PAFRAS

Beyond the edges of healthcare provision: the impact of destitution on the health of refused asylum seekers

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PAFRAS Briefing Papers

PAFRAS (Positive Action for Refugees and Asylum Seekers) is an independent organisation based in Leeds. By working directly with asylum seekers and refugees it has consistently adapted to best meet and respond to the needs of this most marginalised of groups in our society. Consequently, recognising the growing severity of destitution policies, in 2005 PAFRAS opened a drop-in providing food parcels, hot meals, clothes, and toiletries. Simultaneously experienced case workers offer one-to-one support and give free information and assistance; primarily to destitute asylum seekers. PAFRAS works to promote social justice through a combination of direct assistance, individual case work, and research based interventions and analysis.

Below an underclass, destitute asylum seekers exist beyond the periphery of society; denied access to the world around them and forced into a life of penury. To be a destitute asylum seeker is to live a life of indefinite limbo that is largely invisible, and often ignored. It is also a life of fear; fear of detention, exploitation, and deportation.

It is from the experiences of those who are forced into destitution that PAFRAS briefing papers are drawn. All of the individual cases referred to stem from interviews or conversations with people who use the PAFRAS drop-in, and are used with their consent. As such, insight is offered into a corner of society that exists beyond the reach of mainstream provision. Drawing from these perspectives, PAFRAS briefing papers provide concise analyses of key policies and concerns relating to those who are rendered destitute through the asylum process. In so doing, the human impacts of destitution policies are emphasised.

Introduction

In July 2009 PAFRAS published a briefing paper focusing on the provision of healthcare to refused asylum seekers and analysing developments in government policy on healthcare provision to them. Written in the wake of an appeal court ruling that withdrew free secondary healthcare provision from refused asylum seekers, *Beyond the Edges of Healthcare Provision* (4) also looked at access to primary (GP and dental) care provision; theoretically unaffected by the ruling. This new briefing paper, written one year later, brings us up-to-date with developments in the policy arena and reflects on the ramifications of policy for the lives of the people with whom PAFRAS works.

Background

Charging for certain treatments (prescriptions, spectacles) has been a part of the NHS since 1952. It wasn't until 1989 however; with the introduction of *National Health Service Act* in 1977 that a British government introduced measures to explicitly target individuals not ordinarily resident in the UK for charges for secondary care.[1] A piece of secondary legislation, *Statutory Instrument 306*,[2] enacted in 1989 was the first serious attempt to codify who, below the Secretary of State himself, was responsible for the charging of individuals not ordinarily resident in the UK. Even after the enactment of *S.I. 306* enforcement of charging regulations remained patchy at best.

In 2004, in the wake of a series of measures hardening the government's stance toward asylum seekers, the New Labour administration enacted *Statutory Instrument 614*, reforming the existing charging regulations, and published new guidance on their implementation that placed a firm emphasis on the responsibility of NHS trusts to make charging a core part of their business (13).

The new regulations made it clear that the government wanted irregular migrants and refused asylum seekers to be charged for secondary treatment. At the same time the government put pressure on NHS Trusts to ensure that invoices were raised and charges made while failing to set out clearly what clinicians and hospital managers should do in cases where someone who was chargeable needed treatment urgently. All secondary care was to be charged for and only care which was deemed '*urgent*' or '*immediately necessary*' (terms with no medical precedent, left undefined in the legislation) by a clinician was to be provided prior to the securing of a deposit equal to the estimated cost of the care by the Trust. Aside from a short list of highly contagious diseases with serious public health implications, the only exception made was for those who had already been in the UK for twelve months when they were refused. They were allowed to see through to completion any course treatment on-going at the time of their refusal without charge. Everyone else became chargeable; including refused asylum seekers who the Home Office recognised were unable to leave the UK through no fault of their own.

The harshness of the charging regime, which resulted in many cases of people being refused treatment with long term implications for their health (see 15) was compounded by a significant lack of clarity over its implementation, leading to multiple legal challenges. In April 2008 the High Court dismissed the Department of Health's argument that a person could only be come 'ordinarily resident' through twelve months of *legal* residency in the UK; effectively allowing free secondary care to

1 Section 121 of which gives the Secretary of State for Health authority to charge, on a commercial basis, anyone not ordinarily resident in the UK (8). The legislation does not affect primary care provision.

2 The National Health Service (Charges to overseas Visitors) Regulations 1989.

all refused asylum seekers who had been in the UK for at least 12 months. This advance was short lived however, in March 2009 less than a year later the Court of Appeal overturned the ruling in an appeal brought by the Department of Health; the provisions of the 2004 charging regulations were to be re-implemented. At the same time the Court ruled the published guidance illegal due to its lack of clarity on implementation.

Parallel to their efforts in secondary care, in 2004 New Labour launched a consultation on denying access to free primary care to anyone found to not be ordinarily resident. The results of the consultation, not published until 2008, showed overwhelming hostility to the proposals on practical, public health and humanitarian grounds (12), hostility which appears to have led to the government shelving the idea.[3]

Recent developments

Responding to the Appeal Court Ruling, in February 2010 the Department of Health launched a consultation on new charging regulations and guidance. At the time the new regulations and guidance were presented as a consolidation and clarification of existing regulations and an expansion and clarification on their implementation (9: p.7). Analysis by the medical charity Medact has concluded otherwise, suggesting that they include significant changes to the sites at which the regulations are implemented and broaden the number of bodies responsible for implementing charging regulations and placing a new emphasis on the responsibility of each and every NHS staff member (rather than only specific staff with training on immigration law and the asylum system), to ensure their implementation (16). In this regard there are also wide ranging contradictions within the draft version of the new guidance document that, if uncorrected, will certainly lead to the misapplications of law that will have serious implications on access to necessary healthcare (17: pp.12-14).

The new guidance also perpetuates key false assumptions: centrally, the idea that it is possible to determine whether a condition is urgent or even immediately necessary prior to proper medical examination. As an adjunct to this, the guidance distorts the nature and role of secondary healthcare by underplaying it's role in detecting and identifying diseases. A second false assumption on which the guidance is premised is the idea that health problems can be neatly categorised into those that are *immediately necessary* or *life-threatening* and those which are not. Many problems, if not properly managed, can have life threatening consequences; relatively common conditions such as diabetes and asthma being prime examples.

PAFRAS's service users

As part of a recent project undertaken by PAFRAS which looked at the healthcare needs and issues surrounding refused asylum seekers' access to healthcare a survey of sixty-three service users was undertaken. The data gathered in that survey is used to illustrate the situations of PAFRAS's service users today. In all just over two-thirds of respondents (68%) were male, they ranged from 20 to 59 years of age with the largest number (26 or 41%) being between thirty and thirty-nine years of age.

Our survey shows that the average length of stay in the UK of PAFRAS service users is five years. Actual length of stay ranges from 3 months to 16 years with a majority (63%) having been in the country for between three to seven years. This is significant given that a central tenant of the war of attrition waged on refused asylum seekers' right to healthcare by the government was the coercive force of refusing care; the argument was that treating people humanely encourages them to stay in the UK, while harsh measures encourage them to leave.[4]

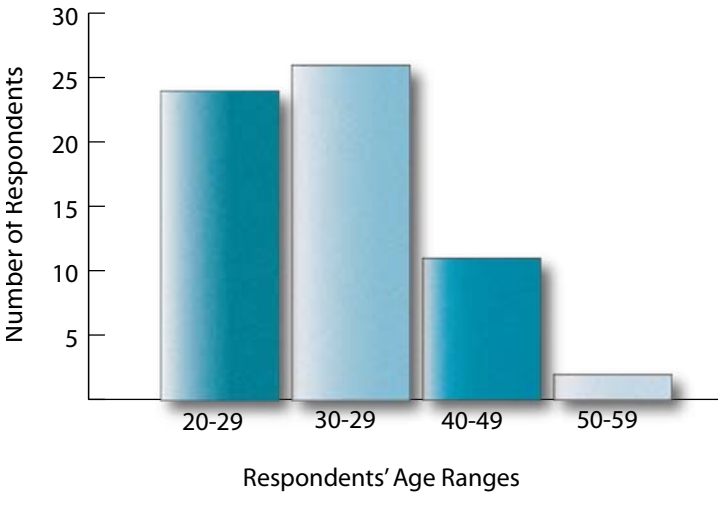

Fig 1: Respondents' Ages

In all 68% of respondents survive without state support, relying on handouts from friends, communities, grass roots and religious, and other non-governmental organisations. Twenty-two percent received Section 4 at the time of the survey.[5]Section 4 support is most frequently given as a temporary, short-term, measure (e.g. for destitute women from the seventh month of their pregnancy until two months after giving birth), therefore—for those who remain in the country for some time, and our results suggest most do—there is likely to be movement from hidden homelessness to Section 4 support

3 We do not yet know whether, under the auspices of budget cutting and in the context of its proposed radical shake up of primary care delivery in England and Wales the coalition government will reintroduce these ideas.

4 New Labour also imagined that such measures would deter people from entering the UK; based on the flawed assumption that access to our healthcare system was a motivating factor for asylum seekers and other irregular migrants and a lack of empirical research.

5 Section 4 support is awarded only in very limited circumstances. To qualify applicants must be too ill to travel; sign-up for 'voluntary' return; or have made further representations for asylum based on hither to unseen evidence.

and back again. In all 90% of respondents remain in the UK regardless of their lack of access to free secondary healthcare, preferring ill health to persecution; and as the survey reveals most do suffer ill health.

Health problems amongst PAFRAS service users

Forty of 63 individuals surveyed reported suffering from 36 different symptoms or health problems. Twelve of these relate to mental health or psychological wellbeing while 24 relate to physical health problems. There were a total of 104 occurrences of these problems or symptoms with each respondent averaging 2.6 health complaints. In all 26 (41%) individuals survey complained of physical health problems and 28 (44%) suffered from mental health problems. Given that in all 79.4% of survey respondents were under 40 years of age and can be considered in the prime of their lives, these figures are alarming.

Health Problems	# Respondents
Physical	12
Mental	14
Both physical and mental	14
Total	*40*

Mental health problems make up 54% of all complaints with 23 (37%) respondents reporting depression. Dr Jo Newell, GP for the Health Access Team, has suggested that refusal of asylum is a significant blow to the mental health of most of those who experience it;[6] a point with which Anne Burghgraef, senior therapist at Solace, concurs:

> "When they get their refusal ... and if they lose their appeal, it really knocks people. Not only are they suffering, they've been branded a liar and they're facing the threat of return. That triggers a downward spiral."[7]

While refusal can have an immediate effect on an individual's emotional and psychological wellbeing, being forced into destitution has longer term impacts on both physical and mental health (1: p.16). Depression followed by stress and insomnia are the most common mental health complaints raised by service users. As the table below shows, there are a total of 57 occurrences of mental health complaints amongst 28 individuals.

Amongst asylum seekers, as with other social groups, mental health problems carry with them a stigma. Because of this it seems likely that in regard to mental health problems, these figures are conservative. Dzmitry Karpuk, metal health worker with PAFRAS, reports that around 50% of the clients he deals with have engaged in suicidal ideation—a common medical term for thoughts about suicide, which may be as detailed as a formulated plan, without the suicidal act itself. Karpuk also notes that 'all clients resist to even speak about mental health problems... they['re] afraid they would be locked up or will fail to get asylum because of it'.[8] Mental health problems also impact on chronic physical health conditions such as high blood pressure or heart disease (5: p.18).

Psychological Symptom/Health Problem	Instances
Depression	23
Stress	13
Sleeplessness/insomnia	7
Anxiety	5
Other mental disorder (unspecified)	2
Anger	1
Fatigue	1
Forgetfulness	1
Lack of confidence/fear	1
Nightmares	1
Nervousness/inability to relax	1
Suicidal ideation	1
	57

The picture of physical health amongst service users is equally grim. The table on the opposite page details the forty-seven occurrences of physical health problems amongst those surveyed. There are 24 occurrences of twelve different chronic conditions and a further 16 occurrences of seven other conditions which can be either chronic or acute in nature. The prevalence and frequency and nature of the chronic conditions suffered from is a testimony to their unsafe living conditions, poor diet and inadequate access to healthcare.

Accessing healthcare

Research by PAFRAS suggests that there is a link between immigration status, or stage of the asylum process and likelihood of being registered with and GP and dentist. The table below shows the percentages of services users with a GP and dentist in four main support status categories which correspond to different milestones in (and after) the asylum process.

Appointments

In all, 38% of respondents have difficulties making and attending appointments with their GP. Of these the largest numbers attribute their difficulty to transportation problems. Other notable barriers to were: simply not having a GP, forgetting appointments and fear of detention and deportation. Health professionals interviewed suggest that, for a variety of physical, psychological and practical reasons forgetfulness is

	# Individuals	GP	Dentist
Destitute	71	48% (*n*=34)	13% (*n*=4)
Section 4	20	95% (*n*=19)	25% (*n*=4)
Section 95	8	100% (*n*=8)	25% (*n*=4)
Refugee	1	0% (*n*=0)	0% (*n*=0)

Percentages of service users registered with a GP and Dentist

6 Interview with the author, May 2010.
7 Interview with the author, April 2010.
8 Interview with the author, May 2010.

Chronic Conditions	Acute Conditions	Either Chronic or Acute	Other
Asthma (1)	Chest infection (1)	Cyst (1)	Mobility problem (1)
Chest pain (2)	Flu (1)	Dental (5)	Pregnancy (1)
Diabetes (1)		Gastritis (1)	Visual impairment (2)
Epilepsy (2)		Headaches/migraine (5)	
Gastric ulcers (1)		Rashes (1)	
Heart condition (3)		Stomach problems (1)	
Hernia (1)		Pain (2)	
High blood pressure (5)			
Liver problems (1)			
Muscular-skeletal pain (5)			
Respiratory (1)			
Stroke (1)			
12 (24)	*2 (2)*	*7 (16)*	*3 (4)*

Types of physical health problem experienced

a significant problem amongst destitute asylum seekers and homeless people more generally (see 17: pp.32-4) leading to severe difficulties in making and attending appointments.

Despite these difficulties the survey does not suggest that PAFRAS service users have great difficulty accessing medication. Forty-seven percent (n=29) of all respondents (73% of all respondents with a health complaint) were on medication of some sort, and most (22 or 76% of those on medication at the time, and 4 who were not on medication at that time) said they did not have trouble accessing medication, as one respondent put it: "I'm only scared with the amount of medication I get." Anecdotal evidence gathered suggests that destitute asylum seekers are frequently prescribed mild analgesics such as paracetamol by GPs unable to or unwilling to engage with more deep-seated, often psychological, problems.[9]

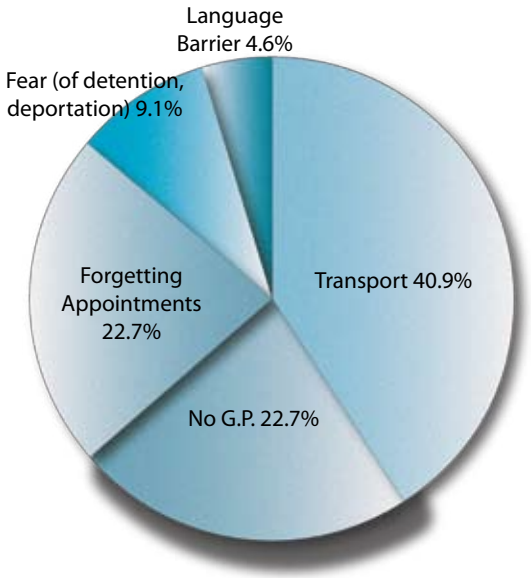

Fig 2: Barriers to making/attending GP appointments

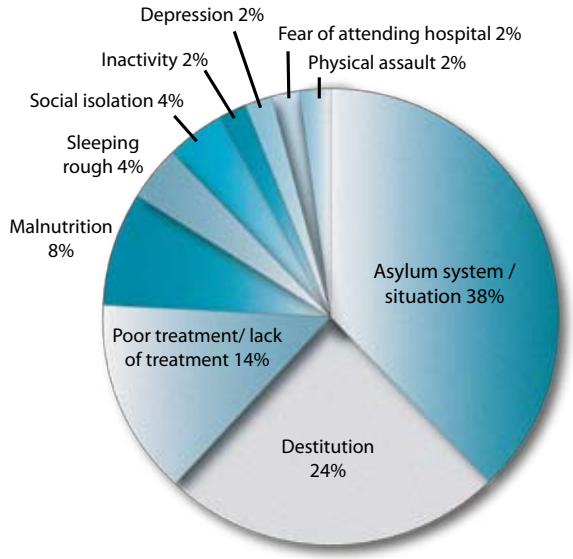

Fig 3: Reasons attributed for decline in health

Charging

Twenty survey respondents reported having received hospital care, eight of whom had their immigration status checked at the time. Four of these were told they could be charged for treatment but only two received invoices. No one surveyed reported being refused secondary care outright due to their being chargeable but unable to pay. Four individuals surveyed reported being charged, and having to pay for dental care and one for prescriptions.

Refused asylum seekers qualify for a HC2 Certificate which exempts them from paying for dental care as well as prescriptions on grounds of poverty. Nonetheless many do not have a HC2, which a normally valid for six months only and must be renewed regularly. There are a number of reasons for this. Language barriers, fear of the authorities or detention, are im-

9 Interview with Ann Burghgraef of Solace, April 2010.

portant but key to this is the chaos, disorganisation, fragmentation and forgetfulness that are consequences of homelessness and hunger. Many lose their HC2 or fail to renew it on time (the process can take six to eight weeks).

The effects of destitution

The picture of service user health that emerges from the survey is extremely poor, despite their having access to medication, primary case and, when they seek it, in most cases secondary care. This serves to highlight the fact that enforced destitution at the hands of the Home Office and the asylum system is the key factor in the deterioration of the health of refused asylum seekers, something which they themselves also believe to be true. It also suggests that many put off seeking medical attention until they are much more seriously ill with attendant harmful consequences.

When questioned 51% (n=32) of respondents said their health had declined since arriving in the UK while 32% (n=20) said it had improved. Sixteen percent (n=10) said that they had seen no overall change in their health. Forty of the 52 respondents who stated that their health had either got worse or improved gave further details when asked what causes they attributed to these changes. Of these, nine indicated that their health had improved because they were either in receipt of medication or treatment from the NHS or their GP or, in two instances, because they had access to the NHS or their GP.[10]

Figure 3, on the previous page, shows the causes attributed to their decline in health by PAFRAS service users. It is notable that the most common cause given is the asylum system itself, identified by 38% of respondents and a cause for the decline in their health. In reality the other causes identified—from fear of attending hospital to sleeping rough or social isolation and inactivity—represent a breakdown of the different ways in which destitution policies impact on their victims rather than independent factors in an individual's ill health.

	Got Worse	No Change	Improved	Not Sure
Destitute	51%	30%	30%	2%
Section 4	50%	14%	36%	-
Section 95	67%	-	33%	-

Changes in Health Since Arriving in the UK

Conclusion

That PAFRAS service users place such emphasis on the ways in which their situation and the asylum system is making them ill is not new; it is a phenomenon noted by the British Medical Association as long ago as 2002 (2; also see 18). The case study on the opposite page illustrates the linkages between the asylum system, destitution and chronic illness very well. Such examples also demonstrate that the destitution policies which condemn so many people to living in abject poverty, abuse and ill health are not only immoral, but counter-productive because they are costly in the long term.

The new government has not indicated its views on refused asylum seekers' access to healthcare, or on the draft 2010 Charging Regulations and Guidance. It is therefore impossible to know whether it will seek to implement these changes in full, in part or not at all. Equally it remains uncertain what, if anything will be the impact of the government's radical proposals to restructure the NHS on refused asylum seekers.[11]

It seems probable that, even without reform of the charging regulations, the government will seek to replace the guidance ruled illegal in 2009 quickly. This is because, notwithstanding those clear examples of refused asylum seekers being charged for secondary care that do exist, the present lack of guidance on how the charging regulations are to be implemented appears to have created a space in which it is possible for clinicians and other staff to ignore the regulations (either out of altruism or for practical reasons) when they choose to. This situation would be very likely to change if the new guidance and regulations (currently being consulted on) were to come into effect, or if, in a more limited scenario new guidance were implemented for the present regulations. Even in the latter case, the fact of there being guidance to follow would be likely to restrict clinicians' room for manoeuvre by raising the profile of the charging regime in much the same way as the 2004 regulations and guidance did (14: p.44).

In clearly making it the responsibility of all NHS staff members to ensure that the charging regime works, the new guidance further reduces clinicians room for manoeuvre, putting pressure on them to conform to policy, were it introduced it may become possible for Trusts to discipline staff for failing to provide other NHS bodies with information regarding a patient's chargeable status. With or without changes, concerted and coordinated efforts at resistance will be required to stop a significant worsening in the situation for refused asylums seekers in coming years. Some hope can be found in the fact that NHS clinical staff, and especially doctors, are a highly privileged and empowered sector of the workforce whose ethical code remains very much at odds with government policy. Nonetheless, resistance may prove especially difficult given

10 It should be noted that two individuals who said that their health had improved also indicated that 'without support my health cannot improve that much' (Survey Respondent 5) and that it was 'slowly improving' but that a lack of a dentist was a problem (Survey Respondent 14).

11 The government is proposing the abolition of Strategic Health Authorities and the replacement of PCT's as commissioners of health services by consortia of GPs. In all the government claims says that it will reduce the management costs of the NHS by more than 45% (11: p.43).

the present dominance of the theme of austerity in public discourse and the revanchist stance of the coalition government towards public spending.

Case Study

The case of X, an Iranian asylum seeker, exemplifies this. X, then in his early thirties claimed asylum in 2000, immediately on entry into the UK. He was refused a little under a year later. When he arrived in the country X was physically fit, but suffering from depression and PTSD resulting from his experiences of being tortured, experiences which has led him to flee his home country. Once in the UK he was prescribed anti-depressants and referred to a therapist. In 2004 he was also diagnosed with diabetes, for which he was prescribed insulin.

X's asylum claim was refused in 2004 but he was too scared to return home. Shortly afterwards his was diagnosed with diabetes. In 2006 he came to live in Leeds where he initially stayed on a friend's floor but ended up sleeping rough for weeks at a time. During this period he saw a rapid deterioration in his health and a marked loss of weight. In the winter of 2007, too ill to be able to attend the drop-in and access PAFRAS' support and having not eaten for three days, X collapsed into a diabetic coma.

By early October 2008 X's condition had deteriorated to the point where Leeds Social Services offered him sup-port as 'destitute plus' under the National Assistance Act 1948. After two months with support X's condition was improving, he was able to feed himself and to climb the stairs unaided. In late December 2008 support was with-drawn as X was consid-ered to no longer qualify as destitute plus. He found himself back on the streets where his health rapidly deteriorated.

Despite having had generally good experiences of the UK health system, X's health and particularly his diabetes have dete-riorated severely over the years. This can be ascribed to his enforced destitution, poverty, poor diet, and lack of choice over what he ate, an inability to cope with medication regimes and frequently lost prescriptions. X has recently had an operation to install a catheter in his leg and is in constant pain. He takes fourteen tablets a day for depression, diabetes and the pain (including pain killers and aspirin to thin his blood).

The tragic irony in X's case is that in spring 2010, after nearly ten years in the UK, he was granted Indefinite Leave to Remain outside of the Immigration Rules as part of the case resolution process by which the Home Office is clearing its backlog in unresolved asylum cases. Since his operation X and has been given a permanent sick note by his doctor who does not believe he will be able to work again.

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