

FEMALE GENITAL MUT

FEMALE



CIRCUMCISIO

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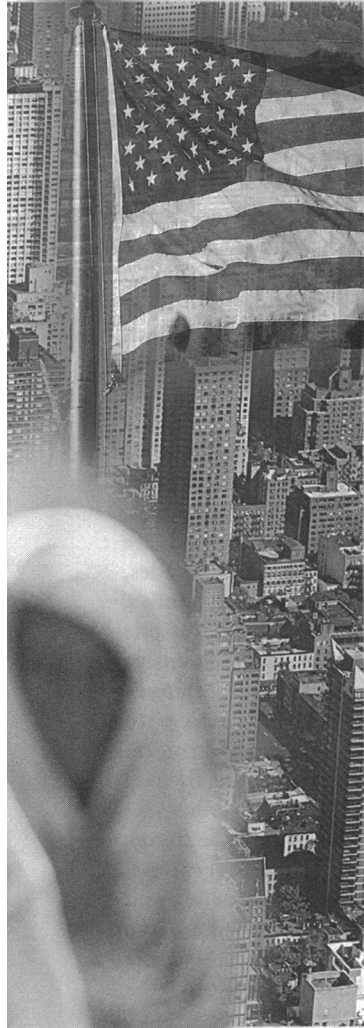
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SYNOPSIS

FEMALE GENITAL MUTILATION/female circumcision (FGM/FC) refers to a group of traditional practices that involve partial or total removal of the external female genitalia or other injury to the female genital organs for cultural, religious, or other non-therapeutic reasons. These practices are usually performed by a nonmedical practitioner in the home or other nonclinical setting. Complications occurring immediately after the practice as well as those encountered months and years afterward can result in disability or premature death. In 1996 Congress directed the Department of Health and Human Services to develop estimates of the prevalence of women and girls with or at risk for FGM/FC in the United States. This paper reports those estimates, as derived by the Centers for Disease Control and Prevention, which showed that in 1990 there were an estimated 168,000 girls and women living in the United States with or at risk for FGM/FC.

In recent years, the practice of female genital mutilation, or female circumcision (FGM/FC), has come to the attention of the American public. After several unsuccessful attempts beginning in 1993, the U.S. House and Senate passed legislation in 1996 making it a crime to perform FGM/FC in the United States on girls under 18 years of age.¹ In addition, seven states have passed legislation since 1995 outlawing the practice, and at least five more have considered legislation (Personal communication, Kathy Martinez, Center for Reproductive Law and Policy, May 1997).

Congress directed the Secretary of the Department of Health and Human Services to "compile data on the number of females living in the United States who have been subject to female genital mutilation (whether in the United States or in their countries of origin) including specification of the number of girls under the age of 18 who have been subject to such mutilation."² The estimates in turn would help the Department meet other requirements of the legislative language, namely (a) identifying communities in the United States "that practice female genital mutilation," (b) developing outreach and education targeting communities in the United States where FGM/FC might be practiced ("Such outreach activities shall be designed and implemented in collaboration with representatives of the ethnic groups practicing such mutilation and with representatives of organizations with expertise in preventing such practice"), and (c) educat-



N Who Is at Risk in the U.S.?

ing health care professionals and students about FGM/FC and the medical complications arising from it.²

Female genital mutilation (FGM) is the term commonly applied, meant to convey the drastic changes in external female genitalia. Some activists from practicing countries use this terminology, while others prefer "female circumcision" (FC), recognizing that women who continue the practice believe they are doing something good, not harmful, for their daughters and that the term "mutilation" is judgmental.³⁻⁵

The Research, Action & Information Network for Bodily Integrity of Women, or RAINBOW, an international advocacy organization founded by Nahid Toubia, MD, and headquartered in New York, recently posted on its website a declaration of values that addressed the terminology issue: "Efforts to empower women cannot begin with using language that offends them.... We accept that the term female genital mutilation has been too widely used to be rolled back. In fact, we prefer to retain the term FGM at the policy level to remind everyone of the effect of this practice on girls and women. However, we advocate the use of the term female circumcision when dealing with affected individuals, parents, or other community members. Consider what an African woman may feel when a stranger asks her if she is 'mutilated' or whether she plans to 'mutilate' her daughter. It is important that we respect the feelings and beliefs of individuals even as we inform them of facts contrary to these beliefs."⁶

For centuries, cultures in parts of Africa, the Middle East, and Southeast Asia have performed various forms of genital surgery on female infants or young girls.³ The purpose has been variously described as a means of preserving virginity, of improving hygiene, or of observing religious ritual. It is considered a rite of passage and a source of great pride and identity as a woman in some practicing cultures.⁷⁻⁹ The tradition survives today, but activists world-

wide, including some in the practicing countries, have criticized these surgeries as child abuse, victimization and subjugation of women, and medically dangerous.^{3,5,10} The World Health Organization, the United Nations Children's Fund, and the United Nations Population Fund have released a joint plan to reduce female genital mutilation in 10 years and completely eliminate it within three generations.¹¹

The World Health Organization describes a number of practices involving partial or total removal of the external female genitalia that constitute female genital mutilation¹² (see "Practices comprising female genital mutilation/female circumcision, according to the World Health Organization"). The procedure can include sewing the vagina almost completely closed after removal of the external genitalia (infibulation). Medical complications of these practices stem from the more invasive forms of FGM/FC and from the fact that they are usually performed by nonmedical practitioners in the home or other nonmedical settings. The instruments used are often knives, razor blades, or even sharpened stones. Immediate complications include infection, extensive bleeding, shock, urinary retention, and damage to nearby tissues.^{7,13} Longer-term consequences include sterility (from chronic vaginal and uterine infections), urinary tract infections, menstrual irregularities, and

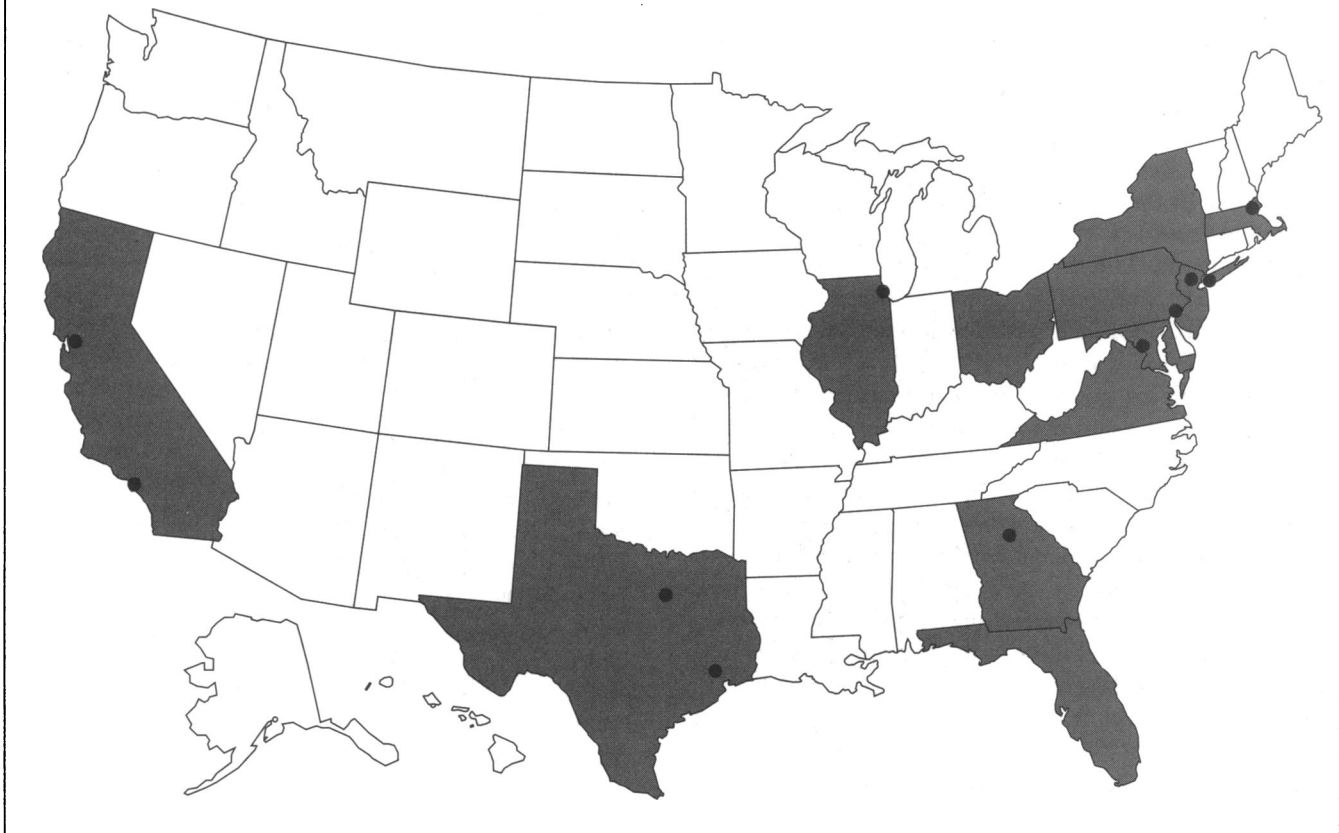
difficult sexual intercourse. Women who are infibulated, the most severe form of FGM/FC, are also at risk for obstetric complications as well as death or damage to the fetus if the scar is not cut open early enough for labor to proceed.^{7,13}

The challenges to the task of gauging the prevalence and incidence of FGM/FC in the United States derive from the complex issues of immigration and acculturation. Depending on the age at which the practice is observed in a particular culture—and this may well vary within a country—it may be reasonable to assume that immigrant women over age 18 have already been subjected to FGM/FC and that a

Activists worldwide, including some in the practicing countries, have criticized these surgeries as child abuse, victimization and subjugation of women, and medically dangerous.



Figure 1. U.S. states and metropolitan areas with the largest estimated numbers of women and girls with or at risk for female genital mutilation/female circumcision, 1990



CDC has developed a statistical model to estimate the number of girls and women with or at risk for FGM/FC living in the United States. Some 168,000 girls or women were estimated using 1990 Census data to have received or to be at risk for these procedures. States with large African immigrant populations were found to have the greatest numbers of girls and women with or potentially at risk for FGM/FC (Figure 1). An estimated 45% of the women and 44% of the girls younger than age 18 estimated to have or be at risk for FGM/FC lived in 11 metropolitan areas.

mixture of those at risk and those already subjected would be represented among the girls under 18 years of age in the United States. It may also be reasonable to assume that the risk to girls of FGM/FC differs depending on whether they were born in the United States. Further, length of residence in the United States of parents and children, regardless of place of birth of the children, may be a critical factor. However, it is unreasonable to assume a certain length of residence as a marker for acculturation and the abandonment of traditional practices. Older family members more recently arrived in the United States may be shocked to come to this country and find that their young female relatives have not had FGM/FC performed; they may try to uphold these practices as a means of maintaining cultural identity despite the objections of the children's parents.

Customs from native lands serve to retain some linkage with homelands for immigrants and may persist for several generations.¹⁴ A practice such as FGM/FC might be expected to differ from dietary or clothing practices in the extent to which it persists after arriving in the United

States—but would it be abandoned more quickly or retained longer? No information appears to exist in the anthropology literature regarding continued practice of FGM/FC after arrival in the United States or other nonpracticing countries. Recent media stories highlight the fact that some U.S. immigrants from FGM/FC-practicing countries consider it important to continue to observe this custom; in fact, some parents have been quoted as saying that they wanted it done so their daughters did not become as “wild” as U.S. women.¹⁵ Toubia suggests that abandoning a practice such as FGM/FC may take some time because of immigrants' desire to maintain their cultural identity.¹³

CDC Estimates

This paper explains the development of estimates by the Centers for Disease Control and Prevention (CDC) of women and girls residing in the United States in 1990 who had or were at risk for FGM/FC.

Two data sources were used to derive the estimates: (a) a

public use dataset from the 1990 U.S. Census based on a 5% sample of total households in the United States; respondents were asked detailed questions about, among other things, their country of origin or ancestry, length of residence, and current place of residence in the United States;¹⁶ (b) country-specific prevalence estimates compiled from numerous sources by Toubia.⁵

An important assumption was made in developing the analysis plan: that immigrant populations resemble those who remain in their homelands in terms of observing the cultural practices of FGM/FC, regardless of when they immigrated to the United States or where they settled.

Using a list developed by Toubia⁵ of the 27 countries with a reported FGM/FC prevalence over 5% (all were in Africa), we identified from the 1990 Census the number of women and girls living in the United States whose ancestry or place of birth was reported to be one of those countries or a larger region in which one or more of these countries are located. The specificity of a country of ancestry or place of birth was problematic. Of the women and girls on whom data were analyzed, only a regional African location was reported for 43%. We divided the practicing countries into these regions and calculated weighted prevalences for each region (Table 1). About 70% of those in the 5% sample who named a country reported being from Nigeria, Egypt, or Ethiopia.

From the 5% sample, we prepared an unweighted count for two age groups (less than 18 years of age and 18 or older) of females reporting ancestry or place of birth as one of the 27 countries or one of the regions that we had identified. Then we applied the appropriate weighting factor to create a weighted population count for 1990 by place of residence. Estimates of the number of women who had or were at risk for FGM/FC were prepared by applying the country-specific or weighted regional estimates of prevalence listed in Table 1. We applied country-specific prevalence rates to the totals of those who specifically named an African country as either their country of origin or place of birth. We used the weighted regional prevalence for those for whom only a region was reported.

Adjusted to the total U.S. population, an estimated 271,000 females were living in the United States in 1990 who reported ancestry or place of birth as a country or region where FGM/FC is practiced. About one-fourth—77,000—were girls under 18 years of age (Table 2).

When we applied country-specific or regional prevalence rates to the 271,000, we found that an estimated 168,000 girls and women living in the United States in 1990 either had or may have been at risk for FGM/FC; an estimated 48,000 were under 18 years of age (Table 2). About three-fourths of these girls were born in the United States. Of the nearly 12,000 girls under age 18 who were not born in this country, some 40% entered the United States between 1987 and 1990; an additional 58% entered between 1975 and 1986.

States with large African immigrant populations were found to have the greatest numbers of girls and women with

Table 1. Weighted prevalences of female genital mutilation/female circumcision (FGM/FC) for regions in Africa, derived from reported prevalences in countries comprising them

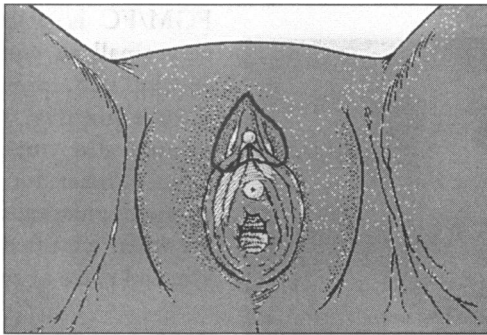
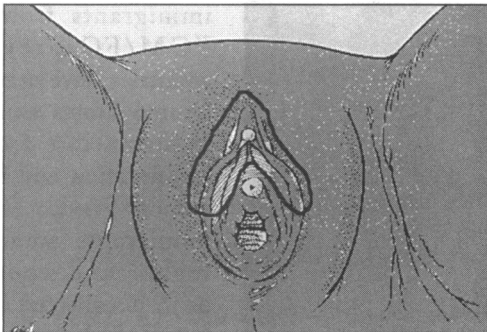
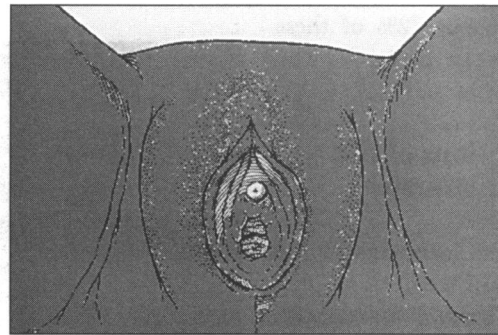
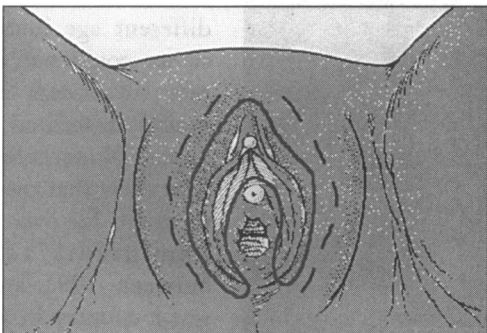
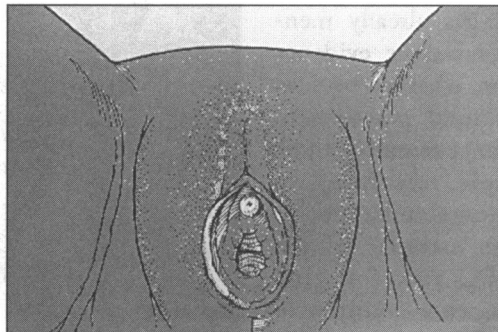
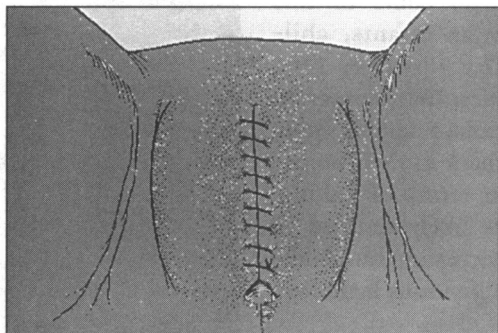
Region	Prevalence of FGM/FC ^a Percent	Weighted prevalence Percent
Northern Africa		80
Egypt	80	
Central Africa		59
Benin	50	
Burkina Faso	70	
Cameroon	20	
Central African Republic	50	
Chad	60	
Côte d'Ivoire	60	
Djibouti	98	
Eritrea and Ethiopia	90	
Gambia	80	
Ghana	30	
Guinea	50	
Guinea-Bissau	50	
Kenya	50	
Liberia	60	
Mali	80	
Mauritania	25	
Niger	20	
Nigeria	60	
Senegal	20	
Sierra Leone	90	
Somalia	98	
Sudan	89	
Tanzania	10	
Togo	50	
Uganda	5	
Zaire	5	

All practicing countries in Africa 65

^aPrevalence data taken from Reference 5.

or potentially at risk for FGM/FC (Figure 1). More than three-fourths (77.1%) lived in twelve states (New York, California, Texas, New Jersey, Maryland, Florida, Illinois, Georgia, Virginia, Pennsylvania, Ohio, Massachusetts) and the District of Columbia in 1990. An estimated 89% of the girls under age 18 in this group lived in 21 states and the District of Columbia in 1990.

An estimated 45% of the women estimated to have or be at risk for FGM/FC lived in 11 metropolitan areas (Figure 1). Some 21,000 of the girls younger than 18 (44%) lived in these same areas. These include the metropolitan areas of the following cities: New York City; Washington, DC; Los Angeles-Long Beach, California; Houston, Texas; Chicago; Philadelphia (including suburban communities in New Jersey); Atlanta, Georgia; Oakland, California; Newark, New

Figure 2. Three most common FGM/FC procedures**AREA EXCISED****AREA HEALED****Clitorrectomy****Excision
of clitoris
and labia
minora****Infibulation**

Figures adapted from Rainbo's teaching materials, July 1997

Practices comprising female genital mutilation/female circumcision, according to the World Health Organization (WHO)

- excision of the prepuce, with or without excision of part or all of the clitoris (clitorrectomy);
- excision of the clitoris with partial or total excision of the labia minora;
- excision of part or all of the external genitalia and stitching/narrowing of the vaginal opening (infibulation);
- pricking, piercing, or incising of the clitoris and/or labia; stretching of the clitoris and/or labia; cauterization by burning of the clitoris and surrounding tissue;
- scraping of tissue surrounding the vaginal orifice (angurya cuts) or cutting of the vagina (gishiri cuts);
- introduction of corrosive substances or herbs into the vagina to cause bleeding for the purpose of tightening or narrowing it;
- any other procedure that falls under the [WHO] definition [(all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs whether for cultural, religious, or other non-therapeutic reasons)].

SOURCE: Reference 12.

Jersey; Dallas; and Boston (including suburban communities in New Hampshire). In all, 65% of the estimated number of girls under 18 with or potentially at risk for FGM/FC lived in 35 metropolitan areas in the United States; about 72% of these girls were born in the United States.

Limitations of the CDC Estimates

These estimates of the number of women and girls in the United States with or potentially at risk for FGM/FC have several limitations. As already mentioned, no clear evidence exists on whether or how long cultural practices of immigrants resemble those of people remaining in their homelands, nor is there an estimate of the FGM/FC risk for girls born in this country to immigrant parents or for those who come to this country as infants, children, or youths. Our assumption that immigrant populations resemble those who remain in their homelands in terms of cultural practices likely resulted in overstated estimates. Additional limitations include:

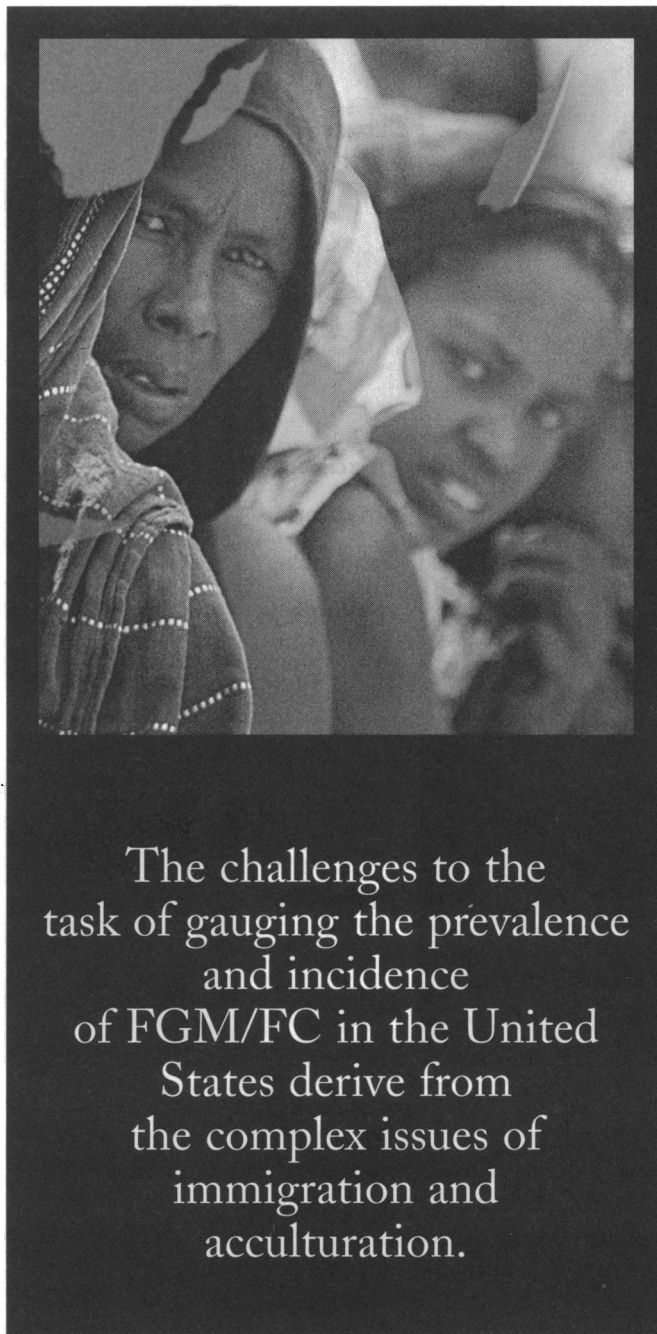
No direct information is available on FGM/FC in the United States. Media reports indicate that the practice exists here to some extent—for example, an Associated Press story from Seattle dated September 13, 1996, related the desire of the Somali community there to observe the practice but to do so in a medical setting, and a hospital's efforts to respect and observe the practice without actually performing it. (This situation was later resolved with the hospital withdrawing from any participation.)¹⁷ Some families may return with or send their daughters back to their homelands to carry out the procedure.¹⁴ However, no national data exist on how common these scenarios are.

The Census data we used are based on a sample, so some range of error must be acknowledged. A 5% sample of U.S. households is quite large. Yet the population of interest, women who reported ancestry or place of birth as a country where

FGM/FC is practiced, is very small in comparison to the U.S. population. Consequently, the 5% sample did not yield a large number for analysis of the population of interest when stratified by age, sex, and place of residence.

1990 was seven years ago. Significant numbers of immigrants from high-FGM/FC-prevalence countries have entered the United States since then. Information from the Immigration and Naturalization Service (INS) on immigrants admitted by region and country of birth is collected in a different fashion from the Census data and includes different age breakdowns, so we could not incorporate these data into the model described in this paper. Nonetheless, INS data show that the country of origin for over 121,000 immigrants admitted between 1991 and 1995 was a country in Africa in which FGM/FC is practiced.¹⁸ Countries that are the source of large numbers of immigrants (more than 1000 annually) and in which a high prevalence of FGM/FC has been reported would be expected to contribute the most to any increases at the state

level in the number of women and girls at risk. In general, the 12 states and the District of Columbia identified in our model continued to experience high rates of immigration from FGM/FC-practicing countries through 1995. The numbers of immigrants from these countries fluctuated somewhat from 1990 to 1995, with two exceptions: Somalia and the Sudan showed marked increases in immigrants to the United States over this period. States



that were not among the 12 above but were most affected by this trend included Washington, Minnesota, and Tennessee.

Countries of origin were not available for many respondents. In fact, for 43% of the women and girls on whom data were analyzed, a region of Africa or the continent itself was reported instead of a specific country. We considered ancestry from an FGM/FC-practicing country more important than simply being born in one because we wanted to include in our model all U.S. residents who potentially had or may be at risk for FGM/FC. But it is possible that some number of those who responded "Africa," and perhaps even named a country, have actually been in the United States for many years if not generations. While their numbers may include some long-time resident women who have already had FGM/FC, they probably also include women so acculturated that even their daughters would be at low or no risk.

The accuracy of the country-specific FGM/FC rates is unknown as is the extent to which prevalences vary within individual countries. Demographic and Health Surveys underway in a number of countries will provide more accurate estimates of the prevalences of FGM/FC when they are published.

The ability to derive reliable estimates of the geographic distribution of FGM/FC among residents in the United States, as requested by Congress, was limited by the small sample size for the population of interest in the Census data.

Girl children born since 1990 in the United States to Census respondents are not accounted for. This number could be derived from applying age-specific fertility rates each year to the Census-derived estimates. Further refining of the estimates would involve adjusting for deaths and out-migration as well as making the appropriate age adjustments. These calculations were not pursued because of concerns that the estimates in the model already contained a potentially large range of error; further statistical adjustments could compound the error even further, yielding estimates that may have even less value than a point-in-time 1990 estimate.

Alternative Estimates

The only sure way to obtain an accurate count of those with or at risk for FGM/FC in the United States is to per-

form physical examinations on all female residents of the country. Various forms of female surgeries are reported to have been performed on women in this country as late as the 1950s for a variety of conditions including hysteria, masturbation, excessive sex drive, and sexual disinterest.^{3,7} Physical examinations on some 130 million girls and women would be impossible for a number of obvious reasons, including cost.

Birth certificate coding of mothers with FGM/FC is another approach that has been discussed, but it would identify only those women who bear children and would have limited use in deriving accurate prevalence estimates. It would have some value in identifying infant girls potentially at risk, although acting on this information to reduce risk would require an extensive network of medical, social, and public health services to ensure follow-up education and counseling until the girls reach age 18, the age of consent. Telephone or other types of interview surveys are not feasible because of the difficulty in achieving a large enough detection rate to derive valid estimates, the sensitivity surrounding the wording of the questions, and in the end, limitations on the accuracy of results based on self-reports of a condition that is stigmatized, and now illegal, in the United States.

One possible approach to capturing the effects of FGM/FC (but not the prevalence) would be to add appropriate codes to the International Classification of Diseases—Clinical Modification. (Version 9 is currently in use, referred to as ICD-9-CM.) None of the existing codes is specific to FGM/FC. Automated searches of medical records for the relevant codes, or routine record-based reporting of relevant diagnoses, would enable monitoring of some of the health effects, including reproductive health effects, of FGM/FC and the related use of health services.

The Next Steps

Legislation outlawing FGM/FC in the United States is necessary, but not sufficient, to stop the practice.^{6,9} Given the Federal law, it now seems unlikely that medical professionals would be consulted by women having the procedure or seeking it for their girl children. Therefore, such practices would not come to the attention of authorities except in the case of an emergency, in which case it would be too late to stop the procedure and probably too late to repair any injury. RAINBQ also raises the concern that the "well-being and

An estimated
168,000
girls and
women living
in the United
States in 1990,
including
approximately
48,000 under
the age of 18,
either had
experienced
or were
potentially
at risk for
FGM/FC.

Table 2. Women and girls in the United States from countries with higher than 5% prevalence of female genital mutilation/female circumcision (FGM/FC) and those estimated to have or be potentially at risk for FGM/FC, by age group, based on 1990 U.S. Census data

U.S. women and girls	Age group				Total	
	Younger than 18		18 or older		Number	Percent
	Number	Percent	Number	Percent		
Reported ancestry or place of birth as country with prevalence of FGM/FC higher than 5% ^a	77,000	28	194,000	72	271,000	100
Estimated to have had or to potentially be at risk for FGM/FC	48,000	29	120,000	71	168,000	100

^aPrevalence data taken from Reference 5.

status of entire communities could be threatened by the overzealous investigation and prosecution of immigrant groups believed to practice [FGM/FC].⁶ They also note that "broad criminal prohibitions run the risk of driving [the] practice underground or the growth of an overseas travel industry to provide services."

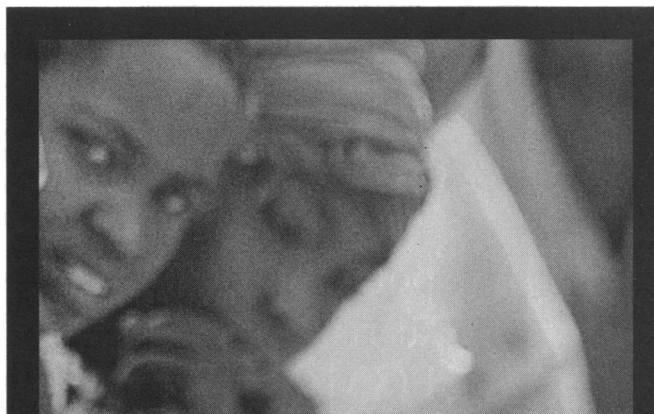
Clearly, education directed toward at-risk populations and social, public, and medical service providers is critical. The model presented in this paper used 1990 Census data and published estimates of the prevalence of FGM/FC in African countries to derive an estimate of 168,000 girls and women living in the United States with or potentially at risk for FGM/FC. Moving beyond this model to improve these estimates requires addressing the limitations described above. Nonetheless, the geographic distributions of estimated prevalence derived from this model, as well as information about immigrant and refugee settlement in the United States available annually from INS, should suffice to guide public health and social service officials in carrying out the educational components of the legislation, and should guide policy makers in pri-

oritizing areas for these efforts. To be successful, efforts at any level to eradicate the practice of FGM/FC in the United States must involve the immigrant communities themselves. Efforts currently under way by the U.S. Department of Health and Human Services include convening a series of "town meetings" with immigrant communities across the country for the purpose of developing education

and outreach programs. The Department is also reviewing existing medical curricula to determine recommendations for the education of health professionals.

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