

# Chapter 7

## Vulnerability and Marginalized Populations

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### 7.1 Introduction

Public health practitioners attempt to identify and then remove, or at least reduce, threats of harm. However, harm does not affect everyone in the same way. Some people and communities are resilient, whereas others are more susceptible to potential harm. Much public health work is carried out by, or on behalf of, governments. Where people or communities are at great risk of harm, government has a clear and firm responsibility to protect its citizens. One way of describing a potential source of such a risk of harm is to focus on the idea of *vulnerability*. This introduction explores the concept of ‘vulnerability’ and the role that it may play in public health.

Vulnerability is a concept often used in public health ethics and more broadly in bioethics—but its exact meaning is unclear. Roughly, it indicates that an individual or group is thought to have a particular status that may adversely impact upon their well-being, and that this implies an ethical duty to safeguard that well-being because the person or group is unable to do so adequately themselves. This concept, although important, consistently eludes precise definition. The difficulty in defining the concept arises from disagreement as to how to characterize the idea of “special status” and to whom it applies. As a result, more and more categories of individuals and groups are being classified as vulnerable in an ever-increasing range of situations. This raises the concern that almost everyone can be classified as vulnerable in some

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way and, in turn, that almost every activity now requires this additional attention. If true, then the concept of ‘vulnerability’ ceases to be useful because if everyone is vulnerable, then no one is.

There is currently no clear, single, definitive account of this concept that is universally accepted, although numerous different approaches have been adopted by, for example, various international bodies in their guidelines. In this chapter, we shall critically examine some leading definitions of vulnerability and attempt to explain and classify them to make clear the differences in approach. Then we will offer an account of vulnerability that seeks to provide a universal basis for the everyday use of the concept while avoiding the pitfalls associated with the other definitions. Our approach aims to reduce the concept to a simple role, not as a basic moral concept in its own right, but as a marker, or signal, to public health practitioners that something in the situation before them requires ethical attention. The real ethical work is to be done by the practitioner, not by vague appeal to the idea of vulnerability, but via the application of other concepts and ethical concerns that are already familiar in public health and bioethics. We shall use case studies to illustrate how this approach works.

## 7.2 Different Approaches to the Concept of Vulnerability

Before looking at the approaches taken to define vulnerability, a worthwhile starting point is to examine the concept that can be derived from the term’s everyday use. Vulnerability, in line with the etymological root of the word meaning “to wound,” is widely interpreted as

(V1) Open to harm or under threat of harm.

This basic definition is perfectly adequate, for a range of uses, with context determining the nature and kind of harm at stake. However, such a definition only captures a broad background use as to how the concept should be employed. Though this definition will be sufficient for most purposes, further clarity and greater specificity of the concept is needed here. In attempting to refine this basic definition, several challenges arise. First, how we formulate any definition will change whether or not we see someone as vulnerable. Therefore, in providing a more substantial definition, one has to avoid the problem of inadvertently excluding those who should be considered genuinely vulnerable or including those who are not vulnerable. Second, if we want the concept of vulnerability to function as something that generates a duty or responsibility to prevent harms from befalling people, then we must move beyond a basic, factual description and include some normative ethical element, something along the lines of what Goodin characterizes as “the principle of protecting the vulnerable” (1985, 110).

Providing a sound definition of vulnerability that satisfies these elements is more difficult than might be expected. Hurst (2008) captured this difficulty well by likening it to the attempts of six blind men trying to describe an elephant. As each blind man touches a different part of the elephant—the trunk, ear, tusk, tail, etc.—they cannot agree on how to describe the animal. This analogy maps directly to the challenge of defining vulnerability. Because different perspectives abound on what con-

stitutes the grounds of vulnerability, consensus on the definition is difficult to reach (Schroeder and Gefenas 2009).

Much of the focus on vulnerability in the bioethics literature has been in research ethics, where many international guidelines recommend or impose some duty to provide extra protection for those considered vulnerable. However, these guidelines generally fail to define the concept (although the Council for International Organizations of Medical Sciences [CIOMS] (2002) does provide a definition) and, instead, list groups commonly considered vulnerable (U.S. Department of Health, Education, and Welfare 1979; World Medical Association 2013; CIOMS 1993). Although this practice is slowly changing, strategies for analyzing and defining the concept are usually limited to simply adding or subtracting from a list of properties, conditions, or categories that typify what it is to be considered vulnerable.

The approaches taken to define vulnerability beyond everyday use (V1) can be categorized broadly into three basic types:

(V2) Vulnerability is a universal condition that humanity has in virtue of our physical or social nature (Fineman 2008; Hoffmaster 2006; Turner 2006; Rogers et al. 2012; MacIntyre 1999; International Bioethics Committee of UNESCO [IBC] 2013; and to some extent Hart 1961).

or

(V3) Vulnerability involves one or more specific attributes, contexts, or group types (Rendtorff 2002; and this is perhaps also the approach taken by the International Bioethics Committee of UNESCO when it considers what it calls special vulnerabilities, 2013, 5–6).

or

(V4) Vulnerability involves one (or more) familiar but overarching ethical concept(s) (Goodin 1985; Wrigley 2010).

Before we critically examine each approach, it is worth noting that all definitions are perfectly adequate depending on what we want the concept to do or what role we want it to play. One possible explanation for the failure to produce a single, universally agreed-upon definition of this concept is that, put simply, those who use the term have different aims and roles in mind.

### 7.3 Concerns Surrounding Approach (V2): Universal Condition

Approaches to the concept along the lines of (V2) use vulnerability to mark every human as somehow open to harm—including physical injury, dependency on others, loss of power, and so forth—just by virtue of being human (Fineman 2008). Hence, by that logic, everyone is vulnerable because we all have bodies that can be injured, disabled, and fail through illness and old age. On this view, we are also

vulnerable because whilst we live in social units that require interdependence, high quality interaction does not always exist.

(V2) is a very particular way of thinking about the concept of vulnerability inasmuch as it motivates and drives discussion of the human condition in general. However, the major problem with such accounts is that the general truth that we, as humans, are open to harms of various kinds or that we live in social groups, fails to pick out a special category because it applies to absolutely everyone. It becomes difficult to talk of ‘degrees’ or ‘types’ of vulnerability on such accounts. This, in turn, has led to the criticism that such an approach results in the “naturalizing” of the concept, whereby it is held to be normal or natural to be vulnerable in one way or another (Luna 2009). Of course, if the idea behind using the term ‘vulnerable’ is (a) to articulate a fundamental aspect of the human condition, (b), to say something substantive about the interdependence of humans, and, perhaps, (c) to thereby affirm a natural commitment to human solidarity, then much substantive (and controversial) content is built into the concept, and our discussion moves far from the everyday meaning of vulnerability. If we are all vulnerable, then appealing to this concept as a means to avoid a harm or seek special protection becomes problematic, as it is hard to see how particular priorities can be set.

This approach makes vulnerability far too broad to serve as anything other than an underlying presumption about all human beings, and so it is unable to generate ethical duties beyond what we owe to every human by virtue of being human. As a result, this approach does not provide an account of vulnerability that can identify cases where people or groups are potentially open to harm in any special way.

## 7.4 Concerns Surrounding Approach (V3): Specific Attributes, Contexts, or Groups

In direct contrast to the approach taken in (V2), (V3) characterizes vulnerability by identifying it with some specific attribute, context, or group membership. This approach focuses on vulnerability *in terms of something*, such as physical vulnerability, social vulnerability, vulnerability *in terms of lacking capacity*, vulnerability *in terms of belonging to a certain identifiable group*, or vulnerability because of belonging to a marginalized population, etc.

This approach to defining the concept is an excellent way of illustrating the sorts of conditions that we might want to pick out as requiring special consideration in terms of susceptibility to harm. As such, (V3) serves as a useful heuristic device because it gives examples of the sorts of things that are often considered vulnerabilities. However, this check-list approach is to borrow David Lewis’s (1986) phrase, an attempt at explanation by “way of example,” whereby we provide some key paradigmatic examples or illustrations of what constitutes vulnerability and state that vulnerabilities are “these sorts of things.”

This approach does a poor job of defining vulnerability. Listing everything that falls under a concept, even if it were possible, does not give us a good definition of that concept. (V3) neither tells us whether the examples listed are appropriate nor guides our decision making on controversial cases where identifying someone as

vulnerable is unclear. Further, by using the (V3) approach, attention is directed away from the underlying question of what vulnerability *is*; and instead, the focus is on whether or not to add a particular group to a continually expanding unstructured list of examples (Rogers et al. 2012). Of course, any such list might prove useful as an aide memoir during, for example, an emergency event. Such a pragmatic role may be useful, but it should not be mistaken for an ontological category or conceptual boundary.

The (V3) approach has therefore met with the criticism that it is both too broad and too narrow to satisfactorily define vulnerability (Levine et al. 2004; Schroeder and Gefenas 2009; Luna 2009). Concerns about being too broad stem from the list of vulnerabilities becoming inflated to the point where “virtually all potential human subjects are included” (Levine et al. 2004). As such, the same concern for (V2) applies to (V3), since both approaches fail to specify in sufficient detail those who need additional or special protection from harms.

(V3) is also, potentially, too narrow because it focuses all attention onto specific or group characteristics and therefore fails to address concerns outside the particular designated categories (Rogers et al. 2012). It will, therefore, potentially miscategorize certain individuals or groups as *not* being vulnerable if, for example, they are a group that has not been encountered previously or if some trait has not made it onto the list of specified characteristics. Moreover, by focusing on specific or group characteristics, (V3) can stereotype individuals who fall under category headings (Scully 2013). If, for example, we assign names to different categories of vulnerability (e.g., ‘the elderly’, ‘the disabled,’ or ‘women,’ or ‘the poor’ as categories of vulnerability), then many people could be classified as vulnerable without them necessarily being at any greater risk of harm.

## 7.5 Concerns Surrounding Approach (V4): Overarching Concepts

The (V4) approach explains vulnerability in terms of one or more overarching but more familiar ethical concept(s). Perhaps the best example of this kind is Goodin’s (1985) account of vulnerability, which builds on the everyday use of the term (V1)—open to or under threat of harm— but goes a step further by exploring what the relevant harms might be. This leads Goodin to interpret “harm” in terms of a person’s “welfare” or “interests” so giving us an initial definition of being vulnerable in terms of ‘*being susceptible to harms to one’s interests*’ (1985, 110–114).

However, as the concepts of ‘welfare’ and ‘interests’ can in turn be open to a great deal of interpretation, including the possibility of focusing on subjective explanations involving the satisfaction of preferences or desires, further clarification is needed. To this end, Goodin suggests that a particular sub-group of interests, that is—people’s “vital interests” or “needs”—are the universally important welfare considerations that we need to be concerned about. On this view, one is vulnerable if one’s needs are threatened. And one is most vulnerable if one’s most vital needs are threatened.

Goodin also adds an explicit normative role to the concept of vulnerability by imposing an ethical duty to safeguard the potentially vulnerable from harm. This role is imperative if the concept of vulnerability is to be anything more than a factual description of an individual's or a group's characteristics. Goodin does this by linking his account of vulnerability to the "principle of protecting the vulnerable," which is, essentially, an obligation to protect the vital interests of others. Hence there is a direct link between the classification of someone as being vulnerable, with a requirement on the part of others to protect them from any potential harms.

Despite being a highly influential account of vulnerability, this approach has been criticized. One concern is that it potentially promotes widespread paternalism in an attempt to meet others' needs (Rogers et al. 2012), thereby characterizing all vulnerable people as, in some way, being helpless. This criticism misses the mark, though, because being vulnerable by Goodin's account does not mean one is powerless. More telling, however, are the concerns that this account does nothing more than reduce the concept of vulnerability to the well-recognized concept of needs, together with a moral theory that demands we aid those in need. In essence, this implies that the concept of vulnerability is redundant and could be replaced with the concept of being in (serious) need.

## **7.6 Simplifying the Concept of Vulnerability (V5): The Moral-Marker Approach**

Rather than continuing this attempt to define vulnerability along the lines of the approaches already mentioned (**V2**, **V3**, and **V4**), an account of vulnerability can be offered in much simpler terms. Instead of seeking a substantive definition that tries to establish conditions for vulnerability, another option is to interpret the word "vulnerability" as nothing more than an empty marker or signal for potential moral concern. This approach can be seen in Hurst's view of vulnerability as a sign of "increased likelihood of incurring additional or greater wrong" (2008). However, this view can be taken further. A formal moral-marker approach simplifies the account of vulnerability by avoiding any reliance on moral theory or preconceived wrongs as part of the definition. On this account, vulnerability will simply be

**(V5)** A marker that additional consideration needs to be given to whatever existing ethical issues there may be.

It can be seen that what is then in dispute between the different accounts presented is what sorts of considerations are the relevant ones. However, if we stop at the point where "vulnerability" is recognized as just a warning marker, we don't need to engage with the substantial task of trying to provide a catch-all definition that somehow incorporates all physical, mental, or emotional, etc. cases that might constitute vulnerability. Instead, we can focus on substantive ethical concepts such as harm, consent, exploitation, etc. and explore how each applies to the particular case before us. On the basis of this approach, "vulnerability" says nothing at all about what generates the need for any special scrutiny because the substantive ethical weight of the

concern (and how to address it) requires us to engage with these substantive moral concepts. So, for example, it says little to talk about marginalized populations as being vulnerable, but if we recognize the ‘moral marker’ of vulnerability here, we might then explore how exploitation, inequity, and harm are relevant when deliberating about a particular case. One of the priorities for educating public health professionals about ethical issues is to seek to increase their sensitivity to the relevant features of each situation, rather than teach them the formulaic application of rules or vague concepts such as that of “vulnerability” (Coughlin et al. 2012).

The (V5) approach offers other advantages as well. For example, it avoids stereotyping based merely on belonging to a specified category; it avoids exclusion on the grounds of not already being on the list of vulnerable groups; and it avoids the vacuity of identifying “all” as vulnerable, while maintaining the crucial aspect that the concept marks out the need for special ethical scrutiny. Trying to provide more substantial components to the definition of vulnerability diverts scrutiny and energy from where it matters most—sensitive, rational thought about specific problems—and instead, promotes a formulaic approach to ethical safeguarding.

Although other writers on vulnerability, such as Levine et al. (2004) and Luna (2009), criticize this approach claiming generic guidance about paying “special attention” or giving “special consideration” to something is not useful, the same criticism could also apply to an account that identifies specific categories or relies on some overriding concept. For example, if we try the specific category or context route (V3) so that, say, we hold “the elderly” vulnerable, how would that guide our actions without reference to established concerns about, for example, physical harms or exploitation? The same holds true of (V4) accounts such as Goodin’s focus on vulnerability as being open to harms to one’s interests, which then requires further analysis of “vital” needs. The best that can be said for such accounts is that each provides something of a heuristic, teaching anyone who wants to learn ways in which harms or wrongs might arise.

The importance and implications of these issues become apparent as we consider the various cases in the rest of this chapter. The implications of (V2), the approach focused on vulnerability as arising from the human condition, is that all are vulnerable, including the police and immigration officials in Blight’s and McDougall’s cases, the public health officials with responsibility for launching national programs to reduce Sudden Infant Death Syndrome (SIDS) in the Jonas and Haretuku case, and the prison governor in Christopher et al.’s case. This outcome demonstrates the key problem with this view. The very concept of vulnerability ceases to have much meaning, although presumably there might be a retreat to the thought that some individuals and populations are ‘more’ vulnerable than others, although it is unclear how this is to be specified.

Many of the cases could more obviously be used to endorse (V3), the approach focused on specific groups, contexts, or categories. Many of these cases focus on marginalized groups within society, such as prison inmates (Christopher et al.), immigrants, asylum seekers, refugees (McDougall; Blight), substance abusers (Christopher et al.), minority communities of various kinds (Bernard et al.; Blight; Jonas and Haretuku), and the poor (Vergès et al.). This is a traditional, influential, and powerful way of thinking about vulnerability. However, as stated previously, this approach has its problems. Does it necessarily follow that if you belong to one of these groups that you are vulnerable? You may well be at increased risk of harm

of various kinds if you belong to such groups. However, you might also be at increased risk of harm as a recreational drug user, skydiver, or American football player, although individuals belonging to such groups are not likely to be seen, intuitively, as being necessarily vulnerable.

The more specific focus on providing a normative explanation for vulnerability presented in the work of writers such as Goodin (V4), is more useful, in that we can begin to clearly identify subgroups that are at risk of harm to their vital interests (the girl fed through a tube and unable to feel pain involved in a forced deportation case: Blight), rather than just being routinely disadvantaged (the surrogate encouraged to take on that role because of poverty: Vergès et al.) or at increased risk of harm due to the cultural traditions or choices of their parents (Jonas and Haretuku). How should we think about risk factors and vulnerability? Some will think of smoking around children (increasing the risk of SIDS) as being an individual's choice. Others will argue that it is unfair to assume that it is always individuals that are responsible for such choices and the resultant outcomes, as people may be addicted to nicotine or they may have become smokers through the influence of norms within their social environment.

The advantage of the 'moral-marker' approach (V5) is that it allows us to dive beneath the surface offered by the label of 'vulnerability' and offer more sophisticated explanations for the situations described in the cases, as well as providing the opportunity to develop strong normative reasons to respond. For example, all of these cases are about various kinds of injustice, disadvantage, and inequities in society, and their impact on individual and community health. They are appropriate issues for those working in public health to be concerned about precisely because they provide reference to the identification of various harms at the population-level, and many of the solutions to these issues will have to come through collective and public action.

As the discussion of the different approaches to defining vulnerability considered above illustrate, most of the approaches to vulnerability do little more than encourage us to engage in additional ethical scrutiny using already well recognized and well understood moral concepts. The final 'moral-marker' approach (V5) suggests that this is exactly what the concept should be used for, and nothing more.

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## **7.7 Case 1: Reducing Sudden Infant Death Syndrome in a Culturally Diverse Society: The New Zealand Cot Death Study and National Cot Death Prevention Programme**

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### **7.7.1 Background**

Sudden Infant Death Syndrome (SIDS) involves the death of apparently healthy sleeping infants, usually within the first year of life. It is a diagnosis of exclusion, that is, it denotes an unknown cause of death (Willinger et al. 1991; American Academy of Pediatrics 2011). It is also known as cot or crib death and is classified as a form of Sudden Death in Infancy (SUDI).

Unlike many public health issues, SIDS unites clinical and forensic considerations, as this finding of cause of death can determine attribution of criminal (and moral) responsibility. Police collect evidence and coroners assess the circumstances of the death and release judgments. This is the method by which a SIDS death is determined. Context heightens the ethical significance of SIDS diagnosis, research, and prevention.

In 1991, when the New Zealand Cot Death Study (NZCDS) commenced, New Zealand's rate of SIDS was high by international standards at 4 deaths per 1,000 live births (Mitchell et al. 1997) compared, for example, to the Netherlands (1.3/1,000 in 1989) (de Jonge et al. 1989) and Hong Kong (0.3/1,000 in 1986–1987) (Lee et al. 1989). Within New Zealand, SIDS deaths occurred in the indigenous Māori population at twice the rate of the non-Māori population (Mitchell et al. 1994). The reason for this significant disparity was not well understood.

The NZCDS was the first national case-control study designed to identify risk factors for SIDS. By comparing infants whose deaths were attributed to SIDS with a representative sample of live births, within a year, the NZCDS had identified a number of risk factors. The study confirmed an association between increased risk of SIDS and lower socioeconomic status, along with a range of associated maternal factors, including fewer years of education, younger age at first pregnancy, greater number of previous pregnancies, and lower attendance at prenatal classes (Mitchell et al. 1991). The NZCDS selected three risk factors to address among this range of findings: lack of breast-feeding, maternal smoking, and placing infants to sleep in a prone position (Mitchell et al. 1991).

The ensuing national prevention campaign focused on publicizing these risks, which parents were seen as able to influence. These were categorized as 'modifiable risk factors.' Many parents changed their practices in response to the campaign (Cowan 2010). Abandonment of the prone sleeping position was the most readily and widely adopted measure and is credited with delivering the largest proportion of the national reduction in SIDS rates (Mitchell et al. 1997). Factors that were less susceptible to parental alteration were classified as 'nonmodifiable risk factors.' Nonmodifiable factors included the baby's sex, the mother's age, and the family's socioeconomic status.

Analysis of the second year's data revealed another risk factor: bed-sharing (Mitchell et al. 1992). Bed-sharing was categorized as a modifiable risk factor, and parents were advised to avoid sleeping on the same surface as their baby or allowing

others (for instance, other children) to do so. The study's findings were immediately fed into the prevention campaign.

Communicating with parents about this particular risk factor became more problematic than initially anticipated. The difficulties partly reflected a developing understanding about the subtle nature of bed-sharing risk. While early messages counselled against all bed-sharing, subsequent findings prompted adjustments (Cowan 2010). Now bed-sharing is not viewed as a significant risk unless coupled with maternal smoking or with the baby's bedmate being intoxicated or excessively tired. Other factors such as the baby's age, the site, and duration of bed-sharing have also been identified as affecting the magnitude of risk. These considerations make it difficult to summarize the risk in a way that is scientifically sound and that parents can easily understand. Also, the prevention campaign took place against a backdrop of numerous changes in prevailing thought since the 1950s about the causes of SIDS. These changes were associated with changing advice about parental practices, which created uncertainty within families about which advice should be followed.

The cultural significance attributed to bed-sharing meant that there were different reactions among groups to advice not to bed-share. While bed-sharing is not traditional among New Zealand European (Pākehā) families, it is firmly rooted in Māori and Polynesian child-rearing practices (Tipene-Leach et al. 2000). In these communities, bed-sharing is seen as positive and beneficial, promoting bonding between mother and child and enabling mothers to comfort and care for their child (Abel et al. 2001; Tipene-Leach et al. 2000). The message that bed-sharing is risky had serious implications, then, for Māori and Polynesian child-rearing practices.

The early years of the SIDS prevention campaign succeeded in reducing the rate of SIDS, but the tenor of the anti-bed-sharing message alienated many, particularly indigenous Māori, consequently turning whānau (wider family networks) away from SIDS prevention messages altogether (Stewart et al. 1993; Tipene-Leach et al. 2000; Cowan 2010). Some interpreted the campaign as blaming Māori for infant deaths. After an infant death, the involvement of police, pathologists, and a coroner's court compounds overtones of culpability, intensifying the guilt and grief associated with the loss of a child (Clarke and McCreanor 2006).

Several years after the ongoing SIDS prevention campaign was launched, rates of SIDS among Māori remained disproportionately high. In 2009, the rate of SIDS for Māori was 1.5 per 1,000 live births, compared with 0.6/1,000 for Pacific Peoples, and 0.3/1,000 for Other, including Pākehā (Ministry of Health 2012).

Several modifiable risk factors for SIDS, including maternal smoking and bed-sharing, are more prevalent in the Māori community. Māori parents less frequently attend prenatal classes than non-Māori parents. Along with the modifiable factors, many nonmodifiable factors are more likely to apply to Māori families, including lower socioeconomic status, younger age of mother at first pregnancy, greater number of pregnancies, and fewer years of education (Mitchell et al. 1993). These contributors to rates of SIDS among Māori do not receive the same level of scrutiny in the media as modifiable parental practices, and prevention campaigns continue to focus upon altering parental practices.

A sense of injustice and a perception that the state lacks a true commitment to addressing the societal factors underpinning SIDS prevails in parts of the Māori community. The prevention campaign's focus upon discouraging bed-sharing contributes to the community's sense that the campaign undermines rather than supports traditional Māori practices. In particular, the coronial process—the investigations into the cause of death, the invasive process of autopsy, and the slow return of the body to whānau—cannot easily accommodate the deep-felt need of whānau to complete the traditional Tangihanga process, the spiritual rituals and burial proceedings following a death (Clarke and McCreanor 2006; McCreanor et al. 2004). Nor is the high profile of the bed-sharing risk matched by a commitment to tackle other risk factors, which may require more resources. Some have therefore called for examination of the process by which risk factors are categorized as modifiable or nonmodifiable (Tipene-Leach 2010; McManus et al. 2010).

The government has committed substantial resources to culturally appropriate SIDS prevention for Māori and Polynesian families and is conducting trials of appropriate supports for families to bed-share safely (Tipene-Leach 2010). Meanwhile, criminal proceedings against Māori parents relating to the deaths of their infants while co-sleeping continue to receive media attention (R v Tukiwaho 2012; APNZ 2013). No wonder, then, that the strong sense of parental responsibility for SIDS deaths, where bed-sharing is a factor, remains. Although inequities underwrite the high exposure of Māori families to both modifiable and nonmodifiable risk factors, both government-funded health promotion and media coverage of SIDS remain focused on parental practice.

### **7.7.2 Case Description**

Following high-profile media coverage of the greater burden of SIDS among Māori, new funding is available for a SIDS prevention campaign to reduce SIDS in Māori and Polynesian families. Part of this funding is reserved for the generation of new guidelines acceptable to Māori. There is also an opportunity to brief the Minister of Health and the Minister of Social Development about measures that can reduce rates of SIDS deaths among Māori infants.

### **7.7.3 Discussion Questions**

1. Evidence suggests that several factors affect the magnitude of risk and that bed-sharing in the absence of these factors does not significantly increase the risk of SIDS. But the interplay of risks can be complex and difficult to communicate effectively in a national campaign. Can a definitive “no bed-sharing” message be defended, on ethical grounds, if it causes less confusion but overstates the risk to some groups? What are the most important ethical considerations here?

2. What weight should be attributed to the cultural significance of bed-sharing when generating guidelines, and why? Should risks that relate to culturally significant parental practices, such as bed-sharing, be treated differently from risks relating to practices that are not held to be culturally significant?
3. Māori and Polynesian families value bed-sharing because of the health and social benefits they attribute to it. These benefits are not captured in studies investigating SIDS risk. Should the health and social benefits attributed to bed-sharing by families who practice it be accorded weight when formulating guidelines? If so, how much weight? If not, why not?
4. Colonization has imposed and continues to impose an assault upon Māori culture. Anti-bed-sharing advice might be seen to extend that assault, privileging a narrow range of health concerns. The inherent beliefs and practices that led Māori to value bed-sharing, such as bonding between mother and child that promotes strong social bonds, seems particularly worth preserving. How can respect for Māori social practices and ways of viewing the world inform SIDS-related health promotion? How much difference does the magnitude of the relevant health risk make? If the risk is less serious, would you favor a different approach?
5. Consider how risk factors might be categorized as modifiable or nonmodifiable. What role should fairness play in this process?
6. Consider the role guidelines might play in coroners' investigations to identify contributing factors to an infant death. Should this possibility be kept in mind when guidelines are being drafted? Why? Why not?
7. Does parental responsibility require compliance with child health guidance? How should parents evaluate conflicting or changing advice about risk?
8. Parents can control some risk factors for SIDS, but others involve broader societal issues, such as socioeconomic status. Does social justice require that prevention campaigns targeting parental practices be coupled with efforts to tackle social and economic disparities and inequities? Who should be responsible for ensuring that this is the case? What should researchers do when they identify a parental practice as risky if resourcing for broader action is not forthcoming?

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## 7.8 Case 2: Medical Tourism and Surrogate Pregnancy: A Case of Ethical Incoherence

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### **7.8.1 Background**

Advances in biotechnology regularly generate novel ethical challenges that fall between the cracks of safeguards designed for conventional cases. Innovations—especially in reproductive technologies—can even create new classes of vulnerable people. Such novel cases often force us to thoroughly reexamine ethical safeguards and reveal the legal and ethical gaps.

Panama, like most Latin American countries, divides its health care system into public and private systems. Public insurance covers roughly 81 % of the population (Contraloría de la República de Panamá 2012). Families lacking permanent work and unable to afford insurance can find public assistance for health services through the Ministry of Health (MoH). The MoH by law regulates most health research and health services, including regulation and supervision of hospitals and public and private clinics (Asamblea Nacional de Panamá 1947). The private system, although legally supervised by the Ministry of Commerce, exists mostly free of external control and relies heavily on self-regulation. Medical doctors, after initial MoH certification, are no longer monitored (Decreto de Gabinete 1970).

Like the certification process, the ethical guidance that applies to doctors is not overseen. Although a Panamanian Medical College code of ethics has applied to doctors since 2009, its ethics committee meets only to consider malpractice charges brought against doctors (Colegio Médico 2012). Independent associations for medical specialties exist, but they focus on academic and social matters, not on public health issues. Only recently have some associations begun to discuss the ethical, legal, and social implications of their specialty-related health topics such as transplantation, blood banks, storage of biological tissues, sale of organs for transplant, and rights and obligations of organ donors and recipients.

In response to a growing burden of maternal mortality, sexually transmitted diseases, and adolescent pregnancy, the World Health Organization in 2000 began a

sexual and reproductive health program (World Health Organization 2000). This initiative prompted the Panamanian government to begin covering infertility problems and permitting the public health care system to treat married couples (Ministerio de Salud 2000). Although the MoH did not include in-vitro fertilization (IVF) and surrogate pregnancy in this program, a public institution, the Gorgas Institute for Health Research, announced in 2011 that it would launch an IVF program in 2013 for couples with limited resources (Soto 2012). The government, however, was silent about IVF, so the regulations governing IVF remain unclear. However, a law governing organ transplantation, which permits donation of living cells, comes closest to offering legal guidance for IVF. This law requires the donor and recipient to give written consent but does not permit the donor to receive compensation. Nor does it protect the health and confidentiality of the donor and recipient or offer treatment of medical complications (Asamblea Nacional de Panamá 2010). Nowhere, does this law or any other address surrogacy.

Medical tourism is a new and growing industry in Central America, where a quarter of the world's medical tourism occurs (Martinez 2011). At 16 %, Costa Rica commands the largest industry share in Central America; but according to estimates of its National Science and Technology secretary, Panama will achieve a 12 % share in 2015 through services offered by its four private hospitals. At these hospitals, medical tourism may represent nearly 20 % of the patients being treated. The patients, who come mainly from Canada and the United States, usually seek surgery for orthopedic problems, infertility, and cardiac disease. Although private advertisements for medical tourism have been appearing since 2007 (Sbwire 2013), lawmakers have not yet created a national legal framework to address the issue.

Couples from neighboring countries or the United States come to Panama seeking infertility treatment because it is inexpensive, is largely unregulated, and performed by Panamanian doctors noted for technical ability. Moreover, anyone who travels to Panama for treatment is entitled to receive it. IVF using fertilized eggs from anonymous donors has become standard practice, but surrogacy is not officially offered. No medical or legal problems with IVF surfaced until 2011 when the Panamanian MoH was asked to weigh in on a high-profile case of an abandoned child born with severe birth defects to a Panamanian woman acting as a surrogate for a foreign couple.

### **7.8.2 Case Description**

A Panamanian woman, who was married with two children, had a primary school education. She worked in her own home but was experiencing economic difficulties because her husband could not find permanent employment. Why she agreed to surrogacy is unknown, but presumably economic considerations played a major role. Because her first two pregnancies had presented no problems, she signed a surrogacy contract to carry the fertilized egg of a married couple who had traveled to Panama seeking surrogacy services. Little is known about how the foreign couple and the Panamanian woman came to know each other, because no lawyer



participated in this transaction. Nor did the surrogate's husband learn of the transaction until after she had signed the contract. Why no one thought to include the husband is a mystery. After signing the informed consent form, the surrogate was inseminated in a private clinic in Panama. Doctors involved in the case state that they followed medical recommendations and obtained the informed consent of the surrogate and the egg donor. Neither the procedure nor the pregnancy presented any problems, but the surrogate unexpectedly died after severe complications developed during delivery. These complications, which also caused hypoxia and convulsions in the newborn, left him with severe cerebral paralysis. As a result of his birth defects, he will never walk or speak and will require care for the remainder of his life.

The couple rejected the child, arguing that the contract specified "a healthy child." The husband of the Panamanian surrogate also rejected the child claiming it was neither his wife's, nor his, especially as he had not participated in the contract. He also pleaded that he now had to cope with his wife's death and raising two motherless children. Appealing to the MoH, the clinic sought state custody of the child. The MoH offered medical assistance, but it declined to accept long-term responsibility for the child. Instead, the MoH charged an ethics panel to examine the case and, pending its outcome, sent the child to a religious orphanage.

The ethics panel has been charged not only with making a ruling on this case, but in recommending measures to regulate surrogacy in the future, particularly cases involving medical tourism.

### **7.8.3 Discussion Questions**

1. In the context of surrogacy and medical tourism, who is responsible for raising this child, and who should pay for his care and upbringing? What role should government and professional associations play in these cases? What is the responsibility of doctors involved in such practices?
2. What measures should the ethics panel recommend to protect vulnerable women in the future who have agreed to surrogacy?
3. What ethical basis could justify compensation for surrogates or their families in the case of death or injury to the surrogate?
4. What measures should the ethics panel recommend for protecting medically compromised and abandoned infants when surrogacy-involved pregnancy or delivery goes radically wrong? How should informed consent forms be modified to anticipate such outcomes?
5. Do cases of medical tourism require international regulation of medical technologies? If not, why not? If so, how should the panel's ethical arguments be incorporated into legal agreements between countries to guarantee the protection of vulnerable populations?

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## 7.9 Case 3: Compulsory Treatment for Injection Drug Use after Incarceration

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### **7.9.1 Background**

Injection drug use is a major public health problem, with an estimated 3.5 million users in the United States (Armstrong 2007) and 15.9 million users worldwide (Mathers et al. 2008). Between 24 and 36 % of U.S. adults addicted to heroin pass through the criminal justice system each year (Rich et al. 2005). Compared with the general population, injection drug users have higher rates of HIV, tuberculosis, hepatitis B and C, and sexually transmitted diseases (Baussano et al. 2010; Nelson et al. 2011; Weinbaum et al. 2005). Injection drug use contributes to correctional and community-level transmission of these conditions and threatens public safety because users frequently engage in criminal behaviors to support their drug use.

In the United States, more than two million people are incarcerated (Glaze and Parks 2012), and an estimated 70–80 % of U.S. inmates have at least one substance abuse problem (Karberg and James 2005; National Center on Addiction and Substance Abuse at Columbia University 1998). At least 40 % of state and federal inmates injected drugs in the month before their arrest (National Center on Addiction and Substance Abuse at Columbia University 1998). Moreover, 95 % of drug users return to drug use within 3 years of release from prison (Marlowe 2006). Compared with the general population, prisoners are nearly 13 times more likely to die of any cause in the 2 weeks after their release and 129 times more likely to die from an overdose (Binswanger et al. 2007).

Rates of incarceration are also substantially higher among minority groups, with African American males being more than 6 times as likely, and Hispanics males more than 2.5 times as likely, to be incarcerated than white males (Carson and Sabol 2012). African Americans and Hispanics also experience higher rates of conviction for drug-related offenses than whites (Carson and Sabol 2012) despite comparable rates of injection drug use between whites and Hispanics and lower rates among African Americans (Substance Abuse and Mental Health Services Administration 2007).

Although inmates make up only 0.8 % of the U.S. population, about 22–31 % of Americans with HIV, 40 % with tuberculosis, and 29–43 % with chronic hepatitis C pass through the correctional system each year (Hammett et al. 2002; Weinbaum et al. 2005). In the general community and prison population, minority groups bear a disproportionately high burden of new HIV infections and hepatitis, particularly among injection drug users (Blankenship et al. 2005; Centers for Disease Control and

Prevention 2013; Estrada 2002). Successful strategies to limit the spread of infectious disease, therefore, need to include interventions with effective substance abuse treatment that target minority groups, particularly anyone with a criminal background.

Correctional programs that link prisoners to treatment for substance abuse and related illnesses upon reentry to the community may reduce risky behaviors that contribute to high post-release mortality rates, bring much-needed care to a vulnerable and medically and socially disenfranchised population, and interrupt transmission of infectious diseases to the broader community. However, despite the lack of widespread access to such services during and after incarceration, perhaps the greatest obstacle to effectively treating drug users is poor motivation. In the United States, 95 % of people with untreated substance abuse fail to recognize the need for treatment (Substance Abuse and Mental Health Services Administration 2012). When people with substance abuse do present for care, it is often because of external, coercive pressure (Fagan 1999). Indeed, coercive strategies have long been used for treating individuals with substance abuse who do not otherwise seek help (Nace et al. 2007; Sullivan et al. 2008). One common argument in favor of coerced treatment is that it restores autonomy to people who have lost their ability to control their addiction (Caplan 2006). Another reason coercion may be necessary, in at least the initiation phase of treatment, is because permanent cognitive deficits can result from extended drug use (Sullivan et al. 2008).

The World Health Organization has concluded that legally coerced treatment is justified if due process and effective and humane treatment are assured (United Nations 2010). Still, although compulsory substance abuse treatment is frequently used for *pretrial* offenders, studies find little evidence that it reduces subsequent drug use (Perry et al. 2009). Indeed, findings are largely mixed about whether legally coerced substance abuse treatment—irrespective of a person’s criminal justice involvement—works in different settings (Klag et al. 2005). Similarly, there are inconsistent findings on the effectiveness of coerced drug treatment in the U.S. criminal justice setting and concerns about a lack of experimental controls in those studies that suggest relative efficiency (Hough 2002; Marlowe 2006; Zhang et al. 2013).

Several reviews conclude that coerced treatment is certainly more effective than no treatment (Hough 2002; Kelly et al. 2005; Marlowe 2006). Emerging data suggest that coercive substance abuse treatment for *parolees* reduces rates of reincarceration; however, data are lacking on whether other clinical outcomes are improved (Zhang et al. 2013).

### 7.9.2 Case Description

You serve as the director of Substance Abuse Services (SAS) in a western state in the United States. Rates of substance abuse, particularly injection drug use, are higher than the national average. Several large cities in your state have among the highest rates in the country. SAS shares data and conducts collaborative research with the Department of Correction (DOC) and other state agencies within the Department of Health (DOH), of which SAS is a branch. Your research efforts have

identified needle sharing among former prisoners, most of whom are members of minority groups, as the source of most new community cases of HIV and hepatitis B and C. You also found that more than half of these infected prisoners do not continue treatment when released and have high rates of reincarceration.

Following aggressive implementation of a statewide prison-based screening and treatment program for infectious diseases, your state has experienced a marked drop in prevalence of these diseases among prisoners. However, for three straight years rates have increased steadily and disproportionately among injection drug users, with rates rising faster among minorities.

To confront this problem, you have successfully worked with representatives from the DOC to offer methadone maintenance programs to opioid-dependent prisoners and have hired reentry specialists to help parolees get treatment for substance abuse and infectious diseases upon release. Unfortunately, to date, only 10–15 % of recently released prisoners who are eligible for these voluntary services have used them.

The governor has issued a directive to think creatively and foster better interagency collaboration so programs can be developed to reach the other 85–90 % of recently released prisoners who inject drugs or have infectious illnesses. You have been appointed to a task force along with other high-level representatives of state agencies, including the DOH, DOC, Department of Parole, and Department of Mental Health, to identify and implement other potential solutions. One suggested policy option is to establish compulsory post-release substance abuse treatment as a condition of parole that would be linked with voluntary infectious disease screening and treatment. Your own interagency research suggests a high rate of transmission of HIV and hepatitis B and C from needle sharing with former prisoners who have been incarcerated multiple times and have not been treated successfully. Accordingly, the target population would be recently released prisoners who have two or more incarcerations and at least one drug-related conviction, a history of injection drug use, and either HIV or hepatitis.

### **7.9.3 Discussion Questions**

1. Given your research findings that most new community cases of HIV and hepatitis B and C result from needle sharing with former prisoners, most of whom are minorities, how would you defend or object to this policy proposal given it will disproportionately subject minority groups to compulsory treatment as a condition of their parole.
2. If such compulsory drug treatment for prison releases is shown to have little impact on community rates of infectious disease, what effect would the program need to have on recently released prisoners for you to support its use? Given a parolee's vulnerable status in society, would you support the program if it reduced criminal recidivism alone? If not, what other outcomes are important to you and why? Would outcomes have to be clinical, or could outcomes reflect a parolee's well-being or functioning in society?
3. What are the ethical implications of implementing (and funding) compulsory treatment for released prisoners in a community where availability of (or funding for)

- voluntary treatment is currently inadequate? To what extent does lack of access to voluntary services (and other social determinants of health such as income and education) contribute to the need for compulsory treatment, particularly among people who are vulnerable to substance use, incarceration, and infectious disease?
4. Public resources and facilities are already in place to provide involuntary treatment for certain health conditions (e.g., tuberculosis and mental illness). Suppose that some mental health advocates object to the proposal to introduce compulsory drug treatment by arguing that it would divert funds from treating people with serious mental illness, including those with criminal histories. People with serious mental illness, they contend, constitute a far more vulnerable prison group, many of whom have co-occurring substance abuse problems. If true, how will your thinking about the case be influenced? Why?
  5. Suppose someone argues that the compulsory treatment program under consideration is another example of society's punitive approach to managing substance abuse. To what extent do you agree or disagree with this argument? Why?

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## **7.10 Case 4: Unanticipated Vulnerability: Marginalizing the Least Visible in Pandemic Planning**

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### **7.10.1 Background**

Influenza is a common respiratory pathogen that affects the nose, throat, bronchi and lungs. The virus is spread through droplets and small particles when people cough or sneeze. Though influenza regularly affects people worldwide, the emergence of novel influenza virus subtypes has the potential to cause a pandemic (World Health Organization [WHO] 2008). In such a case, the population's low immunity can lead the virus to spread rapidly with high rates of sickness and death. Although no one can predict when a pandemic will strike, attack rates of 25–45 % have been suggested with mortality rates varying greatly depending on the virulence of the strain (WHO 2010).

With a virulent strain of pandemic influenza, many patients will become extremely ill, and their need for specialized treatment and intensive care may exceed resources. In addition, front-line health care workers will face great risk of becoming ill, dwin-



dling human resources further and straining the health care system (WHO 2008; University of Toronto Joint Center for Bioethics 2005). In anticipation of these human and physical resource shortages, hospitals, public health agencies, and states have created plans to prepare for an influenza pandemic. Such plans typically include health services, public health measures, priority setting, and resource allocation and usually direct surveillance, preparedness, and response (WHO 2010).

Pandemic plans typically aim to minimize serious illness and overall deaths, but more comprehensive plans also refer to special needs of vulnerable groups. The term “vulnerable,” however, often is left undefined, and, if specified (e.g., the elderly), it usually refers to increased biological or medical risk of succumbing to or transmitting pandemic influenza (Uscher-Pines et al. 2007). Few plans refer to vulnerability in social or economic terms (Uscher-Pines et al. 2007). This lack of specificity raises questions about whether (and how) special consideration ought to differ for vulnerable conditions, such as being homeless, being immunocompromised, or living in a remote community. Even when plans do mention such vulnerabilities, have decision makers or practitioners consulted the people in these categories about their needs in such situations? (Uscher-Pines et al. 2007) More importantly, has anyone reconciled the aim of minimizing sickness and death with the oft competing aim of meeting the needs of the vulnerable?

Meeting the needs of the most vulnerable while being mindful of health equity and social justice has been a long-standing tradition of public health (Beauchamp 1976; Krieger and Birn 1998). In particular, public health interventions targeting the social determinants of health have been heralded as an effective way to combat systemic inequities that lead to disparities in health outcomes (Wilson 2009). However, some challenge the notion of vulnerability as a static condition that can be predefined. Broadly defined categories of vulnerability can exclude people not traditionally seen as vulnerable (such as health care workers), while including people thought to be vulnerable who, with the right supports, can actually participate in the emergency response (e.g., retired older adults) (Mastroianni 2009). Considering and doing something about the context-specific needs of those who might be most vulnerable during a pandemic, can easily become a complex, ethically fraught task.

A further complication is that the interventions taken in response to a pandemic can unintentionally render some people more vulnerable (Mastroianni 2009). Most pandemic influenza plans, for example, seem to focus on hospitals, directing attention to managing intensive care unit (ICU) bed and equipment shortages and distributing resources in high-acuity settings. Such plans often call for redeploying workers from community settings to hospital settings. Because many of these workers already work part-time in the community and hospital sectors, this option is appealing. But if workers are shifted from community health care settings to hospitals, people in the community who depend on these workers may become vulnerable from the intervention.

### **7.10.2 Case Description**

It has been 1 week since the World Health Organization officially declared the presence of an influenza pandemic. Person-to-person spread has been confirmed in several Canadian cities, and emergency rooms in your large metropolitan city overflow with influenza patients. Because routine cases usually fill the medical floors and intensive care units to capacity, there is concern that the surge of influenza admissions will overwhelm resources. To set priorities and possibly reallocate resources within the health care system, the regional health authority has called a meeting in anticipation of the surge in admissions. As the lead of the local health emergency management program, you are asked to attend.

A couple of hours before the meeting, you listen to a call on your answering machine from Julia, a friend and the director of the local community care access center (home care agency). This is the largest center in the region, employing 600 and subcontracting 20,000 health and community service workers through other agencies. Professional services that are subcontracted include in-home nursing, occupational therapy, physiotherapy, social work, speech and language therapy, and nutritionists; nonprofessional services include personal support workers and health care aids and attendants who assist with activities of daily living.

Having become aware of the upcoming meeting with the regional health authority, Julia wonders why no one from the community-based organizations that care for people in home settings has been asked to attend. She appreciates the media focus on the available ventilators and ICU beds in local hospitals, but she is concerned with the lack of attention on vulnerable populations in the community. She has heard rumors of plans to reallocate some nursing and personal support workers from community settings to acute care hospitals and asks if officials have considered that such a move may require some people, who normally manage their illness at home, to be hospitalized. Convinced that someone representing the community should attend priority-setting discussions, she urges you to advocate for such a presence.

Thinking on various levels about how you would respond to the message even as you plan for the meeting, you are particularly struck by how such decisions could adversely affect Julia herself. Her multiple sclerosis is serious enough to require the daily assistance of a personal support worker to help her get from home to her office.

### **7.10.3 Discussion Questions**

1. In what ways does this case challenge conventional notions of who might be considered vulnerable during a pandemic?
2. What does Julia's exclusion from the meeting say about the attitude towards vulnerable populations at the administrative level?

3. How might a decision to shift financial and personnel resources from the community to the hospital setting deepen the health and social inequities that many vulnerable populations already face?
4. Would it be fair for Julia to ask her community workers to work more hours because the needs of the community have increased? What if the workers feel safer working away from the gravely ill at the hospital and prefer to increase community work at the expense of hospital work?
5. If the workers remain in their communities with their patients, it could mean they are able to help fewer members of the population than if they attended their shifts at the hospital. What is more important, treating more people or giving priority to the vulnerable or less privileged?
6. Do those who develop pandemic plans have a responsibility to identify people whose vulnerability might increase during a pandemic? If so, how should planners identify these people?
7. The document you received before the meeting indicated that one of the discussion topics will be priority setting, particularly the scarce resource of ventilators. The document proposes that a physical disability should disqualify a person from having access to a ventilator. How do you balance the need for rationing scarce acute care resources, like ventilators, with social justice values that advocate for the respect and consideration of those who are vulnerable due to systematic social disadvantage? How will you discuss this matter with Julia?
8. In light of Julia's message, how would you begin to identify systemic barriers that limit the inclusion of vulnerable populations in planning for a pandemic? How would you involve these populations in determining if barriers exist that may significantly limit their access to essential health services available to other populations during a pandemic?

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## 7.11 Case 5: Can Asylum Seeking Be Managed Ethically?

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### 7.11.1 Background

Migration is a challenge managed against the backdrop of international accords and the social and historic circumstances peculiar to each country. The 1948 *Universal Declaration of Human Rights* (UDHR) states “everyone has the right to seek and to enjoy in other countries asylum from persecution” (United Nations 1948, Article 14). In 1951, the newly established International Organization for Migration (IOM) began promoting “humane and orderly migration for the benefit of all,” affirming that all migration can be managed (IOM 2013). The United Nations (U.N.) estimated 221 million migrants worldwide in 2010 (U.N. 2013). EUROSTAT estimated 1.7 million immigrants, including forced migrants, in the European Union (EU) in 2011 (EUROSTAT 2014).

Sweden, a Nordic country that joined the EU in 1995, has a long tradition of monitoring the health of its residents. For example, its National Institute of Public Health, the National Board of Health and Welfare, and Statistics Sweden monitor public health trends, and a national center monitors suicide and mental illness (the National Centre for Suicide Research and Prevention of Mental Ill-Health). “Health on equal terms” is a political priority in Sweden that aligns with the country’s strongly egalitarian and multicultural traditions dating back more than 300 years (Linell et al. 2013; Westin 2000, 2006). However, social contingencies throughout Sweden’s history have put pressure on these values and traditions. For example, poor harvests and famine in the mid- to late-1800s triggered extensive emigration, virtually closing borders when

emigration ended in the 1930s. In the 1940s, the borders reopened first for refugees from neighboring countries, then, in the 1950s–1960s, for labor immigrants from European countries. From the 1970s onward, the focus shifted to family reunification of migrants and refugees from outside the EU. According to Statistic Sweden's figures from 2012, of its 9.6 million population, about 15 % are foreign born (Statistics Sweden 2013). The Swedish Migration Board (SMB) suggests that 16 % of residencies granted in 2012 were on refugee, protection, humanitarian, or similar grounds (including temporary grounds) (SMB 2014).

The term migration management (MM) was coined in the 1990s, although the MM field originated in the 1950s (Widgren 1994). The rise of MM coincided with a time when several factors, including the mechanisms of colonialism and the Cold War, worked to control and minimize global migration. But other factors also influenced MM, such as resettlements after World War II; efforts to safeguard rights of refugees and migrant workers rights led by international organizations (e.g., the International Labour Organization, the United Nations High Commissioner for Refugees and the International Organization for Migration); and regional initiatives that removed immigration barriers to improve national economies (e.g., the Organisation for Economic Co-operation and Development and the Treaty of Rome). In the mid-1970s to mid-1980s, Western countries jointly attempted to harmonize entry controls, efforts that the third pillar of the EU's 1993 Maastricht Treaty later incorporated (Maastricht Treaty 1992).

Policies enacted since this treaty have focused on deterring unwanted migrants, arguably to the detriment of human rights and refugee protections (Fekete 2001). By 2002, experts suggested that reducing unwanted and unauthorized immigration could increase public support for integration assistance for foreign residents in Western countries (Martin and Widgren 2002). But this focus on reduction had the side effect of criminalizing “unwanted” migrants. By implying that unwanted migrants could pose a national security threat, policy instruments such as the 2006 Schengen Borders Code may have fed xenophobic tendencies (Schengen Borders Code 2010). Article 5 in the code includes, for example, a statement about entry conditions for short-stay, third-country nationals, that they are not “... considered to be a threat to public policy, internal security, public health, or the international relations of any of the Member States.” At any rate, such increased deterrence and control measures do restrict access to work, housing, health care, and independent legal advice, and even separates families (Johansson Blight et al. 2009). Not surprisingly, detention policies harm health with disproportionately high rates of poor mental health, suicide, and self-harm amongst detainees (Silove et al. 2000; Cohen 2008). Moreover, evidence suggests that such controls have resulted in the rejection of asylum claims of torture survivors and people with severe health problems (Steel et al. 2006; Migration Court of Appeal 2007; Johansson Blight 2015). The evidence also suggests that controls led to children suffering due to exacerbated vulnerability in detention and to unaccounted deaths of forced migrants at Western country borders (Grewcock 2009; Steel et al. 2011). These injustices prompted repeated appeals to national law, the UDHR, and the Convention on the Rights of the Child and calls for change to relevant World Medical Association (WMA) documents such as the Geneva and Lisbon declarations (Hunt 2007; Bodegård 2014; Johansson Blight 2014; Johansson Blight et al. 2014).

An especially poignant example of the health challenges found among asylum seekers, especially children, is the condition known as pervasive arousal withdrawal syndrome (PAWS) (Bodegård 2014). This condition presents as pervasive loss of functioning and profound social withdrawal and apathy (Söndergaard et al. 2012; Envall 2013; Bodegård 2014; Johansson Blight 2014; Johansson Blight et al. 2014). Few children show signs of severe PAWS upon arrival in Sweden; however, routine data on incidence and prevalence are lacking (Envall 2013). Surveys conducted in the past 10 years have identified anywhere from 30 to 424 children with this condition (Envall 2013). Common predictors include exposure to severe persecution, human rights abuses or other traumatic experiences in the country of origin, and the prospect of deportation to countries with poor human rights records. Other signs of distress include suicide attempts (Johansson Blight 2014). PAWS commonly affects health and functioning gradually, over time rendering a child unresponsive and unable to eat or drink without support, which makes the condition life-threatening. Unfortunately, the required health assessment of asylum seekers is insufficient for detecting PAWS in its early stages (Johansson Blight 2014). Typically, static measures of health (such as the use of yes/no check boxes) are used, and life events such as discrimination, traumatizing episodes, or prolonged stress carry little weight in the health evaluation process requested by the migration authorities. From a health perspective, broader and more culturally appropriate assessments are recommended instead, such as illness narratives, family medical history taking, and recording of past and present social contexts (Bhugra et al. 2010). If adopted, more cases of PAWS could be identified, prevented, and treated. No cases of children dying with PAWS have been reported in Sweden, but there has been no systematic follow-up of children deported from Sweden (Envall 2013).

### **7.11.2 Case Description**

The Swedish Migration Board (SMB), the ultimate authority on deportation of asylum seekers, announced it no longer deports children with PAWS. After this announcement, however, the media reported on a rejected asylum seeker, a 14-year-old Roma girl<sup>1</sup> with the condition, deported with her family to their country of origin (Edquist 2013; Myhrén 2013). During deportation, the girl who had lost all ability to function, was being fed through a feeding tube, and was unresponsive to pain. Upon arrival at their home country, the family was refused entry due to the girl's advanced illness and was eventually forced to return to Sweden.

A family friend in Sweden said that widespread persecution of Roma people in the family's home country had restricted the 14-year-old girl's life. For example, the girl had never attended school because her parents feared she would be ostracized, teased, ridiculed, or even physically hurt. The friend explained that the symptoms of

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<sup>1</sup> The Roma people are an ethnic group who trace their origin to the Indian subcontinent, sometimes referred to as gypsies.

severe PAWS began the previous month after Swedish police visited the family's home in Sweden.

According to the SMB, the police who enforced the deportation reported that when they first visited the family, the girl was attending school, and although said to be somewhat shy and withdrawn, she appeared relatively healthy. A routine health assessment of asylum seekers to assess barriers to enforcing deportation found no medical or other reason to impede deportation. This claim conflicted with the statement of a therapist working for a human rights organization, who said he had informed the SMB about the girl's history of discrimination, trauma, and her state of complete function loss, which included her inability to communicate and engage in social interaction. In their defense, police say they followed standard procedures and stand by the initial assessment regarding deportation, which prompted no grounds for halting deportation.

Upon returning to Sweden, the family was detained in an immigration facility, where the father at first was separated from the family. At the time of the media reports, the family had been reunited and was awaiting a new SMB decision on whether they should again be deported.

You are a member of a commission established to decide the outcome of this case and come up with ways to improve the asylum and deportation system. Other members of the commission include medical officers, public health officials, lawyers, and former immigration officials.

### 7.11.3 Discussion Questions

1. Who are the main stakeholders and organizations in this case? What are their primary interests and obligations?
2. What bearing does vulnerability or increased risk of harm have on public health's obligation to prevent or mitigate harm to an individual? What impact should legal status have on that obligation?
3. What are the goals of the asylum and deportation process, and what are the values that drive these goals? How should these values be prioritized?
4. What decision would you make in this case?
5. Based on your prioritization of values, what recommendations would you make to improve the asylum and deportation system?

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## 7.12 Case 6: Tuberculosis Screening, Testing, and Treatment among Asylum Seekers

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### 7.12.1 Background

Tuberculosis (TB), an airborne transmissible bacterial infection that most commonly affects the lungs, has been dubbed “the greatest killer in history” and one of “human-kind’s worst enemies” (Selgelid 2008). TB is typically contracted after prolonged close exposure to the coughing and sneezing of people with active infections.

Although only 5–10 % of people who are infected (but who are not HIV positive) become sick or infectious at some point during their lives, untreated TB kills about two-thirds of those it does infect, despite the availability of effective medicines since the 1950s (World Health Organization [WHO] 2012). Since 1995, the WHO standard for treatment has been directly observed therapy, short-course (DOTS), which involves people watching patients swallowing their pills. Treatments delivered through DOTS are inexpensive and 95 % effective, although 6–9 months may be required to cure ordinary active or latent strains of the infection (Minion et al. 2013).

Inconsistent or partial treatment—when patients do not take their medicines regularly for the required period because they start to feel better, because doctors and health workers prescribe the wrong treatment regimens, or because drug supply is unavailable due to cost or unreliable due to lack of regulation—has led to TB strains that resist one or more first-line drugs (i.e., those most effective and least likely to cause adverse side effects). Drug-resistant TB has been documented in every country surveyed (WHO 2012). A particularly dangerous form of drug-resistant TB is multidrug-resistant TB (MDR-TB), defined as the disease caused by TB bacilli resistant to at least isoniazid and rifampicin, the two standard anti-TB drugs. Curing MDR strains of the bacteria is much less effective (with a 30–40 % failure rate in Canada, slightly better than the global average of 52 %, according to Minion et al. 2013), costs much more, produces reactions that diminish compliance, and may take as long as 20–24 months (Public Health Agency of Canada. 2014). MDR-TB accounts for 1.2 % of all TB cases in Canada, for example, and typically costs five times as much (\$250,000 vs \$47,290 per patient) (Public Health Agency of Canada 2014; Menzies et al. 2008).

TB has retained dramatically high levels of incidence, prevalence, and morbidity and mortality worldwide, especially in developing countries, because social, political, and economic factors (rather than simply biological ones) play key roles in infectious disease patterns. Recent global estimates put the numbers at 15 million active, and perhaps 2 billion latent (asymptomatic) infections, with 9 million new infections yearly, and 1.5 to 2 million deaths per year (95 % of which occur in sub-Saharan Africa and Asia) (WHO 2012). TB is the world's leading cause of preventable death among young adults, and the leading cause of death among those who are HIV positive, since the infection tends to affect and progress quickly in those whose immune systems are compromised by other conditions, particularly HIV but also measles, malaria, or alcoholism. TB is thus often referred to as a “classic social disease” and a “disease of poverty” because of its association with overcrowding, malnutrition, stress, destitution, and rapid social change. TB has also been dubbed the forgotten plague because it rarely affects the wealthy, who are largely insulated from exposure (Kim et al. 2005; Ryan 1993). Thus, although TB was extremely common in eighteenth- and nineteenth-century England throughout the industrial revolution, infection rates declined substantially when housing, sanitation, nutrition, and labor conditions improved and endemic infections all but disappeared in developed countries well before effective drugs were widely available (Selgelid 2008).

TB, though relatively uncommon in Canada today with around 1,600 cases reported annually, is costly (\$58 million in direct costs, and \$74 million total related expenditure, in Canada in 2004) (Menzies et al. 2008), frequently results in hospital

admission, and retains an 11 % mortality rate (Greenaway et al. 2011). Foreign-born persons account for 65 % of active TB, although they make up only 20 % of the population. Up to half of recent immigrants and refugees to Canada are estimated to harbor latent TB and are thus at risk of progressing to active infection, and TB in refugee populations is about double that in other classes of immigrant populations (Greenaway et al. 2011). Those most at risk domestically are the urban homeless and aboriginal communities, followed by residents of long-term care and correctional facilities, and then the staff who work in such institutions (Public Health Agency of Canada 2014).

The cornerstone of TB ethics, according to the WHO, is the protection of individuals and communities through the proper treatment of infected individuals (active and latent) and the prevention of new infections. These goals are said to rely on the promotion of key values including social justice and equity, solidarity, the common good, autonomy, reciprocity, effectiveness, subsidiarity, participation, and transparency and accountability (WHO 2010). The WHO also stresses, in cases where involuntary isolation or detention measures are implemented, the importance of using the least restrictive means necessary to achieve public health goals, as set forth in the Siracusa Principles. These principles require states to ensure that such interventions are proportional to the risk of public harm, necessary and relevant to protecting the public good, and applied without discrimination (WHO 2010).

### ***7.12.2 Case Description***

On a chilly gray autumn morning, Canadian Coast Guard officials take into custody 77 people (66 men, and 11 boys between 8 and 16 years of age) after their vessel, suspected to have been abandoned by human smugglers, is found adrift off the northwest Pacific coast. All immediately claim refugee status and are transferred to a provincial prison, the nearest facility judged sufficiently secure to detain them, review their claims, and physically examine them per immigration procedures. Overcrowding at the criminal correction center, already an issue, becomes severe with the addition of these individuals, many of whom are housed four or five to cells designed for only two people, and often in portable trailers parked in the prison yard. The asylum seekers are subject to the same institutional rules as criminal detainees: they must wear prison uniforms and are significantly restricted in making or receiving telephone calls (Nakache 2011). The federal Refugee Protection Division and provincial health authorities jointly appoint you as a member of an ad hoc local public health unit task force responding to the situation.

Canadian immigration law requires asylum seekers in the country to undergo a medical examination, including screening to assess potential burden of illness, linked to ongoing surveillance or clinical actions only for TB, syphilis, and HIV (Gushulak et al. 2011; Gardam et al. 2014). Within 48 h, medical examinations and chest X-ray results suggest active TB in four of the new detainees: two adults and two brothers ages 6 and 11. Based on their overall health conditions and patient

histories (to the extent that these can be verifiably ascertained under the circumstances) and TB epidemiology in the region of origin, the medical team strongly suspects all four to be infected with MDR-TB, and cultures are thus ordered. The tests will take 2 weeks before results can confirm the presence of drug-resistant strains (6 weeks are needed to confirm negative cultures).

The Canadian Immigration and Refugee Protection Act (IRPA) (Government of Canada 2001) and accompanying regulations (Government of Canada 2013) stipulate that people likely to be a danger to public health or a “public charge” (defined as likely to make excessive demands on health or social services but likely unable or unwilling to support themselves) may be deemed inadmissible for refugee status. However, considerable discretionary power, particularly for children and others in need of protection, is built into the law and related regulations, and initial decisions by immigration officers are generally subject to appeal (Bailey et al. 2005; Greenaway et al. 2011). Section 249 of the IRPA regulations, moreover, sets out special requirements for minor refugee claimants, including the duty to consider the availability of local childcare arrangements, of segregated spaces in detention centers, and of education, counseling, and recreational services (Government of Canada 2013).

### ***7.12.3 Discussion Questions***

1. Although all 77 refugee claimants have been screened for TB, they have not been tested for TB. Given the journey and conditions just endured by this group on board the cramped vessel, should the task force advise local public health authorities to test all claimants for active or latent TB? Why or why not?
2. What recommendations should the task force make concerning ongoing detainment conditions? What information should be provided to the current residents and staff of the regional corrections center?
3. Given the clinicians’ conclusions, should second-line TB treatment be immediately offered to the four affected refugees? If they refuse treatment, should treatment be compelled? How and why?
4. When news breaks locally of the TB status of the two young brothers, community leaders of the same ethnic background offer to shelter the boys and oversee their treatment. Discuss the relevance of the principle of “least restrictive means” to such a scenario, and indicate when or whether local public health authorities should consider community care and support approaches to MDR-TB treatment.
5. Three months into their detainment, the claims of several refugees are rejected. Hunger strikes and violence among the detainees ensue. How should the task force respond?
6. Consider a scenario in which the status of one of the two adults suspected of being infected by MDR-TB is subsequently confirmed and the patient is denied refugee status as well. What are the costs and risks of the repatriation of MDR-TB cases

compared with standard TB cases? Do the task force, public health authorities, and provincial or federal authorities have any obligations under such a scenario?

7. How should the goals of public health and those of immigration policy be balanced?

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