of a more politically-oriented approach to therapy via "therapeutic witnessing" as a clinical strategy.

The framing of refugee trauma for each of the disciplinary perspectives examined so far (primary care medicine; psychiatry; and psychology) suggests the potential of the compelling work being done in this field. Influenced by a range of academic works in anthropology and health-related fields (including psychiatry, psychology and public health), the work in this area has begun to examine socio-cultural dimensions relevant to trauma, fuelling energetic discussions about the nature of trauma amongst refugees within the UK.

The works of Pat Bracken and Derek Summerfield in particular have prompted rigorous debate about the social construction of PTSD and its application to individuals and communities in a post-war context. Bracken (1998) drawing upon critical works in anthropology has urged us to question and 'deconstruct' trauma and the use of PTSD as an

analogous concept. That these terms and concepts have acquired an equivalency, he argues, warrants questioning and brings us back to the fundamental aspects of what creates a refugee.

*.. the way in which individuals and communities experience and cope with the suffering of war depends on social, cultural and political aspects of their situation. The current discourse on trauma systematically sidelines this social dimension of suffering; instead it promotes a strongly individualistic focus, presenting trauma as something that happens inside individual minds (Bracken 1998:38).*

Bracken objects to the widespread application of this framework which positions the individual in isolation from their social world. Whilst acknowledging that PTSD as a diagnostic tool has merit and value in socially and culturally appropriate contexts (i.e. Western societies) he questions the appropriateness of a psychiatric paradigm for understanding the experiences of refugees. Instead he calls for a framework that has less limiting conceptualisations of health and illness, and a greater inclusiveness of ideas about distress and suffering that are informed by individual, cultural and social beliefs (including health and illness but not limited to these notions).

Derek Summerfield has acquired a certain prominence as a leading proponent of a socio-cultural approach to trauma and refugees. He shares with Bracken the objections to widespread and indiscriminate use of the diagnostic label PTSD and the proliferation of psychosocial intervention programmes that often accompany its use in war-affected areas and amongst refugee populations (Summerfield 1999). Summerfield is increasingly less willing to acknowledge the value of PTSD than academics like Bracken. Instead he calls into question the integrity of the diagnosis.

The medical discourse on trauma has a heuristic value and some of those diagnosed as having post-traumatic stress disorder do have clinically significant dysfunction, however it is labelled (and post-traumatic stress disorder will sometimes do). However it might be timely for mental health professionals to review our definition of the disorder as a disease and decide whether it has sufficient robustness and explanatory power to apply to the diverse uses to which it is now being put (Summerfield 2001: 98).

Drawing upon prominent international work in this area (Young 1995), Summerfield dislodges PTSD from its reified position pointing out the specific socio-historical elements which have fused, forming the diagnostic 'reality'. The importance of essays by Summerfield on this topic cannot be underscored enough, the above cited article in 2001 (Summerfield 2001) yielded over 60 email responses to the editor of the BMJ, some quite heated in their defence of PTSD and a psychiatric reading of trauma.

In highlighting the social construction of PTSD, Summerfield importantly calls into question the way in which understandings of appropriate response and 'personhood' have come into the fray with an imposing judgement that is interpreted as reflecting 'objective' scientific knowledge. This conflation of beliefs about what constitutes normal and abnormal behaviours or experiences results in a medicalisation of distress according to Summerfield. These basic tenets underscore his framing of trauma as a health issue for refugees. Forceful in his argument against the notion of universal responses to adversity, Summerfield advocates an approach that moves away from the psychologising of individual experiences and towards a social justice framework: "*war is not a private experience and the suffering it engenders is resolved in a social context*" (Summerfield 2000: 233).

Across academic and clinical discourses there is an ambiguous relationship to PTSD in connection to refugee health. For the most part however, there is an acceptance of the

framework, particularly in applying to ‘severe’ situations (i.e. torture). More so there is a call for a more ‘holistic’ framing of refugee health that is conscious of the impacts of social and cultural dimensions in shaping and defining experiences, how they are manifested, interpreted and the strategies employed for their resolution.

The idea of recognising alternate expressions or manifestations of distress emerges quite strongly across the academic and clinical literature on trauma and refugee health within the UK. Influenced by an extensive body of anthropological work on health, illness and distress has helped to orient researchers and clinicians in the UK to a spectrum of expressions for and experiential components of distress (Green 1998, Kleinman and Good 1985, Nichter 1981).

Burnett and Peel (2001b) incorporate elements of this in the detailed assessments they advocate as the ‘standard’ practice in primary care medicine. Having brought attention to the presence of non-specific pain (headaches, for example) as an entryway into the concept of psychological distress they raise the flag of somatisation for physicians. Somatisation has come to figure prominently in discussion of refugee mental health, conventionally understood as the unconscious manifestation of psychological experiences via physical expressions (Epstein, Quill, and McWhinney 1999). In describing some of the health impacts of torture, Burnett and Peel outline the concept of somatisation as applicable to refugees:

Survivors of torture and organised violence commonly complain of symptoms, such as sleeplessness, nightmares, weakness, lethargy, headaches, abdominal pain, and neck and back pains, which do not seem to have a physical basis and may last for up to two years. They may think these are of physical origin and expect investigations and treatment, but they are often in fact aware of the interrelations between physical and psychological symptoms (Burnett and Peel 2001a: 608).

Conflicting ideas emerge here about the nature of somatisation and culturally specific idioms of distress. Underscoring this are assumptions about the nature of awareness and understanding that people have about what they are experiencing both physically and emotionally. Drawing upon the construct of somatisation is one way to render the complexities of culturally constituted ‘ethnopsychiatric phenomenon’ manageable within the context of primary care (Baarnhielm 2003) Introducing the concept of physical expression for psychological or social distress promotes a more responsive general medical service that is less likely to minimise the influence of social factors.

Within the realm of conventional psychiatric literature on refugees and health, there is a strong emphasis upon features of PTSD that may correspond with non-traditional expressions of stress (by Western standards) (Hodes 2002, Turner 2000). Turner (2000) illustrates this with a discussion of the traditional and non-traditional ‘psychological’ reactions of torture survivors:

PTSD (incomplete emotional processing); depressive reactions secondary to loss and adverse life events; somatoform symptoms; and probably most significant of all, the effect on personal value systems – for example changed personal religious or political beliefs in a just or meaningful world (Turner 2000: 296).

The last ‘symptom’ highlighted – suggestive of a moral or existential crisis – seems initially to be out of step with the idea of a formal psychiatric classification. Instead, Turner has, strategically, shifted between diagnostic frameworks, drawing instead upon the ICD

classification for Personality Changes after Catastrophic Events<sup>46</sup> (of which torture is included) (Turner 2000, Turner 2004). This disorder is characterised by a ‘permanent and irreversible’ transformation in the individuals’ interaction with the world around them, including the ability to engage with their social world and feelings of ‘emptiness or hopelessness’ (WHO 2003). Despite the qualifying feature of ‘enduring personality change’ as a chronic condition, Turner argues that this allows for a broader appreciation of the complexities of trauma for some refugees:

This move beyond simple psychiatric diagnoses into the realms of complex trauma reactions is helpful because it moves the survivor away from a sense of being reduced simply to a naive categorisation and allows the individuality of the experience and, importantly it social and political context to be considered (Turner 2000: 296).

That this is in fact an aspect of recognised psychiatric diagnosis remains under-emphasised. Instead, Turner interprets the existential changes as something more akin to the individual nuances of distress that may be informed by social or cultural influences. Mezey and Robbins (2001) echo these sentiments arguing that these features embody many of the intricacies of repeated trauma experienced by certain groups including torture survivors, that the PTSD framework does not. Problematically, this perspective fails to appreciate the intent behind alternate or indigenous idioms of distress, and finds itself relying upon a framework of pathology outlined within Western psychiatry rather than anything emerging from the experiences of individuals.

Literature emerging from the field of psychology offers an interpretation of “idioms of distress” that is more in keeping with the intent of this concept. Papadopoulos (2002)

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<sup>46</sup> Explicit details of this diagnostic category are presented in Appendix 5, accompanying the explicit descriptions of the DSM and ICD categories of PTSD.

highlights dimensions of refugee trauma which may fall outside of the current conventions of a psychiatric diagnosis.

Under conditions of deprivation, and with a multiplicity of losses, individuals, families and their communities seem to “freeze up” and the repertoire of their feeling, perceiving and functioning becomes restricted... externally it could have all the symptoms of a dissociative state and, in a sense, it is one. However, on closer examination, it could be discerned that it is more the result of the primary loss of home rather than of the long list of the secondary and tangible losses (Papadopoulos 2002: 32).

The metaphor of ‘being frozen’ is one where distress may be played out in clinical terms. However, whilst there is some recognition with the dissociative features common to stress reactions, Papadopoulos argues that this state of being which he associates with ‘nostalgic disorientation’ is often *qualitatively* different than the dissociation that accompanies reactions like PTSD. The loss encapsulated within what he describes as a state of ‘frozenness’ may warrant a closer look: “*To understand this lack as a loss in the ordinary psychological sense is to miss the rich meaning and complexity that the loss of home entails*” (Papadopoulos 2002: 15).

The elucidation of loss becomes an exercise in charting out the attributes of home (in this case), where home comes to represent more than simply the loss of place and structure but an indicator of identity and a connection with a particular social and cultural reality. This offers an alternate way of framing the experiences of refugees and suggests a sense of the broader intrinsic dimensions of distress that may be expressed in a variety of ways, meant to represent a variety of meanings. Within the psychological literature however, inevitably most roads lead to some form of pathology.

Papadopoulos strives to balance this vision, making a case for therapeutic work that is more informed by concepts of ‘witnessing’ and reconciliation. Nonetheless the inclusion of a therapeutic component (defined in a Western sense) implies that there is a need to ‘rework’ or resolve the experience of distress in a managed way by a professional therapist.

The delineation of alternate interpretations of distress has been an area of considerable research within medical anthropology and social medicine (Green 1998, Kleinman 1986, Nichter 1981). Within what I have termed the socio-cultural literature related to refugee health in the UK, there is an emphasis upon separating out expressions of distress as they are locally defined and understood and charting the distinctive forms this may take (physical, psychological and social manifestations).

Bracken (1998) explicitly delves into the cross-cultural psychiatric research in an attempt to shed light upon alternative understandings, definitions and interpretations of distress and trauma. This emerges as a critical part of his ‘de-construction’ of the diagnostic framing of PTSD:

[J]ust because we can identify particular symptoms in different cultures, does not indicate that it has the same meaning in these different cultures. For example, most peoples report the experience of nightmares. However, the meaning of nightmares varies greatly. In the West, these are generally understood to be inconsequential and have little effect on waking life, but in many non-Western cultures, where dreams are understood to be a bridge to the spiritual world, nightmares mean something very different and can have major effects on waking life (Bracken 1998: 41).

Bracken uses nightmares to illustrate the commonalities of experience: everyone has nightmares; it is just that they are interpreted differently. Interestingly the example of a ‘nightmare’ minimises the exotic-ness of different manifestations of distress, whilst conjuring a feature of traumatic stress (nightmares form a core element in the intrusive

recollections that are often a cardinal part of PTSD). However in his texts Bracken draws attention to the contrasts that exist with the framework of PTSD by introducing a range of ways in which people define and express suffering differently and more importantly how they cope. Pushing for a theoretical transformation Bracken calls for the need to revisit ‘ethnopsychiatry’, highlighting contextual elements (social, cultural and political realities) that shape localised ‘idioms of distress’ and attending to the ways in which “*these realities structure the individual’s response*” (Bracken 1998: 41).

Summerfield moves the discussion from Bracken’s theoretical pursuit of local models of trauma to hammering out explicit cases. In some ways this merely reflects the nature of their distinctive styles. Summerfield (2000) re-introduces the idea of somatisation as an alternate expression of stress and suffering:

Some researchers see somatic symptoms as physiological responses driven by stress: others emphasis their communicational element—these may be the only available expressions of the collective distress of powerless and persecuted people denied societal acknowledgement and reparation (Summerfield 2000: 232).

Like Bracken, Summerfield discusses alternate expressions of distress as instruments of social or political complaints as much as individual emotional or psychological ones. Citing the response of refugees from Bosnia approached for a psychosocial programme, he illustrates his point: “*we are not mad, we are betrayed*” (Summerfield 2002: 1106).

There is a tension highlighted in these works, from a purposeful drive to re-shape the theoretical understanding of trauma to one inclusive of indigenous understandings. The challenge is to re-think the assumptions that operate about non-western expressions of distress, moving beyond current perceptions which rely heavily on somatisation as a central

expression of trauma towards recognising broader social and political idioms of distress.

This leads us into the final theme that surfaces throughout the academic and clinical work in the UK: the socio-political implications of trauma and the strategies that are advocated in response.

## Socio-political implications of trauma

Discourse on the psychological health needs of refugees within primary care suggests some impact of the highly politicised discourse on refugees and the process of asylum in the UK.

What is articulated and reiterated across disciplines and perspectives is an ambition to recognise the highly politicised atmosphere that refugee health is positioned within, with a balanced understanding of the issues at hand. Often however there is a danger of becoming drawn into current socio-political debates in the UK on asylum and the legitimacy of refugees within the UK.

In the series of BMJ articles by Burnett and Peel (2001a, 2001b, 2001c), the socio-political issues that surround refugees in the UK surface as a primary subject from the start, effectively setting the parameters for discussion. Burnett and Peel begin by tracing the conditions that have given rise to the numbers of refugees in the UK and address misconceptions about asylum seekers, roll-calling a list of extreme situations (including massacres and death squads) before identifying the array of health risks that may accompany the processes of forced migration and exile. This series of articles offer as a starting point into refugee health issues an outline of the socio-political environment surrounding asylum seekers and refugees in the UK. From here they move into a detailing

of basic health needs (covering the breadth of reactions, while emphasising the familiarity of issues). Here they begin to discuss the idea of intervention:

Many people may wish to tell their story, which in itself may be therapeutic but it should not be assumed that people must go through this in order to recover as some find it extremely distressing (Burnett and Peel 2001a: 545).

Talk is introduced as an option towards the resolution of issues, although they are cautious in exercising a full endorsement of counselling, noting: *“its usefulness depends on an individual’s socio-economic background and cultural orientation”* (Burnett and Peel 2001a: 545).

The guidance that comes through primary care strives to be academically and clinically comprehensive in nature. This commitment to ‘holistic’ care is strong throughout the texts. For clinicians however these frameworks may be filled with competing ideas about the meanings and manifestations of trauma, and what the role of primary care is when it encounters the issues of trauma and refugee health. There are numerous complexities to working with refugees around health issues within the current system of care. Hargreaves (2003) in her discussion on the health ramifications of Section 55 of the immigration act (which specifies the withdrawal of support for refugees who fail to claim asylum in a timely fashion) touches upon some of the ways in which a diagnosis of a psychiatric condition may prove useful in facilitating access to services or support not otherwise available (Watters 2001). Evidence is conveyed through the use of dramatic stories of clinical observations of a GP in Dover. These serve to confirm the vulnerability of those excluded from support: *“one of my patients affected by this is most certainly a victim of torture – the whipping marks were obvious”* (Hargreaves 2003: 1108). The ‘obvious’ visibility of torture helps to articulate the failure of the system in locating people of real need as well implementing or

mobilising care to help that person who is perceived to be at the extreme end of vulnerability. Later this same GP relates his struggle with legislative boundaries:

I'm now involved in making a professional judgement as to whether one Somali lady is 'mentally fit' to be denied access to emergency accommodation, food and basic funds while she claims asylum in Britain (Hargreaves 2003: 1108).

Faced with a situation that is likely to be distressing in some form to anyone (homelessness and no economic support), one answer is to diagnose the individual with a recognised mental illness which enables them to be considered vulnerable enough to be receive full support<sup>47</sup>.

Underscoring the medico-therapeutic conceptualisation of trauma related to conflict and other disasters there is an assumption of political neutrality (Almedom and Summerfield 2004). Yet in talking about refugees and trauma, the literature may draw upon the language and imagery of a socio-political nature, including terms and concepts that call to mind a social justice agenda. The ideas of 'testimony' and 'witnessing' achieve just that. The concept of witnessing suggests active work towards social justice while the idea of testimony encapsulates both aspects of this concept and a therapeutic component. Turner (2000) offers insights into the evolution of 'testimony' as a therapeutic construct.

Testimony begins with a simple re-telling of the 'story' of trauma. However through a process of examination, questioning, and a re-framing of experiences and emotions the individual re-creates their story towards a reaffirmation of personal and political agency. As

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<sup>47</sup> This is an ongoing dilemma within the homelessness sector in which only certain categories of individuals are deemed to be 'unintentionally' homeless and therefore eligible to receive the support of the state. The difficulty for many individuals who are homeless is the 'catch-22' that throws up barriers at every turn. Gaining entry into the systems of care that would be able to diagnose or legitimise a claim of unintentionally homeless requires a certain level of stability, including being registered at a GP which in itself requires an address.

a strategy, testimony is often discussed as emerging out of post-dictatorship Chile as much about liberation as an emotional or psychological ‘recovery’ (Agger and Jensen 1996, Chopp 1986). This tool aims to combine a heightened sense of the socio-political dimensions of trauma and consider its relationship to health for refugees. In practice this technique may draw upon more conventional modes of Western therapy including an individualised counselling format.

[t]he treatment is structured so that after a period of establishing trust, the sessions are tape-recorded and transcribed. These transcripts are the material of future sessions and are revised and developed by the survivor until at closure there is a comprehensive account (Turner 2000: 298).

The re-framing of an understanding of trauma is therefore driven by the therapist’s interpretation of the events and their interpretation of the psychological affect and functioning of the client. Papadopoulos advocates a similar approach which he terms “therapeutic witnessing”, suggesting: “*it enables and empowers individuals, families and communities to re-story and restore themselves by connecting with their totality rather than focusing exclusively upon the devastating impact of secondary losses*” (Papadopoulos 2002: 34). Active ‘re-structuring’ is promoted involving both the individual and the therapist as collaborators. As much as these techniques profess a new form of empowerment, it is difficult not to see the links that exist between this and more conventional psychotherapies.

The action that is deemed critical in the face of trauma for refugees has perhaps been most pronounced in the introduction of ‘psychosocial trauma programmes’. Derek Summerfield, a great critic of such endeavours, questions the assumptions that have underscored the rapid and extensive proliferation of ‘psychosocial’ interventions within post-conflict settings and with refugee populations (Summerfield 1999). Ultimately the expansion of such

programmes has been criticised as promoting a particular understanding of trauma and post-war resolutions which are intrinsically linked with PTSD and a ‘medicotherapeutic’ perspective.

Trauma programmes certainly can be seen cynically by those for whom they are intended, they can be experienced as patronising or indeed as a form of pacification. In Bosnia, people derisively referred to the aid delivered to them through a model that did not offer physical protection, restitution, or justice as “*bread and counselling*” (Summerfield 2002: 1106).

The discourses about trauma, socio-political context and refugee have strived to promote a framework that endorses psychosocial intervention, which is believed to be inherently valuable and restorative. However this paradigm has been confused with the construct of a psychological pathology of trauma and a Western psychiatric perspective on resolution. The ideas of witnessing and testimony are largely presented in an uncritical way; naturalistic and inevitable in tone, somewhat distanced from a clinical perspective. They carry images associated with the specific mechanisms of procedural justice that have emerged post WWII, such as Truth and Reconciliation Hearings, or testimony for International War Crimes Tribunals more so than the therapy sessions that Turner (2000) depicts, or the group programmes that Summerfield (1999, 2002) critiques. Over time as these terms are used to refer to a range of interventions, however, this distinctiveness is lost and the socio-political aspects are in danger of being absorbed by a clinical model.

The murkiness of academic and clinical discourses on the meanings of trauma for refugees – both from a broad understanding contrasted with PTSD to the concepts of local understandings of distress – and the options for resolution, are situated closer to a psychiatric vision than a socio-cultural one. However the fact that such a lively debate is being undertaken to challenge assumptions and answer a call for the inclusion of social or

cultural dimensions points to a discourse that is not statically positioned within the framework of PTSD.

Access to academic discourse for front-line health and social care professionals comes through professional and public forums, such as local conferences or seminars. Leading UK academics exploring issues related to trauma and refugee health are often called upon to lecture or hold workshops with front-line clinicians as a means of theory and research interacting with the practices operating on the ground-level. One illustration of this is reflected in fieldnotes of a one-day conference on mental health and refugees in East London.

Derek Summerfield is next. You get the sense that he is the real draw here. People had been milling around at the back – looking at the paltry few information tables, and helping themselves to the available snacks. When he gets up to speak, people scramble for their seats. He begins by talking about what he sees as the '*mental health-isation*' of experiences of asylum seekers and where they came from. Comments on the unexplored set of values that are operating; the judgements made. Whose framework counts? He critiques the most recent advertisement for the Medical Foundation for the care for Victims of Torture which speaks of psychological scars due to torture and how they may be essentially permanent: '*it takes a lifetime to heal*'. This suggests a permanent marking, a disability in a sense. Raise the core question: '*is traumatised short for mental disorder? Does traumatised mean 'in need of counselling*' Summerfield is an intriguing speaker to hear at an event like this. People are clearly excited by his talk. (Fieldnote 28/10/2002)

It is often difficult to see how the excitement and intrigue of an event and the ideas that are generated are converted into practice. At best we can gain some insight into the impressions that are left upon front-line workers when they encounter sessions such as this. Mary, a caseworker at a refugee community organisation provides outreach and assistance to women refugees also attended talk by Derek Summerfield. Her work tends to be grounded in the day-to-day practicalities of resettlement, however, increasingly she finds herself drawn into

discussions on psychological trauma and its meaning in the lives for refugees. The question of mental health issues for refugees brings to mind recollections of that lecture:

Mary: He was talking quite powerfully, it was quite powerful stuff.. he was basically saying that he thought that the idea of asylum seekers as victims and always in need of mental health counselling because of these awful things that they have been through – war, rape, and torture and imprisonment and the idea of them as always damaged and in need of support and a talking cure, the idea of bringing everything out and talking everything through, he was very suspect about that (...) and it was interesting to hear him talk about that and about always seeing asylum seekers as victims and always trying to push them off into these counselling mental health projects and he was saying the approach should be much more holistic and that services should be much more geared up to dealing with practical issues that asylum seekers – the practical issues that resettlement in this country brought, decent accommodation, schools for your kids, being able to live on the benefits that you've been given, training and assistance to work.

Mary articulates her strong impressions of the crux of Summerfield's message, and begins to think about these ideas in relation to her work: "*And my gut feeling without having done any great research on this is that that is probably very true*". Through this example we can gain some sense of how concepts are translated from academic work through to clinical and professional perspectives (and practices) in health and social care.

An interactive relationship exists between the perspectives outlined in academic and clinical discourse and those expressed by front-line service providers working with refugee populations in the UK. This work is informed and influenced by theoretical and clinical insights (the consistencies and contradictions), ultimately giving shape to the working philosophies and practices on the ground in refugee health and resettlement, across disciplinary frameworks. What emerges moves beyond theoretical conceptualisations of trauma, towards the practical application(s) of 'trauma theory' into the daily lives of service providers and individual refugees.

## VIII. MAPPING SERVICES AND PHILOSOPHIES

The landscape of health and social care agencies is comprised of key services and organisations working to identify areas of need, improve access to services, and facilitate the transition process from arrival through to resettlement for refugees. There is considerable variation in the proximity of these services to refugee communities depending on whether their role is in direct service provision or more distanced in the form of advocacy or policy work. In addition there are specific features that help to shape the identity of the service. This may be the identification of a unique configuration of goals, or be defined by geographical remit (local, regional or national services). There is often considerable overlap in terms of these roles and relationships, owing to the metes and bounds of limited resources.

Traditionally health care services have not been proactive with refugee communities, instead tending to react to issues and difficulties once they have emerged. It is only in the recent restructuring of primary care service delivery models that specialised services have been ‘earmarked’ for populations identified as having specialised needs or as ‘hard to reach’. Strategies have been devised to ensure the provision of comprehensive primary care services to people where they live or spend time (clinics often operate out of temporary accommodation sites or community centres). The high geographical mobility of refugees within the UK however presents its own challenges with continuity of care difficult to achieve, potentially leading to gaps in care or treatment.

Understanding providers conceptualisations of refugee health and in particular the construct of trauma calls for an excavation of the nature of their work: how they define it, what shape

it takes within the environment they work in, the philosophies which they feel inform their work, and the way all of this translates into practice. In this chapter I discuss the nature of services and where providers locate themselves in relation to the spectrum of agencies dealing with refugees in resettlement, the specific working philosophies and practices that providers rely upon, and how this links to psychological care issues and understandings of trauma.

## Mapping the Nature of Services

At the heart of service provision are the following broad categories of service ‘type’: community based refugee advice and support programs; primary health care services; clinical or mental health services; and self-help or user-led community groups. Community based programmes can offer a range of activities, many of which are related to the identification and referral of people to appropriate health and social care resources in the community. The practical issues of life in resettlement are dealt with within this realm: from helping to navigate the complexities of bureaucracy to registering with appropriate systems of social care and health care. Organisations of this nature may operate on a broad geographical scale (e.g. regional or national) or may be locally based with a specified ‘catchment’ area (e.g. a borough or neighbourhood).

For example, a small community based project serving refugees and migrants in east London provides a range of programmes specific to helping people settle into UK society, including navigating health and social care bureaucracy and learning, more informally about life in resettlement (from accessing inexpensive food in the local area to taking steps towards job training). The mandate within such services is typically to guide refugees to

key services rather than to provide them with services directly. For example, there is an emphasis upon directing individuals and families towards appropriate health services instead of offering such services in-house. As an information and advice service they assume a primary role within the community. This can include acting as a centralised resource centre for people as they seek out information about how to access local services, ranging from registering with a GP to enrolling in English classes.

Refugee organisations offer both practical advice and support on resettlement issues as well as providing links to clinical services. Less formal mental health services may be offered in the form of specialised groups or crisis counselling. Such services are typically provided in conjunction with an external agency or through special funding sources to enable the availability of appropriately trained professionals to offer therapeutic services. Services of this nature are more typically overseen by social work staff or specially trained counsellors rather than by licensed psychologists or psychiatrists. The intent is more goal-oriented than in traditional psychotherapy, and may be vaguely referred to as ‘psychosocial’, intended to cover a gamut of issues in daily living. Common ways of providing psychosocial support services are: through ‘befriending’ or ‘mentoring’ schemes (where local volunteers are trained to offer informal social support); through quasi-therapeutic groups (these are usually informally constructed activity-focused groups; membership is often determined by shared demographic features); and through the use of one-to-one case management services (these are typically goal-specific, but provide some degree of psychosocial support or advice).

There are a number of underlying assumptions that quickly emerge about the levels of distress amongst this client group sufficient to require intervention and the nature of interventions that would help in the process of adjusting to life in the UK. For example,

Carl, the director of a local community-based organisation for refugees describes the nature of a psychosocial group targeting women refugees that operated out of their centre.

Carl: For the moment it is (...) just somewhere safe for them to come outside of their homes, with crèche facilities so they can begin to talk amongst themselves. And to offer counselling and relaxation therapy...because they lead very stressful lives.

Psychosocial projects that are offered as part of community-based refugee support services – such as the group that is noted above -- are not in a strict sense ‘therapy groups’. Instead they are more informally designed and may identify tangible needs related to resettlement as a starting point. The aim at this level is typically to offer support that is often less explicitly psychological in nature and more targeted in intent. Referral to more in-depth or specialised psychological treatment may therefore be a central part of the care offered. However, these providers may find that themselves providing interim psychosocial support while waiting to link people up with appropriate services (waiting lists for specialised psychological care services are notoriously long in densely population regions, such as the London area). Informal ‘counselling’ may therefore be offered under the guise of care management services. Such services are intended to be directed in nature, focusing upon clear and attainable goals within a limited period of time.

Local refugee services demonstrate considerable success as access points for refugees. In many instances there is a desire to provide as comprehensive a range of services as possible, approaching the concept of ‘one-stop’ services , despite the limitations that exist on resources of staff, time and expenses. The formal remit of many such organisations is broad enough to allow for flexibility in the actual services offered. The range of resettlement needs that are typically identified include registering with the NHS, enrolling children in

school, securing referrals to English language classes and other social or economic resources, and referrals to specialised counselling services when appropriate.

As well as being the first ‘port of call’ for refugees within their new community, service providers at this level strive to be aware of changes as they occur within immigration legislation in order to effectively act on those changes in terms of procedures, entitlements, and regulations at the ground level. Service providers need to be able to identify and interpret the needs of refugees throughout stages of resettlement while working within a system of care that can undergo rapid transformations in terms of rights and entitlements. Despite efforts to ensure that front-line services meet the needs of refugee groups in the communities they serve, the environment in which they operate is constantly changing. Providers may find themselves struggling to meet the needs of a client group that is in constant motion, and need to maintain a current sense of what services are available, accessible or of limited use.

Health care has emerged as an area of particular importance in the resettlement of refugees. Within the framework of nationalised health services that are available to all individuals residing in the UK (including refugees and asylum applicants who are pending or on appeal), primary care emerges as critical in determining the nature of evaluation(s), the initial course of treatment(s) and whether referral to specialist or secondary care is necessary and appropriate<sup>48</sup>. A diagram outlining the system of care within the National Health Service is contained in Appendix 16.

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<sup>48</sup> The National Health Service (NHS) has been in place in the United Kingdom since 1948. Funded through central taxation, the NHS offers citizens and residents free medical care from the point of entry. Whilst technically access is assured, in practice surgeries have the ability to refuse to enrol a patient providing there are adequate grounds. An example would be living outside of the geographical catchment area. (Bank-Anthony 2003).

At a local level, medical care services are coordinated and administered through Primary Care Trusts (PCTs). PCTs are responsible for the allocation of services to meet the needs of a population in a given geographic area. Primary care health services include the following: GP surgeries, community health clinics or walk-in centres, and specialised nurse-led health outreach teams. The work of primary care is extensive – providing the first formal assessments of health and well-being for refugees in the UK, offering necessary treatment, and where appropriate referring on to secondary health care services.

Within traditional primary care, services are provided via the GP, nurse-practionner, health visitor or practice nurse. Typically this would involve individual consultations or assessments, and occasionally communal services such as specialised groups (i.e. new baby clinics), but not anything specific to mental health care services. The willingness and availability of GPs to enrol refugees in their surgery may vary considerably<sup>49</sup>.

In order to minimise the strain that exists within traditional primary care services, specialist care services have emerged as an effort to meet the need of hard to serve communities, including refugees. This has taken the form of specialised health teams or clinics with an explicit focus upon refugee health. For refugees structural issues related to service delivery have emerged as a core issue, reflecting limited access to basic health care. For providers this constitutes the first hurdle in addressing issues for refugees related to health.

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<sup>49</sup> While some research suggests that registration with GPs among refugees has in the past been noted to be relatively high (Carey-Wood, et al 1995), others argue that GP surgeries themselves erect considerable barriers – registering people on only a temporary basis, requiring that refugees demonstrate their right to access in ways that the average resident in the UK is not required (e.g. documentation confirming their identity and legal status). Recent discussions about the extent of ‘health tourism’ have raised questions about the right to national health care. Refugees have been caught in this crossfire and have been cast as problematic in their use of the NHS (Borman 2004).

Accessing basic care has been a fundamental issue for refugees and the range of providers who work with them. Mary, a case worker in a refugee community organisation, speaks about the frustration she encounters navigating these systems and the strategies she uses for overcoming barriers to care.

Mary: I almost always have to end up going to the local health authority to nominate a GP to take on a client, because they will approach three and get turned down on every one and end up having to go to the local health authority and say: 'Can you nominate a surgery for this client?' (...) I mean I'm not sure how much that is specifically because they are asylum seekers.. I know the whole health services in certain parts of London is finding it difficult and it may be that non-asylum seekers would have the same experiences of not being able to get on to a GP list --- but it wouldn't surprise me as well to learn that receptionists, who are the gatekeepers, find out that someone is an asylum seeker and immediately don't want to take them and try and turn them away.

For services working with refugees there are enormous barriers set up within the system of care. In part the obstruction is believed to be related to the status and identity of 'asylum seekers'. Mary, above, is cautious and consciously adds a caveat that the difficulties in accessing primary care may not be limited to refugees, and may reflect population-wide constraints. However there are strong suspicions that there are systems of exclusion operating within the health care services (something not completely unheard of)<sup>50</sup>. The presence of such suspicions (or fears) may fuel divisions within front line services working with refugees. Alternately this may promote a more determined approach by front line workers towards ensuring that health links are made and followed up on.

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<sup>50</sup> Many advocates of refugees suspect that this occurs regularly, although it remains an area that has yet to be explored in a systematic way. Stories have surfaced in tabloid newspapers asserting an undue strain placed upon local GP surgeries by the vast numbers of 'asylum seekers', evidenced by reports of doctors turning away refugees from their surgeries, out of fears of being overwhelmed by 'demanding and time consuming patients' (Raymond 2003).

The broad geographical remit of some agencies (for example providing social care to refugees across London) may contribute to a sense of strain. Front line workers are often left with few options and limited opportunities to cultivate community specific linkages within the NHS. Ultimately this leads to an over reliance upon a limited selection of resources. Providers may then be faced with having to exercise caution in the use of these resources. Anna faces similar issues in her work. As a health worker with a refugee organisation that provides a range of services to refugees across the UK, including initial health promotion, her role has centred on helping people to navigate the NHS and to access appropriate systems of care. In a sense she acts as a liaison between community based non-medical services and primary health services. She encounters obstacles that are a step before assessment and consultation, often related to issues of language:

Anna: On a daily basis this is just a reality, so there is no point calling a GP service to get an appointment for a client who speaks some African language, or French or Spanish and then they get inside they haven't got an interpreter and it is just a waste of time. (...) sometimes I have to send someone [as an interpreter] simply because if I don't send someone I just get bogged down with this kind of in-fights – 'this is your responsibility' 'no, it is not ours' and if someone is sick, they are not going to feel really happy to hear this kind of argument on the telephone.

The 'in-fighting' that Anna speaks about is broader than simply professional divides between health and social care, although this is often the starting point. The bigger issues at hand may relate to the understandings of basic needs, but questions also emerge about exclusion (intentional or not). For Anna the failure to respect the issues of language place their ability to work with this client group in a precarious position. She draws upon this opportunity to challenge providers to accept responsibility for comprehensive care, rather than allowing them to place the onus upon refugees or providers serving refugee communities.

The logistics of language difficulties and cultural (mis)understandings means that for refugees the time allocated for consultation is often grossly inadequate. The provision of interpreter services may prove difficult to arrange upon short notice resulting in the use of family members as ad hoc interpreters in consultations. Other options include Language Line<sup>51</sup> services which, while theoretically ideal, can fall short of the mark, either unable to provide the requisite language<sup>52</sup>, or providing interpreter services that may be viewed as inappropriate (i.e. male interpreter to discuss reproductive health issues). With these complications GPs are less likely to offer comprehensive health screenings as part of the primary care consultation and may feel pressured due to time constraints (it is generally accepted that language and cultural interpreting places additional demands in terms of time).

In terms of mental health services, formal care with refugees in London covers a range of psychiatric and psychotherapeutic services. This includes psychiatrists, psychologists, psychotherapists, and other mental health professionals (social workers that provide counselling). These services largely function via referral, with very little in the way of self referral, with the majority of these services offered on an 'outpatient' basis<sup>53</sup>. Psychological services are offered on either a one-to-one basis or in group sessions. The nature of services will be determined by the agency's specific philosophy, by the needs that are perceived about the communities they are serving, or the particular philosophy or working style of the therapist.

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<sup>51</sup> Language Line is a UK based charitable organisation that provides interpreting and translation services, (both face to face and interpreting by phone). This service has achieved particular success in creating partnerships with basic services in the UK including medical services through the NHS.

<sup>52</sup> At last count Language Line services provides interpretation and translation services for up to 150 languages.

<sup>53</sup> Inpatient clinical care is generally indicative of more extreme clinical situations such as an individual deemed as posing a danger to themselves or others.

At a London-wide mental health clinic, Joyce, a psychologist, runs groups with women refugees, in addition to more standard individualised sessions. Each of the women selected for the group have undergone an individual screening with Joyce. The groups however are much broader in scope: including individuals from different cultures, at different stages in adapting to the UK, and with great variation in terms of languages spoken. Despite the lack of a common language (few have achieved fluency in English) she finds success in the sense of warmth and connection people make with one another as they work through activities, communicating with each other in whatever way they can:

Joyce: (T)he aim of this group was to teach them that although they may have left behind countries, often family, friendships, their reputations, they've lost everything to come here – nonetheless, they've landed not on another planet, but in another country where there are human beings who understand some of what they have been through and if they can connect up with that world, if they've got the internal resources to connect up with that world, then they will be able to make use of whatever this country is able to offer them... it's not wonderful, but it's a lot better than what they have come from in many cases.

The intent of the group it would seem is less geared towards formal therapy of any kind, but more directed towards establishing networks of support and comfort. There is a commonality of experience that the group draws upon in terms of both past experiences of violence and exile, and current experiences of being disenfranchised. However, there is little formal discussion between participants about the nature of their experiences during conflict or in the process of exile. For some, this service would be considered quite ambitious.

Joyce notes that as the group has progressed, improved language skills allow group member to increasingly engage with each other in new ways. In the meantime, a group of this nature may allow for the exploration of the physicality of their experiences (positive and negative) in a setting that offers a sense of protectiveness without placing demands on the women to 'reveal all'.

More often, clinical work takes a more traditional form of one-to-one consultations that are broken down into one hour sessions (clinicians are quick to note that sessions with refugees require much more of a time commitment to ensure that issues of language and comprehension are dealt with). In an ideal sense this is a portrait of clinical work where patients have sufficient time to explore their concerns in individual sessions, over a period of time that allows for a natural and easy clinical progression. Yet Lydia, a psychologist, acknowledges there are real structural constraints placed upon her work, limiting the time that she can spend with most patients:

Lydia: There are lots of dictates from above now about how we should be working, what model we should be using, and how many sessions we should be...

I: Oh the 'after x number of sessions you should feel fine'

Lydia: [laughs] Quite often it's six. And if you are a therapist you have to argue for why you need to provide more than six... actually sometimes that is useful. Sometimes it is useful to have it that clear a limit, it's fairly short and you can work in a different way ...and you can achieve something. But in my experience with this client group... the beginning takes so long, the building up of trust.

There are therefore clear parameters imposed by the system of care that provide shape and definition to clinical work. For clinicians this can be met with ambiguity. On the one hand, having established boundaries can shape the work in definitive and focused way. On the other hand, such boundaries fail to recognise the unique conditions under which sound clinical work with refugees can take place.

Self help or user-led services can serve as an important resource for newly emerging communities. Similar in nature to advice and support services, peer support offers less formal connections to the community around refugees than either primary care or clinical services. Unlike any of the professional-led services however, peer support is directed by

the community, which could suggest a more finely-tuned assessment of and response to community needs. The “Besim” programme in East London for example, emerged out of the Kosovar refugee community to address the needs of the Albanian-speaking refugee and migrant population within this area. Deni, a refugee from Kosova began the program formally in 2000. The programme began with a women’s support group and activities for children, which have served as the cornerstone of community projects. Within the groups there has been a process of open consultation where the women participants themselves have informed the nature of Besim’s projects. As a result the events and programmes ideally evolve over time, reflecting the changing makeup of the community, and the shifting needs that emerge as part of the resettlement process. The events run by Besim allow the Albanian speaking community to shape services to reflect their needs. One of the striking directions taken by Besim has been the emphasis upon the facilitation of social and cultural events as much as the more ‘practical’ resettlement focused activities.

Deni: Well you know, it is something that usually there would be a party, a wedding each year among all the families and the music – the music that we really miss and it is the only place that you can dance. So you know your really enjoy it, and for the children as well. And everyone has fun... so I think it is quite good for them as well and they really need it as well. They don’t know how many people are around...to learn how big a community it is!

The shift in focus is away from the obligations associated with immigration and the logistics of adjusting to UK society and towards reconstructing a sense of belonging and community. The creation and promotion of community is a central aim of user-led organisations. Within refugee communities this is of considerable importance, given the high degree of social isolation. Peer-led services work towards common goals whilst promoting a socio-cultural resource. Amongst Albanian speaking refugees in East London, for example, few people realised how large the Albanian-speaking community was, especially those who were newly

arrived refugees. A common story amongst people is of overhearing someone speaking Albanian in unlikely settings (open markets, bus and train stations) and initiating contact based on that. For Deni, who had been volunteering with a local community-based refugee service (at Transfiguration Centre), a real sense of the extent of Albanian-speaking community came through her participation in a university-sponsored research project on nutrition as an interpreter.

Deni: Well they [the researchers] used to pay £10 to get interviewed and it was quite good.. We just needed to find just one (person) and then they would know 2 other people and they would get £10! And everyone wanted that 10 pounds, that's good! And the interview was nothing to do with immigration, or anything to do with war so basically, people were happy. It was about nutrition and what did they eat.. so really it was no risk here. And 10 pounds! So it was quite good. And so I found out there were so many neighbours that spoke my language!

The women she met through 'snowball sampling' on a research project were the ones she approached to collaborate when she decided to start a women's support group. User-led organisations such as this have challenged pre-conceived ideas about the sense of vulnerability and degree of personal agency of women refugees in resettlement. A woman's support group may seem at first glance to be directed by conventional (western) perceptions of health, vulnerability and risk, in practice the group works to address a broader (and less clinically defined) spectrum of concerns which include isolation and the need to re-create social connections.

More clinically defined services which incorporate a 'user' or peer component strive to straddle the worlds of provider and participant in ways that re-shape the user as a conventional service provider. The Carysfort Centre offers psychological (clinical) services that have been created by and for refugees. The focus is decidedly different from the community-directed peer structure of Besim. However it is nonetheless 'peer-led'. Refugee

clinicians aim to bridge gaps that exist between mainstream clinical modalities and the experiences and perspectives of refugees. Philip a clinician there explains:

Philip: Working in a clinic for refugees and as refugee counsellors is helpful for refugees and asylum seekers, even it is beneficial for us – it helps us to rehabilitate, learning to live with our pasts, and to see our future, and also to appreciate the present. So, and we knew that unless this kind of approach –refugees trained into refugee counsellors providing counselling services (...) unless [that kind of] ‘counselling’ is given by refugee counsellors, [counselling] couldn’t benefit the refugees and asylum seekers.

The fundamental position offered is that refugee counsellors have the most to offer refugee clients. This is, perhaps, at the heart of user-led initiatives. However the work at the Carysfort Centre also reflects formal specialist training in psychological models of counselling and as such there is a decidedly professional component that is intrinsic to the services offered. This is quite distinct from the more grassroots framework that has driven the work of Besim, where the staff, volunteers and users emerge from the same community and are at (roughly speaking) the same point in resettlement. At the Carysfort Centre the focus is on mental health care that is formed by a collaboration of refugee experiences and a psychotherapeutic paradigm. Philip envisions this work as inherently collaborative; where the therapeutic process benefits both counsellors and refugees. Counsellors who have lived through the process can offer hope and insider knowledge of resettlement, while at the same time benefiting themselves from the process of actively confronting their experiences of exile and resettlement.

While theoretically the nature of services is distinct for each agency, in practice there is considerable overlap in the way services work with refugees. As they articulate their working philosophies and typical practices or routines, we begin to get a sense of the tangible ways in which trauma is understood and approached in refugee resettlement.

## Philosophy and Practice

In the course of interviews providers explained the ideologies underscoring the work of their agency (often in relation to the broader scope of services) as well their positioning as individuals working within the specific agency. Across services there are similarities and contrasts in terms of the working philosophies underlying the provision of services. Terms like ‘holistic’ and ‘multidisciplinary’ figure prominently, as providers work to contrast the conceptual frameworks that shape their work with those fixed more firmly within a biomedical perspective. Yet it is more within the day-to-day actions that providers communicate most about their philosophies and practices; how they define and operationalise their work and their observations about the issues facing refugees in the UK.

Joanne leads one of the newly emerging specialised health teams focusing on refugees and other marginalised populations outside of the scope of mainstream services (refused or excluded from services or ‘hard to reach’ within the community). Her team provides primary health care services within focused clinics. These clinics are in effect travelling medical services, where the team will offer on-site health assessments within hostels, hotels and other community based setting on a regular basis.

Joanne: It’s a multi-disciplinary team – so we have nurses on the team and we have multi-lingual refugee health workers, and so we see health very holistically, so when we do an initial health assessment, we try to find out what has happened to someone in the past. What has happened in the events of exile? Because that is indicative of the physical and mental health problems. And then find out what is happening to them in their lives here and find out what is influencing them and their health.

There is a comprehensiveness that permeates the philosophy of her work from the understanding of health and health care (holistic), to an explicit professional approach (multi-disciplinary), the inclusiveness of services (multi-lingual), and the temporal framing

of her assessment (from pre-exile to present-day). The realities of her work are inevitably less-clear cut and more reactive to the dynamics of a fluctuating system of care and an ever-changing population. Like many of the providers, the initial description of an assessment was presented into an almost ideal way. However, its implementation could prove more difficult in reality, especially when dealing with quite sensitive issues.

Working with primary health care services can in practice become a matter of ‘choosing battles’. Like Joanne, Anna, a health worker at a refugee community organisation has had to be creative about how best to tackle obstacles to care. One option that Anna has capitalised upon is the use of local chemists who are willing to talk with people about their symptoms and advise, while arrangements for registration with a GP are explored. This can serve as a bridge to treatment, enabling at a minimum simple health concerns to be dealt with quickly. Deciphering what is a simple ‘headache’ and what is not; however, is often not a straightforward process.

Anna: Basically I just put down what the problem is regarding these headaches, because I can’t just say ‘*Take paracetamol*’, because how do I know? So they go to the chemist who would give them the paracetamol, or whatever, and they don’t have to pay for anything. But if it is anything that is acute, I have to send them to Accident and Emergency. There are cases like that.

This balancing of what resources can be drawn upon becomes more and more complex for health workers like Anna, as the rules around eligibility to NHS care (a current issue within the UK) shift or where there is confusion and room for misinterpretation. This is further complicated by competing notions of what are the critical health issues for this population at any given point.

The understanding of what needs to be assessed brings to the foreground some of the guiding philosophies of care. Each provider routinely lists an array of physical and mental health issues they believe to be common amongst refugees, with psychological trauma figuring prominently. There is a strong identification with psychological needs that are articulated (although not explicitly cast as ‘psychiatric’ in the form of a diagnosable condition). In part this stems from the fact that the services involved in the research reflect more community-based rather than hospital based work. This may influence providers’ perceptions about the nature of their work and the precepts that underpin it. Nonetheless, despite this, there is a striking presence of a psychiatric paradigm when providers speak of ‘trauma’ as a specific health issue for refugees. Initially this emerges in relation to the presence of symptoms and strategies for minimising them.

While some clinicians expressed a wariness regarding the use of any psychopharmacology, there was also recognition by biomedically trained providers that medical approaches could offer some benefit for clients in alleviating symptoms. Sandy, a medical doctor in a primary care setting, summarises:

Sandy: Well I think.. yeah... (it is) very common that people can’t sleep, people have nightmares. I think for a proportion of those ones, one would actually say they were severe. Some people would actually be treated with anti-depressants.

This approach is rooted in a pragmatic desire to both identify and alleviate symptoms. As a physician, Sandy is clear that she wants to minimise the discomfort that her patients experience. At the same time she advocates the use of more psychologically based clinical work to get to ‘the heart of’ emotional or psychological issues. This willingness to merge biochemical and psychological therapies seem to surface more with medically trained providers than those whose orientation is exclusively psychological. Instead people often

professed a sense of disquiet with the use of psychotropic medications. Philip at the Carysfort Centre explains the philosophical distinctions that he makes:

Philip: Ours is not only psychological, it is psychosocial. And we don't think that the medical the – well, we understand that people should take medicine when prescribed by their GPs, but we don't [agree with it] (...)we think that once somebody starts taking medication it becomes very difficult for that person to rehabilitate and to come back again – his own...

I: You wouldn't object if they have been prescribed from their doctor, but you wouldn't endorse from this end.

Philip: We don't take any case of client who is on medication (...) the service is not geared for that kind of intervention. This is not a psychiatric (service) where there is kind of a backup team. This is just talking therapy where people are just coming to share their thoughts and their issues.

Philip voices a strong reaction to the idea of including pharmacology as a therapeutic strategy. In this discussion he articulates a strong ideological distinction between a psychiatric framework and a psychological one. The issues that are being dealt with in the Carysfort Centre are depicted more as difficulties in living, and not a specific psychiatric issue. There is in addition, a desire to locate suffering within some aspect of the 'social' world (even if under the guise of psychosocial) that resists an individualistic model. Medication would be locating the issue *within* the individual, impeding (as they argue) the ability to recover: '*it becomes very difficult for that person to rehabilitate and to come back again*'. While this perspective may seem exacting, in a sense the agency ensures clarity in terms of their position and what services they offer<sup>54</sup>. Philip is firm in the boundaries of the agency's work. There is a concerted effort to establish distance from a biomedical model, and towards analytic work that is informed more by a cross-cultural knowledge and

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<sup>54</sup> More often, providers express some openness to working with pharmacological treatment modalities. In addition some providers were explicitly interested in pursuing behavioural approaches to issues of trauma, such as Cognitive-Behavioural Therapy (CBT). CBT is brief, focused therapy that is often directed towards relieving symptoms related to traumatic stress or anxiety disorders (Basolgu et al 2004; Livanou 2001).

awareness (shaped by the insights and experiences of the clinicians). Conceptually the clinical work here draws on psychoanalytic humanist, and existential theories within psychology. The intellectual framing of the therapy that is offered is therefore informed by multiple perspectives simultaneously. The clinical work is individually shaped to reflect specific needs whilst taking into consideration socio-cultural experiences and background. This hybrid is not as diffuse as it sounds, with the central tenets remaining grounded in a psychotherapeutic framework of care that is ideally holistic in nature. This, Phillip asserts grants a certain sense of coherence to their services. Moreover identifying and working with the commonalities of conflict, exile and resettlement are central to the ethos of this 'user led' clinic.

Lydia, a psychologist who works with refugees within a primary care setting in East London, offers therapy that is more illustrative of 'standard' psychological care within the NHS. The specific service she is part of is unique in that it is located within a primary care GP surgery. Ideally this suggests an opportunity for greater inclusion of psychological concepts into the processes of primary care. At a minimum the screening that is undertaken within the surgery means that front line health professionals are consciously evaluating who is and is not in need of professional psychological help as part of their primary care services. Lydia's position there places her in a much more collaborative role with the frontline health professionals in primary care. However she is acutely aware that her position and working philosophy may not only differ from the other staff, but may operate in complete contrast.

Lydia: I'm the mental health bit of the team. Everybody else is quite health – medical model, and my addition to the team was a decision to create a holistic kind of care package. It's very unusual to have a fully attached or even a part time attached psychologist as part of primary care team.

Lydia does however note that in the beginning referrals to her were somewhat overzealous and indiscriminate. Their ability to identify and screen has at times been less than thorough: *“In the beginning I just got every refugee!”* This in itself suggests an element of the understanding that operates within the general (medical) practice; that every refugee is in need of therapy. Interestingly Lydia's role is not meant to only address the needs of the surrounding refugee communities, but rather those of the broader 'general' population. This process of filtering through a barrage of referrals means that clinical sessions are (initially) consumed with a secondary screening of the appropriateness of the referral. Explaining the nature of her role, she describes it as involving *“lots and lot and lots of explanation”*. Walking people through the process of these sessions can be a struggle as she finds people unfamiliar with or uncomfortable with the process of talking about intimate aspects of their lives and her role quickly becomes one of instruction (*“we call it psycho-education! But I hate that!”*).

Psycho-education (by various names) is a recurring theme within practices linked to refugee health. Underscoring this work are a number of assumptions about the need to teach refugees about the value of therapeutic interventions as well as providing specific tools for the individual to communicate in ways that correspond with this framework (using the language and concepts of psychology).

Lydia is very conscious of debates within academic and clinical circles about what she terms as the '*privileging of a discourse*' regarding health issues and refugees. In her work she struggles to balance between the '*mind-body dualism*':

Lydia: Some of our clients will come in and they'll tell me about the physical discourses... and then my agenda is '*no, no, no, it's the emotional one*'. "*Let's talk about your presentation – this is how you experience the stress in your body*" and you know I'm parodying myself... but sometimes you might have that kind of slight clash between models that we work really, so that the whole body mind dualism thing is something that we hold different [views on].

Lydia captures the struggle that providers often face in trying to avoid a simplistic reading of idioms of stress and trauma as 'either-or': body or mind. Achieving a balance between this dichotomy is an important part of what Lydia's work with refugees. However the nature of her role dictates that she move the conversation towards the articulation of psychological distress in psychological terms. Lydia is a practitioner whose work is informed by a complex knowledge of socio-cultural frameworks of distress. Reconciling this with the working philosophy of her practice within a formalised health system becomes harder to achieve in practice.

The structural issues that accompany clinical work play a fundamental role in shaping the way clinical work takes shape within practice. Claudia, for example, is a clinician with an NGO that provides specialised and time-limited 'crisis' counselling services to women refugees. As with many people based in community-based non-governmental agencies her job duties are expansive in contrast to the structure of her position. Claudia functions as a one-woman team on a part time basis. Despite her acknowledgement that this is "*quite unreasonable*" in terms of the level of commitment required, she is quick to note that "*people have to want to do it for the love of it*".

In the course of our interview she develops this idea more completely. For her, the clinical work that she does is infused with a philosophy of social justice. This philosophy functions as a powerful underscore to her understanding of traumatic events, her assessment of trauma in the lives of the women she sees, and what she feels as vital as an intervention. The nature of mainstream services, she believes, is informed by limited ideas about mental health:

Claudia: I think that is because it is always linked with mental illness. Here I think we do have a conceptual problem, i.e. when people ask me ‘*how do you define yourself?*’ ‘*how do you define your counselling?*’ And I would say.. well actually my counselling is not medical – it is philosophical. It is more philosophical than psychological, because I think a lot of the crises and these are my observations – when you experience gender persecution i.e. sexual violence – that throws you into a moral crisis. Because you are in a position of anarchy and it shows also the bankruptcy of authority, right?

Claudia offers a distinctive philosophy which is clearly informed by a particular socio-political vision (she would argue informed by her own experiences of exile from South America). Her work is heavily imbued with questions of an existential nature. She sees her role as one of coaxing into the open the profound personal transformations that she believes are an inevitable after-effect of violence. There is a strong moral and spiritual component to this work, which seeks to minimise the privilege of a psychiatric vision. In examining her work further, she strongly contrasts her position with that of primary care physicians and what she describes as mainstream medical treatment, who she thinks are likely to “medicalise things” and prescribe medication routinely, if not indiscriminately. However Claudia does not dispute the *possibility* of psychiatric distress as an element of trauma, she simply advocates a framing of trauma that is more comprehensive in its perspective, inclusive of less ‘diagnostically defined’ variables and steeped more with phenomenological questions about the meaning of suffering.

Claudia asserts a strong ideological stance when describing her work. The fervent way that she speaks of her working philosophy is something that she strives to implement in practice. At times this may mean that she approaches sessions in a tenacious manner, which may not achieve the desired effect. In talking she shares a story of an occasion where she, in her own words, '*missed the boat*'. Faced with a woman who engaged in sex work, Claudia struggled to get the woman to recognise what she sees as the ethical issues in this work. The woman, however, is unapologetic for her choice to willingly participate in sex work. This becomes a hurdle they are unable to get past. The woman discontinues counselling and Claudia never sees the woman again. This is an extreme example, and it may seem like an obvious clinical error to not impose one's perspectives on a client. Yet what becomes clear from Claudia and across the discussions with providers is that much of their work involves doing just that albeit in more subtle ways.

Through their interactions with refugee providers strive to balance idealised definitions of their work and of the issues that surround refugees to the more concrete accounts of how they work through their expectations and respond to their observations of what refugees 'present' with. This process of negotiation is chronicled through an exploration of the patterns, strategies and inconsistencies as providers move between what they anticipate, what people present with and what they believe should be happening. This trajectory through discourses and practices has relevance in informing the understandings of women refugees around trauma. What emerges is a sometimes complicated portrait where providers strive to work within the confines of their roles(s) and the systems of care, whilst meeting the challenges of working with this population. Couched within these practices are more explicit understandings of trauma and the needs of refugees.

## **IX. ASSESSING HEALTH, DEFINING TRAUMA**

In health care services, assessment tools are at the heart of a consultation. The assessments used across health and social care agencies seem to focus upon the identification of critical life events sustained during the course of forced migration and conflict and its relationship to health. Joanne, the team leader for a nurse-led specialist health service for refugees, articulates the significance of this assessment. She notes a strong inter-relatedness between past events, current resettlement issues, and health. This is the critical point in time where an initial disclosure of past traumatic events is likely to occur, and determinations are made about the meaning of those events in terms of current physical and mental health.

Joanne: People are quite open. We will ask if they have had a traumatic event, or if they are experiencing discharge or are pregnant, we will ask if they know who the father is, or we will ask people if they have been raped.

Past critical events serve as the core of this understanding of trauma. For women refugees this is most often talked about in relation to experiences of sexual violence. For Joanne, there is a value in breaking down the experience of rape into health-related issues. Focusing upon the impact(s) of rape in a very structured and tangible way means that the process of asking people unimaginable questions becomes manageable. There are health needs and risks related to rape (unplanned pregnancies and sexually transmitted infections) which clearly warrant immediate attention from a medical perspective. This sense of urgency drives the decisiveness in Joanne's health assessments.

The centrality given to sexual violence in the life narratives of women refugees may however mean that there is an overshadowing of the less striking and more nebulous experiences such as loss. Moreover the central position accorded to rape may reduce the

meaning of 'trauma' to an event isolated in time and space. Daria, struggles with the positioning of rape in relation to other critical issues women face in resettlement. When asked to talk about the main issues for women, her initial and immediate response is the unexpected: gender roles and domestic violence.

I: For women, what are the main health issues you're finding...?

Daria: [I]t would be .. the change of the roles within the family.... because sometimes in their homeland they may have been at home and their husbands would have been the breadwinners and when they come here and the woman sometimes goes and educate themselves, probably she will find a job and that causes the exchange in the roles, and sometimes men fall behind the women because of their skills and so sometimes you see the marriages even break up, and probably they can no longer tolerate it..

This is an intriguing revelation as 'trauma' as a discrete and definable event fades into the background and instead sociocultural aspects of exile and resettlement move to the forefront. It is only when Daria refers to slides of a recent presentation summarising the work of her team she 'self-edits', stating: "*The issues for women are rape*".

The prominence of sexual violence as salient feature of the discourse on women and war makes its mention in relation to women refugees somewhat inevitable. Joyce echoes this sentiment. In her work with women refugees she observes:

Joyce: Before people go into the group we see them on their own. And it always comes up there. But in the group it is never mentioned by name, it is called '*the thing that happened to me*' or '*what happened to me*' or '*when those things happened*'. They never say... they never call it what it is. Because it is too awful. And this is a woman only group.

Providers emphasize the central role of sexual violence in the aetiology of trauma and actively encourage women to reveal and discuss their experiences. However this may place women in an awkward position between a clinically endorsed 'need' to disclose and the

coeval 'need' to remain silent about their experiences. The repercussions of not remaining silent are recognised by providers: women who openly acknowledge sexual violence run multiple risks from a stigmatised identity to a very real threat of losing their families. Any discussion of sexual violence for these women brings to the forefront cultural beliefs about honour and shame. Joyce elaborates:

Joyce: The husband of one of the women in the group says *'if we have permission to stay here, ok we will have a good life – but if we have to go back to Kosovo, I will divorce you because I can not live with my family with the knowledge that I have a raped wife'* and that's one of the terrible things about Kosovo, because if you are a raped woman you are a dead duck as far as your father and your brothers, and your uncles are concerned. They don't want to know you. There are many stories to confirm that.

Yet despite the extreme social repercussions that are linked with disclosure, the pressure to disclose remains an integral part of the clinical or working relationship. This tension between revealing and not-revealing is one that surfaces again and again in discussions about women and trauma.

In an interview with Lucy, a psychologist in a specialised mental health programme for refugees, she echoes the sentiments of other providers, noting that *'the first thing to be discussed is sexual violence and rape'*. It is unclear how often sexual violence is raised as an issue by the women, or acknowledged in response to inquiries by providers. Lucy notes that she asks women quite pointedly within the context of a clinical encounter and finds that most are comfortable discussing this once they are reassured that absolute confidentiality will be in place. The prominence of sexual violence in discussions with providers about health and trauma-specific issues for women involves 'staking out' a position on the diagnosis of PTSD.

## Framing Post Traumatic Stress Disorder

When it comes to labelling what they see, providers are cautious of relying upon the framework of PTSD and actively strive to approach the concept of trauma in a different way. There is a reluctance to reduce people's experience to 'diagnostic criteria' and a desire to work within an ethos of 'holistic' intervention amongst both clinical and non-clinical providers. This orientation is manifested in the language that gets used. There is at once an engagement with -- and a movement away from -- the word 'trauma'.

For example, on the one hand refugees are often described as 'traumatised' without elaboration. When Joanne is asked to comment on what she sees within the community of refugees that she works with, many of whom are newly arrived, she is direct in her definition of traumatised as mental health problems, moving quickly to a litany of symptoms or expressions.

Joanne: For most of the people we see, they are actually traumatised. They are suffering from mental health problems (...) a lot of anxiety, insomnia, flashbacks, panic attacks, and we see a lot of people with gastric problems – a lot of them due to stress, but also a lot due to changes in diet. And then we also see a lot of psychosomatic illnesses, a lot of headaches, um, you know just generalised pain, really.

The detailing of specific symptoms and/or behaviours is critical. This grounds the concept of trauma in specific physical or behavioural complaints. Most often the list of physical reactions that people exhibit are linked with the criteria outlined in the diagnosis of PTSD. Consequently the conceptualisations of trauma that emerge in the narratives of providers (across agencies and professional orientations) frequently make use of elements of PTSD. Typically core symptomatic features include flashbacks, numbness, weeping, and nightmares.

In looking back over Joanne's description there is a sense of moving through the cardinal features of PTSD, from nightmares and flashback through to somatisation. She is clear in her idea of somatisation, distinguishing between physical problems that are 'wounds' from those which may be a manifestation of distress (*"we also see a lot of psychosomatic illnesses, a lot of headaches, um, you know just generalised pain, really"*).

For Claudia, an understanding of trauma is described drawing upon the symptomatology of PTSD. However, there is also an impression of something more profound happening here. The person is not just experiencing nightmares or anxiety; there is a quality of existential crisis that comes out most strongly in her observations and experiences in working with refugees.

Claudia: Well usually you could detect or sense someone – this is not going to sound scientific – so sorry – But this is what it is you usually sense someone's short breath, for example, [*gasps for the tape*], and they go like that every two minutes during the conversation.. Totally unconscious of it – they don't know it. And it usually takes someone that is that perceptive that would maybe begin with inquiring along that way '*when did you start with that..?*' And they will go '*what?*'... and then they will go back to.. and try to work that out. I'm not saying that we try to assume that everyone is traumatised, but suddenly a lot of our clients display symptoms of post-traumatic stress, like the short(ness) of breath, like the um, they weep a lot for no reason.. or as soon as you speak to them they burst into tears. Or have reoccurring nightmares, very frightened to go to sleep without the lights on...they are forgetful, they get lost very easily... they cannot learn English. They refuse to acknowledge that they are here.

This final notion – '*they refuse to acknowledge that they are here*' is a particularly powerful one. In some ways this captures the essence of Claudia's definition of trauma, which she characterises through the image of people moving through life lacking a consciousness of experience – not a dissociation per se, but a lack of being 'present' in the world. This may be manifested physically through erratic patterns of breathing or socio-behaviourally through an inability to adapt to a new environment and new life circumstances.

For Claudia, trauma reflects a combination of philosophies and concepts which she draws upon to interpret and define trauma for refugees. Critical to her conceptualisation of trauma is the recognition of political features as well as psychoanalytically informed theories on human coping and development. There are similarities with PTSD as far as the concept of trauma as ‘event-inspired’ and in the emergence and expression of specific trauma symptomatology. However the ‘crisis of trauma’ in her paradigm is more suggestive of what she refers to as a moral crisis: “*a position of anarchy*”. Her role as she sees it is less about diagnosis and more about reflecting a way of interpreting critical events and emotional reactions that is intent on bridging the individual with the socio-political. Her interpretation of the political is however intensely individualistic. The interpretation of political struggle is not one that is external but one that is internalised as an existential struggle.

As discussions on trauma come into sight, providers find themselves wading through biomedical terminology, including a heavy reliance upon psychiatric language, its meanings and implications in clinical and non-clinical settings. Lydia, the psychologist based in a local surgery, offers a thoughtful account of what trauma has come to mean in relation to diagnostic frameworks and PTSD in particular.

Lydia: It’s a term that’s been settled on because it’s the privileging of diagnostic categories in the way in which the health care system works. And also because of the way in which services get set up. You can fund things that have a diagnostic label and provide specialist service for it and that means the client group gets drawn off and put somewhere all by itself.

There is a utility to the use of PTSD as a reference point or marker of distress within refugee populations. Diagnostic categories determine the availability of services and who specifically may make use of those services. Inevitably these issues are linked with funding

streams: formal diagnoses may lead to enhanced funding for services. The practicalities and logistics of using or not using a diagnostic framing of trauma is something that providers struggle with. Lydia continues:

Lydia: I don't think it is all that helpful. I always look at diagnosis as being a functional process. When is it going to be useful to use a diagnostic term? And I just don't think it tells enough about people in general. And it's a shorthand way of communicating about a client's difficulties. Sometimes it is useful and it is necessary, but unfortunately sometimes it boxes you in.

In this case, Lydia critically evaluates the uses of a trauma label (as in PTSD). She goes on to break down trauma in ways that retrace the nature of experiences and identify behavioural expressions. There is a sense of linking trauma to a broader framework though, as she highlights something similar in tone to an 'existential crisis' when she mentions 'multiple loss' and 'loss of identity' as the core issues at the heart of 'trauma like presentations'. This framework of drawing upon elements of PTSD, yet away from a technical formulation of PTSD is noteworthy. This is in a sense a shift away from psychiatric nosology and towards the less clearly defined issues that many refugees are grappling with.

While open to acknowledging the symptoms of PTSD, providers seldom subscribe to the *complete* diagnostic framing of refugee problems. The term 'trauma' may suggest a formal diagnosis such as PTSD. In seeking to avoid the use of diagnostic labels, terms like 'distress' are evoked in an effort to summarise the experiences of emotional pain and suffering. Amy, a program coordinator for a London-wide support and advocacy group for immigrants from Eastern Europe captures the ambiguity that many professionals feel towards the use of the label of PTSD.

Amy: I think maybe it is medicalising people's experiences and reactions. But perhaps it is a helpful medicalising (...) I suppose that you could draw a comparison with something like dyslexia with kids and how a long time back dyslexia wasn't recognised and people just couldn't spell or didn't – it just wasn't really understood. But actually by creating that word or having the concept or understanding sort of fuelled a lot of research into it and people into education and psychology and the development of programmes to help them... and I suppose that would be the good thing about being diagnosed with PTSD.

Others providers are more cautious, concerned that the diagnosis may be casually or inappropriately used. Despite a strong belief amongst providers that a diagnosis may have value as a means of accessing services, there is a growing recognition that the converse is also true as providers realise that a diagnosis may contribute to new forms of exclusion.

Sandy, a physician in primary care is acutely aware of the ease with which psychiatric diagnoses can be used. She raises questions about the use of PTSD, its appropriateness and whether its use actually works against people's interests.

Sandy: I'm apprehensive. I'm not doubting that it (PTSD) exists. But I've never found it a useful diagnosis. And I don't know, I think people have used it rather simplistically... but actually it gets used rather sloppily, really. It is quite interesting the effect that it has – the effect that it mostly has is to put people off. And they say *'right well we won't deal with that'* Like, I got a thing recently that was about referrals to a psychologist and it said these are the things that we do and these are the things that we don't do. And at the top of the things that *'we don't do'* is Post-Traumatic Stress Disorder.

A label of PTSD may then mark an individual in a negative way, imposing new stigmatised identity on those already designated as 'other'. In this sense the concept of having 'special needs' becomes a liability. The negative connotations for a diagnosis are linked with the constraints of service provision within a system of stretched resources.

The strain experienced within services is voiced over and over by providers who may find themselves in a 'no-win' situation: wary of labelling someone with a diagnosis, but unable to offer secondary health care services (particularly formal clinical services) without doing so. There is, however, an active use of the concept of trauma as defined within a psychiatric paradigm, most often as a hybrid of PTSD. At the same time there is a wariness of the use of PTSD as a label, and a genuine apprehensiveness of over medicalising the experiences of refugees. In part the struggle to move away from a reductionist diagnostic framework emerges from questions about the core meaning of a traumatic response: is it normal or is it pathological?

Daria: I think, first of all I think first it is an unusual situation for somebody who is having a normal reaction.. it is a normal situation, the person is perfectly normal. So I have to explain that anybody that has been in that situation would be affected. Because they are normal human beings who have been in extreme situations. So if you are not affected by rape or torture or witnessing somebody else being tortured, or one of your relatives being killed, or gone missing.. then how could you not be affected by that?

As Daria notes above, there is a common-sense feel to discussions about traumatic reactions and traumatic events. On the one hand she asserts the definition of traumatic responses as a '*normal reaction to abnormal circumstances*'. Yet there is room left for the idea of severe reactions (verging on pathology), which are presented as 'to be expected'. This way of presenting clinical stories where (obvious) traumatic events lead to (obvious) traumatic reactions is something that surfaces again and again in the narratives of providers. Moreover, these stories help to shed light upon the complex interactions that occur between these understandings of trauma and clinical interventions in practice.

## The Horror Story

Typically providers will describe their work and the work of their agency as a way of charting out the philosophical structure of their work and the practical guidelines for their work. With the horror story, the brochure-like depiction of their work becomes slightly unhinged, as providers delve into stories where things are much more complex. Practices and philosophies are less clear-cut and more responsive to chaotic circumstances. In these stories the qualifiers are that the response of these individuals is both ‘understandable’ and ‘unavoidable’: it becomes evidence that ‘everyone has a limit’. Through graphic illustration, providers use the horror story to convey extreme circumstances of trauma. The extreme and graphic nature of the detail given in some of these stories suggests an almost voyeuristic quality. The intent is clearly to shock. However, these stories also offer recognition and validation for clinicians, where the intense and difficult nature of their work and the challenges they face is openly acknowledged.

In the more explicit stories the language carries particularly violent imagery. Joyce, a psychologist working with women refugees describes a woman that she has worked with in extreme detail. The woman who had been raped during the war in Yugoslavia:

Joyce: And this little girl, for the first time ever, who had been gang-banged by Serbian soldiers for two days before being chucked out onto the streets and she must have been about 19 at the time and this was her first sexual experience.

The graphic quality of her language is key. It manages to convey a sense of shock and revulsion that makes the assessment of traumatic stress inevitable. Joyce goes on to describe in (much more) graphic detail the intimate details of this woman’s life that are exceptionally tragic. Having sought asylum in the UK, the woman begins to settle in.

However through a series of events, she is coerced into sex and ends up pregnant. When her only family in the UK learn of this, they throw her out of their home. Joyce remarks: “*In some ways I think I’ve never quite understood what traumatised is until I saw this girl and the state she was in, she simply could not speak.*”

The ‘horror story’ emerges within provider narratives as an illustration of extremes. The people depicted have been through extraordinary circumstances and as such it is only natural that they would suffer distress in equal measure. These individuals are depicted as having understandably hit a limit in their ability to cope. As Daria, the health worker who works as part of a refugee health team describes:

Daria: For example we have this girl through one of our colleagues. And there was a problem with language, she needs someone that speaks her language. And she is a victim of torture, and she is living her in a very emotional situation. And they asked me to visit her, and when I approached her, *she was a really shattered person* (emphasis added).

Daria goes on to describe how the woman had essentially stopped functioning, unable to do simple tasks necessary for survival in the UK. She explains “*the scars they’ve got – the scars are too deep*”. There is a common-sense quality to such statements which seem to confirm the idea that the individual has undergone a psychologically damaging event. In light of discussions on ‘trauma’ the horror story reveals suffering that is both extreme and self-evident: anyone would be traumatised in response.

Providers also use the ‘horror story’ to shed light upon the complexities of trying to define and work on the issues of ‘refugee trauma’ in resettlement. The story details the array of structural faults that operate for providers, depicting a system that is bureaucratic, chaotic, and grossly under-resourced. These are tales where system failure and extreme human

suffering combine. The story illustrates the obstacles that service providers must navigate and provides evidence of the value of their work within a 'swamp' of services.

For Mary, a support worker providing targeted outreach services, the combination of an exacerbated sense of need and an absence of appropriate care fuels situations of extreme distress for women refugees. Here she describes the difficulties of women accessing reproductive health care, critical for a population she defines as primarily victims of sexual violence.

Mary: It's certainly becoming more difficult and we are coming across more and more desperate clients for one reason or another... Just yesterday we had a call from a family planning unit in London, the woman was ringing up to see if we could help because she is getting increasing numbers of women coming to her to seeking terminations, and (..) the women coming in are coming from all different places in London, and she is finding it very difficult to help them to access appropriate services in the boroughs that they are coming from..

Mary highlights an unspoken link that is often made between women refugees and sexual violence, which is reproduction. Women who are pregnant as a result of rape emerge as an almost iconic image in the horror story (men refugees come to embody the quintessential political refugee who has undergone torture). This image helps to sharpen the importance (and potential impact) of strained resources in the lives of refugees. Without immediate access to appropriate care these women may find themselves effectively forced to continue pregnancies, heightening their sense of distress and trauma. This suffering, in conjunction with the features of a hostile system (one that may be marked by racism, bureaucratic delays or inconsistencies) reveals the nature of trauma for these providers and legitimates their belief /conviction in the necessity of professional (clinical) support.

Providers struggle as they go through a series of challenges – questioning the orthodoxy of a psychiatrically charged vision of 'trauma', calling for a greater consciousness of

'indigenous' coping mechanisms and strategies, struggling between the power and attraction of PTSD while struck by the invisibility of social justice. The pull towards a psychological language and framework is not easily embraced, instead people hedge behind words and phrases that they hope will move away from a reductionist psychiatric model and towards more nebulous terminology such as 'distress' to summarise emotional pain and suffering. The struggle at the 'front lines' is striking. Anna summarises this: "*the barriers have just been raised (..) it's become more of a battleground I think.*"

The meaning of trauma as the psychological 'state of being' is defined by providers by an assortment of models, philosophies and practices that are used interchangeably and often in an impromptu fashion. It is in the stories of their work that a strong sense of psychiatric discourse comes through. What accompanies this are certain unquestioned ideas about mental health, illness and suffering. As part of this paradigm there are specific beliefs operating about the type of interventions that are appropriate for addressing trauma (such as counselling) and the conditions that are necessary for successful resolution of trauma (explicit disclosure and the need to talk about experiences).

There emerge distinctive ways in which trauma is defined and addressed by providers and by refugees themselves. In part this is directed by their specific experiences. For providers conceptualising trauma comes through sustained professional development, working with a in a highly politicised climate, as well as clinical exposure to the lives of refugees in resettlement. For women refugees the dynamics of exile and resettlement combine to shape their understandings of trauma.

## X. LIVES IN RESETTLEMENT

### A Kosovar Community in London

‘Downsview’ is a borough noted for consecutive waves of immigrants as well as a strong ‘indigenous’ British culture (East London ‘cockney’). As a result the neighbourhoods that make up Downsview are an eclectic mixture of cultures and histories. “Edwin Avenue” and “Roxton Park”, two neighbourhoods within the borough of ‘Downsview’, are very different in terms of tone and feel, but share key features including demographics. The commercial landscapes of Edwin Avenue and Roxton Park share features associated with poverty and struggle: ‘chicken and chips’ shops that mimic larger fast food chains like KFC or MacDonald’s; phone centres that specialise in inexpensive long distance rates to developing countries; ‘pound’ shops characterised by a miscellany of household goods; ‘knock off’ fashion outlets, selling replica handbags and perfumes along with low-cost sets of luggage. The franchises that do operate in these areas tend to be on the lower socioeconomic scale. These are stores that are manageable in an economy of stretched resources.

Roxton Park is a colourful neighbourhood marked by a bustling high street, a traditional ‘East End’ open market, and is home to a popular football team. When you exit the local underground station you are immediately situated on an active main (‘high’) street. The shops that comprise this busy commercial area bear the hallmarks of urban ‘multiculturalism’ – traditional British ‘Pie and Mash’ shops interspersed with African and Asian shops selling saris, tunics and African woodcarvings. The open market offers fruits, vegetables, meats and fish alongside bolts of fabric, miscellaneous household items (detergents, kitchen supplies, decorative items), and inexpensive clothing and jewellery.

The activity of the main street quickly fades as you turn off onto one of the residential streets. Tree-lined streets of single-family terraced Victorian style homes are typical. As with other areas of London – and the East End in particular – there are pockets of post-war ‘purpose-built’ low-rise flats and the occasional low rise ‘tower block’ of flats. Churches, mosques and schools are interspersed throughout. Despite the robust commercial sector of the high street, Roxton Park conveys a strong sense as a ‘family’ neighbourhood marked by a mix of extended and multi-generational living (predominantly within the Asian and African communities) and many young families (Eastern and Central Europeans).

Edwin Avenue shares many of the broad features of the community surrounding Roxton Park. However the main street lacks the heightened energy of Roxton’s thriving economy and is, instead, a dissonant assortment of services and industries: carpet suppliers, automotive supply shops, army and navy supplies stores, interspersed with the occasional pseudo-American ‘chicken and chips’, pub or a locally owned and operated grocery store. There are a number of inactive sites: former nightclubs and shops that have been boarded up or left vacant and a vacant lot which used to house a local church that burned down.

Situated between Roxton Park and a more formalised town of Ossington<sup>55</sup>, the neighbourhood surrounding Edwin Avenue feels less defined in its own right. The main street has the feel of a thoroughfare, an access route to or from the surrounding areas but not that of a coherent main street. Unlike Roxton Park there is limited public transport access to the area relies upon car or bus, or resorting to the nearby commuter rail system. These features converge and contribute to a sense that Edwin Avenue is less established and

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<sup>55</sup> The distance from Roxton Park to Ossington is less than 5 km, with Edwin Avenue situated approximately half way.

integrated as a neighbourhood. However there are signs of movement with the opening of an up-scale coffee and sandwich shop and an up-market pharmacy that boasts a diverse product range including children's clothes and cosmetics. There are also more formalised community buildings here: a local library housed in an architecturally historic building (Grade II listed) and a local community centre, the Clifden Centre. The Clifden Centre is a modern built community centre that houses a number of local community groups and sponsors neighbourhood activities. The centre boasts a small café and shop for arts and crafts (although the store is seldom open), a gymnasium, a collection of table games, a church hall, and general meeting rooms and offices. The Besim Programme – a user-led organisation serving the Albanian speaking community (refugees, asylum seekers and migrants) has secured office space here and the site functions as its organisational base.

The residential area surrounding Edwin Avenue is similar in nature to that of Roxton Park, with many single family homes as well as newer housing developments. An added feature of this area is a close proximity to a conservation area that spans North-East London. The parkland area situated close to Edwin Avenue is predominantly grassland, with small ponds scattered throughout. This green space is a stark contrast to the motorway feel of the actual avenue, and yet, these two features combine to create a sense of expansiveness in the area.

The neighbourhood around Edwin Avenue is made up of a population similar to that of Roxton Park. Families with small children are a common sight, particularly around the library (where the Sure Start crèche is also located) and the local community centre that hosts a number of groups and activities.

My introduction to the Kosovar community in East London began at Roxton Park. A local church-affiliated community centre (Transfiguration Centre) is the organisational base for

specialised services for refugees and migrants living in the area. The Transfiguration Centre offers advice, case management services, free clothing and furniture, as well as a 'food co-op' where residents can get fresh fruit and vegetables for a minimal cost. The Besim programme was running a weekly group for women and their children at the Transfiguration Centre (this continues to be one of the locations where Besim hosts events, for example summer activities for children including karate and traditional folk dancing classes).

The initial women's group at Roxton Park is quite large and includes up to 25 women. The number of people attending fluctuates, but there is a sense that the Albanian speaking community surrounding here is large. Demographically there is a significant mix amongst the women in age ranging from early 20's to 40's. The dress code is predominantly urban casual (trainers, jeans) with a preference for gold jewellery. All of the women carry mobile phones, with a noted preference for the latest models<sup>56</sup>. Virtually all the women have small children, and subsequently the groups must accommodate their needs. The children are permitted to play freely while the women will arrange themselves in informal semi-circles and talk. There may be music or a video playing in the background, an occasionally an activity to focus the event. For many of the women the groups offer an opportunity to get to know members of their community and to reduce the sense of loneliness and social isolation in their lives. The women possess various levels of skill in speaking and understanding English, with few exhibiting a sense of fluency and comfort in speaking it. However despite this the women try as best they can to converse with me and the other English speakers around.

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<sup>56</sup> Some of the women enjoyed teasing me about the phone I carried which was a significantly older model.

The women's group at Edwin Avenue is much more intimate in nature. On average about 10 women attend regularly (on a weekly basis). This group have established a strong comfort level with each other and have shared personal stories of their pre-war, wartime, and exile experiences. As well there is a greater sense of physical intimacy created by a smaller meeting space. There is a formal crèche connected with this site through a local Sure Start programme, which allows for the women's group to be held in a physically separate space from the childcare. Children are not wholly excluded from this space, and there is some fluidity between the two rooms, however the room designated for children is a formal crèche and as such has toys available and activities to maintain the interests of the children as well as trained childminding staff.

The Besim programme has become a critical part of resettlement within this community of Albanian-speaking refugees and migrants in east London. Initiated by a woman refugee from Kosova (Deni) and supported by a core group of volunteers, the programme was initially housed under the Transfiguration Centre services for refugees and migrants. At the beginning of my fieldwork within this community (March 2003) the programme was in the process of moving out of the Transfiguration Centre, and towards a more clearly defined stand-alone status in the community. Staffed only by volunteers for the first of its life (including Deni's role) the organisation has steadily grown to include three paid staff (one full time; two part-time) along with 10 volunteers. The range of projects and services that have been offered through this user-led program is impressive, including women's groups,<sup>57</sup>

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<sup>57</sup> These groups actually have a dual purpose, serving the needs and interests of the women and their children. Deni would also like to develop services/projects that could meet the needs of men in the Albanian-speaking community, whose needs she acutely notes are often overshadowed by projects for women and children.

and specialised projects for children and youth, cultural events. In addition there are current projects in development including occupational training (Information Technology, Childminding, Beauty and Complimentary Therapies) as well as projects with more of a psychosocial emphasis (befriending schemes). Over time, the location-specific groups have lost their strong geographic distinctiveness, as Besim-sponsored events encouraged a greater inter-mingling of the Albanian-speaking community across local neighbourhoods.

## Stories of Exile and Resettlement

Denisa: .. it was so hard, so difficult. To leave my country, to come here, and to seek asylum and to be a refugee. It's so so hard, so difficult for us. But we – we did that because we haven't had any other way. The war started in my country and everyone was going somewhere

Women's stories of their journeys -- from leaving Kosova to navigating systems of care in the UK -- help to shed light upon their experiences of stress and distress, the understandings they have of 'trauma' and the way this has been expressed within their lives. The journey out of conflict and into exile is characterised by stories of uncertainty and danger. The process of leaving – from the initial decision to flee through to arrival is captured in poignant tales that convey a heavy emotional burden, despite the process of telling and retelling their 'story' as part of the course of seeking asylum and securing care services in the UK. In these stories of resettlement few women volunteer explicit details about the events that preceded their flight. More often women make shrouded reference to the experiences during wartime without an elaboration of the nature of events, speaking in terms that convey an enormity of loss and a chaos of which singular events are merely part

of. This is conveyed in strikingly simplistic terms: *'we've suffered'*. Denisa, conveys a sense of the profound difficulties faced by her family in the period leading up to war and their eventual forced migration. She accents the ongoing harassment by authorities and the growing sense of chaos and instability: they have little choice but to leave.

Denisa: [It] was so hard, so difficult. To leave my country, to come here, and to seek asylum and to be a refugee. It's so hard, so difficult for us. But we – we did that because we haven't had any other way. The war started in my country and everyone was going somewhere... It was so difficult to stay there. Everyday war is coming there. Killing people. So terrible thing that happened there. And my husband was involved in politics.. he was being search by police and our house... and you need to do something...

She goes on to explain: *"you couldn't imagine and the war started and then we didn't know where our relatives or families were. It was such a difficult period for us, and like a nightmare"*. Beyond specific 'critical' events, leaving Kosova is also portrayed as the result of a cumulative process of victimisation. The everyday instances of coercion or aggression, exclusion or surveillance are often muted in the accounts of people's lives suggesting that some aspects of suffering (the more subtle forms of violence, victimisation and coercion) go undetected (Smyth and Fay 2000).

Most of the women who have taken part in this research would have made the transition from adolescents to adults during the years of systematic exclusion and 'bureaucratic' marginalisation that was common within Kosova for Albanians. The distinction comes at the end of this period when the situation intensifies and people find themselves targeted within communities. For some women, this situation is amplified. As part of a mixed marriage, Lira and her husband had been socially excluded within their community and shunned by their families of origin long before the war. Gradually as there is an escalation of unrest and the political situation becomes unpredictable, they become more visible and a

source of suspicion to those around them. Finally they are left with no choice but to flee. Their experience of exile follows a pattern of exclusion and harassment that is assembled through small injustices and intensified over time.

The journey and entry into the UK assumes a common pattern for women and their families, differing only slightly in terms of details (route, travel partners or the nature of being discovered by police). Silvana describes arrival into the UK with her husband and small children in the back of a lorry:

Silvana: It was really hard for us to stop the lorry, to make the driver stop the lorry. We tried really hard to make him to realise that we were inside the lorry. We got our arms out and got them like that to wave like that to flag him. The children were crying because they were scared. And then after some time the lorry stopped. And he stopped and he called the police and he didn't open the door until the police came.

The 'agent' responsible for travel arrangements has generally revealed little information on what to expect for the women and their families (tending only to instruct women to keep their children quiet or face certain deportation back to Kosova). However, for many the conditions were not only oppressive, but dangerous, leaving some with little option but to make their presence known.

Vilora: It was so hot and you know the children were nearly dying. And they (ferry officials) took us from downstairs, from where the lorries were... and they said '*don't be scared of the police or any.. don't be scared of anything*'. We said you know we were so dirty and smelly and they said to us '*you can have a bath*' and they gave us new clothes as well... [Then] when the ferry was stopped, the police came and they took us to the police station or prison – who knows what it was. And we stayed there for 2 hours and from there they put us in a hotel for the night. In the morning they took us to the Home Office and they interviewed us.

Most of the women had their husbands and children travelling with them, helping to ease some of the vulnerability that accompanied this journey. For women travelling alone the

sense of dislocation is palpable. Juliana is one of the few women who came to the UK without family or other real support in place. Her only contact was an 'agent' involved in arranging her travel. Along with other refugees she tried to figure out next steps:

Juliana: I didn't know where I would go. And we arrived at the home of the agent – we went to where he was and he said '*You are in the UK. Now you have to go and apply for asylum*'. And I asked him '*What is this? Asylum?*' But he couldn't give me any explanation. It was around three o'clock in the morning. And I went back and three o'clock in the morning and I spent three hours at the bus station and they just left me... and I heard some Albanians (speaking).

Juliana's case is unusual in that she is travelling alone. As a young woman this is rarely done and, perhaps, this is indicative of the urgency in which she left Kosova. Nonetheless her story highlights the level of confusion that people experienced coming into the UK.

There is a lack of understanding of the construct of 'asylum' itself: it lacks coherence for people. Instead what they recognise immediately are the signs of 'being under suspicion'.

Lira arrived independent of her husband, travelling with her small child. She describes the series of 'trick' question meant to trip her up or her husband:

Lira: When I arrived they asked me straight away, I gave to the officer the telephone number and I said 'This is my husband' And he said they phoned him and said 'look we've got your wife here. She is saying that she is from Albania. She is claiming from Albania' and what it was, was they were tricking him, because I am not from Albania. And my husband said 'look if she is saying that then send her back to Albania, because my wife is not from Albania!'

I: Oh my God! So they tried a trick!

Lira: Yes, yes. They used it as a tricking question...they try to figure out if you are lying. There was a postal thing with Kosova, a question they used to ask about Kosovo: what colour are the postage stamps: Blue or red? There are none! [laughs]

Lira describes this episode with humour now, but she notes at the end how overwhelming she found these questions: "*But we were so stressed, we left everything behind and it wasn't easy for us*".

These initial interactions with the asylum and immigration system depict a bewildering scene. With no reference point against which to place the concept of asylum and resettlement, people are left to struggle with what this means, often in isolated ways. Historically newly arriving immigrant populations make use of whatever migrant contacts exist (friends, family) within the host country (Kelly 2000). Harnessing these contacts often helps to ease the transition. This is typically a crucial element in the resettlement of ‘spontaneous’ refugees. However, refugees arriving from Kosova (through UNHCR humanitarian relief efforts or spontaneous arrival) had little in the way of an established migrant community in the UK. As such they were left with little option but to rely upon loose family or social network connections, or (more often) information learned from complete strangers.

Subsequently the introduction to asylum procedures is more startling than expected for women as they try to grapple with the circumstances they are now in. This is further evidenced by the fact that most of the women did not claim for asylum as independent applicants and instead were listed as dependents under their husband’s claim – even when advised upon entry that they could and should apply independently. Initially there was a common misunderstanding about the meaning (and consequences) of filing independently. Most women believed thought that by filing independently they would be physically separated from their husband, and therefore the family divided within the UK. For example, Deni described one case where, despite the urgings of immigration officials for a woman to file a separate asylum claim, one Kosovar woman refused, insisting: *‘No no. My husband is my husband. I will not break up the family’*.

It is unclear whether women are, as a matter of routine, offered the opportunity to be interviewed separately from their husbands in immigration interviews, an element which would impact heavily upon the decision to disclose sensitive information in support of a claim (Zimmerman 2004). For most women, individual asylum claims were filed later in their stay in the UK on the advice of advocates and attorneys.

Having arrived in the UK and dealt with the preliminary processing through immigration, the women found themselves then faced with the complexities of accessing essential support (housing and economic benefits). The nature of social services varies greatly within the UK, and ease of access is often a matter of luck and geography<sup>58</sup>. The police or local representatives of the Immigration and Naturalisation Directorate (IND) typically directed people towards social services (although people note much confusion about 'who's who' in services and officials at this point)<sup>59</sup>. Often, there is randomness to the quality of support that people are given, which often fuelled a keen sense of vulnerability. Uncertain about where to go or what to do there is immediate confusion coupled with feelings of abandonment and displacement, as Dafina describes in her arrival:

Dafina: And I was in a very bad state. I didn't know any word in English. A taxi was called for us and they sent us to a hotel. And they just left us there. And we didn't know anything...and my son and me were scared and we were crying. And we couldn't cope.

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<sup>58</sup> Among this sample relatively few women and their families had a period of living outside of London. Cities such as Liverpool and Birmingham are described in especially positive terms for the comprehensiveness of the support given, whereas the services within London suggest a much more mixed picture.

<sup>59</sup> For example, one woman reports that when her family were shuttled through the process of arrival, the distinction between officials was not clear to them. As a result when they thought that they were claiming for asylum, they were in fact registering with social services. Such errors can be attributed, in part, to language. The service systems in place at the time were largely unfamiliar with emerging refugee populations, and often failed to provide appropriate language interpreting or translation services.

Dafina and her son find themselves, in effect, stranded, with little understanding of where they have ended up, unfamiliar with the core elements of the culture and unable to speak the language. Where they could, people relied upon other Kosovars or people with dual language skills (English/Albanian) who could help to walk them through the process of navigating an often-complicated system of support. Etleva describes the frustrating search for support:

Etleva: Friends directed us to social services. They had a small house so they couldn't accommodate us there (...) We asked so many social services to accept us and they didn't they said 'no, no, they can't help us'. And then just in 'Downsview' they accepted us. It was really hard, you know, they didn't want to accept us as well. But you know, they accepted us because we had small children.

There is a strong element of dislocation that comes through these stories of arrival.

Common to the narratives is a sense of being shuttled between agencies. Few people were linked with specialised social care agencies (e.g. refugee community organisations, health care services) to start, however those that did receive specialised services for refugees were quick to note their positive experiences. Dea and her family for example were lucky enough to find themselves in one of the wealthier boroughs of London. The support they received is described as "luxury treatment" by one of the other women, who enjoyed teasing Dea.

Dea: When we came they really supported us in.. well everything... they gave us counselling, talked about how to bring up children here. They were really looking after my family and for me. You know, really counselling and seeing how we were feeling and everyday they used to come to our hotel and you know looking after for my son and me. They saw that we left everything behind and what we lost was so big, and they were just trying to support us. And even now I can remember that she was supporting us for two.

The nature of the support that Dea finds, interestingly incorporates some form of counselling as well as the more tangible everyday support that helps them prepare for life in the UK ('how to bring up children here'). There is typically no question of whether to

accept or refuse such offers of care. The women are open to whatever services or referrals are made available, in the hopes that this will ease the transition for themselves and their families.

For Dea, the care and support given is exceptionally good; with providers displaying a willingness to go beyond their professional remit. At one point Dea finds herself at a hospital attending to urgent health concerns. The support worker that she was assigned from an asylum team displays exceptional sensitivity to the vulnerabilities that Dea is experiencing that is noted in small gestures: *“She stayed with me there in the hospital until they found an interpreter. She went shopping and bought underwear for me and everything.”*

Such experiences were highly unusual in this group of women. This is not to say that people did not receive and appreciate such services later in their stay – however early contact with other providers was often marred by the negative reception they felt at social services. Decisions were often caught up in an illogical maze of bureaucracy. One couple, for example, separated in transit, were advised to file for economic and housing support separately from each other. Then, having done so found themselves unable to live together and receive support. Biljana was placed in a single room at a hotel for newly arrived refugee along with their small child, her husband forced to live elsewhere:

Biljana: They said ‘No he can’t stay in the same room with you because he gets DSS’. And at ten o’clock at night the manager of the hotel would come up and to ask ‘Can your visitor go out now?’ That was hard that time. After I went to the social service every day crying to them ‘what I can do with a small child? How can we stay separated?’

Bureaucratic errors such as this only served to heighten the sense of vulnerability and insecurity that people experienced during this time. In the logistics of getting settled (ensuring that appropriate formal processes are dealt with including housing, benefits and legal support) the women assume a determinedly pro-active role. The women are responsible for registering the children at school and ensuring that the family is signed up with a local GP surgery. These actions are portrayed by the women as ‘accidental moments of agency’, driven more by a survivalist ethos of “doing what you have to” than any sense of mastery over the complexities of their life here.

For the most part the women have adopted a pragmatic approach to services, exemplified by a willingness to utilise what services they are referred to. Few have had contact with the larger community based organisations serving refugees (e.g. The Refugee Council), instead tending to utilise localised agencies (in part this is shaped by the practicalities and limitations of movement throughout the city whilst caring for small children). There is however a strong feel of precariousness in their stories, where the rules and expectations of resettlement are unclear and the women struggle to position themselves in the world.

## Finding Community

The women have actively sought and created a loosely defined community for themselves in Downsvie. Unlike many immigrant communities there was not a fully formed Kosovar community (established through cycles of migration). Nor was there a well-defined Albanian speaking community<sup>60</sup> and Albanian-specific agencies were quite limited until recently (reflecting more consistent patterns of immigration over time) (Barjaba 2000). The

early phase of resettlement in the UK for these women is defined by a strong sense of dislocation. With most women having small children, a lack of language skills in English and placed in single family housing there is a marked social isolation. For women, it is initially in caring for their children and other family members that they are placed in direct contact with systems of health and social care. Enrolling children in school or registering with a GP or social services were some of the ways in which women met people in their neighbourhoods. However, it is in the more informal activities of resettlement that women begin to gain a sense of the wider Albanian-speaking community: shopping in a local market, taking their children to local parks, and finally taking part in local charity events.

Nafiye explains:

Nafiye: For the experience of living here it is important...you listen, you listen at the market.. even if you don't know anyone.. you start by talking about oh 'where do you live' and you try make friends. It is hard to make friends with people when you are in our situation. So you listen and when you hear someone speak your language...

These typical ways of meeting fellow Kosovars, hearing people talk in the area, approaching people to chat at markets became important sources of information sharing for local residents. Through these resources the women began to identify others from Kosova within the borough. Susanna describes her initial recruitment to attend one of the Besim programme's women's groups:

Susanna: There is a lady that lives quite close, that is a neighbour of ours that we met with another lady, at the market when we shop. We met at the market, because it is like when I said to you before we know each other by sight – meeting each other. The other lady said that we have a project that helps women.. Kosovar women, and maybe we can help you as well, and I said *Ok, let's go ahead and let's see.*

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<sup>60</sup> The Albanian-speaking community is largely defined as including Albanians, Kosovars and some Macedonians.

The activities and groups offered through Besim however allowed the women to come together in an even closer way; to strike up friendships but also to become actively involved in collaborative projects. For the broader Albanian speaking community, Besim has filled the role previously occupied by a defined kinship network (linked by tribal or clan affiliation) in their homeland. Hosting special events (parties, performances of local musicians) the women have reconfigured their social lives in the UK to create close facsimiles of a kinship network in Kosova or Albania.

For the most part the women's group functions as a forum to share practical information and experiences or to simply socialise with discussions grounded in the present and the process of 'getting on with their lives'. My involvement in the weekly women's group enabled me to interact with the women outside of formal interviews in a relaxed environment and encounter first-hand the warmth of their interactions with each other.

In one of the first groups at Edwin Avenue for example, Deni leads the group in a playful activity (a variation of musical chairs) as a way of learning each others names. There is a silliness to the activity as we are forced to yell out each others names, and compete with each other for one of the vacant chairs. The game is however valuable because it tackled social uncertainties and awkwardness and placed us all firmly in the same position. By the end we are all exhausted from laughing and running around, but we have learned each others names (albeit pronouncing them badly). There are few settings where this would work, and perhaps on this day the particular group of people has ensured that it works.

Nonetheless it does help to create a particular comfort level, and functions as an intriguing equalizer in the interactions. There are other episodes where I get to be party to the playfulness that the women have with other:

In the time at the women's group, the women were light-hearted and playful. I made light chit-chat with a few and we had coffee. They seem to be getting used to having me around. Deni puts on some videos and some of the women start spontaneously dancing. It is one of those surreal scenes. Dirty Dancing is on and Deni starts pulling people up to dance. I am standing to the side thinking: please not me. Please not me. Naturally this results in me getting dragged up to dance with Deni. (I find these sorts of things horrifying. Thankfully this fizzles out quickly, and I can go back to observing) The final number in the film though is a treat to watch. One woman, Lira, does a hilarious routine mimicking Patrick Swazye in the final dance number complete with lip-synching and a running slide down onto her knees. She is a complete bundle of energy. The women break into peals of laughter. (Fieldnote 22/04/2003)

More often the groups are less energetic, tending to be more along the lines of coffee and conversation<sup>61</sup>. There is a charming quality to the interactions that exist amongst the women in this particular group (Edwin Avenue) where humour has assumed a position of prominence. The women enjoy each others company greatly and will make fun of both themselves and their situations.

One morning for example, one of the women is remarking on a recent phone call she received from someone claiming to be from the Home Office who is giving her a hard time about her application and raising the threat of deportation. It then turns out that it was not someone from the Home Office at all but one of the other women who is playing a joke. For everyone this is quite funny and animated conversations ensue. The story is quite telling about the 'coping' strategies that are employed to deal with the anxieties of daily life in resettlement. Waiting for the (hopefully positive) resolution of asylum claims is a

constant and pervasive pressure for these women and their families. At the point of conducting this research many had been living in the UK for up to 5 years, and remained uncertain as to whether, ultimately, their claims for asylum would be recognised.

Laughing at these circumstances, at the near-permanent state of insecurity that they live under is one way in which these women turn powerlessness on its head. The women cleverly parody their own fears, and in the process draw attention to their resiliencies. There is an element of stoicism, reflected in an almost matter of fact quality to the way in which women initially speak about their journey and how they managed to deal with the hardships intrinsic to it. Humour is in some ways, an extension of this. The women use this to re-affirm their ability to cope, and perhaps more pointedly their determination to withstand the challenges that resettlement poses for them. This is one way in which they successfully contest a position of powerlessness in their lives.

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<sup>61</sup> While often the women will talk amongst themselves in Albanian, there is a real concerted effort to ensure that I am not ignored or excluded. A number of the women speak English well enough to translate.

## XI. LOSS, TRAUMA AND IDIOMS OF DISTRESS

The ways in which the women articulate their experiences are grounded in the everyday struggles, insecurities and instabilities that mark life in the UK. It is in the early struggles against an unfamiliar backdrop that the women convey more sensory accounts of loss and suffering.

Dea: When we came here it was just really really hard because we just moved from one country to another country and we left everything behind, so that we lost everything you know. The 30 years of our lives was just gone. We lost everything and we'll never get it back again.

There is a profound separation that Dea makes between life in Kosova and life here that defines her experiences as the end of one lifetime and the (forced) start of another<sup>62</sup>. Many of the arrival stories of the women share such observations where loss figures prominently, and is talked about in the terms of everyday things. Nafiye describes having arrived at a hotel (a typical temporary housing site for newly arrived refugees). Along with her family, they are greeted by other refugees who help them deal with the necessary logistics of being here (getting food, medicine for her child who has a fever). It is in this moment that 'exile' and 'asylum' are made tangible for Nafiye and her family.

Nafiye: [t]he bread, it wasn't – it didn't taste like our bread! I don't know, but at times you want something you know, and but you think 'oh will I get used to it?'. In the beginning it's true you come from wars and everything, but maybe it because of everything you become more frightened about small things – you notice the small things.

The longing that Nafiye articulates for the 'small things' of what was her everyday life, conveys a sense of the fundamental experience of loss that is an inherent part of the

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<sup>62</sup> This brings to mind the writing of Eva Hoffman, who describes her experience of exile as fuelling a bipolar vision of the world: "*Spatially the world becomes riven into two parts, divided by an uncrossable barrier. Temporally, the past is all of a sudden in one side of a divide, the present on the other*" (Hoffman 1999: 46).

women's lives. Loss is identified and expressed in indirect ways by the women, often conveyed through the small (but conscious) acts to counteract it: the re-building of homes, the accumulation of personal artefacts, and the creation of community. For example most women left without the mementos of their past: personal and family photographs, the personal artefacts and collectables that form an important outwardly expression of our identities. In their life here there is a drive to 'create' a new physical sense of their lives. Photographs become a key way. The physical recreation of a sense of home is another. Homes are quickly transformed from 'temporary housing sites' to homes, quickly filled with 'knick-knacks' and decorations that present 'confirmation' of an established home. Ugresic (1996) captures this sense of the idea of photographs as a measure of 'our world': "*Refugees are divided into two categories: those who have photographs and those who have none*" (p7). From this we begin to see some indication of the understandings of trauma for these women and their families, but also some hints at their tactics for 'coping' in the face of these.

Deni: Trauma is present in the refugee because you know just one day you lose your house and all your world and all your life is just gone away.

Loss and the transformations that accompany war and exile, as well as the specific instances of violence (critical events) give shape to their perception of the aetiologies underpinning the construct of trauma. The way that women describe their experiences is often expansive in nature not hinging upon one singular event, but rather as experiences assembled in a cumulative fashion. Typically simple statements are used to convey the enormity of 'critical events': "*Because of what happened to me in Kosovo*". There are suggestions both by the women and those around them that this serves as a way to deal with the 'unspeakable' nature of some events – such as sexual violence. At the same time a terse

summary of an event in this way also achieves a certain closure to the conversation in a society dominated by talk.

Few women speak frankly about the experience of sexual violence during the war, Dafina however, describes the anguish of this in explicit terms as she explains the current uncertainty she lives under while awaiting the outcome of a long pursued asylum claim. Her revelation emerges in the context of discussing the possibility of a refusal and involuntary repatriation. Her comment is harsh, but direct:

Dafina: There is no way that I can go back. I will find a way to kill myself. Even if they put me on a plane, I will find a way to kill myself.”

In her brief remark, the cultural politics around sexuality, honour and sexual violence that have been highlighted in the background text (see chapter II) come to life in the circumstances of Dafina’s life. Her ‘defiance’ about the idea of (forced) repatriation comes on the heels of recognition of what life in Kosova would be like for Dafina and her children: she would be publicly identified as a rape victim and her children (and extended kin) dishonoured by association.

For most women the acknowledgement of sexual violence emerges more in hushed and muted tones rather than the direct and factual way that Dafina describes her experience of rape. Her assertiveness, however, carries a double-edge. On the one hand she is taking control of events and her open acknowledgement of ‘what happened’ assumes a position of power that challenges the tradition of honour and shame. At the same time a public statement about her experiences has potential to harm her more than help her. People now know explicit details of her situation both here and in Kosova and in a sense this may set

herself up for stigma and exclusion. The desperateness that she expresses at this point suggests that she feels she has little to lose.

Other women tend to mask any references to their experiences during the war. One woman chose to reveal this through the indirectness of the interpreter (*D: ... she's been raped and she has been really badly treated... she has been tortured.*) where the interpreter switches in her presentation from the first person to the third. Often switches with pronouns and the interchange between first person and third are 'glitches' in the course of the interview. Notably in this particular interview, it is the only point where such a transition is made.

More commonly women disguise the mention of critical events such as rape or any violence experienced. A common way of speaking about this is to talk about the need to conceal certain experiences from their spouses. One of the implications of this referencing is that things related to sexual violence can not (typically) be raised with their husbands for fear of reprisal.

Etleva: Well I have had a problem but I couldn't say anything to anybody... because my husband was always with me. It is not enough to ask me in front of my husband about my problems.

As in the immigration interviews, many initial meetings with health providers fail to establish the nature of women's experiences and possible complaints associated, in part because of a failure to appreciate the need for complete privacy and discretion especially from those closest to the women. This basic point, that Etleva was never asked about her experiences or any difficulties she was having outside of the presence of her husband meant that she simply did not disclose and did not receive any health and social care services as a

result. A similar issue emerges for women in primary care consultations when their children are often called upon to act as stand-in interpreters.

In the context of health complaints, understandings of trauma and suffering for refugees are often narrowed and moulded into tangible physical and emotional experiences. The women draw upon a vocabulary of aches and pains (which are now understood as linked to an emotional experience) as well as common Western mental health expressions (feeling depressed, nervous, or anxious). In terms of physical manifestations of 'distress', the women frequently mention 'headaches'. For women 'headaches' embody a range of discomforts – some physical, some more decidedly emotional in nature. Dafina describes her understanding of the causes underlying her constant experience of headaches:

Dafina: And I was so stressed and I think that the trauma that I had gone through was affecting me really really hard.

The assumption of a somatic relationship between physical symptoms and emotional states has been quickly absorbed by the women. Headaches have come to embody distress, quickly becoming the shorthand for communicating psychological issues.

Having learnt this vocabulary the failure of professionals to recognise headaches as indicative of psychological distress can be a source of frustration. Women convey a sense of futility when GPs respond to complaints of headaches with prescriptions of paracetamol.

Sonije remarks:

Sonije: It is terrible! A hundred every time you go! A hundred tablets. They must have a lot of them! Or [it is ] very easy for the doctor I think [to go]: here you go.

Dafina echoes this complaint: “*I was complaining to them that I used to get headaches and they just would give to me paracetamol. About a hundred pills. And the only solution for them was paracetamol*”. For Dafina, the sense of having her complaints discounted is amplified by the indignity of having to use her son to interpret during a medical consultation. While her son is all too familiar with her wartime experiences, it is another thing for him to be placed in a position of articulating this to a health professional.

Language issues inevitably complicate the consultation process. With many doctors failing to arrange for appropriate language services, consultations end up including children as ad hoc interpreters, or the reliance upon rudimentary forms of communication to decipher the nature of the complaint. Susanna describes her ‘conversation’ with a GP about her recurring headaches:

Susanna: It is like when I go and see the GP, like show him. So if he says ‘*What is wrong?*’ I show him [gestures, pointing to head] [laugh] and I say ‘*I’ve got a problem*’ and he gives me a prescription and it is ok.

Susanna is – as a result-- not explicit about her personal problems when in the confines of the GP surgery. As is the case for a number of the women, managing to convey any physical or psychological health issues is a challenge given communication barriers and the sense of time constraints in visits with the GP. Talking in the comfort of her own home, she allows herself to be a bit more explicit about her feelings:

Susanna: In the past when I feel that I am a bit withdrawn or nervous or this kind of thing or feeling very low. I get very low, without having noises, even the small noises.

She does not tie these emotions to particular events or experiences, but when she experiences this she removes herself from the people around here (no small feat in her household) to cry or simply be alone without noise or distraction.

In contrast, Sonije suggests that her headaches are related to the absence of activity – in a way less a reflection of past stressors, and more indicative of the uncertainties of the present:

Sonije: It's the.. now that we are in this country.. we are '*bored*' .. sometimes they [the Home Office] said soon.. [but] they never say anything fixed for us. Sometimes we are like wild with worry...and that is no good...because for our family we worry, we are thinking for our future, for our children, for us. That is the problem with headache, why I have headache. I am waiting for something. I have been for 4 years here waiting.

For Sonije her pain is the culmination of the ambiguity of asylum that her and family experience on a day-to-day level. The '*boredom*' she highlights is a profound state of inertia that she feels they are trapped in: her husband is unable to work, her children struggle in their adjustment to a new culture. Over time the '*boredom*' gives way to a sense of '*worry*' that consumes her and leads to headaches, in a circular pattern of distress.

This sense of paralysis in daily life is one articulated by many of the women, which they explicitly link to the uncertainties of life in resettlement. Erika, finds it hard to reconcile the sense of everyday anguish that she feels, torn between past experiences and the present anxieties of resettlement:

Erika: It has been really hard coming here and we didn't have any friends and we didn't know where to go. I cry, I just cry. I would love to do things but I don't know where to go or where...

For Erika there is a pervasive feeling of being overwhelmed, which she believes stops her from moving on in her life. Etleva shares this sentiment, summarising what she feels are the issues facing her and her family here:

Etleva: We have been here 4 years now and it is just that we don't know where we are going to be tomorrow. It is just the waiting and the waiting. And you know, every day we think '*tomorrow we could be sent back*'.

For Etleva, an ongoing threat of a refused asylum claim means their lives are at a standstill. While this leads to a certain distress, she is careful to distinguish this from what she identifies explicitly as her "*mental problem*". For this (which she is reluctant to elaborate on) she notes what she sees as at the heart of this: "*It is because of what has happened in the past it is not to do with here.*"<sup>63</sup> In Etleva's life, two forms of distress are co-existing: one that is located in the present, reflecting a shared experience within her family, and one whose origins are firmly located in the past and is intensely individual in nature.

There were other women, though, for whom distress – particularly in the form of headaches marked the onset (or continued presence) of more severe symptomatology. For Jete, headaches have come to be characteristic of more profound feelings of mental or emotional instability:

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<sup>63</sup> There are allusions to a critical event or events that happened within Kosova in conversation with her; event(s) she has felt largely unable to talk about and prefers to keep hidden from her husband. All of this is suggestive of sexual violence, however was not explicitly confirmed in the course of the interview.

Jete: I used to have headache. Lots of headache. And I was feeling very tired. But maybe it was because I was put in a hotel. And then, that one had a great effect on me, maybe. The night before was feeling very very still. My son was crying and I couldn't sleep [long pause]. I'm walking I'm walking and it comes over me like a wave.

She finds herself immobilized by a sense of anguish. Jete describes feeling consumed by shame and fear, largely inspired by past events but intensified by current anxieties. In processing her experiences and contemplating the horror of being repatriated, Jete retreats from those around her, caught up in this wave. The sensations she catalogues paint a compelling portrait of a woman caught in an internal struggle. Unable to articulate her experiences to those around her, she initially finds herself immersed in bodily sensations: headaches, surges of cold sensations throughout her body, heart palpitations, and sleeplessness. In hindsight she draws loose connections between events, tentatively commenting: "*Maybe it was the first trauma that I went through. Maybe it was the journey*". Her narrative of this period is a jumble of distress (past and present), one that she finds difficult to make clear – describing it as '*this strange feeling*'.

Jete: I was scared that I was going to die. And I went to the fridge to get some water and I thought no – I'm not getting water because I'm going to die if I have some water. We had to change it there and then. I'll never forget what has happened to me, this strange feeling. And then I was like this for two years.

During this period Jete find herself moving between new and the old understandings of psychological issues and the how to resolve them. Through her doctor she is prescribed anti-depressants and referred to a psychologist. Her family encourages her to 'just forget everything' that has happened in the past, although initially they only have a partial understanding of what it is she has experienced. Eventually she achieves some form of reconciliation between herself and her family by revealing the nature and extent of her

experiences (past and present) to her husband. Throughout Jete's narrative there are hints that what she has experienced is related to something sexual.<sup>64</sup>

For other women, there was a similar hesitancy in describing past experiences. Biljana is more direct when she states that she has experienced mental health issues. She attributes these to "bad experiences" in Kosova, but does not elaborate. Biljana has confided her feelings -- in part -- to her husband. She is unwilling to tell him all that she has gone through, or entirely what she feels in the present. There is a sense of uncertainty as she tries to convey the nature of her physical and emotional experiences:

Biljana: I was really scared. *Anxiety?* Yeah, *anxiety*. And not sleeping in the night. This and bad dreams in the night.

The language of western psychiatric discourse is commonly evoked by the women, as evidenced by the terminology of '*anxiety*', albeit somewhat tentatively as articulated by Biljana above. Women come to be introduced to these terms and ideas throughout the activities of their daily lives: through contact with service agencies across a spectrum of fields (schools, social care, and aid organisations) and, perhaps most often, through contact with their GP. Primary care health services are critical in shaping the understandings (or 'working misunderstandings') of mental health issues and subsequent treatment options. For most women this process begins with a visit to the GP. As most of the women in this study are mothers, visits to the GP are an inevitable part of life in the UK.

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<sup>64</sup> She described herself as 'unable to be a wife' and found herself drawn to a more extreme form of Islam (typically not practiced amongst Kosovar Muslims) including wearing a full Burkha in order to conceal her body.

The use of psychiatric terms by the women bears more of a resemblance to the popularised ideas of everyday angst, where anxiety, depression and stress are not used in a clinically prescribed way. Despite a lack of everyday familiarity with western frameworks of mental illness, they have come to accept these ideas easily. When asked about the links between distressful experiences or feelings in the present the women however largely shy away from establishing cause and effect. The assumption that all roads lead back to the traumatic event is a pervasive one that permeates the lives of these women and their families through their contact with services and their designation as ‘refugees’. However, their understanding is more diffuse, extending the edges of aetiology beyond past ‘critical’ events to incorporate the uncertainties that they live in now (or as Etleva expressed earlier: a concept of dual forms of distress coexisting yet emerging out of different aetiologies).

For Merita, the things that she experienced and witnessed are re-lived in anxiety and nightmares, and would meet conventional notions of trauma within psychiatry.

Merita: In the daytime I am much better, but when the night time comes it becomes very worse. Even if do [have] a reaction – it is not as how a normal person does. For example at night time I wake up and I want to go out. I want to open the door and go out... to get out [gestures].

I: Oh, like when you are still asleep? Like ‘sleep walking’ ... like this [gestures]?

Merita: Yes, yes. Like this. I sleep with my youngest son. And this is the way that we have decided that we have to do because I cannot control myself, I am not conscious of what I do. And I see in dreams all of the massacres that have occurred and after that I am so stressed and so frightened... and so I wake up and I can’t sleep anymore and I just wake up and open the TV, you know, switch on the TV and just having a coffee and stay there because I am scared to go back to bed.

At first glance, her narrative seems almost ‘textbook’ in its depiction of psychiatric trauma. Yet what she considers the crux of her pain is not grounded exclusively in the past, it is also the uncertainty of her present and the fear of the future. Her fear was a reasonable one. At

the point of interviewing her, she was beginning her last appeal for asylum and the fear of deportation was clear and persistent. This sense of profound uncertainty is constant in women's lives, as they work their way through the asylum process, as well as the appeals process. Trauma then becomes a more complex mix of the past and present; not simply grounded in one devastating moment in the past – but something more dynamic in their lives.

While most women did not speak of such intensive periods of turmoil, almost all of them were referred for counselling in some form (whether through locally-based programmes with 'social workers' or 'health workers' or more formally to psychologists and psychiatrists). A substantial number were also prescribed medication (usually anti-depressants)<sup>65</sup>. However, the assumption that *all* of their headaches represent 'somatised distress' is one that the women may struggle to comprehend. Lira summarises this aptly:

Lira: Lots of times I've got a great (as in severe) headache and I thought it was just a great headache.

Lira raises a valid point about the assumptions that have been created around physical pain experienced by refugees. She states emphatically that were she in Kosova the last thing she would consider would be to seek mental health support for her headaches. Yet as the women have quickly learned headaches have come to be emblematic of the distresses associated with being a refugee.

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<sup>65</sup> Appendix 11 summarises the referrals to mental health treatment and prescriptions for medication received by the women and (where known) their families.

The women commonly profess a lack of knowledge about psychological issues, noting how they need to learn these things, beginning with a new vocabulary of distress, and then learning the 'value' of talking. This idea of seeking professional help to talk openly about problems is described by the women as a wholly new concept, one that needs to be explained and contrasted with the more serious understandings of mental illness (as extreme and disabling forms) that they are familiar with from Kosovar culture. The women suggest that mental health issues do not have a strong presence in everyday life in Kosova, evident only in extreme forms that require institutional care. Subsequently this idea that there is a continuum of psychological and psychiatric distress is understood as a new concept for the women and their families. Accompanying this new conceptualisation of psychological issues has come new interventions, most notably the idea of counselling and 'talk therapy'. For the women there is a complex relationship to this idea of 'talk', which must be poised against cultural beliefs (which take a less favourable stance on personal disclosures) and perceptions about the value of talk as a tool of access (to services and to immigration status).

## **XII. THE POWER OF ‘TALK’**

Counselling has become such a standard response to crisis that when those are put on the spot by journalists and asked how they are dealing with the situation, one of the first answers is likely to be that those suffering have been offered counselling (Árnason 2001:299).

Trauma is understood and responded to in distinct ways by providers and by refugees.

‘Talk’ emerges as critical to both perspectives, understood as vital to a therapeutic transformation, as a means of effecting or negating community support, and as a means of steering through the exigencies of systems of asylum and health care in the UK.

In conversations with both providers and refugees, explorations of ‘talk’ provides insight into the more localised understandings of health and illness related to trauma that are operating related to refugee resettlement. Encapsulated within discussions on ‘talk’ are respective views on the meanings of trauma, intervention and recovery.

### **Talk as ‘Therapy’**

Psychological counselling assumes a central position in conversations with providers on refugee health and trauma. The nature of counselling (ranging from informal advice and support to formal therapy sessions) varies according to agency setting, philosophy and the level of specialised training of the provider. An explicit link is consistently made between psychological counselling and Western conceptualisations of psychiatry and mental health. This framework is typically contrasted with non-Western perspectives which are understood to be more reflective of traditional ethic and cultural belief systems.

This understanding crosses the range of services and professionals. Mary, an outreach worker finds this idea emerges through her work. Her role does not involve conducting psychiatric or psychological assessments, but rather to identify areas of basic need and refer people on to appropriate services. In essence though, this means she must confront people's understandings of their needs and their knowledge of Western models of health and social care.

Mary: The concept of counselling is a very western concept of counselling, the way we do it here, I think...and people don't quite understand why they should, or what the point is of therapy. But having said that, people don't really – people haven't really resisted it. I mean I've suggested it as an option obviously, people make their own choices, I say 'it's a option for you' and in my experience women have generally gone for it. [] because although it is an alien concept, I think the idea of just talking and being able to just tell someone your stories, or tell them to you, is very empowering.

Talk therapy or counselling has emerged as a particular way of understanding and framing the processes of distress, mental health intervention and recovery. Disclosing issues and exploring them through counselling is routinely promoted as a strategy of choice for the resolution of trauma, particularly for refugees (Agger 1992, Herman 1992). There is an assumed intrinsic value to talk therapy that is articulated across services. As Mary notes above: *"I think the idea of just talking and being able to just tell someone your stories, or tell them to you, is very empowering."* The notion that disclosure confers a psychological release and helps to promote a sense of empowerment for an otherwise powerless population is both persuasive and widespread.

Counselling is commonly portrayed as normative within western cultures, with non-medical non-professional methods of care or intervention, discussed in reference to non-western cultures. These distinctions serve as an important backdrop to the work of providers; where

they situate themselves and their work in relation to this dichotomy both philosophically and pragmatically. Amy, a support worker with a refugee organisation, reviews what is frequently believed to be at the heart of these differences.

Amy: I think it partly has to do with different family structures. I mean, Kosovar people seem to be very close not just to their nuclear family, but also to their aunts and whatever – sometimes their extended family is quite big. Um, that sort of fulfils the role that a counselling service would have... perhaps people don't go off and see counsellors or professional people for advice, but would advice that you would get is within your network

The use of family members or community leaders (or elders) to mediate issues or advise is generally cast as typical of non-Western interventions or strategies of care, whereas any form of professional medical or therapeutic care is understood as Western.

For many of the providers, this balancing of Western and non-Western perspectives is something they have often encountered first hand. Daria, is a therapist on a small health team. In addition to her work with a localised health team, she has trained to provide counselling services in a specialised peer-run program for refugees. The knowledge and experience gleaned from her role as a community health worker and her background as an immigrant herself helps to define the services she believes are necessary to shape effective mental health work with refugees.

Daria: People could go to their GP, and the GP will refer them to the mainstream counselling service, and the counsellor will say '*well this is your time, you can use this time to talk about your issues*' But with refugees and asylum seekers that doesn't work. So ours is kind of psychosocial because we see the psychological as well as the social issues.

For providers who have themselves been immigrants or refugees, the distance between provider and client is diminished. Within explicitly peer-led counselling (and implicitly

elsewhere) these providers often straddle the world between ‘user’ and ‘professional’.

Daria capitalises on this knowledge, shaping services that she believes recognise the issues facing refugees (beyond individual concerns) and that the idea of targeted time for individual reflection may not prove successful as people struggle through this unfamiliar notion of social care. There is however a clear and determined acceptance of counselling as a framework that works. Therapeutic sessions are presented as an opportunity for refugees to express their range of needs in a forum that provides more than just ‘counselling’: these are peers who offer what they define as ‘therapy’ in a psychological sense but are also conscious of providing support of a peer nature. This as a distinct form of counselling is difficult to gain a sense of. Philip, who explicitly identifies as a refugee-peer counsellor tries to explain their work, contrasting peer counselling with mainstream ‘Western’ counselling.

Phillip: Probably for you as a westerner probably begging somebody for help... is demanding – you could interpret it as ‘begging’ or an aggressive way of asking for something, but probably for the other person, from the same cultural background that could be ignored.... [through] our training as refugees as such, we are more experienced, more knowledgeable when dealing with psychological, social, practical issues when it comes to refugees and asylum seekers.

There are a number of ideas at play here. First there is the idea that having lived through something similar – whether as refugees or immigrants – is critical. This prepares the provider for what may be experienced by the refugee. Implicit in the perspective put forth is that these qualities (empathy and insight) are ones that can not be conveyed by training, but can only be learned through shared experience. Second, Philip suggests a negative understanding by Westerners of ‘someone asking for help’. He begins from an almost defensive place equating someone asking for assistance with ‘begging’ (from a Western perspective) as contrasted with a ‘partnership approach’ that is conveyed through peer-led

counselling. This depiction of the inherent conflict between refugees and traditional Western frameworks of services bolsters the idea of peer-led services, and differentiates such services as operating from a position of shared perspectives. Finally, underlying this contrast there is an assumption operating about the blanket acceptance of Western psychiatry across developed countries. Philip develops this idea, making it more explicit:

Phillip: Counselling for you is simple, for Western people from Western cultures. For us counselling is different (...) in most of the refugee communities, counselling is never heard [of]. So the expectation from the mainstream counselling services is different from our expectation. We approach counselling from our background, from how we relate counselling as not defined by the Western definition – where we don't abide by it, we don't take literally what counselling is.

Ultimately, Philip questions the Western 'take' on counselling, and puts forward the argument that it can best be employed as a hybrid, a mutation away from traditional beliefs of the individual's home culture, but also away from a blind acceptance of the western framework in itself.

Discussions with peer counsellors were compelling for this staking out of polarised views. Assumptions were presented about what Western beliefs are or should be with respect to the use of counselling as a clinical strategy for dealing with distress and trauma. 'Traditional' non-Western methods of resolving individual or community level distress are openly referenced (such as the use of community leaders or elders for support). Anna for example stresses how for many refugees, social and familial networks have constituted the system of care they are most familiar with, in direct contrast with medically-based interventions:

Anna: Because there is not the culture. It is not like a medicine [based] culture, that you would have to have a counsellor -- for anything you can go to somebody and you can talk with. This is an issue, this [has been] all collectively provided within the community. It is the elders, it is your family, it is your neighbours, it is your uncles and aunties, and friends, and parents of your friends who are supporting you. So if there is an issue they are there for you. So it is done through the community, you don't need to go for counselling.

Despite the strong recognition of non-medical, collective (kin or community-based) resources, these methods are rarely endorsed as useful interventions in resettlement. Instead they are spoken of, almost nostalgically as something that had been useful in the past but are not appropriate in the context of resettlement. The realities of forced migration and conflict have hit at the heart of social networks, with families and friends divided by the geographies of exile. The additional dispersal of incoming refugee populations has further amplified the sense of distance from pre war communities to the fragmented households in resettlement.

Amy notes: "*obviously that's very hard for a lot of people when they come here, and even if they were able to come with all of their families*". However, as illustrated by the Kosovar women the creation of new communities is feasible over time and perhaps critical to a meaningful resettlement.

Peer clinicians may see their role as providing translation, interpretation and instruction, moving between traditional and western models, and ideally demonstrating a familiarity and comfort operating within both worlds of intervention. In practice, the challenges of their work can often prompt them to draw upon strategies of closest reach, which often means relying upon Western psychological paradigms. It may be that given the constraints of health and social care there are limited opportunities for organising and implementing alternative models.

Addressing issues of trauma and distress within this framework has required a way of speaking ‘a new language’. Disclosure emerges as a critical component. As such one of the first things that must be conveyed by providers and accepted by the women is a willingness to reveal intimate details of their life. The manner of speaking about these issues provides an indication of the discomfort that people experience with this new ‘call to talk’.

Daria: It is something difficult for people to talk about what has happened to them. Or [the] details actually. Or sometimes, it is talked about in a way that makes it seem less, like it is nothing... they talk about it in almost a ‘bored’ way – so to them that was what life was about and why should they bring up these things

The absence of emotion in speech can be interpreted as suggestive of a profound level of suffering, one that is inarticulate in nature. It remains unclear whether this in fact reflects a lack of familiarity with the process and an absence of a comfortable vocabulary to engage with. Yet providers are unambiguous in their belief that most refugees have had little or no exposure to a Western framework for defining and understanding distress, as well as their appreciation of methods of intervention.

Disclosure is presented as a critical aspect of the framework that refugees must work within, in resettlement. The individual *should be* willing to openly talk about the events that happened to them (and continue to talk about the ongoing impact of those events). Moreover while deemed necessary for the success of any clinical intervention, there is believed to be a therapeutic merit to the process of talking in and of itself. For many providers this remains an unexplored point, accepted as critical to the success of any intervention.

For ‘providers’ who are closer to the experience of immigration and of being a refugee, some questions are emerging about the assumptions inherent in the processes of disclosure and ‘talk’. Deni, the coordinator of the Besim Programme, is cautious in offering a blanket support for the idea of counselling. She acknowledges its value in many cases, but also recalls the discomfort that she has been witness to as both an interpreter and as a service-user.

Deni: Counselling? Well... it helps.. I have seen some people like A. for example [who it helped]... I haven't gone to the Medical Foundation or anything like that ...but I have seen counselling and I have seen going to the mental health [service]... and the way that mental health does it is ... it pressurises you .. so it is ‘*well how do you feel? Why do you feel? Did you eat?*’ and it is like the police. I hate it. Even being an interpreter I hated it.

The coerciveness that Deni notes here is something that may often accompany the process of assessment and yet is seldom frankly explored. Amongst the providers interviewed there is almost universal acknowledgement that disclosure *can be difficult*. However this is typically emphasised for people who have undergone the most extreme situations of violence (torture victims and women who have been raped, for example). Moreover the difficulties around disclosure are only acknowledged in limited circumstances. Certain disclosures, such as revealing the details of sexual violence to family members or other community members, are highlighted as carrying risks of stigma and social exclusion. In terms of services, the difficulties around disclosure are most often mentioned with respect to immigration hearings. Providers acknowledge that certain sensitive topics may not be revealed in the context of an immigration interview or hearing due to the highly stigmatised nature of some events. Yet discomfort with disclosure in health and social care settings are seldom acknowledged beyond the initial and typical unfamiliarity between client and provider. Claudia, who provides crisis counselling to women refugees sees full disclosure

as an integral part of her work, and insists on a heightened level of detail and intimacy from her clients.

Claudia: Yes, well you know things like sexuality for example, you know, that have got to be touched on. We're talking about sexual violence, and so on. We have to get into the nitty gritty. Sexual activity be it by force, torture or whatever it would shatter and kill your sexual sensations, which [these sensations] will be very similar to those ones that you do have when you have sex for sexual pleasure, right. That's what we need to get to grips with before they can move on.

For Claudia, there is an urgent need for women to address their experiences of sexual violence. Through an open confrontation of the events, resolution may be achieved and the women able to reclaim their sexuality and potential for sexual pleasure. These are compelling ideas that appeal on a fundamental level of social justice. Despite any coercive undertone, Claudia is committed to helping her clients who have been raped to resolve any issues around sex and sexuality. Yet at the same time this example highlights the disparity between new and old cultural habits around disclosure. For her the resolution of the issues around sexual violence requires a frank investigation of the details of events and emotions. Disclosure then is understood as part of the process of coming to terms with the traumatic event and learning to separate positive aspects of sexuality from the horror of sexual violence. Ideally this process opens the door to new ways of coping.

The determination by Claudia to explore previously uncharted areas for women emerges from her personal convictions as a feminist and what she sees as her role as an advocate for other women. She strives to practice what she preaches in her personal philosophy and her work as a clinician. However, the heightened level of scrutiny that she feels is critical to the resolution of sexual trauma is something that many people may be uncomfortable with.

The belief in full disclosure is aligned with a heightened value of talk therapy and its curative values: by ‘getting things out in the open’ issues can be dealt with and meaningful changes can occur. This perspective is presented as somewhat self-evident, and in keeping with conventional views commonly held within Western society. This is best evidenced in the views of those providers who are not explicitly defined as therapists, but rather operate as advocates or sources of advice on resettlement.

Felicity is an outreach worker with a specialist programme serving the needs of women refugees across London. In theory her job entails helping women sort through issues related to housing, benefits, and practical elements in resettlement. With respect to health care, her role includes linking women with appropriate agencies, including primary care physicians.

Felicity: And people don't quite understand (...) what the point is of therapy. But having said that (...) people haven't really resisted it. I mean I've suggested it as an option obviously, people make their own choices, I say '*it's a option for you*' and in my experience women have generally gone for it. [] because although it is an alien concept, I think the idea of just talking and being able to just tell someone your stories, or tell them to you, is very empowering... especially if you haven't been listened to.....And you know when I go and speak with women, honestly, often I get kind of a torrent of '*This is what happened to me*'..

In her experience, women crave the opportunity to talk about their experiences, even when such practices are not normative to their home culture. For Felicity, this confirms the value of talk as a therapeutic intervention. Moreover, the fact that women are willing to accept referrals to services is understood as a tacit acceptance of the idea of counselling.

Intriguingly she highlights the idea of talk in a dual sense. As a form of therapy it is ‘an alien concept’, however she also notes that women frequently discuss their lives in an open and unsolicited way in her home visits with them. Felicity attributes an ‘empowerment’

value to the active storytelling these women practice; however, she also assumes the same to be true of formal talk therapy. The distinctive forms of talking are not contrasted, nor are the power differentials that may exist explored across these situations.

For some providers talking about traumatic experiences raises concerns about a heightened sense of vulnerability with respect to refugees and ‘trauma’. ‘Re-traumatisation’ is perceived to be a risk as a result of talking about sensitive or horrifying experiences, where the individual finds herself overcome and effectively re-experiencing traumatic events. As Sandy notes within her practice, some providers had some difficulty at first in asking sensitive questions: “*People were very hesitant around rape and torture*”. Using experiential methods such as role play, she was able to convey the need to explore sensitive topics to her staff, pointing out that it was normal for people to get upset discussing such intimate and painful events “*it doesn’t quite mean that they are falling apart.*” Wariness or discomfort with raising sensitive issues is something witnessed more at the levels of primary care and community services, once entered into the world of specialised clinical services, there is, however, an accepted explicitness about approaching sensitive topics.

Tied in with this is the idea of the transmission of traumatic stress to the person hearing stories of violence and conflict. This idea of transmitting ‘secondary traumatisation’ is spoken of primarily in terms of the need to provide ongoing support to staff. Joanne noted that some of her colleagues were clearly uncomfortable with the stories they heard from refugees:

Joanne: I have met some professionals who don’t want to talk about traumatic events because they are afraid of what it’s going to bring up – and so, can they cope with it? So can you actually manage what someone is telling you? And how can you help them, and do you have the skills to be able to work with someone who is very traumatised?

For Joanne tackling these types of staff anxieties has meant that she needed to be very pragmatic and assertive about offering support to her team. This meant scheduling in regular meetings with her staff and insisting upon sessions with an external clinician to minimise the long term impact of dealing with often painful life histories on a daily basis.

The hesitation of front line staff to openly inquire about sensitive issue is met with less compassion by other providers. A strong sense of indignation comes through in a discussion with Joyce who wonders '*who are these people?*' that feel uncertain of asking sensitive questions. In her mind providers should feel comfortable listening to the stories of extreme events and be able to intervene appropriately and accordingly. If they lack training, they should simply ask for it; if they can not handle the issues, they should get out of the field. Perhaps Joyce is playing devil's advocate here; challenging the accepted beliefs about the need for professional training in order to address sensitive issues with potentially vulnerable populations. The realities within her work and the work of the other providers are such that there are no simplistic philosophies or rules of practice operating.

The value of talk is something that goes largely unquestioned with vulnerable populations. In the experiences of these women that pressure is amplified. There is an assumption of the merits of disclosing to providers -- which is aligned with the idea of the value of talk and its inherent therapeutic value. This contrasts greatly with the traditional understandings and experiences of the women who struggle with the idea that they would seek to, or benefit from, revealing intimate things to a stranger.

## Talk in Resettlement

In resettlement, the women find themselves engaging with the ideas of talk and disclosure – from the immigration officers who they interact with upon arrival to the health and social care providers who encourage them to ‘work through’ their trauma in counselling. Beyond professional interactions though, talk also surfaces in traditional Kosovar cultural beliefs and practices related to gossip and the balancing of private and public knowledges.

Almost all of the women have been referred for counselling in some form (whether through locally-based programmes with ‘social workers’ or ‘health workers’ or more formally to psychologists and psychiatrists). A substantial number have also been prescribed medication (usually anti-depressants), as have their family members. Women have been typically open to trying both approaches despite their professed lack of familiarity with the frameworks of counselling and mental health treatment.

Sometimes counselling and services are presented as problem-specific (for example, family counselling, or for domestic violence). Family-oriented services in particular are talked about in a way that suggests that they ‘make sense’ to people – with the family as a unit of intervention which would seem to be more in keeping with Kosovar cultural beliefs.

However in cases of domestic and sexual violence, the value in treatment sometimes seems less clear. Erika openly acknowledges that she is a victim of domestic violence. While she willingly accepts counselling, in the end she conveys a sense of futility about the situation.

Erika: I have taken some good counselling... one month or so. They said I need to make an effort to get it out... what it feels like.

I: Was that strange?

Erika: Well you know, when I say ok I would talk and try to explain for an hour.

I: OK, over time did you find it made you feel ok, or...

Erika: It did help, but really just I would go out from there and not think about it...after all everything is between a husband and wife and this is all.

For Erika there seems to be a dissonance occurring between the belief that counselling and talking about her difficulties has been helpful, and the distance that she puts between her life and this experience (*"I would go out from there and not think about it"*). It is unclear whether Erika's positive statement about counselling is one of perceived social desirability, or if in fact the process of revealing offers some respite from the obligations of being a wife in Kosovar culture, where marital violence is accepted as unfortunate but a husband's right. There is however a sense in her description that there is pressure to respond to counselling in a certain way: *"they said I need to make an effort to get it something out of it"* suggests a transition from the expectation to simply reveal experiences to 'work' (through talk) on the issues raised in the counselling session. Talk, Erika quickly learns, is supposed to move to the next level, beyond disclosure and towards active reflection and strategising for change.

Like many of the women Erika articulates openness to these experiences, despite some residual discomfort with the idea. In this exchange she takes on this new concept of talk and counselling to a limited degree. In the end she remains loyal to traditional beliefs about the marital relationship. Ultimately; *'everything is between a husband and wife'*. The tacit acceptance of violence against women in Kosovar society perhaps makes such assertion inevitable. However the fact that women in the community are speaking about domestic

violence and are willing to consider some intervention for this suggests some shift in the working definitions of critical social and interpersonal phenomenon.

The uncritical way in which counselling is described is typical of initial conversations about mental health and mental health services for the women. Juliana is a young woman who received intensive outpatient care. Alone in London and struggling with the impact of torture and a solitary journey into exile, Juliana struggled in the UK with severe depression and suicidal thoughts. For her, entering mental health treatment helped her to come to terms with her new life in the UK, although she acknowledges it is still sometimes a struggle:

Juliana: They help me.. I don't know what it is.. But they do really help me. So, I'm not the same person that I was when I came here..

I: You notice a difference.

Juliana: Yes...they make me to feel normal. There are days that I feel bad and down... yeah, there are days that I feel problems

When asked about her current state of functioning, she comments: "*A bit better, but I don't feel...I feel very powerless*". This almost reluctant observation emerges despite the ongoing support she has received and despite having received her status as a refugee (one of the few women to have this at the point of data collection). When she speaks of the day program she attended, there is sense of sadness on her part that she is no longer involved with them on a regular basis. As a younger woman on her own and despite the community support around here, she lacks her own sense of kin – a critical element in Kosovar society.

Juliana's experience was somewhat exceptional. Only one other woman articulated such a difficult period requiring intensive care.

The initial enthusiasm that women exhibit for counselling seems to suggest an element of ‘social desirability’ operating, where women feel obliged to speak of mental health services in positive terms. Nafiye in a discussion on counselling services begins with an eager recounting of how valuable and beneficial it was to talk. Later, she seems to rethink this:

Nafiye: I don’t know... I think some things will stay there. And there is no cure for things like this. How you tie up your life..it depends on the person.. Some people might feel helped by counselling and therapy. It was good to get out things... but I just have to learn to live with it... everyone has to find their own way out. You can not make it work... it did not work for me

This subtle retraction over time was something not uncommon amongst the women, typically surfacing in more surreptitious ways in everyday conversations. Deni, in her dual role of provider and member of the refugee community, articulated this struggle in her discussion on the sometimes coercive nature of counselling, where the information gathering nature of clinical assessments takes on an interrogatory tone. The image she projects is of a panel firing questions at the client without consideration of the permutations of grief and suffering. The woman who refused to be interviewed also communicates this sentiment aptly: *“It starts from the beginning – ‘when you ask how many children do you have? And I have lost 2, they were killed in the war. So how do I explain how many children I have without explaining that?’”*. Tired of being asked to talk about things that had happened, she remarks that the classic suggestion that *‘she may feel better as a result of talking’* has never materialised, instead it made her feel very sad and was not very helpful.

For other women, however, contact with counselling and therapeutic services has been more positively received. Merita attributes the changes in her life to the constructive support she received from attending regular sessions with a local psychologist.

Merita: Before I was scared a lot. I was really scared. And like anxiety.. And not sleeping in the night. This and bad dreams in the night. (...) I went to see this woman ... She was very good. All that time that I couldn't go out, or go to school. But she gave me help, I found it very good. Now I am trying.. I am going to school.

However as with many front line services, her relationship with this provider was time-limited and she was referred on to have follow-up with someone else: "*It was difficult to adjust. It is very hard to speak with people that you don't know*". For Merita (as with many of the other women) the relationship with counselling and therapeutic talk is further complicated by the tensions that exist within her life about disclosure and non-disclosure within her family. Her husband for example, while aware of the initial counselling that she underwent, remains unaware of her current sessions – reflecting a conscious decision by Merita not to disclose. Revealing and not revealing are constant issues in the lives of these women.

The way in which this community has quickly become close knit (for the women at least) carries burdens as well as benefits. One of the lesser enjoyed aspects for the women are related to 'gossip' within the community. My first sense of this comes in conversation with Deni following a particularly emotional interview with a woman. I ask Deni about the traditional ways in which someone might deal with a distressing event in Kosova. She explains that (traditionally) there is a greater likelihood that someone will simply '*suffer quietly*' than openly confide in others about sensitive matters. She refers to a common Kosovar saying: '*if your teeth can not hold it, why should mine*'. Confiding in someone does not mean that you can expect confidentiality. Instead there is the opposite; you should expect that by doing so you may have placed yourself in the midst of a gossip mill.

Later in conversation with another woman, Sofije, this idea surfaces again.

Sofije and I are taking a break mid-interview. The room is filled with children who are on a break from their mother tongue classes, and so too loud to continue with the taped part of our discussion. We remain sitting and chatting. She tells me that if she walks down the street with a male relative -- unaccompanied by her husband or other women -- then she leaves herself open to rumour and gossip. Her honour and therefore that of her family is at stake. This aspect of her community she finds oppressive calling it 'small-minded' (Fieldnote 12/08/2003).

Through gossip the cultural construct of honour and shame emerges intact and demonstrates an influence on life in resettlement. Ana, one of the interpreters I worked with at the beginning of the interviews, echoes these sentiments. She notes the endurance of gossip and its connection to honour/shame ensures that women who have experienced sexual violence are less likely to discuss this with anyone out of fear of repercussions.

For Jete, the disclosure of her experiences and the chaotic emotions she had been feeling was initially met with outright rejection by her husband: "*When I tried to talk to my husband and tell him that 'I haven't got any feeling' he just left me – went out and left me.*"

The severity of his reaction, while horrifying on the one hand, suggests something very in keeping with Kosovar tradition as outlined by the women. It is only later as Jete and her husband continue talking that they achieve a reunion. Jete's situation is unique in that she has encountered an almost excessive aspect to her suffering: from life experiences across conflict and resettlement to the emotional symptomatology to her efforts to find meaningful resolution. For her the intensity of her suffering made 'talk' a necessity in her mind, it was the only means that provided her with some relief. For many of the other women, the social pressure to *not disclose* may hold greater influence.

Yet, despite the pervasive idea that one should ‘suffer quietly’ to avoid opportunities for gossip (or worse, the abandonment by a partner) the ability of these women, over time, to confide in each other within the context of the Besim women’s groups is worthy of note. It is primarily in the context of meetings with immigration, providers and researchers that the women are formally asked to revisit in detail the events of their exile. In these contexts they are urged to reveal all, particularly those experiences which are most intimate, with the faint possibility of status and/or psychological resolution and well-being. In the women’s groups however the women have taken control of their stories and the cultural stereotypes that exist around them and their experiences. By sharing their stories with each other in some form or another they assert control over talk as it relates to their stories of conflict and exile. They pre-empt the ability of anyone in the community to gossip about them. Through this exercise they establish new rules around the template of honour and shame in their lives. In part this reflects a heightened awareness of the socio cultural changes that they are experiencing in resettlement including gender roles and norms, and the variables within Kosovar society that they can now feel can be manipulated (by them) to some degree.

On a broader scale, participation in counselling is considered compelling evidence of the political legitimacy of a refugee claimant, in the context of suspicion and xenophobia. Reports from the women and from providers indicate that solicitors actively encourage women to compile ‘evidence’ of their or their families health needs to add in support of their claim for asylum. Moreover it does not take long for people to learn of the unique relationship of the Medical Foundation for Victims of Torture (MFVT) and the Home

Office, whereby people under treatment at MFVT side-step the process of dispersal<sup>66</sup>.

Trauma in a sense becomes understood as having currency and value in the lives of refugees.

Being defined within this medico-legal framework as a ‘trauma victim’ legitimises the nature of suffering and persecution that the individual has undergone. Medical or clinical referrals and records then become ‘proof’ of the need for asylum. As Deni and I talk one day, she tells me that she does not think she will ever get her refugee status. Her rationale for this statement is that she believes that ‘only people who have been ‘traumatised’ are getting refugee status. She defines ‘traumatised’ as people who have undergone particularly horrific events (i.e. sexual violence or torture). She notes that while she has experienced periods of feeling ‘depressed’ and has even gone so far as to speak with her GP about this, it is simply not enough.

This perceived currency of trauma emerges regularly in the lives of these women. Faced with the relentless threat of ‘involuntary repatriation’, they have become acutely aware of what are likely urban myths of the asylum process. The image of a profoundly traumatised refugee has come to represent the pinnacle of need – requiring specialised intervention and ongoing support. The mythology is that having such a ‘trauma story’ (evidenced by a hefty medical report) assures legitimate status in the UK. Whether based in fact or not, this premise – of the usefulness of trauma is something promoted by the women and often by the

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<sup>66</sup> The stipulation that individuals under the care of MFVT be allowed to avoid dispersal is a provision agreed to by the Home Office. This ensures that the most vulnerable individuals are able to receive care appropriate to their mental and physical issues related to torture. Carrying a diagnosis of a psychiatric disorder or even receiving some form of mental health treatment may not be sufficient to dissuade the Home Office from rejecting a claim for asylum, however, the belief that it will help stave off at least dispersal and at best deportation is a commonly held presumption.

solicitors they hire for legal support. Dituri, like many of the women has been working her way through asylum appeals in a bid for status. Initial refusals are standard practice and typically have little to do with the merits of the case, instead reflecting procedural decision-making. Dituri explains her current situation:

Dituri: I've lost the first appeal and I have to take the case through the human rights, and if I am lucky, something will happen. [My counsellor] has found someone for me [a new solicitor] who is near here. She has said good things like 'it's okay, you're going to be okay' and she has done lots of reports like medical reports.

The emphasis that is placed upon the completion of medical reports of any kind further promotes the idea to refugees that such accounts carry weight in the ultimate outcome of their asylum claims.

The intersection of these understandings of 'trauma' – one, from within a psychiatric perspectives; and two, from a more localised situation of distress – comprise the essential meaning of trauma in these women's lives. In addition, there is a perceived 'usefulness' to the designation of 'traumatised' that underscores the women's experiences with immigration, and may impact upon their decisions around service use related to mental health. Across the competing perspectives of trauma, talk and disclosure have figured prominently, shaping the social care practices that are offered to refugees in resettlement but also, may challenge women to confront competing cultural beliefs in unexpected ways.

### **XIII. DISCUSSION**

Trauma as a construct has transformed over time, from the gendered disorders of ‘hysteria’ and ‘shell shock’ through to contemporary impressions of suffering that are often embodied in the framework of PTSD. Across its many manifestations, ‘trauma’ has come to stand for a spectrum of physical events and psychological reactions. In its current use, ‘trauma’ reflects this diversity, at once something that is intuitively understood, and yet covering a range of experiences and circumstances (Alexander 2004). At the same time trauma is accepted as part of a vocabulary of psychiatric distress, often made explicit in the diagnostic categories related to traumatic stress, particularly PTSD. This dichotomy – between a normalised understanding and a pathological interpretation drives much of the discussion and debate that surrounds ‘trauma’ within refugee health (Orley 1994).

In examining the competing discourses about trauma and refugees (how it is defined, how it is believed to manifest and how to address it) there are widely accepted elements that shape particular understandings within current academic and clinical literature, in clinical practices amongst health and social care providers, and in the resettlement experiences of women refugees in the UK. First, there is a pervasiveness of psychiatrically informed principles that are highly influential in defining trauma. On the one hand trauma is understood as ‘shorthand’ for the psychiatric disorder PTSD and on the other it is cast as something less pathological and more psychologically indistinct in nature (although nonetheless suggestive of ‘distress’). Second, there is a growing interest in recognising alternative definitions and manifestations of trauma, moving away from an explicitly Western framework and towards appreciating localised definitions and expressions. To what extent this informs clinical practice remains uncertain. Finally, health and social care

interventions respond to broader perspectives on refugees and health. Influenced by academic and clinical theory and evidence as it emerges, as well as socio-political debates taking place within the broader context of resettlement, practice-related discourse on health and trauma for refugees is continually evolving. Public Health literature may seek to operationalise concepts and interventions related to trauma towards achieving consistency in clinical care, in practice providers operate within a system of flux, striving to respond to rapidly changing health needs of refugee populations. Providers struggle against a dominant psychiatric framework, straining to adapt working philosophies and practices to incorporate alternate understandings of trauma and distress. For refugees entering into these systems of care and support (whether formally or informally) new understandings of trauma, strategies of resolution, and notions of identity, are something that is pragmatically negotiated over time.

### Provider Understandings of Trauma

As indicated in the interviews with health and social care professionals, and across the academic and clinical literature, 'trauma' is primarily envisioned and understood for refugees in the UK as a 'psychological' health issue. Discussions of trauma amongst health and social care providers tends to operate largely outside of the boundaries of one discrete institutional discourse. The working definitions, manifestations and means of addressing psychological trauma are informed by a diffuse collection of theories and perspectives that cross disciplines as well as professional and lay categories. The term trauma carries multiple meanings and may be applied in very different ways; referring to both critical events and reactions to events, including 'states of being'. The result is, at first, a tangled mix of psychiatric concepts and popular metaphors associated with suffering, psychological

functioning and impairment. With multiple understandings operating in tandem, the struggle to achieve conceptual clarity on the meaning of ‘trauma’ remains an enduring challenge for all participants.

A psychiatric framing of trauma has become pervasive amongst key actors in refugee health (academics, clinicians, service providers and refugees themselves) in the UK and more broadly within popular discourse in Western society (Rechtman 2004). This particular reading of trauma emerges across settings – not confined to agencies or services that provide psychological care. How each of these key actors interacts with and reacts to such a powerful and persuasive discourse, however, varies considerably. The prominence that has been given to PTSD may reflect relate to its ability to operationalise ‘trauma’ into a coherent and manageable phenomenon (McFarlane 2004, McFarlane and McFarlane 2000)}

An inventory of diagnostic criteria helps to map out the existence of trauma in a clear and tangible way, providing a vocabulary of signs and symptoms that can then be used to identify or rule out ‘clinical cases’. This shaping of clinical cases can be a critical part of the professional role of health and social care providers, particularly in relation to psychiatric or psychological issues (Desjarlais 1999, Estroff et al. 1991). The detailing of symptoms experienced by refugees is also noteworthy as it transforms sometimes-unfathomable experiences (i.e. specifics of torture, for example) into concrete (and sanitised) behavioural codes, helping providers to focus their efforts towards the development of appropriate interventions.

For health and social care providers this link between explicit behavioural criteria and psychiatric conditions (PTSD, depression, and anxiety) has been critical to operationalising understandings of trauma. The checklist of items outlined in diagnostic classification

schemes provides a conceptual grounding, thereby establishing clinically and behaviourally the symptomatology of traumatic stress (i.e. ‘flashbacks’, nightmares, dissociative features) (Jones et al. 2003, Schnurr, Friedman, and Bernardy 2002). Ideally this framework works as a tool, helping providers to define client needs in concrete terms. Problematically, this may also limit the ability to capture accurately the needs and experiences of their clients, reducing trauma to a limited spectrum of incidents and manifestations<sup>67</sup>.

So powerful are the links that have been made between behavioural signs and the presence of psychiatrically defined traumatic disorders that routine diagnostic procedures, such as establishing the clinical thresholds of duration, intensity and the multiplicity of elements, become largely secondary. Instead the presence of key symptoms comes to signify the presence of a clinical disorder. Displaying symptoms *suggestive of PTSD* then functions as a ‘working definition’ of someone as traumatised, if not a clinical one. In reality, the operational definition may actually differ little from a clinical diagnosis, leading ultimately to the same clinical actions and interventions. However in the process this understanding of trauma places it squarely within a medical framework, removing all traces of the social dynamics which have given rise to the experience, and locating suffering within individual markers of pathology (Kleinman 1995).

This process of ‘clinical transformation’ has been well documented with other marginalised or disadvantaged groups, where over time a language of pathology takes precedence, substituting for a discussion of structural issues. Mathieu (1993) charts the evolution of a

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<sup>67</sup> The conflation of trauma with PTSD has been pervasive in popular Western culture. This is aptly illustrated in an exchange between journalists in the Balkans, Barton (2000) notes: “*Fifteen of Ogurlic’s colleagues died in the course of their work. Then a visiting American asks: “Was it traumatic for you?” Ogurlic is quick to answer, in English: “I don’t have PTSD”* (p. 2).

discourse merging mental illness and homelessness in New York City. As debates on economic disparities and the shortage of affordable housing in New York faded to the background, explicit connections were made in public discussions and debates between the 'grotesque' images of homeless people and the de-institutionalisation of state hospitals and asylums. Over time this has transformed homelessness into a mental health issue, deemed worthy of both assertive clinical care and public health research (Hopper 1988, Meyer and Schwartz 2000).

With trauma, there is recognition that PTSD reflects a particular understanding of health and illness, one guided by Western cultural values. Providers strive to rethink a PTSD-infused definition of 'trauma' and move towards an understanding of trauma that positions it within the realm of normal responses (or at least away from a pathologising definition). One strategy that is increasingly employed by clinicians and academics is to create distance from a pathological view of trauma through language. Psychiatric terminology is replaced with clinically neutral language in describing the experiences of refugees. Distress for example, may suggest a profound emotional response, but remains below perceived 'clinical thresholds'. The shift to 'distress' is about more than simply introducing a less travelled term for trauma; it carries with it an attempt to re-situate experiences outside of the diagnostic framing of PTSD and in closer proximity to localised understandings of suffering. On the one hand this seeks to acknowledge peoples experiences and where applicable, identify symptoms; on the other hand there is a desire to move away from the language of psychiatry and medicine, towards more culturally specific understandings of trauma.

Emphasising descriptive terms rather than labelling behaviour is one way providers seek to elicit alternate ideas about the manifestation of trauma. There is a rich body of literature which has highlighted alternative ways of expressing distress, at times articulated through physical expression or symptomatology (Good 1977, Kleinman 1986, Ware and Kleinman 1992). The phrase ‘idioms of distress’ has been used in the anthropological literature as a means of referring to the range of ways in which people express emotional responses associated with suffering within everyday life (Baarnhielm 2004, Nichter 1981). Idioms of distress are often rich in their descriptiveness and variability, more so than the diagnostic criteria that is drawn upon in conventional mental health care -- capturing in some ways the more nebulous issues of loss and transformation that accompany exile and resettlement and moving beyond the one-dimensionality of symptom scales.

This indicates a move that is ideally more inclusive of localised experiences of trauma. However the unfamiliarity of these concepts (certainly in comparison to the ‘psychiatric measures’) may mean that there is greater reliance upon somatisation and dissociation as emblematic of non-Western expressions of trauma. The continuum that is implicit in localised ‘idioms of distress’ can be lost as providers draw upon the descriptive indicator of closest reach. Somatisation as an expression of distress, for example, often becomes a shorthand clinical way of describing distress-related experiences for individuals whose culture of origin is non-western (Kirmayer and Young 1998). Providers seldom make use of formalised clinical diagnostic criteria related to Somatisation Disorder as outlined in the diagnostic guidebooks of the ICD and DSM to determine this; however, preferring instead to use ‘blunt’ notions of what constitutes a somatised state. At its most simplistic this may mean that non-specific health complaints (headaches, back aches or abdominal pains, for

example) may be read as the physical expression of psychological distress (Baarnhielm 2004).

Likewise, detailing traumatic reactions in a non-clinical terminology functions as a way of distancing from a psychiatric vision of trauma and helps providers to re-position reactions to causal events. Core events – from torture, physical and psychological violence to isolation from family and loss of family and home – are highlighted and emphasised to convey both the range and the extremeness of refugee experiences (Burnett and Peel 2001a, Peel, Hinshelwood, and Forrest 2000). In a sense though (and often unintentionally) this harks back to a psychiatric reading of trauma where a pivotal event in time becomes the recognisable site of trauma, from where psychological distress emerges (Herman 1992).

Some questions have been raised in the literature about the privileging of such events, where the most explicit and extreme incidents associated with conflict or persecution are singled out as examples of the ‘refugee experience’ (Papadopoulos 2002). A frank depiction of the horrors of torture or the anguish of sexual violence aspires to operate as a strategy intent on ‘normalising’ the range of psychological responses that may emerge. For many providers achieving a balance between ‘the normal and the pathological’ is critical, and is often related in the axiom ‘*normal reactions to abnormal situations*’. There is a concerted effort to distance the experiences and reactions of refugees from the more conventional forms of psychopathology as outlined within the DSM and ICD systems.

At the same time, providers make use of clinical story-telling as a mechanism to illustrate both the inevitability of trauma for some refugees, and the systemic obstacles that refugees and providers face in seeking to provide appropriate care. The use of extraordinary clinical

stories help to carve out the boundaries of professional work, and is typically accepted as common practice within the fields of health and social care (Allen 2001).

In discussing the dynamics of trauma for women refugees, for example, the aftermath of sexual violence is repeatedly emphasised by front line professionals and academics as the core ‘devastating’ event which women are left to face in resettlement (Goodchild and Ober 2003, Kelly 2000, Olujic 1995b). The centrality that is accorded to sexual violence as a pivotal event within conflict continues a discourse on women refugees that begins in the context of war. Distinctions are made between sexual violence in ‘everyday’ Western society and that experienced within the context of war, suggestive of something inherently more traumatic and more stigmatising in the experiences of women who are raped in conflict (Olujic 1998). Often described in graphic terms and couched within horrific tales of multiple indignities (‘the horror story’), rape takes on a sharp brutality. The presentation of refugee stories within such a light confirms for the provider the presence of trauma and the inevitability of pathology as a consequence. This perspective reflects in some ways the heightened attention that has emerged in response to sexual violence and conflict in the broader social discourse within Western society (and Western media).

For women from certain regions (such as the former Yugoslavia) there is almost a blanketing effect, whereby many providers assume that all or most of these women have been victims of sexual violence in conflict. Cultural knowledge of the women by providers relies heavily upon features that have been popularised within the media. For Kosovar women, this becomes an image of tradition and a docile representation of gender; the quintessential ‘mother in a headscarf’ (del Zotto 2002, Stetz 2000). The heavy accent that has been placed upon sexual violence during the Balkans wars has resulted in a pervasive

image of women as victims of rape. The profound stigma within Kosovar society that is assumed for women who have been sexually assaulted renders the traumatic image complete. The link from critical events (such as rape) to severe and negative psychological functioning (pathology) is easily made. Problematically, reducing refugee experiences to key incidents may distort both the nature of experiences associated with conflict and exile, and limit our appreciation of variations in trauma.

Despite efforts to distance working definitions of trauma from a psychiatric framing and from PTSD in particular, providers endorse the use of the language of biomedical psychiatry ('depression', 'anxiety', and 'stress') broadly and traumatic stress more specifically as an entrée for refugees to articulate and understand their experiences. While seldom adhering to a strict 'diagnostic' framework, a mixture of terms and concepts are instead employed to convey at a minimum a psychological understanding of trauma. The adoption of key psychological terms is often endorsed, suggestive of 'having insight' and the recognition that certain experiences may translate into patterns or behaviours of psychological distress. From a clinical perspective, 'insight' functions as a tool in the resolution of internal distress. The recognition of psychological symptomatology or aspects of a condition or state or being opens up opportunities for intervention. With respect to trauma, despite any struggle that providers have with a psychiatric paradigm, there remains an enduring relationship to 'talk therapy' that is endorsed as a strategy within refugee health and resettlement. There are distinct ways in which providers and refugees define and respond to trauma which are noteworthy in how both approach and understand 'talk' in relation to trauma and refugee health.

## Trauma and Women Refugees in Resettlement

In the interviews with this sample of Kosovar women there is some echoing of these themes. Psychiatry – or at least the *language* of psychiatry – emerges as a new way of talking about health and mental health. The professionals that refugees come into contact with – through legal, medical and psychiatric care, social care and advice services– all encourage them to draw upon the language of psychiatry to represent their experiences to some degree. The framework that women use, however, is slightly different from than of the academic or provider discourse, and seems to operate at a greater distance from the framework of PTSD.

The ‘aetiology’ of trauma, for example, as cast within a conventional psychiatric paradigm hinges upon specific critical events that are located within the past experiences of conflict and forced migration. For the women, however, while there may be some element of what they define as trauma or distress located within the critical events preceding exile, there is at the same time a broader recognition of the significance of everyday uncertainties and struggles in resettlement that may shape their psychological health. Their understanding of trauma is not confined to the core event(s) of conflict and forced migration, but instead moves across time frames and is more cumulative in nature, representing the breadth of their experience over time.

While new to the phraseology of psychiatry the women quickly become adept at the use of diagnostic labels and familiar with the list of symptoms that are expected from them (with particular emphasis on the concept of somatisation). Baarnhielm (2004) notes a similar phenomenon amongst Turkish women who have resettled in Sweden and have been referred

for mental health services related to ‘somatised’ distress. In the course of clinical work, the women are actively encouraged to embrace a psychological language and understanding for their experiences of distress. At points there is a tense juxtaposition between the women’s personal understandings of their experiences which tend to be linked more with interpretations of loss and the new paradigm which asks them to see themselves as physically expressing psychological anguish (read pathology). Over time however, the women adapt, at least outwardly; old understandings of suffering and healing are “...*put aside, cast in the shadows, dropped or changed*” (p53) in favour of Westernized psychological concepts. While visible patterns of adaptation emerge in the women’s description of trauma or distress, culturally informed ways of interpreting and understanding events (that defy a pathological interpretation) remain. Exploring these alternative ways of seeing and experiencing distress can shed light on the multiple meanings of trauma that are being used and how this informs life in resettlement for women refugees.

Despite a cultural endorsement of stoicism and a professed lack of familiarity with the less extreme forms of mental illness, patterns begin to emerge amongst the women as they encounter ‘trauma’ and ‘therapeutic interventions’ where they adapt and accept these conventions as customary. Skultans (2003) in exploring narratives of distress amongst women in Latvia noted a similar transformation where a psychiatric discourse is accepted over time to explain experiences. Lay conceptualisations of ‘nerves’ evolve into loose psychiatric conceptualisations of depression. The psychiatric consultation teaches the individual to recognise depression in a psychiatric form, providing the language of depression as a tool for understanding and defining appropriate behaviours and reactions.

Over time, this 'mimicking' effect where the terms and images of conventional western psychiatry are used to convey their experiences and needs may become subsumed into the working interpretation of distress at a local level. Despite the pervasiveness of a psychiatric paradigm, the women retain elements of an alternative framing of trauma, one shaped by individual experiential and sociocultural influences.

The idea of somatised distress appears as a strong theme in refugee accounts of loss and suffering in public health and anthropological literature (Hinton and Hinton 2002, Kirmayer and Young 1998, Waitzkin and Magana 1997). For the women in this Kosovar community, however, there was some uncertainty about the validity of this idea, accompanied by a more critical questioning of therapeutic interventions they have been directed toward.

Headaches, for example, have been described as a way in which experiences of the war and of exile have been manifested. For these women the disclosure of headaches often functioned as an entryway into health and social care, via a referral for counselling, regardless of whether the woman explicitly expressed psychological distress or not.

For the women, the articulation of distress in their own terms is more descriptive, moving away from the language of psychiatry, to expose vivid expressions of experience that if anything are more evocative of psychic pain. Along with this comes some questioning about the assumptions that are made by others in terms of mental health and about the nature of their needs. The women's accounts of distress are more entrenched in and defined by the day-to-day events that shape the refugee experience including the practicalities of adaptation, the search for a sense of community, as well as dealing with 'what happened' in the contexts of conflict and forced migration. Attention is directed more towards the

identification of individual and cultural modalities for the expression and resolution of trauma.

The women's stories and experiences in resettlement and the way that they frame difficult experiences in their lives also sheds light upon the strategies of resilience that they draw upon. In the course of their experiences in the UK the women and their families have regular contact with systems of care (in both a broad sense and often within a specialised way). Front line medical services and local refugee community organisations are typically the points of entry into these systems of care, and subsequent points of engagement with trauma discourse. New understandings of trauma, however, may emerge from unexpected sources. For example, the construction of trauma as having 'currency' has links with the processes of immigration, where supporting medical documentation of a trauma related diagnosis is perceived as capable of enhancing the credibility of a claimant. In reality, the idea of currency is more complex and uncertain, noted by providers as capable of either facilitating access to care or alternately functioning as a barrier to some services.

While the women minimise the cultural representations that they have held in the past or are familiar with from Kosovar traditions or practices, stressing the need to learn and absorb new 'Western' concepts, this does not mean that there is a blanket acceptance of these concepts. Patterns emerge amongst this group of women in which they accept elements of the language and practice of psychiatry in the UK and adapt them to work with their understandings of and ways of dealing with 'trauma'. There are also unexpected challenges made as they re-interpret the dominant perspectives they encounter. This calls into question some of the assumptions that are made about what they need and want.

In the stories they tell of themselves and their families, unique ways of expressing their experiences of conflict and exile emerge, as well as strategies to reduce the strain of difficult times. Together these elements provide insight into particularised notions of trauma related to the experiences of being a refugee in resettlement. Examining these also sheds light upon aspects of power and powerlessness in the lives of these women through newly configured social norms. Cultural and gendered norms emerge as tools that the women use to locate *and* recreate themselves in their new environment. They ‘play’ with the assumptions that are made about their powerlessness, challenging stereotypes and exerting agency in unexpected ways. To what extent particular ‘tools’ associated with a western interpretation of trauma (language, terms and strategies) will come to be incorporated into individual ‘idioms of distress’ remains to be seen. The women continue to retain distinct interpretations of ‘trauma’ and of interventions, such as ‘talk therapy’ while demonstrating pragmatism about their uses in resettlement.

### Interpretations of ‘Talk’

Psychiatry remains a dominant framework that providers rely upon in conceptualising the therapeutic needs of refugees in resettlement. In part this may reflect increasing calls for ‘evidence-based’ knowledge within health and social care in the UK. There is a growing body of work across academic and clinical disciplines on trauma experienced by refugees in resettlement situations (Marx 1990, Silove and Ekblad 2002, Weine et al. 1998b)

Operating as an unofficial ‘benchmark’ (Eagle 2002), however, experiences are evaluated against a psychiatric vision of trauma, with clinical treatment plans evolving accordingly.

Therapeutic strategies for trauma and distress for refugees in resettlement rely heavily upon notions of ‘talk’ (Kinzie 2001, Weine et al. 1998a).

‘Talk’ assumes particular forms in relation to trauma in discussions on refugee health, primarily for health and social care professionals. First, there is an emphasis upon the process of disclosure, which is understood to have intrinsic therapeutic value. Second, some form of counselling (individual, family or group) is linked to this. Counselling ideally provides a forum for the revelation of sensitive emotional and psychological experiences, intent upon promoting change at behavioural and cognitive levels over time.

The decisive emphasis upon talk as a therapeutic intervention reflects a particular paradigm for understanding mental distress in general, one that is distinctly Western in nature, heavily informed by modern Anglo-American psychiatry (Scull 1999). While there is recognition that other frameworks of mental illness exist cross-culturally, discussions by providers have emphasised the extreme and ‘foreign’ quality that accompanies any such phenomenon. Mental illness and distress is presented as extremely unusual or uncommon and as such ‘highly stigmatised’ outside of Western countries. The extremeness with which this is articulated is important. When discussing Kosova, for example, descriptions of mental health and illness in the pre-war context are presented as extreme, conjuring images of extreme pathology requiring long-term institutionalisation. Beyond this, there is a scarcity of illustrations of the everyday issues of mental ill health. Simplistic interpretations of this disparity regard the events of conflict and forced migration as giving rise to situations that previously were non-existent. This helps to accent the contrast between Western and non-Western conceptualisations of psychological trauma and the meaning of talk as an intervention for Kosovars. Subsequently a limited sense of the pre-war experiences of trauma-related stress or distress exists in relation to Kosova, and the lives of Kosovar refugees.

However, discussions with women refugees yield a more complex interpretation. The everyday psychologising language of individual stress and distress may have had less visibility within Kosovar society due to strong cultural beliefs and social norms, dissuading people from openly discussing their thoughts and feelings due to a fear of gossip. The fear of private experiences making their way into public forums may serve as a powerful deterrent. For women in resettlement, the meaning of talk and its value in relation to trauma may be more uncertain. While for providers, disclosure, the acceptance of referrals and counselling may signal beneficial aspects of talk, taken as evidence of need on behalf of the individual refugee. For women refugees, there is a more complex relationship to talk and intervention services, where disclosure and the use of counselling services may be driven more by strategic needs in resettlement, rather than a perceived psychological value.

Talk in the form of counselling assumes a primary role in conventional western treatment of trauma symptoms. Often this is depicted in a polarised way by academics, service providers and women refugees alike with respect to the positioning of counselling as normative within western culture, versus more community-oriented strategies for conflict resolution or support in non-western cultures. The emergence of ‘counselling’ as a profession in the UK, whilst relatively new, has been embraced as a critical part of the resettlement of refugees (Bondi 2004). Its popularity has meant the widespread expansion of counselling across settings and as a result, its increasing professionalisation, complete with new levels of formalised training. Now entrenched within formal systems of health and social care, the roles of counsellor and recipient are locked into often polarised positions of (assumed) power and knowledge differentials. Counselling has become routinised as the intervention of first response to events of illness or suffering (Árnason 2001).

Despite the widespread acceptance of counselling, there is often an absence of a unified framework that providers rely upon. Terms like 'holistic', 'multidisciplinary', 'multicultural' are used in an attempt to convey some sort of underlying theoretical perspective. However there is often not a coherent theory in place, instead there seem to be a collage of ideas, many not fully formed. In relation to psychiatry and 'mental health services', these concepts are generally accepted. Rhodes (1995) in her compelling account of clinical work in an acute psychiatric unit, details the often contradictory frameworks that operate. Clinicians, while guided by the over-arching model of Western psychiatry find themselves pragmatically selecting aspects of "*a bewildering array of theoretical approaches*" (Rhodes 1995: 4) in an effort to work within the pressures of system that insists upon the rapid intervention and release of patients. Patients do not understand the ongoing ambiguity and contradiction as a clinical 'swamp' but instead as a shrewd use of 'specialised knowledge' that is acquired through the unique circumstances and adapted according to the particularities of the context. Healy (2004) echoes these observations on a broader scale, noting that the popularisation of psychiatric terms and loosely defined conditions has contributed to the identification of new categories of social disorders, related to anxiety and stress. Problematic is the separation of terminologies and concepts from their theoretical frames of reference.

In the context of refugee health in resettlement there is also this sense of marked ambiguity between the use of particular psychiatric terms and the delineation of specific conditions. Providers strive to navigate through competing frameworks for understanding trauma that are informed by psychiatry and cultural beliefs whilst balancing the knowledge that is acquired through clinical practice (something that is often defined by its intuitive qualities: 'it feels right'). Irrespective of what element of a psychiatric framework are utilised by

health and social care professionals, there is a shared appreciation for the value of personal disclosures of sensitive issues, as a means of alleviating stress and moving towards a 'rebuilding of the self' following a traumatic event (Agger 1992, Brison 1999).

The emphasis that is placed upon talk is not an uncommon phenomenon within modern western society, particularly for victims of certain forms of violence. 'Speaking out' is advocated as a self-help strategy for women recovering from sexual violence. Ideally this enables women to take control of their experiences of victimhood and transform them into possibilities for survivorship (Heberle 1996). However, this also has an unintended effect of fixating upon the event of rape or assault as the definitive moment of women's lives, much like the event-focused interpretation of refugee trauma endorsed by providers. Moreover, the benefits of 'speaking out' are seldom critically examined (Sudderth 1998). Typically the argument that has been put forth with regards to such traumatic events is that there is a need to invest effort in undoing unhealthy psychological patterns (Herman 1992).

Within the context of refugee resettlement, a similarly heightened call for disclosure exists. Across their experiences in the UK, from meetings with immigration officials to consultations with health professionals, the weight that is placed upon disclosure makes this an important part of their resettlement experience. There is a hint of coerciveness that exists around the idea of disclosure within health and social care agencies, where providers believe and women are told there is a *natural* therapeutic value to talking about suffering or distress. For the providers, there do not seem to be any internal struggles around this core principle. While they may be conscious of the difficulties inherent in the process of disclosure in some settings (i.e. immigration hearings) there is limited insight into how this may also reflect anxieties within a clinical or social care setting. At best there is an acknowledgement that

disclosure may be difficult, particularly for certain individuals (torture victims, women who have been raped). In addition providers (and academics) recognise the hesitancy that may exist in a more public disclosure (amongst communities of origin). However there is little examination of the issue in light of the expectation to disclose to providers. Instead there is an active promotion of the need to talk as a critical part of coming to terms with trauma and establishing a new life in resettlement. This pattern has been demonstrated elsewhere.

Ong (1995) in her work with Cambodian refugees in California notes the importance that is placed upon talk by providers. Providers urge refugees to learn new concepts and terms about mental health and trauma, and to incorporate these ideas into their lives. This 'medical acculturation' while well-meaning, results in a marked transformation of the individuals' perspective towards that of the provider. 'Talk' figures prominently in this process through the introduction of the terminologies and practices of western psychiatry. These are introduced and emphasised in non-threatening ways, linked heavily with the idea of 'everyday stress'. Clinical terminology is used to re-cast refugee experiences, where stories and experiences of the Khmers are rewritten by providers in 'universal' medical or psychiatric terms. This re-branding of experience suggests that cultural sensitivity is at best limited. Ong suggests that any 'localised knowledge' is used strategically by professionals: culturally defined experiences or idioms are translated into the professional medicalised perspective, which then serves as the shared vocabulary between providers and refugees (Ong 1995: 1248).

The almost routine way in which Kosovar women found themselves referred for mental health counselling could suggest a strong acceptance of a psychiatric paradigm for understanding trauma in the lives of these women. The acceptance of mental health

referrals and prescriptions was not uncommon. Yet, as is suggested by other relevant research, the acceptance of clinical terms or aspects of clinical care may be more heavily marked by ambiguity than by a determined acceptance. Pescosolido and colleagues (1998) note that often there is a ‘muddling through’ process where people fail to exercise clear personal choice and decision-making (but also fail to indicate a clear sense of coercion) in entering or accessing mental health services. Instead they articulate a more nebulous acceptance of referrals which neither endorse nor refuse treatment.

The absence of a shared language in many of the consultations between Kosovar women and health care professionals (with frequently no Albanian-speaking interpreter present) does raise pertinent questions. In such situations there may be a blanketing of refugee health experiences, where certain experiences are understood as intrinsically related to traumatic stress. For example, ‘headaches’ are routinely accepted as evidence of somatised distress and traumatic stress. At the same time these clinical interactions convey new understandings of trauma and frameworks for understanding physical symptomatology for the women. These come to be accepted by some as part of a new vocabulary of distress. The use of new terminologies to describe their experiences does afford a certain intrinsic value that is well-known with medical conditions; where ‘naming it’ affords some sense of comfort and recognition of the individual’s suffering (Vanthuyne 2003). This may be incorporated into individual vocabularies of distress, or come to replace individual understanding of trauma and suffering over time (Baarnhielm 2004).

Accompanying the emphasis on talk and disclosure is an emerging perspective in refugee health that strives to re-locate trauma within the realm of a socio-political context. The adjustment issues that accompany an individual in exile – cultural mis-matches, the struggle

for legal recognition and legitimacy, the navigation through new systems of care and social structures – ensure that the events that made them refugees remain as constant themes, central to the processes of adaptation.

In talking about refugees, health and trauma, service providers have drawn upon the theoretical work in the academic literature that call for a greater attention to social justice matters (Borneman 2002, Das 2003, Laub 1995). The ideas of 'testimony' and 'witnessing' have emerged as critical concepts in shaping understanding of interventions. There is a rich and textured literature on these ideas, where 'witnessing' and 'testimony' merge with psychological discourse (Igreja et al. 2004, Laub 1992a, Laub 1995). The concept of witnessing suggests active work on the part of the professional towards promoting social justice while the idea of testimony encapsulates this along with a therapeutic component for the individual (Weine et al. 1998a).

As with the term 'trauma', the concepts of 'witnessing' and 'testimony' manage to live out multiples roles, evocative of metaphorical ideas about suffering and individual ways of coming to terms with this, as well as practical strategies for a more *therapeutically* shaped idea of psychological restoration. Testimony in Latin America, for example, was an important tool for people to take back control of their lives and resist the coercions of a politically corrupt (and terror-filled) context (Chopp 1986). At a community level, there is a concept of a benefit that operates: individual agency will be achieved, the truth will emerge, and reconciliation can begin (Ross 2003, Wilson 2003). The individual therapeutic aspect to testimony has emerged from the perceived benefits that people experience in the process of 'telling their story' ( Agger 1994, Agger 1998).

Weine (1998a, 1995, 1999) in his work with Bosnian refugees in the US has been particularly vocal about the need to engage with people on a level that incorporates socio-cultural and political features as well as an active promotion of mental health treatment. Similarly, the work of Agger and Jensen (1996) brings to the forefront contexts in which the process of active disclosure, such as that articulated by survivors of political violence in Chile, becomes a means of asserting power in a situation that is by all accounts marked by powerlessness. For Agger (1992) the traumatic story gets used in a therapeutic way through a process of integrating the painful experiences of the individual back into a socio-political context. Fault, stigma, victimhood are transformed and no longer located within the individual. Instead, a new story emerges, with new meanings ascribed that allow for the individual to heal and reclaim political agency in the process.

Whilst there is an increasing body of work that evokes ‘testimony’ as an intervention with survivors of political violence, the conflation with psychological trauma and therapy means that the concept is unwittingly appropriated as part of a psychological discourse. Ehrenreich (2003) notes that despite the strong political origins of PTSD, it failed to mobilise political action in the way it intended to -- instead falling into a working understanding of trauma that ascribes an individualised meaning, hinging upon an internalised constellation of symptoms and not an external understanding of adverse conditions and human experiences. While many professionals draw upon the language of social justice, they have yet to achieve a translation of these concepts into practice.

Yet within the political climate in the UK, asylum and the legitimacy of refugees political advocacy does come into play. The heightened political climate for asylum seekers transforms diagnoses related to trauma into something instrumental (Luebben 2003).

Trauma and the central intervention of talk are then recognised both by providers and by refugees as offering a ‘currency’ of sorts, conferring a sense of legitimacy to people’s claims of political asylum.

Salis-Gross (2004) notes a similar phenomenon in her ethnographic work in Switzerland, where refugees are labelled according to whether they are survivors of violence. The moniker of “violence refugees” marks an attempt to recognise the health and social vulnerabilities that may be unique to survivors of political violence. These individuals carry a certain advantage over other refugees, designated as the ‘good’ refugees, and so deserving of political asylum. Unintentionally this differentiation leads refugees to actively engage with a medicalised discourse on trauma, effectively medicalising themselves and their experiences.

In addition there have been clear links made to the ‘uses’ of the designation of ‘trauma sufferer’ in accessing services. ‘Talking up the numbers’ of PTSD sufferers amongst refugee populations has been acknowledged as a strategy that serves to mobilise key health and social care resources for refugees (Stubbs 2004, Watters 2001). Simultaneously, as noted by the providers interviewed in the study the designation may sometimes function in counter-productive ways thereby limiting access and stigmatising refugees as ‘hard to serve’.

Largely unaccounted for in trauma discourse is the role of *non-clinical* strategies for resolution of trauma for refugees at an individual and on a community level. Instead recovery from trauma is presented as something that intrinsically requires clinical intervention. Yet as highlighted by Fullilove and colleagues (2004) a less individualised

and more *ecological* perspective may get to the heart of how communities re-build and re-ground themselves in the aftermath of life-changing events. They argue that recovery in post-September 11<sup>th</sup> New York City has relied more upon the active promotion of organisational solutions rather than individually focused ones. That some people will or do require professional intervention is not at dispute, but rather whether or not the first line of intervention for most individuals post-crisis should in fact be psychological or more material. The idea that we need to critically re-examine the assumptions of widespread clinical work has not been ignored in the academic discourse (Summerfield 1999). There has been some suggestion that rather than clinical or procedural justice interventions, such as ‘Truth and Reconciliation’ hearings, what people want more is to re-build the basic and tangible aspects of their life: home, livelihood, community (Summerfield 2002).

How people recover from catastrophe is a profound question, but the lessons of history are straightforward: recovery is not a discrete process. It happens in people’s lives rather than their psychologies. It is practical and unspectacular, grounded in the resumption of the ordinary rhythms of everyday life – familial, sociocultural, religious and economic activities that make the world intelligible (Almedom and Summerfield 2004: 386).

This observation is not lost on front-line providers who strive to introduce theoretically informed ‘evidence’ into their work. In this small community of Kosovar women in London, experiences with front line services (of every kind) have been heavily marked with notions of psychological distress and recovery. Yet in their daily lives, what the women discussed and demonstrated was the critical role of community in helping them to re-build and provide support to each other. Through the Besim programme in particular, the women found a sense of belonging that was defined by themselves for themselves and their families. Despite the fact that their lives have been fraught with uncertainty and insecurity as ‘asylum seekers’ in the UK, their collective work with the Besim programme has enabled

them to reclaim their ethnic identity, and invert the meaning of the identity of ‘refugee’ (Verkuyten and Nekuee 2001). Deni, the coordinator of the programme, has actively sought to move the emphasis away from being a ‘refugee project’ and gradually formalising the charity as a resource for members of the Albanian-speaking community.

For those individuals who have been labelled as ‘traumatised’, the issues of identity and disorder may become fused. There is a long history of blending diagnosis with identity for psychiatric patients, where everything becomes “...*obscured by the diagnosis*” (Capponi 2003: 146). Popular conceptualisations of trauma already merge these discourse, referring to refugees as almost permanently marked by their experiences, or ascribed with a chronic identity (Estroff 1993). This notion of a chronic condition differs from the formal diagnostic paradigm, which despite recognising long-term implications of untreated symptoms, tends to promote a treatable disease model. For refugees who are identified as ‘traumatised’, the perception of vulnerability is acute, with a persistent risk of being re-traumatised. When merged with the identity of ‘refugee’ there is potential for a compounding of stigmas (Goffman 1963).

The medicalisation of collective suffering and trauma reflects a poor understanding of relationships among critically important social determinants and of the possible socio-medical outcomes of political violence (Pedersen 2002). People who encounter everyday instances of violence, exclusion or surveillance may under-report experiences of distress in their lives, remembering and confirming its existence only when prompted (Desjarlais 1994, Desjarlais 1996, Smyth and Fay 2000). This suggests a normalisation of some aspects of suffering where less visible forms of trauma and distress may be eclipsed by the high visibility of key incidents (e.g. violent incidents). Similarly, the ways and means of

exercising choice and implementing alternative coping mechanisms may also remain 'hidden' on a daily basis.

The centrality of a psychiatric understanding of 'suffering' for refugees has meant that that individual pathology has been positioned at the foreground of refugee health, with individual resiliencies or agency often overlooked. There is a limited appreciation of the strategies that people employ in seemingly powerless situations and their abilities to implement choice and exercise agency (Desjarlais 1994, Desjarlais 1996). The use of talk as a strategy for responding to and resolving trauma may offer specific benefits to refugees that remain somewhat unaccounted for in practice by health and social care professionals. As much as providers may strive to move their understanding of trauma outside of a psychiatric paradigm, the strategies they endorse (talk and counselling) serve to reaffirm this particular framework for understanding trauma for refugees. More diffuse and localised understandings of trauma are manifested for individuals in resettlement. Yet the pragmatic uses of trauma and talk made use of by refugee women suggest a more complex relationship to the psychological (psychiatric) framework for defining and resolving distress.

## XIV. CONCLUSION

There are few presumptions in human relations more dangerous than the idea that one knows what another human being needs better than they do themselves (Ignatieff 1994:11).

In a critical text examining the nature of social intervention, Michael Ignatieff raises core questions about the underlying assumptions that drive the action of clinical work. The language that is used to convey those needs, he argues, have “...*been worn out with casual overuse in politics*” (p 15). In examining professional and lay discourses on ‘trauma’ for refugees, this image of a tired language has relevance.

‘Trauma’ has assumed a position of prominence as a health issue for refugees. Current understandings of trauma reflect a historically informed evolution through scientific, political and social interests. In resettlement, distinct understandings of ‘trauma’ have emerged across professional and lay discourse(s) and have shaped clinical working practices and everyday expressions of trauma in particular ways.

Presently, notions of trauma within refugee health are based largely within a psychiatric paradigm. Although there is a move towards the recognition of broader conceptualisations of trauma that draw upon anthropological insights into ‘emic’ understandings of health and suffering, as well as a desire to locate these within a socio-political framework, this remains incomplete and a heavily medicalised framing of refugee health endures.

From academic discourse through to lay perspectives there is an interest in deciphering the complex meanings and associations of ‘trauma’ to refugee health. There is strong interest in

exploring the theoretical conceptualisations of trauma in academia, as well as considering the applications and implications of these frameworks in clinical work.

Front-line health and social care providers may not rely much upon written academic work, however, they regularly engage with academic theory through professional conferences and workshops. In this context, they acquire familiarity with the theoretical and conceptual issues being grappled with in academia. Local conferences can act as conduits for the exchange of information and perspectives between these worlds. There are, as a result, significant overlaps as both direct service providers and academics struggle in reconsidering the meaning of trauma and, in the process, limit the medicalisation of experiences.

For women refugees, the influence of clinical perspectives is more acutely felt as they encounter new and emerging definitions of trauma and distress in direct services. Yet there are unique positions and perspectives that are staked out in terms of clinical practice and in the individual manifestations of trauma at the ground level in refugee resettlement.

For health and social care providers, trauma begins with a marked examination of the past. This reading of trauma confines it to specific periods or encapsulated in particular events (e.g. rape or torture). This delineation of life events draws upon previous professional conceptualisations of trauma, for example, the clinical framework of PTSD. There are in addition, important assumptions made about the experiences and expressions of trauma and distress for refugee women. Certain circumstances of conflict and forced migration have acquired a prominence, for example, sexual violence has been designated as a cornerstone event for women, particularly women from certain regions (such as the former Yugoslavia).

Despite efforts to recognise cultural variation in the experiences of trauma and distress, these often owe more to the dominant psychiatric paradigm than to cross-cultural awareness. One example is the assumption that a headache carries with it a distinctive (and ultimately psychological) meaning for refugees in resettlement as somatised distress. As a result, providers routinely interpret non-specific physical complaints such as headaches as evidence of profound psychological trauma for refugees.

In an effort to move away from an explicitly psychiatric reading of this, however, providers strive to detail experiences like physical symptomatology and behavioural expressions; operationalising trauma, and forging a distance from psychologising language. This approach suggests the application of public health tools in practice, where providers strive to chart out the epidemiology of their case loads. However tensions emerge, as providers recognise the limitations of using ‘standardised’ categories and classifications (even if grounded in behaviours and individual expressions) to define and understand the nature of trauma within the lives of refugees. Operationalising trauma in this way recalls the reductionist frameworks of medicine, and may fail to capture the complexities of trauma and suffering for refugees.

For women refugees, the starting points for understanding trauma differ considerably. The women articulate a more expansive definition of trauma that does not conform to the notion of one episode or place in time. Instead, trauma moves across time and situation, from the past through to the present, located as much in the series of events experienced related to conflict, as those encountered in resettlement. In addition, there are rich ways in which the women reveal their suffering that do not always correspond neatly to a psychiatric definition

of trauma. The women draw upon perceptions that are closer to home, those informed by personal belief systems and those of their immediate social networks and communities.

New strategies associated with finding and creating community have emerged as critical ways in which these women 'work through' many of the residual stressors of conflict and forced migration. These work to counteract the isolationist framework of psychiatry, and actively resist the transformation into 'clinical cases'. For some communities, such as the Kosovars, traditional networks have been left fractured or lost due to forced migration (Kelly 2000). The women articulated a clear and profound sense of fragmentation and isolation in their stories of exile and resettlement in the UK. However, upon 'finding community' – often in haphazard ways -- a close facsimile of traditional social networks has been created. Collective activities form localised tools of recovery; as the women embark on restorative exercises, re-building themselves and their lives and eventually moving away from the designation of 'traumatised refugee'. This becomes a very conscious re-construction of relationships and social contexts for recovery that operates at once on an individual and a community level.

Distant from the clinically informed paradigm of providers, these patterns conform less clearly to clinical (psychiatric) ideas about trauma and recovery. Yet, women also find themselves actively encouraged to learn and make use of a psychological language for expressing the nature of their experiences, and to engage with formal clinical services, such as counselling or therapy, as a means of dealing with their trauma. This becomes part of their 'acculturation' into the host society (Ong 1995). Yet the use of health and social services by the women was often driven by pragmatic needs. While many women expressed uncertainty about the clinical needs 'diagnosed' by health and social care

professionals, they were open to exploring these avenues and facilitating their adaptation to resettlement in whatever ways they could.

This process of negotiation, in practice draws upon competing perspectives of trauma, making 'use' of diagnostic labels and therapeutic services, while simultaneously relying upon personal idioms of distress and coping, and constructing new patterns of addressing trauma within a newly established community. Under-examined are the alternative ways in which women refugees may 'make use' of a diagnosis related to 'trauma' or the ways in which this may work against women as they move toward new stages of adaptation in resettlement .

Through disclosure, trauma and suffering are revealed and through counselling 'talk' the individual moves towards therapeutic resolution. Disclosure itself is imbued with a therapeutic value, where 'telling their story' carries an inherent benefit (Agger 1992).

Talk emerges in specific forms for providers and refugee, and as they move through the process of identifying and addressing issues of trauma for refugees in resettlement. For providers this is fundamentally located in a psychiatric vision of clinical care. For women refugees, however, there is an adaptation of notions of talk (beliefs they have come with, and specific beliefs that they have come to learn in resettlement) which yield distinctive benefits when merged with a new construction of community.

The construction of a new community in resettlement allows for a conscious merging of new and old idioms of distress. The women are able to draw upon more traditional Kosovar ways of dealing with distress through humour, dance and social connectiveness. But there is also something uniquely linked with their experiences of resettlement at play, where they

utilise the notion of talk – but on their own terms. In this sense the women make use of the new idioms and strategies that are available to them as they move through phases of resettlement and adapt to life in exile.

Many of the complexities of how perceptions and understandings of trauma are negotiated over time, and bear the impressions of multiple (and competing) discourses on trauma -- may be lost during clinical interactions between refugees and providers, which emphasise a particular interpretation of trauma. The persistence of a psychiatric discourse means that refugees may be routinely perceived as ‘traumatised’ (in a clinically defined sense).

There are as a result assumptions that operate within conventional health and social care services about the ways in which women from non-western countries express trauma and distress (somatised distress). Coupled with this perception is the belief that the unfamiliarity of psychiatric or psychological models of distress requires providers to teach refugees new ways of understanding their experiences in order to facilitate emotional and psychological recovery. As part of this framework there is an emphasis placed upon the need for refugees to learn new ways of understanding and expressing their experiences (particularly verbally) in order to facilitate their emotional and psychological recovery.

This ‘one size fits all’ approach fails to recognise many of the strengths that individuals demonstrate within their everyday lives. While some concept of resilience has not gone unnoticed in refugee health related to trauma, there is at the same time some disquiet about its use. The intent behind the idea -- to recognise the skills and strengths that people carry with them or develop in the face of adversity (Rutter 1987) -- may be lost or distorted, reduced to what one provider called “*a hugely undermining, patronising word*”.

Problematic is the reduction of alternative models of coping to simplistic strategies either loosely informed by culture ('traditional' coping strategies, which may or may not be defined) or by psychiatry (through psycho-education, where people learn 'how to be resilient') (Garland, Hume, and Majid 2002)

In exploring the perspectives and working practices of health and social care providers, public health practices that are operating related to refugee health and resettlement in the UK are highlighted. Heavily influenced by a psychiatric paradigm, providers across health and social care settings strive to operationalise trauma in a way that enables them to respond with clinical assertiveness, despite the ambiguities they face in understanding and conceptualising trauma. For women refugees, conceptualisations of trauma reflect more diffuse understandings; informed by a fusion of traditional and individualised beliefs about suffering, Western notions of trauma and psychiatry, and idioms of distress and healing shaped by an emerging community. Moreover the women have uncovered notions of and make use of trauma as a 'resettlement-specific' tool.

Ignatieff (1994) argues that the language that we use often fails to capture the experiences of those deemed 'in need' and in the process, to do justice to the genuine intent of the helpers to alleviate suffering. Part of the inherent difficulty in resolving such a dilemma is the realisation that establishing a common 'language of needs' can not in itself reconcile the contradictions that exist in terms of our needs, only allowing us to contrast one need against another (p 137). There are rich and distinct interpretations of trauma operating 'on the ground' level of clinical practice and refugee resettlement.

Public health related to refugee trauma has sought to emphasize much of what is shared in light of psychological trauma; the common behavioural signs of distress, the populations at risk, the common strategies that work for to alleviate suffering. Drawing upon anthropological influences can enable us to see a greater diversity of 'idioms' of trauma and suffering, alternative ways of understanding suffering, and non-medicalised strategies for reconstructing lives in resettlement.

The ability to account for a range of experiences (and expressions) of suffering and along with this a range of restorative measures (of which 'talk' may be one option) is routinely absent in health and social care settings for refugees. While there is no doubt that for some individuals a psychiatric reading of trauma can be both beneficial and necessary and that psychological models of treatment may also prove useful in alleviating distress.

There is a however a need to question the fundamental (and widespread) assumptions that are made with respect to the meaning of trauma and the needs of refugees as they operate across health and social care agencies, and the therapeutic value of 'talk' that is routinely prescribed as necessary to the processes of successful resettlement.

Good practice in clinical work is both complex and multi-dimensional (Ingleby 2004). Uncritically applying a psychiatric framework may prove more detrimental than beneficial. Evidence from other sub-populations designated as vulnerable (e.g. chronic psychiatric patients or the homeless) suggests that clinical goals may obscure some of the larger social and structural issues at play (Hopper 1988, Lyon-Callo 2000).

As illustrated here in the perspectives and experiences of clinicians and women refugees in resettlement, philosophical paradigms, working practices and decision making about services are enacted in complex ways. At the ground level of clinical practice and daily life in resettlement, people navigate competing discourses on trauma guided by (sometimes) contradictory personal and pragmatic choices. The context and mechanisms under which people operate – how they function and find ways to enact and express agency in the face of broader structural forces provide important clues to the processes of psychological risks and resiliencies that operate in the lives of displaced individuals.

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## **XVI. APPENDIXES**

## Appendix 1: UNHCR Definition of the term "Refugee"

### 1951 Convention Relating to the Status of Refugees

#### Article 1

A. For the purposes of the present Convention, the term "refugee" shall apply to any person who:

(1) Has been considered a refugee under the Arrangements of 12 May 1926 and 30 June 1928 or under the Conventions of 28 October 1933 and 10 February 1938, the Protocol of 14 September 1939 or the Constitution of the International Refugee Organization; Decisions of non-eligibility taken by the International Refugee Organization during the period of its activities shall not prevent the status of refugee being accorded to persons who fulfil the conditions of paragraph 2 of this section;

(2) As a result of events occurring before 1 January 1951 and owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it.

In the case of a person who has more than one nationality, the term "the country of his nationality" shall mean each of the countries of which he is a national, and a person shall not be deemed to be lacking the protection of the country of his nationality if, without any valid reason based on well-founded fear, he has not availed himself of the protection of one of the countries of which he is a national.

B. (1) For the purposes of this Convention, the words "events occurring before 1 January 1951" in Article 1, Section A, shall be understood to mean either

(a) "events occurring in Europe before 1 January 1951"; or

(b) "events occurring in Europe or elsewhere before 1 January 1951",

and each Contracting State shall make a declaration at the time of signature, ratification or accession, specifying which of these meanings it applies for the purpose of its obligations under this Convention.

(2) Any Contracting State which has adopted alternative (a) may at any time extend its obligations by adopting alternative (b) by means of a notification addressed to the Secretary-General of the United Nations.

C. This Convention shall cease to apply to any person falling under the terms of Section A if:

(1) He has voluntarily re-availed himself of the protection of the country of his nationality; or

(2) Having lost his nationality, he has voluntarily re-acquired it, or

(3) He has acquired a new nationality, and enjoys the protection of the country of his new nationality; or

(4) He has voluntarily re-established himself in the country which he left or outside which he remained owing to fear of persecution; or

(5) He can no longer, because the circumstances in connection with which he has been recognized as a refugee have ceased to exist, continue to refuse to avail himself of the protection of the country of his nationality;

Provided that this paragraph shall not apply to a refugee falling under Section A(1) of this Article who is able to invoke compelling reasons arising out of previous persecution for refusing to avail himself of the protection of the country of nationality;

(6) Being a person who has no nationality he is, because of the circumstances in connection with which he has been recognized as a refugee have ceased to exist, able to return to the country of his former habitual residence;

Provided that this paragraph shall not apply to a refugee falling under section A(1) of this Article who is able to invoke compelling reasons arising out of previous persecution for refusing to return to the country of his former habitual residence.

D. This Convention shall not apply to persons who are at present receiving from organs or agencies of the United Nations other than the United Nations High Commissioner for Refugees protection or assistance. When such protection or assistance has ceased for any reason, without the position of such persons being definitively settled in accordance with the relevant resolutions adopted by the General Assembly of the United Nations, these persons shall ipso facto be entitled to the benefits of this Convention.

E. This Convention shall not apply to a person who is recognized by the competent authorities of the country in which he has taken residence as having the rights and obligations which are attached to the possession of the nationality of that country.

F. The provisions of this Convention shall not apply to any person with respect to whom there are serious reasons for considering that:

(a) he has committed a crime against peace, a war crime, or a crime against humanity, as defined in the international instruments drawn up to make provision in respect of such crimes;

(b) he has committed a serious non-political crime outside the country of refuge prior to his admission to that country as a refugee;

(c) he has been guilty of acts contrary to the purposes and principles of the United Nations.

UNHCR. 1996. *Convention and Protocol Relating to the Status of Refugees*. United Nations High Commission for Refugees.

## Appendix 2: Asylum Procedures and Status Categories

### Making an application

Asylum seekers can make their application at their port of entry to the UK - a 'port' application – or to the Immigration and Nationality Directorate (IND) if they have already entered the UK - an 'in country' application.

### Asylum Screening Interview

This interview will establish the identity and nationality of the asylum seeker. Interpreters will be present where necessary. Asylum seekers and their dependants will have their fingerprints taken to guard against fraudulent or multiple applications.

### Fast Tracking

Some applications are fast-tracked. For example, those that appear straightforward may be referred to the Oakington Reception Centre, near Cambridge. Applicants are required to remain at Oakington for a period of about seven days while their case is decided. In other cases an applicant may be required to attend a reporting centre at regular intervals until their claim has been decided.

### Evidence about the claim

Asylum seekers may provide evidence to support their claim in two main ways. These are by completing a Statement of Evidence Form (SEF) and by means of a face to face interview with an immigration officer or an asylum caseworker. Other documents may be provided if the applicant wishes and, if so, they must be translated into English. Most applicants will be given a SEF to complete and return to IND within 10-working days. The SEF must be completed in English. If the SEF is not returned in time, the application may be decided on the information already available. There will normally be an interview to enable the asylum seeker to describe their experiences and explain the basis of their claim. An interview may take place on the same day as the claim is made or, more usually, at a later date once the SEF has been returned. If the interview takes place on the same day that the claim is made, the information sought on the SEF is collected during the interview. Although an applicant may bring a legal representative to the interview, there is no legal right to legal representation and an interview will not normally be delayed simply because the representative is not present. An interpreter will be provided free of charge if required.

### Decisions

Asylum claims are considered by caseworkers or immigration officers who are specially trained to consider applications in accordance with the 1951 UN Refugees Convention. Each claim is examined individually on its merits. The caseworker must decide whether the facts show a reasonable likelihood of persecution to the asylum seeker for a Convention reason in the event of a return to their country of nationality or habitual residence. To amount to a 'well-founded fear of persecution' a judgement by the Law Lords decided that the fear must be objective. A decision will be made on the basis of the information contained in the SEF, any other documents that have been provided by the applicant in English, and the interview. Caseworkers have access to detailed Country Assessments to assist them when considering the claim. Decisions are notified in writing. The outcome is

normally sent by post but in certain circumstances, the applicant may be told of the decision in person.

### Refugee Status

An asylum seeker who is recognised as a refugee is granted indefinite leave to remain in the UK. They are also entitled to a Convention travel document and to family reunion.

### Exceptional Leave to Remain

In some cases, applicants who are refused asylum may be granted 'exceptional leave to remain'. This is a discretionary grant of leave made by the Home Secretary, allowing a person to stay in the UK for a limited period of time. Exceptional leave to remain may be granted for various reasons, but it is most usually granted on compassionate or humanitarian grounds.

## Appendix 3: Summary of Immigration Policies in the UK 1993-2004

### Immigration Policies and Practices

Immigration policies in the UK have undergone frequent and substantial changes in recent years reflecting shifting political efforts to address (and control) the rise in numbers of people seeking asylum. These changes have been complicated. Whilst the UK has drawn upon the principles of the 1951 Refugee Convention to guide its domestic policies and practices towards asylum, it was not until 1993 that the Convention was formally incorporated into domestic law. Prior to this period there was no legislation specific to the process of 'asylum', with such matters falling under the broader remit of immigration. Numbers of asylum applications fluctuated between greatly throughout the 1990s, with sporadic declines, followed by periods of consistent escalation. More dramatically, since the formative act of 1993 there have been four separate revisions of asylum law in the UK. Each of the successive immigration acts (1996, 1999, 2002 and 2004) has been fashioned to meet two primary goals. One, to introduce corrective measures to the bureaucratic process (thereby stream-lining the systems in place and reducing existing backlogs); and two, to implement a system that in practice acts as a deterrent, thus minimising the number of false or 'bogus' asylum claims. Briefly the following legislation are examined: The 1993 Asylum and Immigration Appeals Act (HMSO 1993); The Asylum and Immigration Act 1996 (HMSO 1996); The Immigration and Asylum Act 1999 (HMSO 1999); The Nationality, Asylum and Immigration Act 2002 (HMSO 2002); and finally the Asylum and Immigration Act 2004 (HMSO 2004). In addition a summary is provided of the Human Rights Act 1998 (HMSO 1998) which has emerged as a relevant to the issue of asylum, offering a more flexible interpretation of the 1951 Refugee Convention.

### The 1993 Asylum and Immigration Appeals Act

The early 1990s were a period marked by the sudden escalation of asylum applications in the UK. While 1990 saw roughly around 40,000 applicants, by 1991 the numbers nearly doubled, reaching a high of 73,400. The system in the UK had found itself largely unprepared for such a sudden increase in applicants and by 1993 the issue of effectively dealing with the backlog of cases was deemed critical.

Procedures and policies introduced included fingerprinting to enhance the surveillance (and tracking) of individuals. Individual entitlements were curtailed – particularly with respect to tangible benefits such as housing, and procedural rights in terms of appealing the decision-making process (appeals could be made within 48 hours of a decision). In addition the origins of a definitional dichotomy emerges in terms of distinguishing between those who claim upon arrival and those whose application is delayed. This sets the stage for further legal differentiation in later legislation, and helps to fuel a discourse of 'deserving' versus 'un-deserving' asylum applicants.

### The Asylum and Immigration Act of 1996

The Asylum and Immigration Act of 1996 (HMSO 1996) is the legislation which was in existence when many Kosovars entered the UK in 1998. The 1996 Act removed many of the entitlements for support for individuals applying in-country and restricted access to housing, and placed greater conditions around employment. Other notable changes include

the introduction of a list of 'safe countries' which the Home Office designated as not posing a risk of persecution. The significance of such a list meant that countries could be listed as safe based upon the signing of a peace agreements for example. In such circumstances the Home Office would be able to argue against the obligation to provide asylum, and would allow for greater ease in securing refusals and subsequent deportations. In addition, people who had travelled to the UK through one such designated 'safe country' could be declared ineligible for asylum.

### Human Rights Act 1998

Coinciding with legislative change around immigration in the UK, was movement towards shared human rights legislation across European Union (EU) countries. Despite a shared international framework under the 1951 Convention, the working definition of 'refugee' and the ensuing policies and practices of asylum have been determined on a country by country basis. As the EU moves to establish common legislative guidance and practices for asylum and border control this 'individualistic' tradition has come under greater scrutiny and challenge. The influence of EU charters has already begun to be felt through the application of aspects of the European Convention on Human Rights (ECHR) which have been introduced into British law under the Human Rights Act (HRA) of 1998. The HRA allows for a more flexible interpretation of the application of the 1951 Convention. Article 3 of the ECHR and the HRA in particular has been interpreted as extending the principles of the 1951 Convention to "situations of generalised violence" in which the threat is beyond the limits of representatives of the state. Its impact in the case of Kosovar refugees has been largely limited to 'statute of last resort' when the appeal processes of the asylum and immigration legislation have been virtually exhausted.

### The Immigration and Asylum Act of 1999

Revised legislation was introduced under the Immigration and Asylum Act of 1999 (HSMO 1999). A number of elements were expanded or introduced with this new statute, including new conditions around the legitimacy of claims for individuals entering the country illegally, the right to appeal, and the procedural mechanisms for supporting refugees upon arrival in the UK. The National Asylum Support Service (NASS) was introduced as the coordinating service for financial support and housing including dispersal. The policy of 'dispersal' (outside of highly populated areas) and the introduction of a 'voucher' system (in lieu of cash benefits) were administered by NASS, albeit poorly. These two specific policies had significant negative effects within the lives of refugees, contributing to greater social exclusion and marginalisation.

### Nationality Immigration and Asylum Act 2002

With the introduction of an immigration and asylum act in 2002, the emphasis was placed firmly upon the management of asylum seekers within the UK via the use of "induction, accommodation, and removal centres" (Baldaccini 2004). As well the introduction of practices intended to enhance the 'nationality' aspect of the act (the introduction of a citizenship test, for example), asylum seekers encountered additional restrictions in terms of employment, restrictions of freedom of movement and the expansion of 'safe countries'. Problematically these conditions fail to demonstrate an appreciation of the growing complexities of immigration and asylum, including the phenomenon of human trafficking, an increasing issue in the UK.

### The Asylum and Immigration Act 2004

The most recent legislation to be introduced regarding immigration and asylum was the Asylum and Immigration Act 2004. This legislation has sought to tackle some of the issues inherent in earlier acts, including the substantive changes in the determination process

### References

Baldaccini A. (2004) Providing Protection in the 21st Century. Refugee rights at the heart of UK asylum policy. Asylum Rights Campaign (ARC), The Refugee Council: London.

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HMSO (1996). Asylum and Immigration Act. London, UK, Her Majesty's Stationary Office.

HMSO (1998). Human Rights Act 1998. London, Her Majesty's Stationary Office.

HMSO (2002). Nationality, Immigration and Asylum Act. London, Her Majesty's Stationary Office.

HMSO (2004). Asylum and Immigration Act 2004. London, Her Majesty's Stationary Office.

## Appendix 4: Financial Support for Asylum Seekers (2004)

<b>Table 1: Cash Payments to Asylum Seekers</b>	
Designated Categories	Amount per week
Qualifying couple	£61.11
Lone parent aged 18 or over	£38.96
Single person aged 25 or over	£38.96
Single person aged at least 18 but under 25	£30.84
Person aged at least 16 but under 18 (except a member of a qualifying couple)	£33.50
Person aged under 16	£42.27

Source: NASS. 2004a. *Dispelling the myths, telling the facts: The facts about support for asylum seekers*. National Asylum Support Service (NASS), the Immigration and Nationality Directorate.

## Appendix 5: Diagnostic Classifications for PTSD (DSM and ICD)

### **Diagnostic Criteria for PTSD – DSM-III**

- A. The individual experienced a recognizable stressor that would evoke significant symptoms of distress in almost anyone.
- B. The traumatic event is re-experienced in at least one of the following ways:
- (1) recurrent, intrusive, and distressful recollections of the event;
  - (2) recurrent distressful dreams of the event;
  - (3) sudden acting or feeling as if the traumatic event were recurring, because of an environmental or ideational stimulus.
- C. There is a numbing of responsiveness to the external world, or reduced involvement in it. This is evidenced by at least one of the following:
- (1) markedly diminished interest in one or more activities;
  - (2) feelings of detachment or estrangement from others;
  - (3) constricted affect.
- D. At least two of the following symptoms were not present before the trauma:
- (1) hyperaltnerness or exaggerated startle response
  - (2) sleep disturbance
  - (3) guilt about surviving when others have not, or guilt about behaviour required for survival;
  - (4) memory impairment or trouble concentrating
  - (5) avoidance of activities that arouse the recollection of the traumatic event
  - (6) intensification of symptoms after being exposed to events that symbolize or resemble the traumatic event.

Source:

APA 1980. Diagnostic and Statistical Manual of Mental Disorders, 3th Edition.  
Washington, DC: American Psychiatric Association.

## **Diagnostic criteria for PTSD in DSM-111R**

- A. The individual has experienced a traumatic event that is:
- (1) outside the range of usual human experience; and
  - (2) would be markedly distressing to almost anyone.
- B. The traumatic event is persistently re-experienced in at least one of the following ways:
- (1) recurrent and intrusive distressing recollections of the event;
  - (2) recurrent distressing dreams of the event;
  - (3) sudden acting or feeling as if the traumatic event were recurring;
  - (4) intense psychological distress when exposed to events that symbolize or resemble an aspect of the traumatic event
- C. The individual persistently avoids stimuli associated with the trauma or experiences a numbing of general responsiveness. To meet this criterion, a person has to evidence at least three of the following:
- (1) efforts to avoid thoughts or feelings associated with the trauma;
  - (2) efforts to avoid activities or situations that arouse recollections of the trauma
  - (3) an inability to recall an important aspect of the trauma;
  - (4) a markedly diminished interest in significant activities;
  - (5) feelings of detachment or estrangement from others;
  - (6) a restricted range of affect;
  - (7) a sense of a foreshortened future.
- D. The individual experiences persistent symptoms of increased autonomic arousal not present before the trauma. The person must exhibit at least two of the following:
- (1) difficulty falling or staying asleep;
  - (2) irritability or outbursts of anger
  - (3) difficulty concentrating
  - (4) hypervigilance;
  - (5) exaggerated startle response;
  - (6) physiological reactivity when the individual is exposed to events that symbolize or resemble an aspect of the traumatic event

Source:

APA. 1987. *Diagnostic and Statistical Manual of Mental Disorders, 3th Edition, Revised*. Washington, DC: American Psychiatric Association.

## Diagnostic Criteria for PTSD in DSM-IV

The person has been exposed to a traumatic event in which both of the following were present:

1. The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.
2. The person's response involved intense fear, helplessness, or horror. **Note:** In children, this may be expressed instead by disorganized or agitated behaviour.

B. The traumatic event is persistently re-experienced in (or more) of the following ways:

1. Recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions. **Note:** In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.
2. Recurrent distressing dreams of the event. **Note:** In children, there may be frightening dreams without recognizable content.
3. Acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated). **Note:** In young children, trauma-specific re-enactment may occur.
4. Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
5. Physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.

C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:

1. Efforts to avoid thoughts, feelings, or conversations associated with the trauma.
2. Efforts to avoid activities, places, or people that arouse recollections of the trauma

3. Inability to recall an important aspect of the trauma
4. Markedly diminished interest or participation in significant activities
5. Feeling of detachment or estrangement from others
6. Restricted range of affect (e.g., unable to have loving feelings)
7. Sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)

D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:

1. Difficulty falling or staying asleep
2. Irritability or outbursts of anger
3. Difficulty concentrating
4. Hypervigilance
5. Exaggerated startle response

E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.

F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Source:

APA 1994. Diagnostic and Statistical Manual of Mental Disorders, 4th Edition.  
Washington, D.C.: American Psychiatric Association.

## **Diagnosis of PTSD and Enduring Personality Change After Catastrophic Experience**

### **F43.1 Post-traumatic stress disorder**

Arises as a delayed or protracted response to a stressful event or situation (of either brief or long duration) of an exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost anyone. Predisposing factors, such as personality traits (e.g. compulsive, asthenic) or previous history of neurotic illness, may lower the threshold for the development of the syndrome or aggravate its course, but they are neither necessary nor sufficient to explain its occurrence. Typical features include episodes of repeated reliving of the trauma in intrusive memories ("flashbacks"), dreams or nightmares, occurring against the persisting background of a sense of "numbness" and emotional blunting, detachment from other people, unresponsiveness to surroundings, anhedonia, and avoidance of activities and situations reminiscent of the trauma. There is usually a state of autonomic hyperarousal with hypervigilance, an enhanced startle reaction, and insomnia. Anxiety and depression are commonly associated with the above symptoms and signs, and suicidal ideation is not infrequent. The onset follows the trauma with a latency period that may range from a few weeks to months. The course is fluctuating but recovery can be expected in the majority of cases. In a small proportion of cases the condition may follow a chronic course over many years, with eventual transition to an enduring personality change (F62.0).

### **F62.0 Enduring personality change after catastrophic experience**

Enduring personality change, present for at least two years, following exposure to catastrophic stress. The stress must be so extreme that it is not necessary to consider personal vulnerability in order to explain its profound effect on the personality. The disorder is characterized by a hostile or distrustful attitude toward the world, social withdrawal, feelings of emptiness or hopelessness, a chronic feeling of "being on edge" as if constantly threatened, and estrangement. Post-traumatic stress disorder (F43.1) may precede this type of personality change.

Personality change after:

- concentration camp experiences
- disasters
- prolonged:
  - captivity with an imminent possibility of being killed
  - exposure to life-threatening situations such as being a victim of terrorism
- torture

Source:

WHO. 2003. International Statistical Classification of Diseases and Related Health Problems 10th Revision. Geneva: World Health Organization.

Appendix 6: Ethics Committee Application to Conduct A Study Involving Human Subjects

January 2002

**LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE  
Keppel Street, London WC1E 7HT**

Application Number .....  
(To be added by the Secretary)

FORM A

**ETHICS COMMITTEE**  
**APPLICATION TO CONDUCT A STUDY INVOLVING HUMAN SUBJECTS**

This form should be completed, signed by the Principal Investigator and Head of Department, and returned to Phoebe Roome, Personal Assistant to the Dean, LSHTM, Keppel Street, London WC1E 7HT.

Name of Principal Investigator      Brenda Roche

Appointment held      Doctoral Research Student      Date      June 20, 2002

Other Personnel involved      None

Title of project      'Trauma' and the Lives of Women Refugees in Resettlement

I approve this project scientifically.

.....  
(Signature of Head of Department)

Date .....

Received by Ethics Committee

.....

.....

1. *Give an outline of the proposed project. Sufficient detail of the protocol must be given to allow the Committee to make an informed decision. (Attach a summary of the project if this is more convenient).*

Life in resettlement following forced migration is often an unstable process marked by poverty and social exclusion, as well as poor health status. Refugees are considered to be at additional risk for psychological distress due to traumatic events experienced in the context of conflict and forced migration. The concept of 'trauma' has acquired a prominence within professional and popular discourse on refugee health. Trauma and psychological distress related to political conflict and forced migration is largely viewed through the lens of Post-Traumatic Stress Disorder (PTSD). Theoretically the use of this diagnostic category seeks to recognise the impact of extreme circumstances (such as political violence, including torture, sexual violence, and forced migration) on the psychological functioning of individuals. As a diagnostic label, PTSD aspires to recognise how particular events can continue to cause distress individuals long after the fact. This perspective on 'trauma' is, however, clinically driven and as such adopts a limited perspective. There is little attention to the possible shifting definitions and meanings, or the coexistence of individual resiliencies and/or culturally appropriate coping strategies.

Yet despite any questions raised about the meaning of 'trauma' in academic discourse, refugees are increasingly discussed as 'traumatised'. It has been suggested that the conflict in the former Yugoslavia marked a 'watershed' moment, where an entire population came to be viewed as traumatised as a result of political conflict and forced migration (Harrell-Bond 2000). This perception has been amplified for women, given the central role of sexual violence in each of the Balkan conflicts. The centrality of 'trauma' in the discourse on refugee health has led to the widespread implementation of psychosocial interventions with refugee populations.

However, we have little understanding of how trauma is understood, experienced and addressed by individuals and the service providers who help to shape refugee resettlement. How trauma is defined and understood in refugee resettlement has influence in shaping responses by service providers (both towards, or away, from intervention). In order to understand what women's experiences of trauma and their socio-medical needs around addressing trauma, it is important to clarify the definitions and perceptions that are operating in refugee resettlement both amongst women refugees and amongst service providers.

Using qualitative methods (in-depth interviews and participant observation) this research will consider how trauma is defined and understood in refugee resettlement. The meaning of trauma will be considered from three unique perspectives: academic discourse (Epidemiology and public health, anthropology, psychiatry and psychology); professional discourse (service providers who are key actors in shaping resettlement for women refugees in the UK); and from the perspective of women who have undergone forced migration.

2. *State the intended value of the project. (If this project or a similar one has been done before what is the value of repeating it?).*

This work will contribute to the growing body of public health work related to refugee health. Little attention has been directed towards refugee health within the context of

resettlement. The widespread acceptance of a conceptual framework of 'trauma' as synonymous with PTSD has a direct impact on the psychosocial interventions that are designed and implemented for refugee populations. Specifically this study will examine the discourse(s) that exist related to post conflict trauma, its expression(s) and the meaning(s) ascribed to 'trauma' for both refugees and providers. The findings from this research will be able to contribute to the debate on the appropriateness of trauma discourse and interventions in the lives of refugee women.

3. *Specify the number, age, sex, source and method of recruiting subjects for the study. Attach a copy of any advertisement to be used.*

The research will involve three separate phases of data collection. The first phase will be a comprehensive literature review examining the academic discourse on trauma. The second phase will involve two key components: the mapping of community based organisations and identification of key individuals who play a central role in refugee resettlement; and the interviewing of those individuals regarding the discourse on trauma which shapes psychosocial services for refugees and asylum seekers. The final phase will examine the experiences of women refugees currently residing in the UK through a series of one-to-one interviews with women refugees or asylum seekers.

Women refugees and asylum seekers in the UK constitute a 'hard to reach' population. Initial efforts for recruitment will be done through community based refugee organisation. These service providers are likely to have the greatest amount of contact with women in resettlement. Recruitment will be purposive with a focus on women over the age of 18 years (with no upper age limits) from the former Yugoslavia, with a particular emphasis on women from Kosovo. Selection of participants will not be driven by a known history of trauma; instead the research will aim to have broad inclusion framework operating. In addition to recruitment through refugee organisations, snowball sampling will be employed to recruit participants through the social network of women. This strategy will seek to recruit individuals who meet the criteria, but who may not be involved with community based refugee organisations.

The nature of this type of research requires some flexibility around the number of participants, with an aim to achieving 'saturation' in terms of exploring the central themes and constructs. Estimates, based on previous research experience, and in consultation with other researchers, indicate that a sample size of approximately 30 women should be sufficient to achieve saturation (Maureen Miller, personal communication).

4. *State the likely duration of the project, and where it will be undertaken.*

Fieldwork for this research will involve three separate phases beginning in February of 2002 and will be undertaken in London, UK. Geographically recruitment will be limited to the London area where an estimated 85% of refugees resettle (Carey-Wood 1997). The first phase is a comprehensive literature review exploring the discourse that exists on trauma in public health, anthropology, psychiatry and conflict studies.

Phase Two [June through August 2002] is focused on professionals identified as central to the shaping of resettlement for refugees in the UK. Specifically this involves the

identification and 'mapping' of agencies and their different perspectives. During this phase the contextual and structural factors that shape resettlement for women refugees will be explored. Data will be gathered through an exploration of the broad and local service systems that interact with women refugees, with specific attention to women from the former Yugoslavia.

Interviews will be conducted with key individuals whose professional work forms the backdrop for refugee resettlement. These interviews will illuminate how the academic discourse on trauma shapes the practices of social services and medical providers. In addition to the identification of broad based programs serving refugee communities, this phase will include a narrowing down in focus towards the identification of locally based groups. Locally based or neighbourhood organisations are more likely to act as facilitators linking individuals with appropriate health care services.

A final phase of the research [September 2002 to February 2003] will involve individual interviews with women refugees or asylum seekers from the former Yugoslavia, now living in the UK. As with the previous phase, this portion of the research will draw upon the findings from the previous phase. How trauma is defined and addressed by providers has great relevance for the experiences of women.

Personal history interviews will be conducted with a sample of up to 30 women from the former Yugoslavia. In the course of these interviews women will be asked about their experiences of forced migration and resettlement, what they define as traumatic in their lives and the meaning of certain life events from a social/cultural perspective. Particular attention will be paid to the women's ideas about dealing with trauma: are there specific strategies that the women employ to minimise their distress? How do they interact with providers around 'trauma', especially given that they are largely defined as a 'traumatised population'?

5. *Specify the procedures (including interviews) involving human subjects.*

Informed consent plays a critical role in all research studies involving human subjects. The sensitive nature of the interviews proposed in this research necessitates that this process be as comprehensive as possible. Respondents will be approached for both oral and written consent. Women will be given an information sheet detailing the specifics of the research (see attached information sheet and consent form). As a rule, this will be reviewed with the women, to minimise confusion due to literacy issues. It is worth noting that the title indicated on the participant information sheet differs from the official title of the project. This was a conscious decision to allow the topic of trauma to emerge in a natural way within the context of discussing health and services the women have received.

As part of the consent process, each woman will be advised of the voluntary and anonymous nature of the study, the kind of questions that will be asked, the fact that the interview would be audio-taped, and the precautions that will be taken to protect the data. The risks and benefits associated with conducting this research will be clearly explained. Women will be provided with a copy of the informed consent and will be advised that they can decline to answer questions that they feel are too sensitive or stop the interview at any time, or refuse at any point to continue with the entire research study.

Detailed interview guides will have been developed prior to any actual interviewing, during the first phase of research, under the supervision of Drs Karina Kielmann and Charlotte Watts. All of the interviews will be audio recorded and transcribed. This process of transcription should be an ongoing process throughout the course of the research. This is important to identify themes that emerge in the course of interviews that may be then explored in greater detail through the interviewing process. Pragmatically this helps to facilitate data analyses and minimise errors in interpretation.

When possible interviews will be conducted in English. However, given the difficulties faced by recent refugees in acquiring fluency, coupled with the highly sensitive subject matter, it is likely that a significant number of interviews will require the assistance of a trained translator. The recruitment and training of translators will be as detailed as possible in order to minimise problems and errors in the process of interviewing.

*State the potential hazards, if any, and the precautions being taken to meet them (include information on hazardous substances that will be used or produced, and the steps being taken to reduce risks). Give details of the precautions to be taken to ensure the health and safety of staff and other people working on 'off-site' activities and fieldwork. Reference should be made to the School's Safety Manual (<http://www.lshhtm.ac.uk/intra/safety/ofsitwrk.html>).*

This research study will not involve exposure to hazardous substances or pose situations of risk as outlined in the Safety manual of the London School of Hygiene and Tropical Medicine.

*State the procedures or activities which may cause discomfort or distress and the degree of discomfort or distress likely to be entailed by the subjects.*

The subject matter to be covered in these interviews is of a sensitive nature. As with any research study involving human subjects, there is a need to clearly explore issues of confidentiality, consent and the risks and benefits to study participants. In addition, due to the nature of this research, the subject of inquiry carries its own issues.

It is important to recognise the potential adverse effects of sensitive interviewing (Razack 1996). The most significant risk to women participating in this research is emotional and psychological distress related to 're-living' a traumatic event through its re-telling. In preparation for such a possibility, it is necessary that there are established 'back-up' services in the event the respondent requires mental health counselling. The process of identifying appropriate medical and social services, and enlisting their support is part of the preliminary phase(s) of the research.

In addition, it is important to recognise that while the individual may not experience distress at the moment of, or shortly after being interviewed, distress related to the interview may emerge later. Each woman will be provided with an information sheet of services, which list emergency phone numbers of appropriate services in the event of such a situation. It is imperative that the women are accorded every protection necessary to ensure that their safety (physically and emotionally) is not compromised as a result of participation. This

requires that data collection procedures and practices reflect a heightened concern for the issues of confidentiality and informed consent (including the right to refuse participation at any time).

As is often the case in this type of research, participants may benefit from the interview process through the therapeutic value of 'telling their story' (Agger 1992; Kelly 1988). Testimony has been a powerful mechanism in reconciling the destructive effects of trauma associated with both political conflict and sexual violence (Scarry 1985; Muecke 1992; Herman 1992).

The interviews that will be conducted with service providers are by nature, less sensitive. However, it should be noted that the nature of the work conducted by these individuals requires continual contact with distressing accounts of traumatic life events. It is plausible that in the process of discussing the nature of their work, these individuals may draw upon highly emotional material, thereby leaving themselves open to some psychological discomfort or distress.

In addition, narratives of trauma may be equally distressing to the individuals who are asking the questions and immersing themselves in life histories. As such it will be critical that sufficient support is in place for interpreters who are working on this project. There is a need to establish amongst the interpreting staff a meaningful forum for 'decompressing' after each interview. This serves the purpose of ensuring that research staff are given an opportunity to respond to the stresses of interviewing in an appropriate and confidential way, and facilitates a support network within the research group.

8. *Specify the degree of confidentiality to be maintained with respect to the data collected and the method of achieving this.*

Confidentiality is of critical importance to this research. As a group with tenuous legal status in the UK women refugees may express fear or anxiety about the potential misuses of information revealed in the context of an interview, such as the idea that data would be shared with service providers or government agencies. In addition there may be apprehension about information being 'leaked' to other community members (Knudsen 1995). Respondents should be confident that any information revealed in the context of an interview is protected as privileged research information.

All reasonable protections against loss of confidentiality will be taken. All field notes, interview notes, and interview transcripts will be labeled by code number only. All interview subjects will be assigned a number as the only identifying marker for their series of interviews. Respondent names will only appear on written consent forms, which will not be linked with their numerical alias. Personal identification data will be kept separately from other data, and all data will be kept in locked files. Follow up information on respondents will be kept in computerized form in encrypted files. Any individual recruited to provide translation services will be trained thoroughly in maintaining confidentiality and in their responsibilities in this area. This is of paramount concern given the small nature of refugee communities and the network of agencies that provide support services to them.

9. *State the personal experience of the applicant and of senior collaborators in the study in the field concerned.*

Professionally I have ten years experience as a social science researcher addressing health and social issues amongst disadvantaged populations. My research background has included ethnographic studies, program evaluations and randomised clinical trials of preventive interventions. Through these projects I have developed and honed skills in both quantitative and qualitative research, including structured and life history interviewing, designing and administering research questionnaires, data analysis, grant writing, formal report writing, disseminating research results and publishing in research and policy journals.

My research career has focused on the experiences of individuals who have been stigmatised and marginalised within the broader social landscape. Specifically my research has considered issues of identity and social control, gender and trauma, and how these may interact and impact upon health behaviours for individuals grappling with homelessness, mental illness, and/or substance abuse. The difficulties faced by these individuals share many features with individuals who are seeking asylum, including poverty, stigma and social exclusion.

Of special relevance to this research is my experience in interviewing individuals who have encountered extreme life events, including assault and sexual violence. Additionally, my training in conducting clinical interviews using the Structured Clinical Interview for the Diagnostic and Statistical Manual (SCID-DSMIV) provides me with a sound foundation in interviewing related to mental distress, and recognising situation where referrals to mental health providers are appropriate.

Supervision for this project will be provided by Drs Charlotte Watts and Karina Kielmann through the Health Policy Unit of LSHTM. Dr Watts has extensive research experience examining domestic violence experiences of women cross-culturally. Her recent work on the experiences of trafficked women has relevance to the experiences of women seeking asylum in the UK, many of whom have coerced into sex work, and are at high risk for domestic violence. Dr. Kielmann brings considerable research experience on women's health issues. In addition she brings theoretical expertise in medical anthropology and its applications within public health.

10. *State the manner in which consent will be obtained (e.g. verbal, written, witnessed) and supply copies of the information sheet and consent form. Healthy volunteers and patients will require different information sheets and consent forms. (See notes attached at end of this form).*

The informed consent process will provide an overview of the research, the voluntary nature of the participation, potential risks and benefits to the subjects. Initial consent will cover the first interview and include permission for the lead researcher to contact the individual again. The nature of this type of research carries with it the likelihood that individuals may over time, change their minds about participating. As such, the consent process will be reviewed at the beginning of each interview to ensure maximum protection of the respondents' interests. In addition, respondents will be given the option to refuse to discuss portions of the interview, or refuse at any point to continue with the research interview or entire study.

Respondents will be approached for both oral and written consent. This is necessary to minimise the potential for misunderstandings due to limited literacy or language proficiency. Where necessary an interpreter will be used to explain the process of consent and the risks and benefits of the research.

11. *State what medical supervision is available and its location in relation to the subjects.*

In order to ensure comprehensive protection of the women taking part in the research appropriate community based services will be identified. This will take the form of an information sheet with contact details, covering a broad range of issues that may emerge as critical life events (from medical and psychiatric needs to legal and housing issues). In the course of meeting with service providers I will verify and modify this contact sheet as appropriate. This will ensure that sufficient community mental health resources are identified in the event that the interviews create psychological distress for any of the participants. Prior to any interviewing of women, a comprehensive resource list will be created to direct women towards appropriate services. For example, detailed listings of services will include housing resources, mental health services (including self-help and anonymous services), medical services, legal and immigration resources to name but a few broad areas. In order to secure the integrity of the rights of the research participants, no referrals will be made without the explicit permission of any respondent.

12. Is the study initiated/sponsored by a pharmaceutical or other industrial company?  
YES/NO

If YES, name the company

13. (a) Does the project involve pre-marketing use of a drug/appliance or a new use for a marketed product?

YES / NO

(b) If YES, does the company agree to abide by the guidelines on compensation of the Association of the British Pharmaceutical Industry (ABPI) (Clinical Trials -compensation for medicine-induced injury) in respect of patients?

YES / NO

If YES, a written statement from the company to this effect should be attached.

(c) In a study on healthy volunteers does the company agree to abide by the current guidelines of the ABPI for healthy volunteers?

YES / NO      Not applicable

If YES a copy of the proposed volunteer contract should be attached.

(d) What is the regulatory status of the drug under the Medicines Act 1968: Product Licence / Clinical Trial Certificate (CTC) / Clinical Trial Exemption (CTX) / Doctor or Dentist Exemption (DDX)? If CTC, CTX or DDX a copy of the certificate should be attached.

Not applicable

14. Will payments be made to subjects?

YES / NO

If YES give details

15. Will the level of service or support available to study subjects be lower after the study than during the study?

YES/NO NO SERVICES TO BE OFFERED

If yes, give details and describe the steps being taken to minimize the loss in welfare experienced by subjects at the termination of the study.

16. Describe the measures to be taken to communicate the results of the study to study subjects, their representatives, local government, national government and other relevant bodies who could use the results of the study to improve the lives of the study subjects.

Efforts will be made to ensure that the findings are introduced into the academic discourse on trauma and health issues for refugees in resettlement. Currently a key resource for dissemination is through the Information Centre about Asylum and Refugees (ICAR) through Kings College, University of London. This would allow for broad dissemination to academics and community researchers across the UK.

In addition, a critical issue in conducting community-based research is to ensure that research findings are fed back to the community in meaningful ways, thereby enabling the evolution of policies and practices. Upon completion of the research (including analysis and write up) the findings will be made available to the primary research participants as well as community based organisations working with refugees and asylum seekers.

17. Include any other relevant information.

Attached to this document is a copy of the participant information sheet and consent form.

18. Where the research is to take place overseas, the Principal Investigator **must** seek ethical approval, through his/her overseas collaborators, in the country(s) concerned. Approval will not be granted by the LSHTM Ethics Committee until this written approval is submitted.

Please list the countries where research is being undertaken

Other countries .....

UK only (Please list) .....

.....  
.....  
.....  
.....

Please submit formal ethical approval statement given by local committee within each country. If ethical approval has not yet been obtained from a local committee in the country, indicate to whom the proposal has been submitted and when a response is expected.

.....  
.  
.....  
.

Signature of applicant

Medically qualified YES / NO

Other qualifications (please state)

Are you a member of a medical protection organisation? YES / NO

Are you a member of any other protection organisation? YES / NO

**LONDON SCHOOL OF HYGIENE  
& TROPICAL MEDICINE**

**ETHICS COMMITTEE**

**APPROVAL FORM**

Application number: 900



Name of Principal Investigator **Brenda Roche**  
**PhD Student**

Department **Public Health & Policy**

Head of Department **Professor Nick Black**

Title **'Trauma' and the lives of women refugees in resettlement.**

Approval of this study is granted by the Committee.

Chair *T. W. Meade*  
.....  
**Professor Tom Meade**

Date *23.9.02*  
.....

**Any subsequent changes to the consent form must be re-submitted to the Committee.**

## Appendix 7: Interview Guide, Health and Social Care Providers

### Basic Overview of Topics

1. Agency [directive, structure] and current position/role within agency.
2. What is the agency's role in terms of health care services?
3. What are the critical issues that you [agency] see facing women refugees in the UK?
4. Access issues facing refugees in terms of health  
[Probe for social issues, environment issues, as well as typical health problems]

Is there anything specific for women refugees that has come up in your work

### Trauma Specific Topics

5. Trauma is something that people are talking a lot about these days, in terms of refugees. One of the things that I'm curious about is what providers see or come across when we are talking about trauma...
6. When you think about some of your women clients, what types of traumatic events do women mention?
7. Probe for specific dimensions of trauma. What is the range of experiences that they have witnessed.
8. How do the women talk about these events? [probe: how do they describe what they experienced? What are the ways they deal with it now?]
9. How do you/your agency deal with trauma when it comes up? How equipped do you feel to face some of the challenges of addressing 'trauma' amongst refugees and asylum seekers?
10. Are there other ways that you think could help to deal with the trauma that women refugees have experienced?
11. What are some of the community-based resources that you use or would recommend are used for women dealing with traumatic issues?

## Appendix 8: Interview guide, Women Respondents

The idea of this research is to get a sense of your life here; so the services that you have used and the general experiences that you have used.

The best way to start would be if you could tell me a little about yourself?

So, how old are you?

Do you have a partner? husband? boyfriend?  
girlfriend?

Do you have any children? Do they live with you?

I'm interested in learning about people's experiences when they come to live in the UK.  
Can you tell me about when you came to the UK?

When was that?

Where did you stay?

What was that like?

Are you still living there?

Can you tell me a bit about your neighbourhood

Did you know anyone here before coming? [in area/in London/in the UK]

What are the services that you have had contact with since arriving in the UK?

Examples: community groups, English classes, any groups?

Are you still involved with any of these services? Which ones?

A lot of my work is on health. So I wanted to know about any health problems or concerns that you have had since you came to the UK.

Have you seen a doctor? Health visitor? Used an A&E?

[was this for yourself or someone else?

Having children sometimes means you need to use a doctor – have you had to with your children?

How old are your children? [born here? Where, can you tell me about that?]

When people go through extreme situations like the ones that brought you to the UK – they may find themselves feeling very sad or upset ....

Anxious or nervous....feeling hopeless, lonely or unable to do things....

Have you experienced any of these things? Can you tell me about it..

What else: any nightmares? Or feeling unable to sleep or sleeping all the time?

What do you do when you feel like this? Is there anything that helps?

Have you talked with anyone here about it, like a doctor or a counsellor?  
Would you know how to find someone to talk to if you needed to?

Is there anything that you can think of that would need (health care or social services), or something that might help you get used to living in the UK?

Are there any community services that you use? Which ones?

## Appendix 9: Summary of Health and Social Care Providers

<b>Provider ID &amp; Name</b>	<b>Position</b>	<b>Type of Agency</b>	<b>Target Population</b>
001	Counsellor	Advice/training, counselling	Women refugees and migrants
002	Psychologist	Psychological services	Refugees
003	Nurse	Primary care health	Refugees & migrants
004	Health Worker	Primary care health	Refugees & migrants
005	Psychologist	Primary care health	Community residents (predominantly refugees)
006	Doctor (GP)	Primary care health	Refugees
007	Psychologist	Psychological research /services	Broad inclusion criteria
008	Psychotherapist	Psychological services	Broad inclusion criteria
009	Support Services Worker	Legal support	Refugees & migrants
010	Support Services Worker	Advice & Support	Community residents (predominantly refugees)
011	Support Services Worker	Advice, Legal & Support	Refugees
012	Support Services Worker	Advice /Training	Refugees
013	Counsellor	Psychological services	Refugees
014	Support Services Worker	Advice & Support	Refugees & migrants
015	Support Services Worker	Advice & Support	Refugees
016	Peer Support Worker	Advice & Support	Refugees & migrants

## Appendix 10: Summary of Women Respondents

<b>ID</b>	<b>Name</b>	<b>Age</b>	<b>Arrived</b>
001	Deni	32	1999 (lorry) w/ family
002	Susanna	30	1999 (train) w/ family
003	Dafina	35	1999 (lorry) w/ children
004	Silvana	35	1999 (lorry) w/ family
005	Etleva	31	1999 (lorry) w/ family
006	Rada	32	1999 (lorry) w/ family
007	Denisa	40	1998 (boat) w/ family
008	Jete	26	1999 (lorry) w/ family
009	Dea	32	1998 (train) w/ family
010	Juliana	18	2000 (lorry) alone
011	Edita	25	1999 (lorry) w/ family
012	Aurela	27	1999 (lorry) w/ family
014	Lira	32	1999 (train) w/ children
015	Nafiye	32	1999 (lorry) w/ family
016	Dituri	32	1999 (lorry) w/ family
017	Dorina	22	1999 (lorry) alone
019	Sofije	29	1999 (lorry) w/ family
021	Merita	29	1998 (lorry) w/ family
022	Erika	33	1998 (lorry) w/ children
023	Amarda	30	1999 (lorry) w/ family
024	Teuta	38	1999 (lorry) w/ family
025	Biljana	36	1998 (lorry) w/ family

## Appendix 11: Mental Health Treatments Offered to the Women

ID #	Prescribed Medication	Referred to Psychiatrist	Referred for Counselling	Inpatient Care	Any other comments?
001	Y	N	Y	N	
002	N	N	N	N	
003	Y	Y	DK	N	
004	N	N	N	N	
005	N	N	Y	N	
006	Y	N	Y	N	Husband too
007	Y husb	Yhusb	Y both	N	Husband too
008	Y	Y	Y	Y	
009	Y	Y	Y	N	Husband too
010	Y	Y	Y	Y	
011	Y	N	Y	N	
012	Y	N	Y	N	
013	Y	N	Y	N	
014	N	N	N	N	
015	Y	Y	Y	N	
016	N	N	Y	N	
017	Y	N	Referred	N	
019	Y	N	Y	N	Husband too
021	Y	Y	Y	N	Husband too
022	Y	Y	Y	N	Husband too
023	Y	N	Y	N	Husband too
024	Y	N	Y	N	Children too
025	N	N	N	N	

## Appendix 12: Consent Form

### **Title of Project:**

The Health and Life Experiences of Kosovar Albanian Women in London

### **What the Consent Form means:**

The consent form is to ensure that that you understand that being in the study involves. This means that you agree to be a part of the research voluntary and that you understand that you can refuse to answer questions or leave the study at any time.

The form also ensure that I have a responsibility to protect any information that you tell me in an interview, to make sure that your privacy is protected, and respect the fact that you have the right to leave the research at any time.

By signing this form I am agreeing that:

- I have read and understand the information sheet for the above study.
- I have had the opportunity to ask questions.
- I am willing to participate in the study.

\_\_\_\_\_  
Name of Person giving consent    Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent    Date

\_\_\_\_\_  
Signature

## Appendix 13: Participant Information Sheet

### The Health and Life Experiences of Kosovar Women in London PARTICIPANT INFORMATION SHEET

You are being asked to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please ask questions if there is anything that is not clear.

#### **What is the purpose of the study?**

The research will look at the health and life experiences of women who have come from the Former Yugoslavia as refugees or are currently seeking asylum in the UK. If you agree to take part, you will be asked about your physical and mental health, the services that you have used and would like to receive, as well as events and circumstances related to your moving to London.

#### **Who is doing this research and why?**

I am a health researcher with many years of experience interviewing women about their health and life experiences. I am interested in looking at ways to improve the health and community services available to women. Currently I am a student at the London School of Hygiene and Tropical Medicine. This research will be part of my Ph.D.

#### **Why have I been selected and do I have to take part?**

You are being asked to take part because this study is most interested in the experiences of Kosovar women refugees or asylum seekers who are now living in London.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to stop the interview at any time, or leave the study completely. Being a part of this study will not affect any of the services that you receive or your legal status in the UK.

#### **What will happen if I take part and what do I have to do?**

If you take part in this study, I will arrange a time for an interview. You will be asked to take part in one or more individual interviews. If you prefer to be interviewed in a language other than English, an interpreter will be made available.

These interviews will follow a rough outline but you will be able to discuss things that are of interest and importance to you. Each interview takes about an hour to complete. Some of the questions asked may be sensitive and of a personal nature. There are no right or wrong answers. You can refuse to answer any questions, but sometimes people find it helpful to talk about their personal experiences.

You will not be paid for taking part in these interviews, but any travel costs you have will be covered. You will also be provided with information about community based services that may be helpful in the future.

**How will the information be collected?**

The interviews will be tape-recorded, and hand written notes may be taken. I will be the only person who listens to the tapes or reads the notes. Your name will be changed on all of the materials, so that anything you say is completely private.

During the research study all interview tapes and transcripts will be kept securely stored in a locked filing cabinet at the London School of Hygiene and Tropical Medicine. Once the study is over the tapes will be destroyed.

**Are there disadvantages and risks because of being involved?**

There are no health risks involved in this study. Becoming involved will not affect any of the services that you are getting, including any legal services.

Some individuals may find it difficult or distressing to talk about their lives in detail. If you find anything upsetting in an interview, you can refuse to answer or we can stop the interview. If you want to talk with someone about things raised in the interview, I can help to arrange this.

**What are the possible benefits of taking part?**

There are no direct health benefits to taking part in this study. However, sometimes people find it helpful to talk about their life experiences.

**What will happen to the results of the research study?**

This study will collect information on the experiences of women refugees and asylum seekers living in London. The information from this study may be useful for service providers and help them to think about ways to improve their services. The study will also be written up as part of a PhD. Some sections of the research may be published later as shorter articles in academic journals. Your name will not appear in any published documents to protect your privacy.

**Who has reviewed the study?**

This study has been undergone review through the London School of Hygiene and Tropical Medicine ethical review process.

**Do you have any questions?****Contact for further information:**

Brenda Roche,

[Brenda.Roche@lshtm.ac.uk](mailto:Brenda.Roche@lshtm.ac.uk)

Direct Telephone Number: 07 904 923 762

## Appendix 14: Codes for Analysis, Provider Interviews

### Provider Interviews

Provider Perspective [general philosophy /working rules]		
	‘signpost’ – refer towards services	SIGN
	‘direct care’ – offers clinical services	CLIN TX
	non-clinical support services	NON CLIN
	‘working philosophy’	PHILO
	‘reference guides’-documents, influences	REF
Trauma		
Define	behaviour/response of individual – Event DSM	BEHAV EVENT DSM
Aetiology	Loss Sexual Violence ‘Torture’	LOSS SEX VIO TORT
Epi	maximum – ‘what we see is the tip of the Iceberg’ Minimise – ‘normal response to abnormal situation’	MAX MIN
Refugee Response –	behaviour Verbal	REF BEH REF VERB
‘trauma impact’ a.	temporary Permanent	IMP-TEMP IMP-PERM
	b. coincides with exile latency period	IMP-EXILE IMP-LATE
Provider Response (role)	Refer or link with services Medication One to one Counselling Group work Self help methods	PV REFER PV MED PV 121 PV GP WK PV SELF
Counselling dichotomy		WEST-NONWEST
Identity Issues	as refugee As traumatised As ‘victim’ As ‘resilient’	REF ID TR ID VIC ID RES ID

**Additional Codes:**

Community context	CC
Conflict in belief systems	CON BEL
Denial	DENIAL
Perceived Hostility	HOSTILE
PV Identifies as Foreigner	PV OTHER
Resolution of Trauma	RESOLVE
Immigration Policy	INS
Disclosure	DISCLOSE
'Trauma' as legal access	LEGAL
Honour and Shame	HONOUR
Distress	DISTRESS

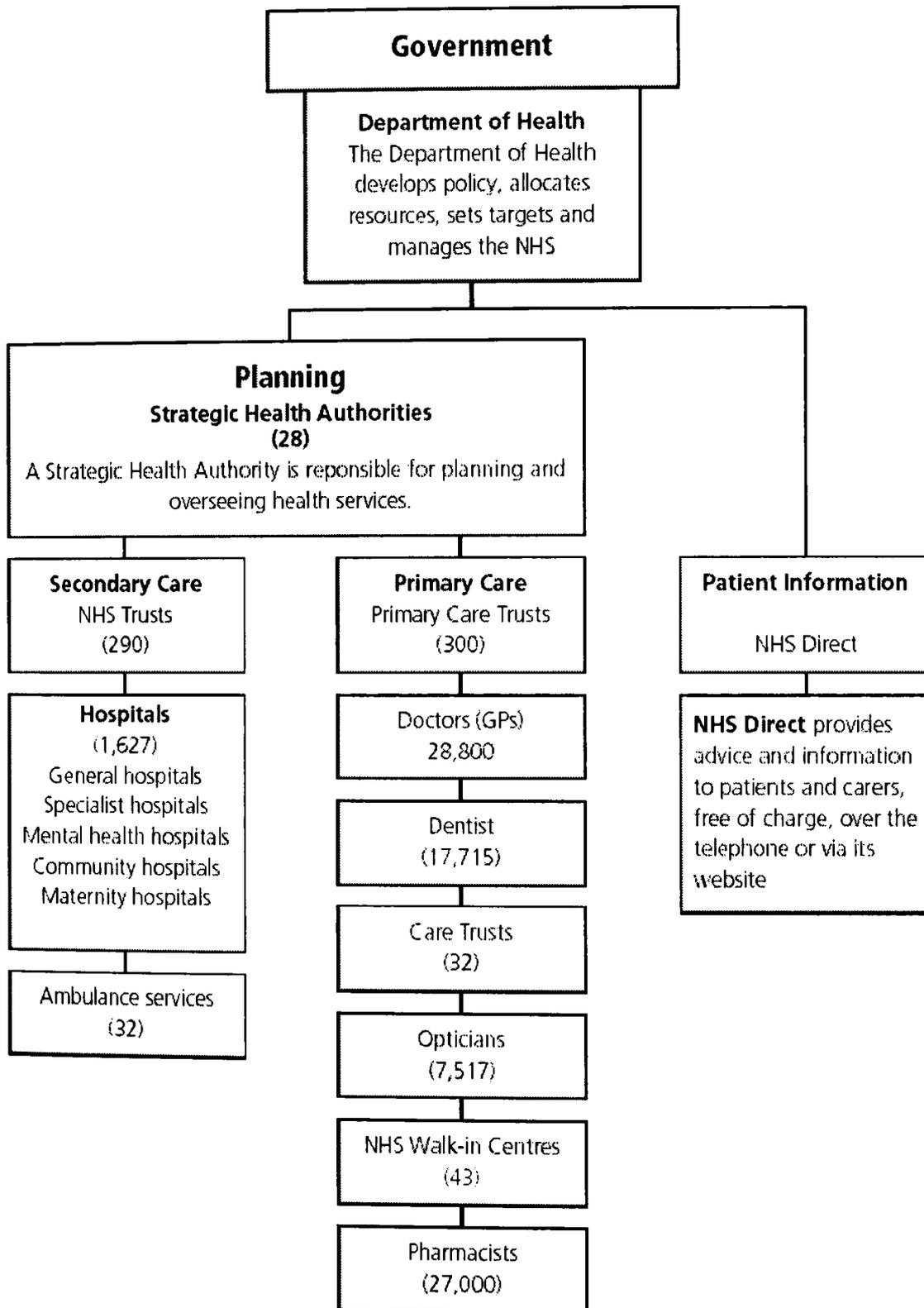
## Appendix 15: Codes for Analysis, Interviews with Women

### Codes for Women's Interviews

Trauma		
Define	behaviour/response of individual – Event DSM	BEHAV EVENT DSM
Aetiology	Loss Sexual Violence 'Torture'	LOSS SEX VIO TORT
Refugee Response	'what happened' behaviour Verbal	UNNAMED REF BEH REF VERB
'trauma impact' a.	temporary Permanent	IMP-TEMP IMP-PERM
	b. coincides with exile latency period	IMP-EXILE IMP-LATE
	Provider Response (role) Refer or link with services Medication One to one Counselling Group work Self help methods	PV REFER PV MED PV 121 PV GP WK PV SELF
Counselling dichotomy		WEST-NONWEST
Identity Issues	as refugee As traumatised As 'victim' As 'resilient'	REF ID TR ID VIC ID RES ID
Community Context	CC	
Resolution of Trauma	RESOLVE	
Trauma as Access to Legal	LEGAL	
Disclosure	DISCLOSE	
Honour & Shame	HONOUR	
Immigration Issues	INS	
Conflict in belief systems	CON BEL	

## Appendix 16: Structure of the NHS

### Schematic of the new NHS structure



Source: Bank-Anthony, B. 2003. *Understanding the New NHS - A Guide to the New NHS for Voluntary Homelessness Organisations*. London: Crisis.

## Appendix 17: UK Academic and Clinical Discourse, Selected Texts

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