

# Public Health Equity in Refugee and Other Displaced Persons Settings

UNITED NATIONS HIGH COMMISSIONER FOR REFUGEES

April 2010

Public Health and HIV Section, DPSM Policy Development and Evaluation Service

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## Acronyms

DALYs	Disability-Adjusted Life Years
HIS	Health Information System
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
IDP	Internally Displaced Person
MSRP	(UNHCR's) Management System and Renewal Project
NGO	Non-Governmental Organisation
proGres	UNHCR's registration software programme
QALYs	Quality-Adjusted Life Years
TOR	Terms of Reference
UN	United Nations
UNHCR	United Nations High Commissioner for Refugees

#### **Executive Summary**

Addressing concerns about public health equity in the context of violent conflict and the consequent forced displacement of populations raises operational and ethical issues for the United Nations for High Commissioner for Refugees (UNHCR). Priorities of service delivery, the allocation choices, and the processes by which these choices are arrived at are now coming under renewed scrutiny in the light of the estimated two million refugees who fled from Iraq since 2003. This discussion document explores key questions of cost and equity as they arise in the context of providing health services to a number of refugee and other populations of concern to UNHCR including those from Iraq. Interviews were conducted with a number of informed and experienced humanitarian practitioners at field, country, and headquarter levels. These interviews helped frame major operational questions that need to be addressed including the status of health care delivery as a relative priority for UNHCR, allocations of resources for health between and within different populations, and strategies for transition and exit.

These important operational questions now faced by UNHCR can to some extent be clarified by reference to relevant ethical theory. A review of the literature suggests that public health equity issues confronting the humanitarian community can be framed as issues of resource allocation and issues of decision-making. The ethical approach to resource allocation in health has been developed primarily within the context of one nation-state and requires taking adequate steps to reduce suffering and promote wellbeing, with the upper bound being to avoid harming those at the lower end of the welfare continuum. Deliberations in the realm of justice and capabilities theory suggest that disparities across nation-states may be acceptable, provided that those who have less are not miserable. No legal or implementation platform now exists for international actors to act to reduce health disparities across nation-states, although norms and expectations, including within the humanitarian community, may be moving in that direction.

In terms of decision-making, most ethical theorists agree on the crucial importance of process in arriving at particular decisions relating to resource allocation. This process should meet standards of transparency, accessibility, fairness, evidence and empirical rationale, options for appeal and revision, and accountability. In assessing the applicability of these standards to UNHCR, the dimension of feasibility must also be considered.

Many possible consequences flow from this discussion of operational issues and ethical guidance. The respondents were close to unanimous in urging UNHCR to devote more attention to health as one of its main activities, in terms of policy, administrative support, and budget allocations. Respondents pointed to the example of the coherence and effectiveness of HIV/AIDS efforts within UNHCR and urged that a more expanded focus on health more generally be placed in similar policy alignment within the agency. It was noted that the aging demographics of the entire refugee population are already driving demand for more advanced and sophisticated health services which UNHCR must now anticipate in its development of overall health strategy. Ethical concerns were expressed about disparate levels of expenditure by population, the extent of the health obligations of an emergency agency like UNHCR, the sparseness of support delivered to many refugee populations throughout the world, and the problem of how to make decisions about the acute needs of individuals whose care required breaking population-based treatment protocols.

A recurrent theme arising from these discussions was the need for UNHCR to re-invigorate its sense of mission as an emergency humanitarian agency and focus on immediate needs for security, protection, and health and welfare of refugee populations. Efforts to meet the increasingly complex demands of populations living in refugee settings for decades and generations are, in the view of these respondents, beginning to blunt the effectiveness of UNHCR's distinctive expertise in acute crises. Respondents see a mounting urgency in the quest for a coherent policy on

transition and exit strategies, an undertaking that UNHCR should initiate with other UN agencies and a range of international institutions and donors.

The theoretical literature relevant to the issue of public health equity comes from several lines of thought in ethics and moral philosophy: distributional ethics, notions of justice, and the quality of processes used for making ethical decisions. Guidance exists for establishing minimum standards of assistance, for evaluating those standards and adjusting them across populations, for assessing whether user fees could ever be made acceptable in emergency situations, and for making exceptions to treatment protocols. A central component of translating and implementing this guidance across the organisation and to all field levels is to strengthen the information assets available to a broader group of actors and to develop and train a wider range of staff in the decision making processes that will be required.

Key ethical principles of relevance to UNHCR include: 1) Distribution decisions within one population of refugees -The argument from justice and fairness would suggest that emphasis be placed on raising the level of those most in need, and thus devoting more resources to their care. The upper limit to this re-direction of expenditures would arrive at the point where measurable and meaningful degradations in the care delivered to the relatively stable and healthy members of the population begin to be seen to place their health status in jeopardy. This principle would also come into play when determining whether to make individual exceptions to protocols of care; 2) Distribution questions across populations of refugees from different countries- This question could be framed as a problem of inequality within one system of care (taking UNHCR as the institution and all refugees around the world as the population for which it is responsible). From this perspective, the question becomes how much inequality can be tolerated for a system to still be declared just and fair. The theoretical consensus from the contractual and capabilities approach is that within-system differences are tolerable to the extent that those at the bottom receive an appropriate minimum bundle of services that provide essential primary goods or human capabilities; 3) Setting limits on extent of care - UNHCR faces the question of whether and how to set limits in several circumstances (i.e. establishing minimum levels of care for one population or across refugee populations; establishing the upper limit (in terms of cost and/or complexity of care) for one population or across refugee populations; and assessing the fairness of user fees). There is no ambiguity about the overall need to establish limits on expenditures and extent of care because the health budget for UNHCR is stretched as it is and the options for increasing that total budget are outside the scope of this discussion; and 4) When and how might exceptions to protocol or established limits be justified? - An implication of this discussion is that as the refugee populations even in poor regions become older or more integrated with their host surroundings, the need to make exceptions will increase. The solution to that observation, however, is probably not to keep making exceptions but to consider raising the social minimum for that particular population.

Numerous findings and recommendations are elucidated according to 1) the respondents; 2) protracted situations; and 3) ethical dimensions of UNHCR's policies. Were some or all of these solutions to be taken up as policy options for UNHCR, major efforts would need to focus on internal processes relating to information and human resource systems, and on external processes relating to legitimacy, stakeholder buy-in, transparency, and accountability.

#### Introduction

Within the United Nations (UN) humanitarian system, the United Nations High Commissioner for Refugees (UNHCR) has a particularly complex and open-ended mission: to protect and sustain the welfare of refugees, internally displaced persons (IDPs), and other persons of concern throughout the world; to promote their return, integration, or resettlement whenever possible; and, in the interim, to provide support for these populations as long as is required. These responsibilities has led UNHCR to develop unique expertise in legal, advocacy, and security arenas and leadership roles in provision of emergency services in austere camp settings (e.g. water and sanitation, shelter, health, and education, all delivered within an envelope of protection and oversight). Fulfilling this mandate with limited funds, raised in annual budget cycles that do not map to the abrupt occurrence of new needs or the extended duration of chronic refugee situations, has required the organization to develop a strong institutional culture around questions of priority setting and resource allocation.

For decades, the main populations who required UNHCR protection and services were from poor areas of the developing world in Asia and Africa. When crises occurred, people would flee across international boundaries into equally poor adjacent host countries. These refugee populations required extensive legal and security support but their emergency service needs, although enormous in the aggregate, were relatively lean when assessed on a per capita basis. The needs of the host populations were similarly constrained by their baseline meager living conditions and very low economic indicators. In general, everyone—refugees and local people—were accustomed to subsistence levels of existence, in terms of required inputs for food, water, shelter and basic health care. UNHCR emergency strategies placed emphasis on ensuring safety for the refugee population, providing the minimum level of services needed to bring crisis morbidity and mortality rates back down to the level experienced in the country of origin, and assuring some measure of administrative coherence and regularity. After this emergency phase had abated, (the time frame of weeks or months dependent on the severity of the refugee crisis and a range of other variables), other services were added (including expanded health care capacities and education).

The infusion of resources occasioned by the establishment of refugee sites within another country required a measured and delicate strategy towards the local host population. Attention to meeting the needs of local people was considered important even early in the emergency phase, with the dual aim of providing a minimum level of support to the refugees and ensuring some level of equivalence in living conditions and services between the two populations.

These priorities, the allocation choices, and the processes by which they are arrived at, are now coming under renewed scrutiny in the light of the over two million refugees who since the 2003 onset of the Iraq war have fled from Iraq into host countries elsewhere in the Middle East. A high proportion of these refugees are middle class, in terms of socio-economic status, and their demographics reflect the age distribution and burden of chronic disease associated with populations from the developed world. After five years of experience in supporting this group of refugees, UNHCR is confronting a host of related issues around budgetary constraints, service equivalence between host and refugee populations, and relative equity (in terms of per capita costs) across the span of refugee populations for whom UNHCR is responsible.

The Public Health and HIV Section of UNHCR together with the Policy Development and Evaluation Service has requested a discussion document be prepared that explores these key questions of cost and equity as they arise in the context of providing health services to this Iraqi refugee population. The intent is to provide a background ethical and operational analysis that would serve to inform a process leading to the development of policy guidelines that would be applicable to an overall strategy for providing health services to refugees worldwide. This document as

requested looks primarily at these issues in relation to refugee populations (as opposed to IDPs or other persons of concern) and considers the situation of urban as well as camp-based refugees.

It was anticipated that a number of relevant issues would be raised that were not specifically identified in the TOR. That has proved to be the case and the findings reflects the broader discussion engendered by the interview process.

#### Methods

The approach taken to information gathering has consisted of interviews by phone with key informants and stakeholders from within and outside UNHCR. For operational reasons, site visits to the field were not undertaken.

A review of the relevant literature, particularly reports, articles, and books relating to population ethics and distributive justice was undertaken. UNHCR and other UN documents were also reviewed, along with reports suggested through interviews with key informants. The bibliography contains a full list of the written materials referred to or relied upon in the writing of this report.

Everyone interviewed by phone had received and reviewed the terms of reference (TOR) for the project. The phone interviews were open-ended, semi-structured conversations with the following ground rules stated and agreed upon at the outset of the phone call: Notes were taken on computer; everything said by the key informant would remain confidential; and, in the event that the report to UNHCR referred to a suggestion or quoted the person who was interviewed, that reference would be cleared in advance by that person. Each interview took approximately 90 minutes. A full list of the people interviewed is attached as Appendix 2.

The interview structure began with mutual introductions, a review and confirmation of ground rules, a brief overview of the TOR, a confirmation that these issues were perceived as relevant and important, and an invitation to add or expand upon any aspect of this overall topic that was of particular interest to the interviewee. The respondent was then encouraged to open the conversation with a general response and set of observations, with the possibility noted that questions for clarification might be asked during that set of general remarks but that substantive questions would be held for follow-up afterwards. In most instances, the respondent talked without substantial prompting or further questioning for at least 20 minutes. Questions and answers then ensued based upon ideas or issues that the respondent had advanced in his or her opening remarks or based upon aspects of the TOR that the respondent had not initially addressed. The discussion usually reached a clear point of closure by about 90 minutes and it was left that further questions or thoughts would be shared in subsequent emails. Approximately one-third of the respondents sent further materials or remarks in that mode.

#### Findings from interviews

The respondents were to a person most gracious about the process, superbly well informed, generous with their time, and deeply thoughtful on the issues. A wide range of responses was received from this diverse set of experienced actors. They are well versed in key aspects of UNHCR mandate and policy. They are also well aware that the policy parameters set a framework for decision-making that evokes a number of ethical issues, particularly relating to priority setting and resource allocation.

The decision to discuss ethical and operational problems together in this section is based on two rationales. The first is that in the minds of the respondents the ethical problems arise out of operational mandates and program dilemmas and are thus identified within a particular empirical context. The second is that much substantive ethical thinking is done within the setting of an actual case or particular situation where the dilemma or tension is sharply framed. To approach a general ethical principle through the lens of a practical problem is considered standard methodological practice.

The respondents perceive the issues raised by the Iraq experience to be vivid and particular examples of wider problems that UNHCR faces in its efforts to promote public health equity among its many refugee populations. The respondents identify three immediate issues in the context of Iraqi refugees and several related operational concerns. They then expand upon the implications of these issues by advancing a broader critique of the ways in which UNHCR now sets strategic priorities and seeks to carry out its mandate.

#### Iraq

#### Immediate ethical issues relating to providing health care for Iraqi refugees

These ethical issues arise from difficulties in attempting to meet policy requirements to provide adequate minimum prevention and curative health care to Iraqi refugees that are similar to that of the local host country services.

#### 1. High and uncertain cost of Iraqi refugee health care

Despite robust fund-raising efforts, the costs of providing services to the Iraqi refugees at a level that attempts to meet their emergency, primary, secondary and tertiary health care needs are proving difficult to sustain. Respondents did not have ready access to actual details on costs per capita or aggregate costs on annual basis but they reported the overall sense that cost over-runs were significant.

#### 2. Disparity in services for local host populations

The health care systems in Syria and Jordan are very different. Syrian has a socialized health care system with good primary and secondary care available to all persons at minimal cost. The Jordanian system is a mixture of Government and private health care with a majority of Jordanians having health insurance that allows them to receive a high standard of health care. Before the current war in Iraq, the Iraqis had a strong health care system that was a mixture of Government and private health care. In order to meet the demand placed by the Iraqi refugee population for medicines, diagnostic procedures, and ongoing maintenance of complex chronic diseases, UNHCR and its subcontractors work primarily with the national Ministries of Health, the Red Crescent Societies, Caritas, and some private physicians and hospitals to provide preventive and curative services to the refugees.

#### 3. High potential cost of attaining parity between local host and refugee populations

It is not unusual for UNHCR to have been faced with the need to raise the level of health care services offered to local host areas when refugees from surrounding areas flow in and are met with an influx of resources and expertise from the international community. It is the extent of the disparity (in sophistication, complexity, and cost) between the different levels of health care afforded the average citizen in Jordan and Syria, respectively, and what the Iraqis appear to need in order to maintain their previous state of health that frames the dilemma now facing UNHCR. To implement the customary strategy of ensuring minimum standards of care for refugees in all situations and then providing similar levels of care to refugees as that available to the host communities, as laid out in UNHCR's public health guiding principles, is complex and costly in the Iraqi situation. It would involve hundreds of thousands of people with chronic disease and costly maintenance medications. UNHCR has to deal with sizable economic, operational, and political issues.

#### Operational problems in managing Iraqi refugee populations

Respondents raise a number of operational problems, specific to the Iraqi refugee situation but noted as recurring in other situations, which in their view constrain the search for practical ways to address the ethical implications of the three immediate issues described above.

#### 1. Registration

The UNHCR registration system, known as proGres, was developed for both camp and non camp-based populations. However, it is often easier to register camp-based populations, where residential and service sites are easily delineated and the populations are often confined to one location. A large and unknown proportion of Iraqi refugees in Jordan and Syria, however, have self-settled in urban areas (particularly the refugees with independent means or relatives in these areas) or (particularly those who are young and mobile) have simply vanished among the growing numbers of undifferentiated recent migrants to the major cities of these two countries. Those choosing to be registered with UNHCR do so only when they believe there is an advantage for themselves, such as receiving food or non food items, resettlement, or access to affordable health services. Therefore, the percentage of the number of UNHCR registered refugees compared with all refugees in the country is unknown and likely changes over time depending upon the financial situation of the refugee and the security in Iraq. This uncertainty in the number of Iraqi refugees makes it difficult to plan and implement programs and assess their effectiveness for those refugees not registered with UNHCR.

#### 2. Record-keeping

The standard process for registering refugees in the UNHCR system is relatively long and detailed. For a number of reasons (ranging from perceived urgency of medical need to reluctance to divulge much information), urban (Iraqi) and camp-based (Palestinian) refugees in Jordan and Syria bypass the registration process and seek care from health facilities directly. The staff at the health facilities allow refugees who have not yet formally registered as refugees with UNHCR to be seen in the health care facilities. These two sets of records (refugee registration and health care registration) do not speak to each other in Syria; however, they do in Jordan. The result is that the refugee may be given medications and receive tests that are outside the protocol and budget that UNHCR has determined are appropriate; and referrals for more advanced secondary care may transpire without reference back to the UNHCR registration system. UNHCR also has difficulties in obtaining follow-up information on what health outcomes the refugee has experienced.

#### 3. Budget tracking

At the beginning of the crisis, UNHCR personnel responsible for administering the health care system for Iraqi refugees in Syria and Jordan have limited knowledge of what funds are available or how much has been spent; the system has gradually improved. The billing system for health services depends upon the process followed by the organisation with whom UNHCR has contracted for delivery of health care. Different subcontractors had arranged different referral systems and different modes and scales of payment; UNHCR was often in the position of just paying the bills without having sufficient oversight control or information about the appropriateness or outcome of the transactions.

In some settings, no financial records are kept and no bills are sent because costs are assumed to be covered under a capitated general budget. Costs relating to referrals and medications outside the capitation agreement, however, are often not tracked.

#### 4. Contracting

The numbers and chronic advanced medical needs of the Iraqi population have outstripped the capacities of the staff in UNHCR at the country level to develop an overall plan of operations with the host Ministry of Health and the private sector providers. A few respondents question whether the issue is simply number of staff or in fact an insufficient number of staff with the requisite contracting sophistication to handle the load. The task is particularly complex in both Jordan, where a developed secondary and tertiary private sector provides reasonable care to those who can pay for it but where, for economic reasons and lack of national health insurance, a significant amount of the local population must rely on the public health care system. In both these countries, in order to arrive at stable and broadgauged referral arrangement for the Iraqi refugees, UNHCR staff need to be able to assess the national and regional health care systems in terms of cost, access, capability, and quality.

#### 5. User fees

The perceived drain on the UNHCR health budget for Iraqi refugees might be abated, according to some respondents, by the implementation of a system of needs-based and income-based user fees. The proposition is seen as particularly reasonable given the fact that many of the Iraqi refugees are moderately well off and that the private sector in both Jordan and Syria are equipped to meet the complex health needs of many of these refugees who in fact could afford to pay for the services. In the context of the Iraqi refugee populations, and throughout UNHCR, however, there has been no agreement on whether and how to develop and deploy user fees, and the major issues relating to consistency and fairness (who should be required to pay, how much should the fees be, and how to keep track of payments) are unresolved.

#### Summary critique of Iraqi refugee operations

The respondents state that as a result of this patchwork of arrangements relating to access, cost, and information flow, UNHCR staff are getting frustrated at not being able to bring things into administrative and budgetary order; refugees are becoming querulous about long waits and occasionally serious discontinuities in necessary care; local providers are upset about perceived inconsistencies and inequities in policy application; and local populations are also beginning to raise questions about fairness.

The situation is aggravated, according to the respondents, by the lack of access that UNHCR field staff have to aggregated information that would allow them to engage in more organized triage processes and better monitor the budget for overall efficiency and efficacy. They do not know how many refugees there actually are in the country and if those registered with UNHCR are the most vulnerable; they do not know what the overall health care budget and expenditures amount to because of fragmented contracts and overlapping time frames for these arrangements; they do not know what their overall health care costs are because they do not know how many of their refugee clients have sought health care and they do not know who among the refugees is accruing costs for services that have not been approved; and they do not know whether the care that the refugees are obtaining is having the desired effect of reducing morbidity and mortality. In this relative information void, the interviewees said, it is very difficult to make reasonable triage plans and policies or to know whether or not, in making an exception to policy for an individual refugee in serious need of advanced care, one is making a decision that reflects an overall assessment of the scope of need on a population scale.

#### **General Assessment**

These issues and concerns led the respondents into a broader assessment of problems and tensions in the way that UNHCR was approaching its health mandate across the world. Many respondents note that these problems are not new but that the Iraqi crisis has forced them to the surface. Three main problem categories are identified as requiring vigorous attention: populations, health, and transition or exit modalities.

It should be noted at the outset of this discussion of major issues that the respondents believe that the UNHCR HIV/AIDS programs hold real promise as a source of innovation for dealing with the problems identified below.

#### **Populations**

This general category of issues relates to distinctions between and within various refugee populations and their host populations. All respondents note that these distinctions, in terms of demographics, income, standard of living, and health status, have operational and ethical implications for UNHCR healthy policies relating to a specific population in a particular host setting. There are also relevant differences in the health care delivery capabilities of the host states where the refugee populations are located. With regard to this category of issues, the respondents believe that the absence of robust information relating to these distinctions and ambiguities in UNHCR policy leads to lack of guidance for UNHCR country staff at all levels of planning and implementation.

#### 1. Distinctions between camp and urban refugees

The first distinction that needs to be made with greater empirical force is that between camp and urban refugees. UNHCR policies in all sectors, not just health, were built to address the needs and concerns of populations in defined locations, often far from urban centers. Two factors have combined to bring about a collapse in whatever urban-rural camp divide might have at one time existed: Wars in densely populated regions of the world have required an increasing number of refugee encampments to be sited near urban areas; and, as the duration of refugee settlement in a particular area has extended, the host population has increasingly congregated towards the nidus of international activity. As a result, in many areas, the geographic, social, and economic boundaries between camp and host settlement have become blurred, with many refugees leaving camps and going to urban areas and many others migrating directly to the cities and towns as they flee their country of origin. These urban refugees mingle with host

country populations and with many other kinds of migrants from their own country and from around the world. In most urban situations, there is limited information available to UNHCR about the numbers of people they are by mandate responsible for and even less information about the needs of this population, in terms of economic support, health care, or protection.

This growing phenomenon of urban refugees has a myriad of implications for UNHCR policy and program. From the health sector perspective, given current UNHCR information systems and manpower, it is much more difficult for field staff to keep track of people when they move to urban areas, to assure that they are receiving minimum levels of care, to coordinate referrals according to protocol, and to manage the costs attached to whatever care they receive or seek out on their own. Because international and local health care NGOs are often working in urban areas in parallel with government-sponsored clinics and the private sector, the options for urban refugees are often more diverse and may be more sophisticated than what UNHCR delivers either directly or through subcontract in the refugee camps. On the other hand, in many situations the standard of care in urban areas may be significantly inferior to what UNHCR can provide in sites that it can closely monitor (e.g. camps), particularly in terms of reproductive health and primary care for infants and children. Respondents point to positive examples where UNHCR has been vigorously pro-active in building contracts with urban providers for a certain package of care to deliver to urban refugees.

The persistent problem, however, is inadequate information and monitoring capabilities. It is not known who slips through the cracks and obtains care elsewhere and it is not possible, through current billing processes, to know in any given urban refugee situation on an annual basis how much UNHCR is actually spending for these refugees, regardless of whether they are seen in UNHCR subcontracted sites or seen outside the UNHCR span of oversight.

Respondents note that the default position for many UNHCR field staff is to assume that urban refugees are managing to find health care on their own and that those who are vulnerable will come to UNHCR. The focus of attention remains on camp-based populations, where it is easier to monitor health care delivery parameters and easier to account for funding. The situation, in the view of the interviewees, has devolved to one where UNHCR staff have little knowledge of the health concerns of urban refugees and little information relating to UNHCR health care costs for this population segment. Given what is perceived to be an increasing proportion of refugees moving into this urban category, it appears that these concerns will need some attention in the near future.

#### 2. Distinctions between refugee and host populations

This second distinction has been explicitly acknowledged by UNHCR leadership for decades and has been amply explored in a range of research papers and formal policy statements. The health mandate with regard to this distinction has been clearly elaborated in two key principles: ensure that all refugees are provided with a minimum standard of health care; and take all measures to be sure that this minimum standard is also available to the local host population. This policy has pragmatic and ethical justification, in that it maintains a sense of fairness and equity between two contiguous groups of people who must, for a range of security and political reasons, be encouraged to live in this adjacency as harmoniously as possible for an indefinite period of time.

Three factors noted by interviewees occasion the need to amplify and clarify UNHCR policy around this distinction between host and refugee populations. Two of these factors are closely related. As an increasingly large percentage of refugees are forced to remain in refugee status for years, if not decades, their health needs are becoming more complex and diverse than can be accommodated by the basic primary health care systems (which UNHCR has often helped improve) available in the surrounding local host areas. A central reason that refugee health needs now include management of chronic illness and conditions of aging is that UNHCR has been very successful in providing the basic health care package that allows these populations to survive to robust adulthood and enjoy greater life expectancy.

Long duration living under UNHCR attention to their health needs has allowed these populations to thrive but has also allowed them to enter the age groups where chronic illness begins to surface. (Host populations throughout the world are also aging, as some function of decreased fertility, improved health, and economic growth.)

These combined factors confront UNHCR with the question of what further elements in a complete health package it now must assume, in order to provide care for its refugee populations who have survived to experience the morbidity patterns of older age. To what extent must UNHCR begin to work with ministries of health at the national level to build up secondary and tertiary institutions of care? What are the limits of UNHCR responsibility for health—when primary health care supports are becoming less relevant to reductions in morbidity than are resources to help sustain older populations with diabetes, heart conditions, and a wide range of degenerative disorders? What defines the scope of UNHCR program and budget for health services, when the issue of reducing morbidity on a population basis moves beyond immunizations and pre-natal care?

The third factor is tied less to the demography of aging and more to the political demography of refugee flows. Conflicts and crises among the more developed countries of Europe, Middle East and North Africa and Asia, including the current one in Iraq, precipitate movements of people across borders who come from societies with higher standards of living and with demographic and disease profiles of older populations. Often these populations seek refuge in host countries that have fewer resources and lack the health services that these new populations require to meet their health needs. Several questions arise that are not addressed in current UNHCR health policy: how does one define necessary health services for older populations with burdens of chronic disease; to what extent should UNHCR take on the responsibility of improving the secondary and even tertiary capacity of the host country when these services are deemed essential for large numbers of refugees under UNHCR mandate; and to what extent should UNHCR shift its focus to expand its health care resettlement policy and seek to move older refugee populations more aggressively into countries with more developed health care systems?

#### 3. Distinctions across refugee populations

The Iraqi refugee crisis has cast in sharp relief the familiar but now acute dilemma of relative resource allocation across refugee populations. On a per capita basis, the budget for an Iraqi refugee is many times higher per capita cost of providing for a refugee in Africa or Asia. The concern about relative equity arose earlier with the 1999 Kosovo crisis, when per capita expenditures for Kosovar refugees in Albania and Macedonia, again a population that was relatively elderly and burdened with chronic disease, was determined to be several times greater than annual per capita costs for refugees elsewhere in the world. 1 That crisis was short-lived, however, and the discussion that it provoked, although illuminating, did not prompt a major reconsideration of traditional UNHCR approaches to the question of how priorities are set and resources allocated.

This third distinction, relating to the level of services and the per capita expenditures for refugee populations with different health needs, is now a matter of active interest among headquarters staff in UNHCR and donor countries. Among the respondents, this issue evokes only moderate discussion. It is well understood and accepted among all respondents that UNHCR had to maintain the health of populations it was responsible for and that older populations, who had been sustained by more developed health care systems, could not suddenly be left to fend on their own simply because they had been forced into refugee statues. It is also well understood and acknowledged that the per capita expenditures and level of health services could reasonably be much lower for refugee populations from very poor nations who had low average life expectancy, high proportions of women and children, and health needs that

<sup>&</sup>lt;sup>1</sup> Macrae J. The new humanitarianisms: A review of global trends in humanitarian aid. Overseas Development Institute. Humanitarian Policy Group report 11, April, 2002:32. Data are aggregated for "south-eastern Europe."

could be met by good primary care interventions. No one among those interviewed believes that UNHCR has the responsibility to address worldwide inequities in health status and health systems.

In this context, however, several key points are raised with the intent of urging UNHCR to develop more robust and transparent policy and more nuanced program alternatives. The first point is that differentials in health expenditure across refugee populations need to be based on comprehensive and valid information and on allocation guidelines, based on this information, that were clear and appropriate, in terms of medical standards and ethical principles. It is not the distinction, or the difference in resource allocation that flows from that distinction, that creates concern among the respondents. The issue is one of fairness, accountability, and health care rationale.

The second point, raised in particular by respondents with a broad range of experience across many different refugee populations, is that these differentials would be more acceptable to them if they could be more reassured that the minimum health standards were being met at the low end of the expenditure continuum. Many of the interviewees say that it made ethical and medical sense to increase the health budget for Iraqi refugees but that it is entirely unacceptable that the existing state of under-funding of health care for poor refugee populations persists. There is considerable intensity advanced on the concern that UNHCR is failing to meet its own minimum standards in many regions and that this practical issue makes the choice to expend additional funds on the upside for the better-off refugee populations considerably more suspect in ethical terms.

The third point is a variant of what has already been discussed in relationship to the changing nature of refugee populations through time. Interviewees note that in many refugee circumstances in Africa and Asia the health care needs of aging refugee populations were requiring a greater expenditure of resources and more elaborate attention to referral mechanisms for secondary care. The health-relevant distinctions between first world refugee populations and those from the developing world are beginning to erode. It would be a mistake, the interviewees believe, for UNHCR not to recognize the ways in which the demographics of their entire refugee population were starting to drive demand for more advanced and sophisticated health care services.

#### Health

#### 1. Relative priority

In discussing issues of equity and public health, the respondents often began or ended their remarks with a look at the larger picture: where did health fit into the overall priorities of UNHCR? This question is logical, in that it could be assumed that the agency's resources would flow differentially based on its overall priorities. This question is also raised by some respondents as an implied rebuke. They express concern that UNHCR at headquarters level does not recognize the significance of health in its overall agenda and is not, in fact, devoting the resources to health that a more enlightened perspective would deem prudent and necessary.

All respondents who deal with the topic of the relative standing of health in UNHCR's priorities note the historical primacy placed on issues of protection, initially defined primarily in legal and security terms and then increasingly, as the human rights discourse pervaded all aspects of UN programming, defined as well in measures to address vulnerability and promote dignity of persons. None of the respondents dispute this primacy and all affirm that protection, in its expanded definition, should remain the first priority of UNHCR. Affirming that, there remains a diversity of views among the respondents as to the relative status that health should be afforded among the other social mandates.

Those respondents who are not health care providers or whose careers had been based more at headquarters are less insistent on this point and observe that it remains unclear to them how much priority actually should be placed on health, as opposed to enhanced protection activities. (Virtually all agree that health should receive higher priority than education, although for some of the interviewees it is a close call). These same respondents note, however, that regardless of their own views, there is increased demand from donors to address the health needs of refugee populations. In settings where refugees were from the developed world, it also appears to the respondents that the pressures from host countries are also increasingly focused on supports for refugee health services.

Those with health backgrounds or extensive field experience (and particularly those with field experience with other NGOs) insist that health should be considered the next essential priority, above others in the social or economic spheres, because ensuring that people survive and attain some minimum level of well being is a prior and more fundamental endowment than education or economic self-sufficiency. In their view, this perspective is not shared by the many within the organization who are not directly involved in delivering health services. This relative indifference, as these respondents see it, is reflected in the relative paucity of people assigned to health at the field level and in the relatively low overall level of budget allocation to health care services. Many note with approval that an exception to this problem of resource commitment is the focused attention given to HIV/AIDS. The marked advances on all fronts relating to this disease, from research to programming to improved health outcomes, suggests to these interviewees that it is entirely possible for UNHCR, were it to commit to doing so, to make substantial and across-the-board improvements in refugee health care.

#### 2. Quality and operations

This discussion of health opened up a window on another topic, closely related to priority-setting. Among those respondents who believe that health should rank higher in UNHCR priorities, the deeper concern is less the relative place of health on UNHCR's agenda than the gap in resources, human and financial, that are needed for UNHCR to fulfill its commitment to meet minimum standards of health care. A number of people interviewed raise questions about the quality of the health care that was being delivered and the capabilities of UNHCR health care operations. As might be expected, respondents with considerable expertise in health care issues are particularly outspoken on these questions, observing that while attention to equity in distribution is worthwhile, more effort should be given to addressing the quality and coherence of the care that is being delivered.

The quality concerns relate to lack of skills and medical understanding on the part of providers, failures to follow standard protocols and interventions, insufficient supplies of basic medications and materials, and inadequate monitoring and follow-up procedures. Although UNHCR works through subcontracts with NGOs and government clinics, the respondents state that these problems are within the capacity of UNHCR to correct but that it would require increasing the numbers of knowledgeable UNHCR field staff who are committed to monitoring the process and course of care delivered at the individual sites.

Respondents also describe their concerns about inadequate registration and information systems, poor management data, particularly on financial matters, and under-developed plans and protocols for coordination and referral to sites within the host country or elsewhere. They attribute these gaps, in large measure, to the paucity of field health staff with sufficient experience and expertise to make the changes that are needed.

#### 3. Individual cases

Many of the issues discussed raise ethical dilemmas but the one that elicits the most intensity of feeling is the question of what to do with individual cases of extreme and urgent need. The dilemma is most acutely felt in the context of refugee populations supported by relatively low budgets for primary health care, in poor areas of Africa and Asia.

Almost all of the interviewees had experienced the anguish of having to decide whether to approve the expenditure of scarce UNHCR funds to save the life of an acutely ill or injured child or young adult. Several of the interviewees have also been confronted with decisions of approving advanced interventions (surgery, cancer therapy, dialysis) that would sustain or salvage the life of an older adult.

All the respondents are familiar with the presiding ethical principle of triage, whereby one must strive to maximize the health of the greatest number of people for whom one is responsible. They also know that this principle would suggest that exceptions requiring expenditures outside of approved budget and protocols of care would have to be carefully defended on non-arbitrary grounds. They easily incorporate in their analysis the basis on which exceptions to this triage principle could be developed: whether one knows that a surplus in required resources does exist and whether one knows for sure that there would be a finite number of exceptions coming forward within a given budget cycle who could be thus accommodated.

The difficulty, as the respondents note, is that it until recently, with the implementation of a new budget tracking system (i.e. MSRP), it was usually impossible to know what the actual annual health budget was for the population, let alone what proportion has been expended.

In some instances, the respondents report that they had made an exception and approved a significant one-time expenditure. In other instances, the decision was made to adhere to the population-based protocol. The respondents state that it is a somewhat easier decision to adhere to protocol if they do not personally know the patient or his or her relatives. It is also easier to make a protocol-based decision if the required expenditure was a significantly high fraction of the estimated overall annual health budget for the population.

The respondents report that having to make such decisions are among the most painful moments of their professional careers.

#### Transition

#### 1. Transition from emergency to development

The length of time that refugees remain in refugee status now far exceeds the expectations of those who framed and affirmed the 1951 UN Refugee Convention or its 1967 Protocol. In some instances, refugee stay in host countries has extended well past the emergency phase of the initial crisis that prompted their forced migration, but a number of political, social, and/or economic barriers prevent their return, their resettlement, or their granting of asylum. In other instances, the precipitating crisis continues to smolder for decades, delaying substantive population-wide resolution. These instances often overlap and they all appear to defy diplomatic ingenuity or political will.

The respondents are resigned to this state of affairs, acknowledging that UNHCR has an essential and unique role in continuing to provide ongoing legal support and protection to these long-stay refugees, the so-called "warehoused" populations. As a result, however, it is pointed out that UNHCR is being driven by circumstance, and not as a matter of strategy, to continue to provide a host of social and economic services (including health and education) to populations who in many ways are moving out of emergency and into development modes. A generation of children has been born with no knowledge of their home country; refugees are gaining jobs and learning customs and languages of their host country; many family members have merged into the host society or slipped abroad, sending remittances back to those who remained. Successful UNHCR arrangements for health and education mean that the agency is paying for and to some extent over-seeing the social welfare of large numbers of people whose legal status

remains uncertain but who in many other respects appear over time to have worked out various forms of functional integration within the region to which they had fled.

The sentiment expressed by the respondents is that UNHCR has now become the agency of first resort in emergencies and last resort in development—filling a gap left by the inability or refusal of the international community and host ministries to take on. A consistently defiant esprit de corps seeps into the discussion at this point in virtually every interview: UNHCR could be proud of its reputation as a "can-do" agency, able to go to remote or austere areas and establish emergency operations capable of saving and sustaining the lives of tens if not hundreds of thousands of people in very short order. In that emergency phase, UNHCR is the only agency with the responsibility and capability of managing all sectors of the response—from security to health. The fact that UNHCR is also granted a unique and tautly political mandate, the protection of refugees, further enhances its standing in the humanitarian community and allows it to make rightful claims at the international level relating to financial support for its operations and diplomatic and political support for security of populations.

But UNHCR is pre-eminently a humanitarian outfit, in the view of the respondents, not a development one. All aspects of UNHCR (its skill set, its budget, its management style, its organizational framework) are oriented towards this emergency mission. Its success is measured in the least time it takes to bring a population back to survival equilibrium and to build an environment of protection and stability for everyone in its charge. Thereafter, UNHCR is hampered by the absence of an exit strategy. In the view of the respondents, the international community as a whole and the host Governments has become excessively comfortable in relying on UNHCR to stay with these refugee populations over decades, taking care not just of their legal and protection needs but their health, their education, and their livelihoods. In the view of this cross-section of UNHCR staff, this extended and broadly defined role is becoming increasingly incompatible with the kind of organization UNHCR was intended to be, and at its best, still is.

#### 2. Duration of UNHCR's responsibility for health

The issue of health figures prominently in this discussion of transition out of emergency phase into development. There is virtual unanimity among the interviewees regarding the question of whether UNHCR should continue to assume responsibility for the health of these populations who had been in camps or self-settled in urban areas for five, ten, or fifteen years. These seasoned observers of humanitarian practice point out the following three main reasons why UNHCR should consider developing a different strategy around health care:

- 1. UNHCR lacks the staff and the expertise to do more than stabilize the health of populations arriving in acute crisis;
- To do an acceptable job of what the agency is now struggling to manage the responsibility of health care
  delivery for large populations over time would require significant re-design of operations, marked
  budgetary increases, and major expansion in the recruitment, training, and monitoring of staff;
- 3. To take on this long-term responsibility would risk the erosion and possible loss of UNHCR's special identity and culture as an emergency, front-line agency with the alacrity and capacity to be responsive to sudden influxes of large populations in the most remote parts of the world.

These three reasons for resisting the notion that UNHCR should proactively embrace the situation it now finds itself in are shared among all the respondents, whether health care workers or not. Those with more years of experience within UNHCR are particularly firm about their concern that a potential loss of identity and sense of mission is at stake, were the agency to persist in trying to manage the health care of large, complex, and aging populations through time. The issue of having to make exceptions for individual cases invariably resurfaces in this part of every interview,

as respondents envision an ever-increasing demand on the part of even poor and remote populations for better and more available services. The increase in demand is in part related to the fact that the populations are aging and need more advanced care or, as they integrate with host populations, they are more exposed to transport or work-related accidents and injuries.

The growing demand is also linked, according to the respondents, to the reach of globalization and improved conditions in at least some corner of the host country or country of origin. Refugees in general are becoming more aware of possibilities and UNHCR is facing a tide of rising expectations everywhere. A certain urgency pervades the respondents views on this issue, in that they believe it will be necessary in a matter of a few years for UNHCR to come to terms with the contradictions between its mandate and what it is best equipped to do and what it is now trying to provide.

#### Summary of relevant theoretical literature

(See Appendix I for expanded account)

A review of the theoretical literature on public health equity, health and human rights, distributional ethics and notions of justice was conducted and yielded three main points of relevance to UNHCR practice and policy on refugee health.

- The dilemmas that UNHCR faces in terms of public health equity across diverse and needy populations are not well formulated and in fact are only marginally addressed in standard writings on bioethics and population ethics;
- 2. The literature on health and human rights looks at issues of disparity, access, or stigma primarily within one national population, not across populations in crisis or post-crisis conditions;
- 3. The relevant normative principles lie in the realm of distributional ethics, notions of justice, and the quality of the processes used for making decisions. Here reference is made to John Rawls, Amartya Sen, and Norman Daniels, who along with other colleagues have made major contributions to this literature.

#### Distributional ethics

Ethical issues certainly arise in conditions of relative abundance (according to which the responsible authorities may tolerate marked inequities in distribution of goods and services or marked disparities in quality) and are approached through practical operations improvements in efficiency or functionality or through arguments about cost benefit trade-offs and what society deems as the "good life." These ethical arguments become much starker in settings of relative scarcity, which apply to most zones of UNHCR activity. Practical operations improvements will do relatively little to bridge the gap between what large numbers of people need in order to survive and what resources UNHCR can marshal for their care. At the population level, UNHCR enters the arena of emergency triage, where decisions on resource allocation may well have proximate life and death consequences. In mass casualty care during military operations and catastrophic disasters occurring in peacetime, the concept of emergency triage is well accepted and responders have been trained in the ethical as well as technical applications of these principles.

According to this emergency concept of triage, the responders must act to maximize the greatest good for the greatest number. In most modern military and disaster settings, this concept is taken to mean to maximize the number of people who can be salvaged within a given set of constraints on resources, including supplies, skills, transport, and time. Humanitarian aid workers aim to meet this same standard, using protocols and guidelines that help organize decision-making and priority setting.

Not much has been written about non-emergency distributional ethics in resource-poor environments. Taking from the robust literature on peacetime distributional ethics in the developed world, where the focus is usually on one macro-system, such as the United States or another western nation, issues of equity arise when speaking about devoting more resources to the young rather than the old, the disabled and ill rather than the healthy, prevention rather than cure, and so forth. Hence the development of technical terms such as DALYs (disability adjusted life-years) and QALYs (quality-adjusted life years).

The fundamental point about distributional ethics is that the answers can be very different from emergency to nonemergency settings and from one social system to another. The ethical perspective intrudes in terms of process. The answers are deemed ethically satisfactory to the extent that the process for reaching them is inclusive, deliberative, consistent, technically sound, and transparent.

Yet this process-based approach has been developed from within the framework of one nation-state, with possible application in other states that have similar socio-economic hierarchies and political cultures. It is not clear how much in this approach is directly transferable to the requirements of UNHCR, an international institution working across and within highly diverse societies, some with good governance and many without functioning state authorities. And even within one society, a focus on a technical analytic process may still not resolve the prominent open question as to what is fair and what is merciful.

#### Notions of justice

Questions of the "just" state and the "just" society have preoccupied serious thinkers for centuries. John Rawls considers justice from the perspective of what the state can provide and perceives it as a form of fairness, not as an element that can solve all wrongs and miseries. A theory of justice, according to Rawls, can achieve three main things: help a society frame its notion of the good life; define how to make that life available to all (an equality of opportunity); and specify what the state must do to make that outcome possible.

Amartya Sen does not see the world as ordered by a liberal consciousness, buttressed by well-functioning and rational states. In his view, "negative" freedom (equality of opportunity) is insufficient to compensate for the lack of access to goods and power that so many poor people in many countries must now wrestle with. He advances the concept of "positive freedom" or "capabilities," according to which the state must provide a basic minimum of resources that will permit an individual to achieve the capability to act on his own behalf.

In either of these constructs, health, as a key social good, could be defined broadly or narrowly. Approaching this question from different directions, both Sen and Rawls tend to view health in somewhat constrained ways. According to Rawls, a just society is one in which real competition flourishes (so as to maximize rewards for talent and effort) but also one in which minimum social supports are delivered to allow an individual to live a minimally decent life. Sen does not directly address the issue of minimum levels of health inputs but does note that in general

what might be considered a minimum level of resources for achieving acceptable levels of capability might vary from country to country, depending upon variations in standard of living.

In a most basic summary of their positions, both would hold that with any social good, including health, the state must strive to meet some reasonable social minimum and both would agree that such a minimum might vary from one society to another.

#### Social minimum, social inequalities, and redistribution of resources

Most theorists on social inequalities propose solutions based on the assumption that the pool of resources is finite and that the questions to resolve are how to make re-distributions within that fixed pool. The discussion in the literature thus focuses on how to accomplish transfers of resources from those with access to abundant goods to those without.

Two key boundary issues appear in this literature on justice and distribution of resources: It is not wise or feasible to try to make everyone in a society equal, in terms of wealth and access to social goods; and 2) it is not wise or humane to make these resource transfers solely on the basis of marginal utility. Reasons behind the first boundary condition are that such transfers would abuse the rights of those who are wealthy, would gravely deflate incentive systems, and might introduce new problems (for instance, how would one assure that the redistribution of wealth was spent on important social goods, or would not impair the further production of social goods, or would not get lost if leveled over a vast number of very poor?). Reasons behind the second boundary condition are that crude economic costbenefit analysis (conducted at a population level) overlooks the key ethical question of relative need. The relative value of a resource transfer is not just what it accomplishes at the population level but also what it means to individuals who receive the resource transfer. Thus transfers of resources to the very ill might not perceptibly raise aggregate measures of population health but would mean a great deal to those individuals and their families who are suffering and to the rest of the population who might anticipate needing those resources were they ever to fall into similar circumstances. This moral view of prioritization in resource transfers is termed "weighted well-being" and is measured over the lifetime of individuals.

#### Health as a priority among social goods

Those who follow in the Rawlsian tradition argue that health is important to individuals and to society but that in the context of a liberal and democratic state it is equally if not more important to devote resources to the maintenance of political and civil structures and to the workings of a competitive economic system. This bounded concept of health is best described by the philosopher Norman Daniels, who has made key contributions to ways of working out disagreements on health care allocations. Sen and others who write from a capabilities approach would offer a more profound role for health, arguing that it is a crucial component in allowing an individual to achieve his or her full capabilities, expressed as a sense of agency and wellbeing. Daniels (and Rawls) would see the state as compensating for inequalities by providing minimum resources to the poor; Sen would require the state to provide resources so that the poor are fully empowered.

#### Health in an international context

Much of the debate on health equity and justice takes place within the framework of one nation-state, which is defined as having legal, economic, political, and military control over a specific population within a specific geographic space. The state undertakes legal obligations and the populace, particularly in the context of human rights, makes claims against the state. Since these dynamics are less articulated in the international arena, it is less clear what role international institutions might play with regard to setting standards for health care or to actual delivery of health to particular populations. Daniels, while noting that Rawls was more focused on the individual nation-state, suggests that in one aspect the international community does play a major role—in terms of defining the obligations of nation-states towards their own populations. In this evolving arena of international norm-setting, Daniels suggest there is latent potential for international institutions to act in a "cosmopolitan" mode on behalf of all people in the world. He would emphasize the latency aspect of this potential, however, by pointing out that the functional and substantive means for dealing with health inequalities across countries do not yet exist.

Sen more readily takes a global perspective on issues of equity, including health, and has been a major force in the establishment of the UN Human Development Reports and the Human Development Index. Those goods deemed essential to the capabilities approach are packaged into three essential indices: to be knowledgeable, to survive, and to enjoy a decent standard of living. Health is a component of all three of these indices. The annual report and index create international political pressure on those countries that are low on the list and on those developed countries that have the means to help improve the standing of those at the bottom. This process goes beyond norm-setting, yet it too plays out in the realm of perceived, rather than statutory, obligation.

#### Making decisions about health allocations

Moral philosophers have engaged in a very interesting debate about rules for deciding ethical questions: is there one unifying rule (as Kant and Rawls would have it) or must people deliberate on the basis of the situation and the evidence, using principles as appropriate (the stance taken by William James, Charles Stevenson, Stephen Toulmin, and others)? (The content of this debate is summarized in Appendix 1.) Of practical relevance here is that whichever position one adopts, there will still be the need to agree on a set of deliberative principles, a process framework for arriving at decisions and for achieving support from the large numbers of people who will be affected.

The work of Daniels is particularly important in defining what this process might look like in the context of making decisions about health care allocations. His view is informed by the technical discussions relating to guidelines and protocols, the increasingly sophisticated analytics around cost-benefit issues, and the consultative approaches advanced by advocates in the health and human rights community.

He defines four major attributes of a fair process for decision-making in health allocations, describing them as conditions that must be met:<sup>2</sup>

- 1. Publicity condition (relating to transparency and accessibility)
- 2. Relevance condition (evidence-based, assessed as fair by a wide group of stakeholders)
- 3. Revision and appeals condition (mechanisms for appeals and revisions)
- 4. Regulative condition (voluntary or public oversight and regulation of the processes)

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 $<sup>^{2}</sup>$  Daniels N.

These conditions do not set forth the content of the decisions that will be reached but in his view will provide the legitimizing framework for making them. It is through such a framework, he argues, that a society can be assured that its decisions with regard to resource allocations are both fair and just.

#### **Ethical Principles of Relevance to UNHCR**

#### The importance of health in UNHCR

Before proceeding to a discussion of key ethical dilemmas that UNHCR now confronts, it is logically necessary to raise the overall question of where the topic of health sits in the relative priority list of UNHCR. The dilemmas proceed from the assumption of having to work within a very limited health budget. The framing question advanced here is whether that assumption should be considered inviolable.

It is a fact that resources available for health are limited, at every level of society—domestically, internationally, and within UNHCR. Yet in every one of these system contexts, including UNHCR, it is possible to conceive of a debate and a resulting decision that would lead to an increased share of that system's resources being devoted to various aspects of health and health care, broadly conceived. The rationale for that decision might be simply the pressure of inescapably urgent need (an aging population, for instance). The rationale might, however, derive from a re-casting of the importance of health in shoring up or restoring individual, group, national or international well being.

In ethical terms, both from contract theorists like Daniels and capability theorists like Sen, the more exploration that is given to the role that health plays in promoting other aspects of the good society, the more health assumes greater priority in the set of primary goods or in the hierarchy of human capabilities. The empirical evidence leads these theorists to suggest that the road to fulfilling several other potentials (or opportunities, in Daniels' term) in human life (capacity to learn, to enjoy relationships, to engage in productive economic behavior, to take of others) relies very fundamentally on meeting health needs. Health needs are described by Daniels as consisting of the following "broad and diverse set:" <sup>3</sup>

- 1. Adequate nutrition
- 2. Sanitary, safe, unpolluted living and working conditions
- 3. Exercise, rest, and such important lifestyle features as avoiding substance abuse and practicing safe sex
- 4. Preventive, curative, rehabilitative, and compensatory personal medical services (and devices)
- 5. Non-medical personal and social support services
- 6. An appropriate distribution of other social determinants of health

A just and fair society aims to promote each individual's opportunities, or, in Sen's term, human capabilities. Health provides opportunities for normal functioning. Degradations in health will constrain these opportunities. Were it really taken seriously, this notion of health as essential to normal human functioning would have great implications for systems founded with the mandate to provide protection and welfare to human populations, such as UNHCR.

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<sup>&</sup>lt;sup>3</sup> Daniels N. 2008:42.

Many of the respondents raised concerns that the UNHCR budget for health was simply too limited to do anything well, whether meet the lowest social minimum or provide the quality of care required in the (admittedly austere) protocols. Other respondents suggested that health needed to be given greater prominence in the institution, particularly as an increasing number of refugees were living much of their entire lives within the UNHCR system. People were no longer seeking temporary emergency support at the level of a lean social minimum; they were seeking the means to live out their lives as refugees in dignity and health. These comments, anecdotal only, contribute to the suggestion raised here in an ethical context: It is perhaps time for UNHCR to re-evaluate the relative position that health now holds on the institutional the priority list. By taking on the obligation to promote normal functioning by meeting the health needs of the population, UNHCR might find other priorities subsumed by and accomplished by this agenda. Recent efforts to address this situation have occurred with increased funding for malaria, reproductive health, gender-based violence, nutrition, water and sanitation programmes under the High Commissioner's Special Projects.

#### Dilemmas of distribution and justice

The above review of the literature on health equity has included passing references to topics or ideas that have direct relevance to the dilemmas and problems faced by UNHCR. This section pulls out those concepts and summarizes them in a format that might be more readily accessible and useful. The selection is eclectic, in that it draws from different systems of thought or argument. No attempt is made to create a new systematic framework of international public health ethics (an endeavor that might attract philosophers in the years ahead). Instead, this brief summary is designed to highlight ideas or approaches that might shed light along the path that UNHCR has to forge every day, as it develops or implements policies relating to the distribution and monitoring of resource use in a setting where need is great, diversity of capabilities and opportunities is high, and, in settings where people lack power and voice, finding consensus on justice and fairness is hard to accomplish.

Four key ethical dilemmas relating to public health equity are identified. The same structure is used to discuss each of them: description of the problem; proposed ethical solution based on the literature; assessment of the capacity of UNHCR information and human resource systems to support the implementation and tracking of this solution; and ways to translate this proposed solution into policy, relying on the four Daniels process conditions.

It will become immediately clear at the end of the discussion of the first of these ethical dilemmas that a major hindrance in all phases of the definition and resolution of each of these dilemmas is likely to be the unevenness and immaturity of UNHCR systems for gathering information and deploying staff at the numbers and skill levels required.

#### 1. Distribution decisions within one population of refugees

UNHCR faces major distributional trade-offs which have as a core decision point the question of whether to maximize the greatest good for the greatest number (which in crude utilitarian terms would mean maximizing average health status) or whether to maximize the greatest good for those most in need (which disproportionately would direct resources to those who are most ill or most at risk and would reduce the positive cost benefit equation by not raising average levels by as much as the first approach). These distributional trade-offs take place at the operations level, within one population, when over the course of an annual budget cycle the demand on available funds becomes intense.

SOLUTION 1.1: The argument from justice and fairness would suggest that emphasis be placed on raising the level of those most in need, and thus devoting more resources to their care. The upper limit to this re-direction of expenditures would arrive at the point where measurable and meaningful degradations in the care delivered to the relatively stable and healthy members of the population begin to be seen to place their health status in jeopardy. This principle would also come into play when determining whether to make individual exceptions to protocols of care.

ANALYTIC PROCESS 1.1: Robust processes would be needed to develop the information base that would allow UNHCR to estimate reliably the baseline health status parameters of the population and the health needs of the overall group and subgroups; and similarly robust processes would be needed to monitor changes in expenditures and track changes in health status. It should be pointed out that these processes are not the ones referred to by Daniels in his recommendations about how to develop just and fair decisions on health. These are subsidiary information gathering processes, without which no rational distributional decisions can be made.

CONDITIONAL PROCESSES 1.1: The justice and fairness processes as recommended by Daniels would come into play at several levels of setting policy around this particular question. To begin with, the publicity condition suggests that the decision to treat those most in need would need to be discussed publicly. The relevance condition suggests that the definition of who is considered most in need would have to be determined in part by epidemiological evidence but also by enlisting the views of community stakeholders. The last two conditions (revision and regulation) are self-explanatory but difficult to put into practice, given the distant institutional relationship that UNHCR has to the population it serves.

#### 2. Distribution questions across populations of refugees from different countries

With Iraqi refugees, UNHCR is now confronting the significant issue of having to pay for more complex health care, leading to large differences in per capita expenditure when compared to other refugees around the world.

**SOLUTION 2.1:** This question could be framed as a problem of inequality within one system of care (taking UNHCR as the institution and all refugees around the world as the population for which it is responsible). From this perspective, the question becomes how much inequality can be tolerated for a system to still be declared just and fair. The theoretical consensus from the contractual and capabilities approach is that within-system differences are tolerable to the extent that those at the bottom receive an appropriate minimum bundle of services that provide essential primary goods or human capabilities.

SOLUTION 2.2: Another approach to this question would be to frame it as one of international disparities—to what extent are these unjust and to what extent can a health-based approach resolve these injustices? Daniels (and other contract-based theorists) is clear on this point: injustice arises only around "socially controllable" sources of disparities; and these sources can only be addressed in the context of the overall political and economic system. In other words, the regime of international justice has not developed to the extent that one can identify international obligations to address these international disparities at the international level. This line of reasoning would suggest that reference to international justice leaves UNHCR with little obligation to affect or change these disparities and that the space for ethically-based decision making must be filled by some other approach to finding just solutions to achieving health equity.

But this guidance is only marginally helpful, because in many substantive and legal ways the world's population of refugees is by definition outside the usual overall political and economic system of nation-states and instead has by law and expectation been encouraged to seek all basic welfare needs from UNHCR. From a narrow legal and administrative perspective, UNHCR does indeed have some "social control" over the source of health disparities and through the UN refugee protection regime, established by international law, is indeed responsible for some kind of

political and economic apparatus (if not a system) within which refugees must live and from which they are entitled to receive protection and welfare benefits. UNHCR, through international contract, has substantial and even openended (because limits are not set in the law) obligations for refugee health.

Hence the real practical as well as ethical dilemma: Through this more amplified reading of international justice obligations, UNHCR in fact does have some responsibility for addressing and redressing these disparities, to the extent they are socially controllable (and many health disparities are very much so); yet UNHCR, as an institution, plays in that intermediate zone where, according to political philosophers, it has neither the machinery of the state nor the legitimacy of political power to exert effective coercion over all possible resources from this population and to fully enlist their voices in support of comprehensive policies that might deal with these disparities.

The reason why the international justice perspective is indeed one of potentially powerful relevance to UNHCR is that institutionally it can be considered to hold nation-state obligations for those outside the protection of their state but in terms of delegated powers (and resources) from the international community of nation-states it has not been granted the effective authority to fulfill these obligations.

**SOLUTION 2.3:** On balance, it appears as if the rational ethical position for UNHCR would be to assert without qualification that in fact, yes, it is one institution presiding over the care of one population and adopt the position suggested in Solution 2.1. In effect, the outcome of the applicability of Solution 2.2 would drive that decision as well.

ANALYSIS PROCESS 2.3: The enormous problem this choice of position carries with it, however, is what was identified in the discussion of Solution 1.1: how to manage the information and human resource systems to describe and monitor the actual issues? If it appeared difficult to do so for one population within one country, it is likely to be even more so when the needs for information and monitoring extend across many millions of people and all parts of the world. The point might be made, however, that these information needs and these monitoring practices are actually very similar, and one flexible and coherent system might actually be possible to roll out worldwide without a numeric increase in resources required to do so. That point does not really apply to the human resource question, however. Every site, through time, would need to have people who are competent and attentive to these analytic processes. To achieve that level of human performance in the worldwide system is a huge task.

CONDITIONAL PROCESSES FOR 2.1, 2.2, AND 2.3: There are several possible approaches, depending upon where one situates the locus of public input and accountability. At one extreme, UNHCR could assert that as the presiding authority over one system for all refugees in the world the Geneva headquarters would convene public hearings and issue public announcements (Condition 1); establish a representative forum empowered to provide input into development of guidelines and protocols (Condition 2); set up a mechanism for receiving suggestions for revision and improvement (Condition 3); and establish procedures for accountability that would engage members of the refugee community as well as the donor groups (Condition 4). At the other extreme, UNHCR might attempt to set up the mechanisms to meet all four conditions within one country. Whether some regional mechanisms might prove more fruitful would be the question underlying a proposed middle-ground arrangement.

In many ways, UNHCR already proceeds as if it were functioning as the presiding authority based in the Geneva headquarters. What it lacks, in terms of conditions for a fair and just policy-making system, are the institutional arrangements for seeking input from affected populations (the UNHCR public) at the several steps of policy formulation and assessment. Donors, currently, fill that space.

#### 3. Setting limits on extent of care

UNHCR faces the question of whether and how to set limits in several circumstances: establishing minimum levels of care for one population or across refugee populations; establishing the upper limit (in terms of cost and/or complexity of care) for one population or across refugee populations; and assessing the fairness of user fees. There is no ambiguity about the overall need to establish limits on expenditures and extent of care because the health budget for UNHCR is stretched as it is and the options for increasing that total budget are outside the scope of this discussion.

**SOLUTION 3.1:** With regard to upper and lower limits, the solutions to questions 1 and 2 apply here. There is no ethical requirement that UNHCR take an egalitarian approach to populations. It is fair and just to establish social minimums and the content and expense of those social minimums may vary depending upon need and the level of primary goods and capabilities to which that population is accustomed. The upper limit on those resources would be reached when within a fixed budget the transfer of funds begins to impinge on the well being of those who are basically healthy or who are accustomed to managing at a lower social minimum. In other words, the extra resources to meet the extra needs of one refugee population cannot be extracted at significant cost to those who are receiving less per capita, either within one population or across a wide range of populations.

(Recall, based on discussion of question 2, that UNHCR in effect has to behave as if it is one institution responsible for many different populations.)

**SOLUTION 3.2:** With regard to user fees, there is substantial support in the ethics literature, particularly among the analysts who take a contractual approach (Rawls/Daniels), for charging a user fee provided that the fee does not restrict access and provided that the fee is fairly assigned across populations or population sub-groups. These two provisos add considerable cautionary complexity, however.

In general, public health authorities agree that charging user fees to poor populations introduces a measurable, and in some settings a very significant barrier to access. Certainly, user fees should not be charged in advance for emergency care. The problem of determining fairness in assigning these fees, and getting around the problem of access barrier, has been addressed in some circumstances by charging user fees according to a sliding scale, or a means test. Those who are very poor pay nothing, and those who are much better off pay the full cost. There are practical issues and trade-offs attached to this solution that in themselves can be daunting, since it takes time, money, personnel and skill to assess the means of an individual who presents for care, and in situations where the great majority of the population are poor there is little gained from this process. The problem of stigmatizing the poor also arises; here the ethical question is whether this identification process could occur without stigmatization or whether the process itself will always lead to some stigmatization as an unwelcome incidental consequence of means inquiry.

The question of user fees links closely to the question of relative social minimums. If user fees were to be charged only above the social minimum for that population, and if UNHCR had instituted a policy of defining social minimums relative to population need and demographic profile, then user fees might be fairly applied across all populations without the need to establish a means test. Access to care that is deemed essential for a given population, recognizing that this bundle of services will vary according to demographic profile of the population, would be free. Access to care above that relative social minimum would require a user fee.

ANALYTIC PROCESS 3.1: These processes would be the same as for 1.1 and 2.1 but would require significant additional technical expertise in specifying and justifying, in epidemiologic terms, what would be the range in the social minimum, relative to demographic profile of the population. In other words, what is essential to provide a 55

year old Iraqi woman in Jordan that would not need to be in the social minimum package for a 55 year old Somali refugee in Kenya?

ANALYTIC PROCESS 3.2: Specification of the costs of each social minimum by population profile would be required. A system for determining the costs of packets of care above the social minimum would need to be established (for each health care zone and each population) and a system for collecting and transmitting fees at the point of service would also be necessary. These processes would require new investment in information systems and human resources, including perhaps enhanced security procedures. Clearly one analytic task would be to determine whether this upfront investment would be balanced out by gains in funds from user fees once the system was up and running. A related task would be to ensure that no unexpected adverse consequences for health or fairness had been introduced.

CONDITIONAL PROCESSES 3.1AND 3.2: These processes would be the same as for question 1 and 2 but would entail significant emphasis on receiving public and stakeholder input for the proposed new policies and for maintaining a steady and comprehensive transparency at all phases of these processes. The decisions reached could very well be fair and just, but if they were not perceived to be so, the entire initiative around limit-setting would fail. Very close attention would also need to be given to oversight and evaluation of these policies, since undoubtedly there would be many new issues arising as these initiatives around relative social minimums and user fees were implemented.

#### 4. When and how might exceptions to protocol or established limits be justified?

A large number of respondents in the interviews said that their strongest ethical concerns arose for them personally when they were asked by patients, families, or other staff to make an exception for an individual case of extraordinary need and/or urgency. The tensions they felt arose from four uncertainties: how much money they actually still had in their local budget (which might allow them to make the exception decision without great risk to other demands on the funds); what precedents existed that might provide them with guidance; what options were there in the region that might be lower cost than trying to arrange a resettlement very far away; and what might be the ethical justification for making an exception in the present, at the risk of constraining options for the protocol-based care of future patients?

The first three of these uncertainties do not raise ethical questions but definitely provide opportunity for administrative and information improvements that would help these field personnel be more secure in whatever choice they make.

The fourth uncertainty is unambiguously in the ethical realm. Although answers might be sought in discussion of distributional ethics and notions of justice, a more direct path to a solution would be to refer to the process of casuistry, whereby individual cases are evaluated and adjudicated in a context of precedent, guiding values, principles of medical ethics, and weighing of best case and least worst case outcomes.

**SOLUTION 4.1:** The first point is that the solution to this problem lies in that body of ethical thought that believes case-by-case assessment is integral to making decisions about justice and fairness at the population level. As Williams James notes: Ethical thinking requires that we "satisfy at all times as many demands as we can...". Furthermore, the most ethical act is that "which makes for the best whole, in the sense of awakening the least sum of dissatisfactions." <sup>4</sup>

<sup>4</sup> James W. The moral philosopher and the moral life. In: Myers GE, ed. William James: Writings: 1878-1899. Library of America. New York, 1992:610.

The second point, viewed in this way, is that it is not only appropriate to encourage senior UNHCR field staff to learn to think about case-by-case ethical reasoning, it is in fact necessary in order to meet the full obligations of justice and fairness. If, for instance, a five year-old refugee boy is hit by a car and requires emergency abdominal and orthopedic surgery, senior field staff would likely decide to spend the money to get him to appropriate emergency and curative care as quickly as possible. Weighing the costs against the benefits (he is young, otherwise healthy, the condition is curable, the technological capacity exists, he can reach it within time to save his life) would suggest that NOT taking this action would, in James' terms, awaken a very large sum of dissatisfactions. Yet stories of not acting in similar settings were shared in the interviews, with respondents saying they were not sure whether to make such an exception from protocol was permitted.

The exceptions cases are often more difficult, in terms of finding the best whole that awakens the least sum of dissatisfactions. What about a five year old boy with a curable form of leukemia, who lives in a refugee camp in northern Kenya? And what will happen when word gets out that he in fact was flown to special care in Nairobi?

Once these exceptional cases are allowed to be taken very seriously, as absolutely valid and important demands on a population-based health care system aligned according to principles of population ethics, there are a number of process and system supports that need to be put into place. But the basis ethical finding from the literature is that the obligation to deal with exceptions, with individual cases, does not go away when one moves from individual care based on medical ethics to population care based on population ethics. In fact, the medical ethicist would assert that the moment you hear about this case, you must act at least in a dual role, as a clinician whose primary responsibility is beneficence; and as a manager in a rationed system.

An implication of this discussion, one not lost on the respondents, is that as the refugee populations even in poor regions become older or more integrated with their host surroundings, the need to make exceptions will increase. The solution to that observation, however, is probably not to keep making exceptions but to consider raising the social minimum for that particular population.

ANALYTIC PROCESSES 4.1: The solution proposed here requires substantial new information, enhanced analytic skill in cost projections, and increased efforts in creative politics to find innovative options. Respondents have proposed increasing the central emergency fund, establishing protocols for making exceptions, new trainings in ethical decision-making, and setting up regional hospital systems that would be designed to take secondary and mid-tertiary range referrals from UNHCR, other UN agencies, and health and development NGOs.

CONDITIONAL PROCESSES 4.1: The advice and guidance from stakeholders, including members from different refugee communities and donors, would be most valuable in framing and legitimating options. Fairness issues would demand the highest level of transparency, so that everyone involved at all phases would know what was possible to permit as an exception and what was not. Very frequent review and monitoring of the new policy and the outcomes of individual cases would be essential in conveying a sense of the integrity of the policy, the soundness of the triage decision, and the quality of the advanced care that was provided.

#### **Overall Findings and Recommendations**

#### Findings and recommendations relating to the respondents

- Senior UNHCR staff (as represented by these respondents) are familiar with the main practical features of distributional ethics and notions of justice.
  - They would benefit from ethical training in the case method in order to become more comfortable making decisions about individual exceptions.
  - Practice in applying the decision-making principles would be helpful at all levels of the organization.
- 2. The respondents are deeply knowledgeable about the ethical and operational challenges facing UNHCR with regard to the Iraqi refugees and also worldwide.
- 3. The respondents identify several areas where major improvements in operation and re-formulations of policy are needed. These suggested improvements are in systems, guidelines, and protocols. Many of these operational and policy improvements bear on ethical concerns.
  - Health information systems (HIS), guidelines, and protocols:
    - Continue roll out of the camp-based HIS (currently in use in 16 countries)
    - Continue development of the urban-based HIS
    - Define the social minimum for populations with different demographic and epidemiologic profiles
    - For exceptions, re-create and expand the central emergency fund and make its exception protocols transparent
    - Establish regional hospital networks to streamline costs and time for transport to secondary and mid-tertiary care
  - Financial and information systems:
    - Improve all aspects with the aim of developing a system of notional capitation and sub-contractor accountability
    - Establish an explicitly separate health registration that integrates with the general registration process (as has been done in Jordan)
    - Consider instituting user fees for utilization of services above those specified in the social minimum
- 4. The respondents identify the growing contradiction between the original mandate of UNHCR and what it is now compelled to do, in terms of expanded services and extended duration of engagement, as posing a short-term threat to the quality of operations and a long-term threat to the integrity of its mission. These threats they perceive as having ethical, practical, and political dimensions.
  - UNHCR, at the senior level, should discuss this problem, which relates not only to health but many
    other sectors, and make appropriate decisions as to where the agency wishes to go and what substantial
    changes might need to be made.

## Findings and Recommendations relating to UNHCR strategy on protracted situations

- 1. UNHCR needs to define the parameters of its responsibility for refugee health to align with the duration of time a given population remains in refugee status.
  - These parameters could be divided into three categories and a layered exit strategy developed depending upon the local context:
    - Health needs that must be met by UNHCR regardless of other variables;
    - Health needs that UNHCR would arrange to have met by host or regional delivery systems; and
    - Health needs that UNHCR would not be responsible for meeting.
- 2. UNHCR has few good options for exit strategies but should consider, in the most long-lived of these protracted situations, developing more substantive plans for transitioning its welfare obligations, including health, to some other entity, which could be the local or national host government or another UN agency.

## Findings and recommendations relating to ethical dimensions of UNHCR policies

- 1. The solutions to major dilemmas of distribution and fairness are already in large measure discerned by senior staff.
- 2. Solutions derived from the literature review are in substantial concordance with ideas suggested by senior staff. These include:
  - The more exploration that is given to the role that health plays in promoting other aspects of the good society, the more health assumes greater priority in the set of primary goods or in the hierarchy of human capabilities.
  - The argument from justice and fairness would suggest that emphasis be placed on raising the level of those most in need, and thus devoting more resources to their care. The upper limit to this re-direction of expenditures would arrive at the point where measurable and meaningful degradations in the care delivered to the relatively stable and healthy members of the population begin to be seen to place their health status in jeopardy.
  - The theoretical consensus from the contractual and capabilities approach is that within-system differences are tolerable to the extent that those at the bottom receive an appropriate minimum bundle of services that provide essential primary goods or human capabilities.
  - Another approach would be to frame it as one of international disparities—to what extent are these unjust and to what extent can a health-based approach resolve these injustices? In other words, the regime of international justice has not developed to the extent that one can identify international obligations to address these international disparities at the international level. This line of reasoning would suggest that reference to international justice leaves UNHCR with little obligation to affect or change these disparities and that the space for ethically-based decision making must be filled by some other approach to finding just solutions to achieving health equity.

- There is no ethical requirement that UNHCR take an egalitarian approach to populations. It is fair and just to establish social minimums and the content and expense of those social minimums may vary depending upon need and the level of primary goods and capabilities to which that population is accustomed. The upper limit on those resources would be reached when within a fixed budget the transfer of funds begins to impinge on the well being of those who are basically healthy or who are accustomed to managing at a lower social minimum. In other words, the extra resources to meet the extra needs of one refugee population cannot be extracted at significant cost to those who are receiving less per capita, either within one population or across a wide range of populations.
- With regard to user fees, there is substantial support in the ethics literature, particularly among the analysts who take a contractual approach (Rawls/Daniels), for charging a user fee provided that the fee does not restrict access and provided that the fee is fairly assigned across populations or population subgroups. In general, public health authorities agree that charging user fees to poor populations introduces a measurable, and in some settings a very significant barrier to access. question of user fees links closely to the question of relative social minimums. If user fees were to be charged only above the social minimum for that population, and if UNHCR had instituted a policy of defining social minimums relative to population need and demographic profile, then user fees might be fairly applied across all populations without the need to establish a means test. Access to care that is deemed essential for a given population, recognizing that this bundle of services will vary according to demographic profile of the population, would be free. Access to care above that relative social minimum would require a user fee.
- Once these exceptional cases are allowed to be taken very seriously, as absolutely valid and important demands on a population-based health care system aligned according to principles of population ethics, there are a number of process and system supports that need to be put into place. But the basis ethical finding from the literature is that the obligation to deal with exceptions, with individual cases, does not go away when one moves from individual care based on medical ethics to population care based on population ethics. In fact, the medical ethicist would assert that the moment you hear about this case, you must act at least in a dual role, as a clinician whose primary responsibility is beneficence; and as a manager in a rationed system.
- 3. Were some or all of these solutions to be taken up as policy options for UNHCR, major efforts would need to focus on internal processes relating to information and human resource systems and on external processes relating to legitimacy, stakeholder buy-in, transparency, and accountability.

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#### Acknowledgement:

Jennifer Leaning, MD, SMH, Harvard Humanitarian Initiative, Harvard University

# Appendix 1

#### Review of theoretical literature

This review has yielded three main points of relevance to UNHCR practice and policy on refugee health.

- 1. The dilemmas that UNHCR faces in terms of public health equity across diverse and needy populations are not well formulated and in fact are only marginally addressed in standard writings on bioethics and population ethics;
- 2. The literature on health and human rights looks at issues of disparity, access, or stigma primarily within one national population, not across populations in crisis conditions;
- 3. The relevant normative principles lie in the realm of distributional ethics, notions of justice, and the quality of the processes used for making decisions.

#### Distributional ethics

There are two basic approaches taken in distributional ethics: Those that apply in conditions of resource abundance (relative to need) and those that apply in conditions of relative resource scarcity. (Resources in this context mean time, money, personnel, and the capacities of institutions, infrastructure, and systems.) If the issue to be addressed is really not one of limited resources but of failure to deliver the proper resources in the proper time frame to those in need, the question may not leave the ethical realm entirely but it moves quickly into practical realities: What must be improved or changed in order to deliver on population needs? These are far from simple questions and many health care systems in developed countries around the world are struggling with them. And certainly even within what might appear to be solely the practical arena, authorities who are found to have engaged in extended or deliberate inaction on this issue of mal-distribution of resources could definitely be vulnerable to charges of real unfairness or held directly responsible for adverse health consequences. These allegations would definitely trigger significant questions of ethics, as well as point to major problems of politics, leadership, and bureaucracy. In general, however, in a context where resources are abundant, controversies over distribution focus on what is wrong at the design and operations levels and on what can be done to improve things.

The ethical realm intrudes when the issue of population needs is closely examined. Although there is some agreement in health care circles on what is required to meet basic needs of survival and basic benchmarks in preventive care at the population level, the discussion becomes quite animated beyond that point and moves in one of two directions: cost-benefit issues or justice issues. Cost-benefit issues revolve around questions of what health benefit is obtained for whom at what further cost. Justice issues arise in seeking answers to such questions as what is the shared or acknowledged view of "the good life;" what role do health status and health care play in that view; and what are the obligations of the state or the public authority to provide for the "good life" overall and the health elements within it?

Ethical issues arise more immediately and starkly in discussion of how to distribute resources when the needs clearly outstrip the resources available. Here allocation decisions reflect not only the efficiency and functionality of multiple inputs but also judgments about what subpopulations will receive certain elements of health care and what ones will not. In resource-constrained circumstances, there will be winners and losers, with real-life consequences. In

emergency settings, such as mass casualty events or military battlefields, there is considerable consensus among practitioners, ethicists, and policy analysts that ethical decision-making has claimed an accepted practice and ethics rationale. The ethics of resource distribution in non-emergency settings, however, generates more attention, research, and controversy. Yet even here the literature applicable to the developing world, particularly in a crossnational perspective, is very thin.

The discussion that follows presents an assessment of current thinking about distributional ethics in resource-constrained contexts, emergency and non-emergency.

#### 1. Emergency Settings

In the situation where inadequate resources have clearly been demonstrated to be a major concern, which is the situation that applies to UNHCR and its health program, the major ethical principle of triage is invoked. The process of sorting on the basis of quality ("trier" in the French, for sorting coffee beans or bales of wool) was transferred to the sorting of battle casualties during the Russian campaign of Napoleon. The urgent need to salvage wounded men to maintain the fighting force led to a survey of men fallen in the field of battle and the retrieval of those who, with medical or surgical intervention, were deemed likely to regain sufficient capacity to return to active duty. The concept of sorting for "quality" remained latent in this application, in that those considered unlikely to survive, or unlikely to survive in sufficiently viable condition to return to battle, were left on the field to die.

The formal term "triage" was adopted by the British and applied to the casualty sorting process they deployed in the early days of World War I. Under the press of very heavy casualties on the Western Front, the British medical command developed a swift and efficient sorting process for its most forward based medical units, at what were termed casualty clearing stations. This military sorting process endeavored to accomplish two somewhat contradictory ends: to make the most efficient use of scarce medical resources by expending them on those most likely to survive and to ensure that the maximum number of survivors could be attained within these constrained resources. This application of the triage concept resulted in sending back to the rear lines anyone who could walk (i.e. only superficial head or trunk injuries and no serious lower limb injury); attending rapidly to those with remediable life-saving injuries; sending back to the rear lines (and deferring all but minimal stabilizing intervention) all those whose wounds were so severe they required intensive resources of time, supplies, and skilled personnel; and leaving to die those whose wounds were assessed as beyond the capacities of the clearing station and unlikely to survive the transport back to the higher echelon of care.

This structure of triage, with its categories of injury severity linked to protocols of care, continues to form the basis for decision-making in all formal Western military medicine and civilian mass casualty care. Its ethical rationale has been linked to Benthamite utilitarian consequentialism, wherein it is argued that the most ethical distributional system is one that maximizes the greatest good for the greatest number. Left unaddressed in this short-hand version is analysis of the categories of "good" and "number:" What good is being maximized and for whom? In any given circumstance, it is in fact necessary to engage in further specification of what lies within these categories, and this specification creates other questions of ethical concern. In extreme military situations throughout the 20th century, in settings where there is no rear echelon within practicable reach and campaign requirements demand rapid field mobility, it has been the quiet practice to devote resources only to those casualties who can return to battle quickly (recapitulating the Napoleonic value chain). Here the greatest good is not life itself, but the capacity to rejoin active combat with minimal delay; and the greatest number is not the number of all those wounded but the number of all those deemed potentially salvageable within constraints of available skill, supplies, and time.

Extreme instances of civilian mass casualty events require similar truncated decision-making: Resources are devoted to those who can be found and extricated in a given time frame, and within that category the goal of maximizing the numbers who might survive dictates decisions as to who will receive attention and who will not. Humanitarian health workers, when faced with overwhelming numbers of people ill with epidemic disease or famine, usually focus on the salvage of children, although there have been recent instances of elders within the community challenging that priority, and suggesting that saving the lives of able-bodied adults might contribute more to the ultimate viability of that community. Here the aid workers assigned greater value to the lives of children whereas the leaders placed most value on community sustainability. In emergency situations in war and peace it is never the case that the entire population of sick or injured is included in the denominator number and it is also never the case that life itself is the good that is maximized—rather only those lives deemed of most value for a given set of circumstances or those lives who can be reached within a given time frame.

As morally difficult as it is to make choices within these triage frameworks, the outcomes are ethically justifiable because a process has been followed, protocols employed, guidelines are transparent to the practitioners, and to some extent understood or assumed by the populations in need. What is considered unacceptable practice within these frameworks, and thus verging on unethical, is not to search out to the greatest extent possible the full scope of population at risk. In other words, serial triage, merely standing in one place and taking care of several people at a time, is not the proper application of the process. To engage in triage according to its ethical mandate is to search continuously for those people who might be salvaged with the resources at hand; to send out survey teams, to organize search and rescue brigades, to bring people back from the interior of camps, to scan the earthquake zone and deploy assets where the need is greatest.

## 2. Non-Emergency Settings

Decisions about the distribution of relatively scarce health resources in non-emergency circumstances have received great attention in the literature but the focus is on deliberations within one political, economic, and health care macro-system, such as the United States. Health economists and health systems analysts participate actively in these analyses. Much attention is given to the merits of different analytic approaches that constitute deliberate or implied trade-offs among the subpopulations who will benefit most from a given expenditure on a defined health benefit or input. This literature is replete with the use of technical definition and quantitative calculations around such terms as cost-benefit, cost-efficiency, quality-adjusted life-years (QALYs), and disability-adjusted life years (DALYs). The fundamental conceptual differences these terms refer to are important: what are the equity issues involved in providing resources for prevention rather than cure, or for the young rather than the old, or for the old rather than the young, or for the very ill rather than the moderately healthy, or for those with certain diseases or health conditions rather than for those without them? Each of these equity decisions depends on what the society in general considers to be most important, urgent, and fair.

The very interesting aspect of the debate around these questions, even within one political culture, is that there is sound ethical basis for choosing among any one of these polarities. The ethical soundness of the decision, however, is as much rooted in process as it is in theory. If the entire community at risk for the decision on resource allocation has been informed of the issues, if the options that are presented have scientific and policy integrity and are not arbitrarily discriminatory, and if in some way the community is empowered to provide guidance to the decision makers, then whatever course of action is subsequently taken can be ethically justified. In other words, the debate on distributional ethics moves directly into the debate on notions of justice and into questions of decision-making processes. This analytic path makes sense and serves to provide plausible guidance in the context of deliberations within one society or nation-state. It becomes less feasible, and thus less helpful, when the question of distributional ethics is asked from

a multi-national perspective. For an international institution like UNHCR, working from a budget that has been gathered across nation-states with the purpose of improving the health of people from many different societies, the suggestion that consensus on notions of justice be reached may seem impractical. It is possible that finding internationally acceptable processes that drive these allocation decisions may prove a more fruitful line of endeavor.

These issues are taken up more fully in the next two sections.

#### **Notions of Justice**

To understand the issues involved in the topic of public health equity requires a perspective on populations, rather than individuals, and an exploration of the ways in which philosophers and other analysts have dealt with the problem of whether and how the values of equity and equality work their way into deliberations about social justice. The concept of justice, with its corollary concerns of the "just" state; the "just" action; the "just" war, and the "just" society, has engaged political, moral, and legal philosophers for centuries. Recent explorations of these concepts that are relevant to health equity include work by John Rawls (who as a political philosopher follows in the Kantian tradition) and Amartya Sen (an economist of broad reach whose writings on entitlements and capabilities, in the context of famine, address philosophical and policy questions relating to public responsibility for population-scale deprivation and poverty). A proponent of the Rawlsian approach is Norman Daniels, who as a political philosopher has written widely on the issue of health equity. Other analysts, including Martha Nussbaum, Sudhir Anand, and J.P. Ruger, have adopted and elaborated upon the view of Sen.

Although an in-depth and technical review of these positions is well outside the scope of this paper, the key contributions and areas of disagreement among these writers are briefly summarized here.

#### 1. Contract approach: Rawls et al

John Rawls argues the case for perceiving justice as fairness. He notes that no one system can address or redress all sufferings or all wrongs. People come into the world with a vastly diverse set of talents and flaws and these play out, in terms of individual trajectories, in ways so myriad that no system of government and no system of ideas can entirely account for, let alone organize them into a common set of opportunities or outcomes. Instead, a theory of justice can do three things to advance and bring about fair and just conditions for people within a given society:

- It can strive to frame the ways in which a society understands the fundamentals of a good life, or what he terms primary goods;
- 2. It can outline the path the society must take to ensure that these fundamentals are made equally available to all members of that society (an equality of opportunity approach); and
- 3. It can define the obligations of the state in helping society achieve this outcome, by ensuring that whatever inequalities exist in income or wealth, the state and society take measures that are aimed at bringing the least well off up to a minimum standard.

A liberal consciousness infuses the world that Rawls envisions. He assumes that society is well ordered. He demonstrates through complex argument that individuals in such a society will be rational and reasonable when it comes to making decisions about the kind of life they want to lead for themselves and the kind of life that should be made available to others. Social policy, in this well-ordered state, would be collectively arrived at and would introduce a measure of fairness that would compensate for constraints in opportunity that the less fortunate might experience.

These concepts, severely simplified here, are elaborated carefully in two of his most prominent works: <u>A Theory of Justice</u> (1971) and <u>Political Liberalism</u> (1993). Were his approach applied to questions of health equity (a topic he did not take up) it could be argued, as Norman Daniels did in his book, <u>Just Health Care</u> (1985), that two key themes emerge:

- 1. Achieving health equity should be understood as achieving equality of opportunity to access health care; and
- Equality of opportunity in access (particularly if access was construed to include access to substantive and high
  quality health care) could only be assured if measures were taken to reach out to those whose health status and
  life circumstances (whether for socio-economic reasons or misfortunes of genetic inheritance) were relatively
  disadvantaged.

These themes Daniel discussed within the context of one developed society, ordered along the lines of a stable and functioning representative government, as Rawls had assumed. Three intellectual and practical insights gained in the years following 1985 prompted Daniels to revise his views, in a work titled Just Health: Meeting Health Needs Fairly (2008). The first insight is that health resources are insufficient to meet the needs of populations even in a society as rich as the U.S. and thus distributional issues are of pressing concern. The second is that health care is much more tightly interwoven with social disparities and the health of the body politic than he had acknowledged in his earlier book (which had focused more narrowly on access) and thus had to be dealt with as a fundamental problem of political as well as social concern. The third insight is that the moral claims for health, in terms of justice and fairness, had to be explained more fully.

In his 2008 text, Daniels frames the "Fundamental Question of justice for health:" "What do we owe each other to promote and protect health in a population and to assist people when they are ill or disabled?" His extended reply in the first three chapters answers three "focal" questions with the affirmative statements he summarizes below:

First, health is of special moral importance because protecting normal functioning helps to protect the range of exercisable opportunities open to people and because various theories of justice support the idea that we have an obligation to protect opportunity and thus health. Second, a health inequality is unjust when it results from an unjust distribution of the socially controllable determinants of population health, as illustrated by Rawls's (1971) principles of justice as fairness. In effect, we cannot have health equity without broader social justice. Finally, to meet health needs fairly, we must supplement the principles of justice that emerge in answering the first two questions with a fair, deliberative process.

(Daniels 2008:140)

Daniels then takes these affirmative statements and applies them to a range of important practical policy questions in health equity. What results from this analysis is a much greater emphasis on how a health system might be structured to meet the health needs of a population, including an assessment of the quality of the care that is provided and the ways in which sustained efforts must be made to redress long-standing disparities; and a much more detailed and technical engagement with distributional issues, from the standpoint of cost-benefit analysis and the fairness of processes used to arrive at resource allocation decisions. Much of what Daniels proposes, in terms of process, will be discussed at greater length in the next section (section 3).

#### 2. Capabilities approach: Sen et al

Amartya Sen takes a different path to the question of health equity. As an economist with deep understanding of the developing world, he has advanced the concept of human capability, what he terms a "positive freedom," to counter the prevailing economic doctrine of non-interference with individual choice or opportunity, or "negative freedom." In his view, people throughout the world cannot rise from poverty and distress simply through state and international policies that do not hinder individual aspirations or efforts. Such policies do not address the fundamental problem of deprivation at the level of entire groups and communities. People cannot act, cannot fulfill their capabilities as agents to change their own circumstances, unless they are granted the means to do so. They must be assured of minimum inputs for survival (safe water and sufficient food and shelter) and must be enabled to earn a living and acquire an education. Without such inputs and support, to speak of the exercise of human rights or the opportunity to choose is meaningless.

According to this line of reasoning, it is the responsibility of governments to provide the resources and create the systems that will sustain these basic human functions. Sen does not argue that every society must provide the same level of supports or even arrive at the same standards for what is basic and essential. He does insist, however, that some minimum must be provided so that within the socio-economic and cultural context of a given society, each human being has been provided with the means to fulfill his own capability to act in his own best interests and to claim his rights from the state. (Sen 1987)

Whether viewed through the lens of human capability (Sen) or of primary goods (Rawls), discussion of the question of health equity could go in at least two divergent directions. One direction leads to the argument that inequalities in capabilities as they relate to health could extend to a very broad range of concerns and potential claims for redress: Interference with functioning, after all, could arise from disease, life style, injury, inherited traits, location distant from a good rehabilitation facility, failure to get a job with a living wage, or even failure to get a job at the wage one believes is necessary for full functioning. Alternatively, redressing inequalities in health from the perspective of improving human capabilities could find a more constrained conceptual space if it were agreed to restrict the definition of health, or the contribution of health required for full functioning of human capability, and insist only that society meet those minimum health standards of survival and reduced morbidity.

Further exploration of this discussion requires addressing at least three important questions:

- 1. What should be the minimum packet of goods the state or other authorities should provide;
- 2. To what extent is the existence of inequalities in the packet of goods compatible with a just society; and
- 3. How might transfers of wealth take place, if inequality is tolerated but misery is not?

The approaches of Rawls and Sen tend to converge in their responses to these issues and the views of other analysts also provide insight, especially to question three.

#### 3. Social minimum, social inequalities, and redistribution of resources

Defining a minimum packet of goods (often referred to as the social minimum question) is one that Nussbaum has taken up. Elaborating on the human capabilities argument of Sen, she has identified ten "central" activities that "seem constitutive of a life that is truly human." (Nussbaum 1999:40-41). These ten activities are:

The capability for physical survival, the capability for bodily health, the capability for bodily integrity, the capability for the exercise of the imagination, the capability for emotional response and exploration, the capability for practical reason, the capability for love and friendship, the capability for connection with nature and other species, the capability for play, the capability for the exercise of control over the environment, including political control.

The list has been examined for traces of Western ethical or cultural bias but in general it has been received with considerable respect and ongoing discussion. It does not, however, in itself, offer much guidance on how to set limits, or how to define what might be the acceptable limit in what to provide, in terms of these capabilities, or, in Rawlsian terms, primary goods. For instance, bodily health and bodily integrity clearly refers to health care, among other concepts. Granted that these capabilities are ones that everyone in the world would value, the immediate next question is what is an acceptable minimum level of "the capability for bodily health?"

There are clearly technical responses to this question, in terms of demographic and epidemiological studies and health needs assessments, etc. But in terms of ethical guidance, many analysts refer to the line of reasoning advanced by Rawls. (Daniels provides a process-based response that links technical expertise with inter-connected methods for gaining guidance and approval from a range of stake-holders. (See section 3).

A just society, according to Rawls, will place great emphasis on freedom and competition, so that it will have real inequalities in the distribution of socio-economic goods, including real inequalities in access to and maintenance of primary goods, such as income and wealth. This just society, however, would need to establish a reasonable social minimum, the set of goods a person needs to have provided to him in order to be able to live a minimally decent life in that society. This level would be set at such a level that anyone in that society would take the chance of having to live at that level for his or her entire life. In Rawls' analysis, this level of social minimum, arrived at in a mode of rational choice (behind a "veil of ignorance" because one would set this level not knowing what one's chance of being assigned to it might be), will be seen as just because it will be set at a level higher than what otherwise might have been defined through less rational, more biased, and more elite-driven social policy.

Sen does not deal directly with definitions of the social minimum but his discussion of inequality implies that the minimum inputs required to achieve acceptable levels of capability in one country may be insufficient in another where the overall standard of living is much higher. In other words, what it takes to fulfill human capabilities in a wealthy society may require not just more resources to maintain the same social minimum as would be acceptable in a poor society but even more beyond that, in order to reach a new, and higher social minimum that would meet the level deemed acceptable in a rich society. As Sen puts it:

To lead a life without shame, to be able to visit and entertain one's friends, to keep track of what is going on and what others are talking about...requires a more expensive bundle of goods and services in a society that is generally richer, and in which most people have, say, means of transport, affluent clothing, radios or television sets, etc. (Sen 1987:18).

These issues of achieving a reasonable social minimum while allowing for some degree of inequalities and disparities among and within freely functioning and diverse societies begs the question of what might be a fair and just approach to the question of resource transfers. Clearly to raise the level of people at the bottom of society who are currently living below the social minimum will require resource expenditure. It is theoretically possible to raise funds and increase the total amount available but most analysts of just resource allocation proceed within the assumption that the overall universe of resources is fixed and the interesting questions lie in the area of what to do within the limits that are exogenously defined. So the discussion in the literature revolves around whether and how to accomplish transfers of resources from those who are abundantly endowed with primary goods (or human capabilities) to those who are not. (Process issues intrude at once and will be discussed later, in section 3.) The theoretical analysis in the literature suggests two key boundary conditions that have achieved some consensus.

The first boundary condition arises in the general discussion of egalitarianism. Few philosophers or scholars engaged in distributional ethics and notions of a just society advocate for a policy of wealth transfer that would make everyone in a society equal (in terms of wealth and access to social goods) to everyone else. To take that step would involve

grave infringements on personal freedom (particularly for those wealthy from whom goods are taken), would erode most incentive systems that drive economic and social activity, and might entail other theoretical and practical problems of enormous complexity. For instance, how might one accomplish wealth transfers to the poor with sufficient sustained control and accountability that these resources were expended on appropriate primary goods; and how might one effect these transfers without so disturbing other aspects of the society that the overall level of primary goods or human capabilities is actually lowered in many other respects? Furthermore, analysts familiar with the situation in impoverished countries are not at all sure that a drive to the bottom, a leveling of wealth, would in fact significantly raise the overall level of primary goods, since the vast majority of people are so desperately poor and living so far below the social minimum that it would take vast expenditures of resources to bring them all to a minimally acceptable level.

The second boundary condition addresses the problem of setting priorities without embracing hard economic solutions to the problem of marginal utility. Here there is more controversy in the literature but in general the analysts of health equity who rely on arguments of fairness and justice are not inclined to agree on a strictly economic formulation of marginal utility, whereby the value of expenditures is discounted when spent at the margin of life or the margin of improvement. In this blunt economic formulation, a given expenditure that will confer a given benefit for a young healthy person is considered to confer a lesser benefit to someone who is seriously ill, unlikely to survive, or near death. This line of reasoning plays into a rather crude cost-benefit approach whereby the overall per capita value (or benefit conferred) will be seen as higher if the expenditures are devoted to those who can gain the greatest benefit from them.

But those who argue in favor of expenditures that are preferentially directed at improving the condition of those who are less well off (and in the health context that would mean those who experience more illness or whose health needs are more severe) look at the question of conferred value very differently. The value of the added benefit to someone who is in greater need of that benefit means that the unit of welfare transferred is in fact greater. Relative need must be factored into determinations of relative value. The aggregate rise in benefit to the society, if it is measured in terms that do not reflect the point of view of the individual in serious need, might be appear lower—but that would be an artifact of measuring the wrong things, or, at least, not all the right things. So, for instance if the metric for cost-benefit were increased life expectancy of a population or mean waiting times at health care institutions, then diversion of resources to the very ill might mean that average life expectancy does not rise appreciably, or waiting times at particular institutions go up by a few minutes. Yet the aggregate measure ignores the very significant social and ethical trade-offs that might lie beneath the surface.

This view of prioritization has been termed "weighted well being" and it is measured over the lifetime of individuals. The moral value of achieving a benefit to an individual (or of avoiding a loss) is increased in one of two ways: by the higher the level of well-being that the individual receives for a given benefit; and/or by the lower the level of well-being that the individual is consigned to experience were that given benefit not conferred.

#### 4. Comparison of Contractual and Capabilities Approaches

The distinguishing parameters of these two approaches to health equity (Rawls/Daniels and Sen/Nussbaum) are not clearly explicated in the literature, despite many articles by these authors and by others with professional and academic interest in this issue. Several areas of dispute do appear to recur, however: the extent to which the capabilities analysis overlaps with the opportunities/primary goods analysis; compatibility of the framing definitions for what constitutes health; the extent to which health is in some ways a more essential primary good or essential capability than, for instance, wealth or education; and the ways in which the definition of health (whatever it is determined to be) integrates into a larger understanding of what constitutes a just and fair society.

At the risk again of serious over-simplification but in the service of finding practical take-home insights, it is possible to discern certain areas of agreement and certain areas of real difference between these two sets of extended explorations of health equity.

The areas of agreement, from the practical perspective of how to organize health care, are with regard to the overlap in the notions of improving human capabilities and providing robust opportunities for obtaining primary goods. Putting aside important philosophical nuances, the bottom line is that both approaches would place very high priority on being sure that everyone in a society has an equal chance at survival and is thus provided with minimum standards of food, shelter, water, and whatever health care is needed to ensure that equal chance at survival. At this minimum level of inputs, there is no important difference between an opportunities approach and a capabilities approach to health care. To reach this minimum standard, both approaches would require substantial resources from the state; and both would require the wealthy in a society to contribute to the welfare of the poor.

The areas of disagreement, or at least the areas where possible disagreements have been surfaced but not resolved, relate to the relative priority to assign health in the array of goods that society must provide; the definition of what constitutes health; and the integration of obligations for health with other obligations the state may have in terms of overall provision of justice and fairness throughout the workings of society (such as ensuring political voice for all, balancing majority and minority interests and claims, managing responsibilities for governance, defense, and infrastructure with efficiency and effectiveness).

It is not surprising that the Rawls/Daniels approach undertakes a bounded account of health in the larger context of what constitutes a just society, since the Rawlsian enterprise encompasses the wide reach of political philosophy and attempts to be comprehensive. In this larger context, Daniels is careful to maintain a focus on limiting the upward pressures on claims for health. Not everything a particular individual desires or asserts to be part of a claim for health against the state can be countenanced as good, appropriate, or possible. Trade-offs intrude early on, as Daniels sees the problem, and distributional constraints demand common agreement on what is considered necessary for the state to provide. Furthermore, as important as health is to the well-being of an individual and the full functioning of society—an importance Daniels has greatly enlarged upon in his second book (2008)—the liberal conception of a just society persists in his assertions that the state must also equally if not more so expend its resources in the protection and fulfillment of those freedoms and opportunities that lie in the civil and political domain.

Sen and others would argue that health has a strong valence in determining a broad range of human capabilities (including the capability of participating in the political process) and thus the efforts of society should be brought fully to bear on making sure that all individuals are able to claim a tangible, substantive sense of well-being and agency. The minimum threshold implied in Sen's view (particularly as amplified by Nussbaum's list of 10 capabilities) is not merely one that would allow a person or his family to get by, live from day to day, and not be sickened by polio or contaminated water. The extent to which the notion of an upper limit is broached arises in Sen's recognition that he is not arguing that society provide for an equality in health status or an equality, but rather for an equal chance at attaining what is full capability for each person. Here we can see the difference between his sensibility regarding the nature of the help provided to the poor or disadvantaged and that of Daniels (and Rawls). Daniels would require the state to compensate for the misfortune of the poor (including their health needs) through provision of resources to improve their welfare (and their health status). Sen would require the state to find resources to empower the poor so that they are capable of taking charge of their lives.

A further distinction between the two points of view on health equity can be drawn in comparing their discussion of the role of international players and other nation-states. Daniels notes that Rawls did not pay close attention to international dimensions until later in his career, and then mainly to identify and decry gross injustices. Daniels, however, in the last chapter of his later book entitled "Inequalities in International Health and Global Justice," takes the international perspective into careful consideration. He identifies two poles in the debate on this topic: the statist argument, exemplified by Nagel, and the cosmopolitan, or egalitarian view. Nagel declares that since only citizens of a nation state can be coerced but also have substantive voice, it is not possible to define what kind of international justice system would provide the basis for resolution of issues relating to international health inequalities. The cosmopolitans argue that individuals are participants in the world; that international institutions have standing in terms of defining norms and creating obligations on nation states (and thus, by extension, on individuals within a nation state); and thus it is possible to conceive of a common international consensus on what constitutes just health care. Daniels, in a nuanced analysis, finds several ways in which Nagel is demonstrably wrong (the World Trade Organisation, for instance, imposes an international order that coerces individuals and can be challenged by them directly, not just through the mediating plane of the nation-state) and tends to favor the direction in which the cosmopolitan stance might take the debate. Daniels notes, however, that the "substance of international obligations" for responding to "health inequalities across countries" is still too undefined to provide a basis for firm arguments regarding justice and fairness. He is positive to future developments in refining this question of substance, summarizing the state of play in this context as follows:

My goal in this chapter has not been to provide a road map to a theory of international justice. Instead, I argue more modestly that there is a fertile area of emerging international institutions where the task of working out international justice lies. This is where the action is. We must move beyond a minimalist strategy that justifies only avoiding and correcting harms. How far we go towards robust egalitarian considerations is a matter to be worked out. In any case, how far we can go will depend specifically on the nature of the institutional structures that are still developing. This work in progress has barely started, but it must break out of the framing of the problem posed by the poles of statism and cosmopolitan individualism. (Daniels 2008:354)

The relevance of these observations to the role of UNHCR is robust. Had Daniels known more about the mission and operations of this international institution, along with several others (UNICEF, ICRC) he might have advanced more forceful arguments in defense of cosmopolitan egalitarianism.

Sen and his colleagues take a vigorous empirical path to a cross-national perspective on global equity, including health, as is evidenced by the major role he played in the establishment of the UN Human Development Index. Here the basic packet of goods or capabilities is compressed into three indices that measure what every nation state would agree is essential to many choices in life: to be knowledgeable, to survive, and to enjoy a decent standard of living. (Sakiko Fukuda-Parr 2003:6) Taking a needs-based approach as well as a fairness one, Sen and his colleagues who draft the Human Development Reports go so far as to suggest that the entire distribution of goods and services in the world bears critical scrutiny. He does not naively argue for immediate direct resource transfers but instead points out that the gross disparities captured in the UN Human Development Index conclusively demonstrate, from a perspective of international justice and fairness, how current strategies relating to foreign aid and trade are woefully inadequate and are failing to close a widening gap between the human capabilities of the most rich nations and those of the most poor.

## **Processes for Arriving at Decisions**

The practice of ethics (as opposed to theorizing about ethics) always involves an argument about the meaning and application of key principles and the relevance of these principles to the case at hand. A considerable intellectual divide separates those moral philosophers who search for unifying principles or one basic way of arriving at conclusions and those who assert that the multiplicity of goods in the world require a case-by-case weighing of possibilities, evidence, precedent, received principles, and who arrive in the end at a solution that is at its core provisional and contingent. In the former school are Kant, Rawls, and perhaps Daniels. (Amartya Sen is sufficiently eclectic in the issues he takes up that he is difficult to characterize.)

In the latter school are Charles Taylor, Albert Jonsen, Stephen Toulmin, Bernard Williams, and William James. Stevenson argues strongly that issues of sentiment, experience, and context are crucial to take into consideration when arguing about or arriving at ethical decisions and he, along with Toulmin and Williams, consider much moral philosophy (and they include Kant and Rawls in this indictment) sterile, boring, and unhelpful. Toulmin explores the method of reasoning used in medical ethics, and other ethical settings, noting that it is always case-based (with precedents and principles in the background). He argues that arriving at a solution in a particular situation involves the process of casuistry, nuanced argument taking up various sides and points of view and then weighing the relative goods and harms that might come from one decision or another. There is never only one good answer and the various principles are often in tension with each other. Ethical thinking is a process of deciding among sets of competing demands.

William James, the pre-eminent 19th and early 20th century psychologist and philosopher, presages this point of view in his essay, "The Moral Philosopher and Moral Life." He begins his discussion of morality by grounding it in human experience. Human minds are capable of moral thinking and do so in relation to other minds, including their own. It is in the relationships between and among other moral beings and their surroundings that moral concerns and moral arguments arise. This mode of moral thinking is iterative and inclusive:

All this amounts to saying that, so far as the casuistic question goes, ethical science is just like physical science, and instead of being deducible all at once from abstract principles, must simply bide its time, and be ready to revise its conclusions from day to day. The presumption of course, in both sciences, always is that the vulgarly accepted opinions are true, and the right casuistic order that which public opinion believes in; and surely it would be folly quite as great, in most of us, to strike out independently and to aim at originality in ethics as in physics. Every now and then, however, someone is born with the right to be original, and his revolutionary thought or action may bear prosperous fruit. He may replace old "laws of nature" by better ones; he may, by breaking old moral rules in a certain place, bring in a total condition of things more ideal than would have followed had the rules been kept. (James 1992:612-613.)

On the whole, then, we must conclude that no philosophy of ethics is possible in the old-fashioned absolute sense of the term. Everywhere the ethical philosopher must wait on facts. (James 1992:613.)

James notes that a general guiding principle might prove helpful in ethical deliberations, not as a prescriptive rule but as a reasoning process for arriving at the choice that seems to best meet competing demands. Here he describes the path the moral philosopher might take when confronted with a moral choice:

... Since everything which is demanded is by that fact a good, must not the guiding principle for ethical philosophy (since all demands conjointly cannot be satisfied in this poor world) be simply to satisfy at all times as many demands as we can? That act must be the best act, accordingly, which makes for the best whole, in the sense of awakening the least sum of dissatisfactions. In the casuistic scale, therefore, those ideals must be written highest which prevail at the least cost, or by whose realization the least possible number of other ideals are destroyed. (James 1992:610)

The case-based approach to ethical decision in clinical medicine that is familiar to physicians and other health care workers derives directly from this tradition in moral philosophy. The practical reasoning provided by medical ethicists and theoreticians relies on the uses of casuistry, informed by a set of key ethical principles that have been elaborated through time. These ethical principles were not deduced from abstraction and were not designed to explain an entire system of thought or provide a unifying political theory. Instead, the key ethical principles familiar to clinicians trained in Western medicine (beneficence, justice, autonomy, informed consent) were developed through hard-won experience and through lessons salvaged from a wide range of actions, including those found (at Nuremberg) to be abhorrent. These principles were built through sustained analysis of outcome as well as intent, and of failure, as well as success. Despite their roots in ancient codes (Hippocrates and Maimonides), these precepts constitute the product of a positive deliberative project launched in the years after World War II.

An essential difference between medical ethics and the moral philosophy in the Jamesian tradition is the focus of decision-making. In medical ethics, it is always the individual patient. Medical training is supposed to include substantive inculcation of medical ethics, providing physicians with the tools to make ethically informed decisions. It is customary in developed medical settings that very difficult dilemmas may be referred to a medical ethicist or a medical ethics committee for ultimate determination. The deliberations of the ethicist and the medical ethics committee become part of the institutional record, to be referred to as precedent in deciding subsequent cases and to be used as teaching examples.

James and other philosophers who resist unitary theories and notions of what James terms "final truth" do not make distinctions between individuals and populations in the applicability of their approach. For them, their arguments about what constitutes ethical deliberation are clearly intended to inform questions of public policy as much as individual choice. The implications of a non-rules-based approach to problems of distributional ethics, however, are that some set of people will need to be in a position to moderate competing demands and maintain a coherent, accountable, and historical record of what precedents have been formed and what consequences have obtained.

It is important to note that those philosophers and theorists who proceed from a more rules-based (whether contractual or utilitarian) view of the ethical domain also find it necessary to develop a deliberative process. This process may be less central to the content of the ethical decision (since rules help guide the choice of the just outcome) but it is essential to its legitimacy (since who is empowered to turn these abstract rules into public policy?)

Here we arrive at the final common pathway for all deliberations about distribution of resources at the population level: regardless of divergent definitions of justice and differing views regarding unitary theories or empirical case-by-case assessment, there is strong concurrence that to transform an ethical decision into policy requires a suitable process. This process is ultimately a political one, because policies relating to populations derive from the power of the presiding authority. In just societies, characterized by some form of legitimate and representative governance, the policy setting process around distribution of valued goods will need to accommodate competing demands and the overall-problem of limit-setting. When the issues of distributional ethics move into the real world, where decisions actually have to be made and implemented, the analysis proceeds to a discussion of institutions and political accountability.

Daniels has devoted substantial thought to what such a process might need to entail with regard to health. Over the years he has developed a set of criteria and system descriptions that would characterize a just policy-setting process, designed to operate within the structure of a stable and democratic governmental system (the just Rawlsian state). His latest (2008) formulation of this process is more complex than his earlier ones and is further informed by three lines of thought: the technical guidelines and protocols designed to improve care as well as contain costs which are embedded in evolved managed care and national health systems in the U.S. and the U.K.; the increasing

sophistication of economic and political arguments on cost-benefit analyses; and the features of systems of consultation and empowerment proposed by health and human rights advocates. He frames the problem in this way:

The general principles of justice for health that we have been discussing are simply too general and too indeterminate to resolve many reasonable disputes about how to allocate resources fairly to meet health needs, and we lack a consensus on more fine grained principles. Moreover, we cannot avoid this problem. It arises in all health systems whether or not they meet other basic requirements of justice—for example, whether or not they provide universal access to preventative and curative public health and medical services.

The moral controversy that surrounds the creation of winners and losers in resource allocation decisions results in a legitimacy problem: Under what conditions do decision makers have the moral authority to set the limits they impose? To solve this legitimacy problem, we must supplement general principles of justice with a fair process for setting limits. (Daniels 2008:103)

## This fair process has the following four major attributes:

- 1. **Publicity Condition:** Decisions regarding both direct and indirect limits to meeting health needs and their rationales must be publicly accessible.
- 2. RELEVANCE CONDITION: The rationales for limit-setting decisions should aim to provide a reasonable explanation of how the organization seeks to provide 'value for money' in meeting the varied health needs of a defined population under reasonable resource constraints. Specifically, a rationale will be 'reasonable' if it appeals to evidence, reasons and principles that are accepted as relevant by ('fair minded') people who are disposed to finding mutually justifiable terms of cooperation. Where possible, the relevance of reasons should be vetted by stakeholders in these decisions—a constraint easier to implement in public than in private institutions (more on this point shortly).
- 3. **REVISION AND APPEALS CONDITION:** There must be mechanisms for challenge and dispute resolution regarding limit-setting decisions, and, more broadly, opportunities for revision and improvement of policies in the light of new evidence or arguments.
- 4. *REGULATIVE CONDITION:* There is either voluntary or public regulation of the process to ensure that conditions 1-3 are met. (Daniels 2008:118-119)

Together, these four conditions define the profile of a legitimate--and legitimating--process for deciding about the extent to which the overall budget for health care resources would be allocated for particular conditions and needs and the extent to which individuals and groups would have access to and find limits placed on their particular claims for health care resources. As Daniels notes, "these four conditions bring decision making about meeting health needs out of a mysterious black box ... and make it possible to assess health plan and public agency decisions in the light of wider societal views about fairness." (Daniels 2008:119)

These attributes of a decision making process are recommended as most likely to support values of justice and fairness in health equity policy within one nation-state. Yet these attributes, such as transparency, stakeholder consultation, development of guidelines and procedures for monitoring and evaluation, and opportunities for revision, are completely transferable to international institutions with responsibility for health care of diverse populations.

However, in terms of substantive guidance about what decisions to make regarding intergenerational equity, reducing health disparities, and priority setting in a rights-based context, Daniels' discussion serves to model rather than inform the recommended decision-making process. The answers, insofar as there are any, will lie in what the affected individuals and groups will do within the process of consultation and revision he proposes. The guiding principles of justice with regard to health that he argued for in the first part of his book (health is of moral importance and health inequalities are unjust if they can be tied to socially controllable factors within the larger society) have some general application in this part of his discussion by providing some overarching benchmarks against which to evaluate the soundness of a particular decision that eventuates through the process he recommends.

# Appendix 2

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